NIHR | National Institute for Health and Care Research

Journals Library

Check for updates

Health and Social Care Delivery Research

Volume 13 • Issue 3 • February 2025

ISSN 2755-0079

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

Elizabeth A Davies, Margreet Lüchtenborg, Rachael Maree Hunter, Renske Visser, Jennie Huynh, Ross Pow, Emma Plugge, Rachel M Taylor and Jo Armes

DOI 10.3310/HYRT9622

NIHR | National Institute for Health and Care Research

Health and Social Care Delivery Research

Extended Research Article

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

Elizabeth A Davies,[1*] Margreet Lüchtenborg,[1,2] Rachael Maree Hunter,[3] Renske Visser,[4] Jennie Huynh,[1,2] Ross Pow,[5] Emma Plugge,[6,7] Rachel M Taylor[8] and Jo Armes[9]

[1]Centre for Cancer, Society & Public Health, King's College London, London, UK
[2]National Disease Registration Service, NHS England, London, UK
[3]Research Department of Primary Care and Population Health, University College London, London, UK
[4]Faculty of Education and Psychology, University of Oulu, Oulu, Finland
[5]Power of Numbers Ltd and King's College London, London, UK
[6]Faculty of Medicine, University of Southampton, Southampton, UK
[7]Health Equity and Inclusion Health, UK Health Security Agency, London, UK
[8]Centre for Nurse, Midwife and Allied Health Professional Research, University College London Hospitals NHS Hospitals Trust, London, UK
[9]School of Health Sciences, University of Surrey, Guildford, UK

[*]Corresponding author Elizabeth.Davies@kcl.ac.uk

Published February 2025
DOI: 10.3310/HYRT9622

This report should be referenced as follows:

Davies EA, Lüchtenborg M, Hunter RM, Visser R, Huynh J, Pow R, *et al*. Cancer in English prisons: a mixed-methods study of diagnosis, treatment, care costs and patient and staff experiences. *Health Soc Care Deliv Res* 2025;**13**(3). https://doi.org/10.3310/HYRT9622

Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

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.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.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.nihr.ac.uk/hsdr.

Criteria for inclusion in the *Health and Social Care Delivery Research* journal
Manuscripts are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HSDR programme

The HSDR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm

This article

The research reported here is the product of an HSDR Evidence Synthesis Centre, contracted to provide rapid evidence syntheses on issues of relevance to the health service, and to inform future HSDR calls for new research around identified gaps in evidence. Other reviews by the Evidence Synthesis Centres are also available in the HSDR journal.

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.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).

Abstract

Background: The increasing size of the ageing English prison population means that non-communicable diseases such as cancer are being more commonly diagnosed in this setting. Little research has so far considered the incidence of cancer in the English prison population, the treatment patients receive when they are diagnosed in a prison setting, their care costs and outcomes or their experiences of care compared with those of people diagnosed in the general population. This is the first mixed-methods study that has been designed to investigate these issues in order to inform recommendations for cancer practice, policy and research in English prisons.

Methods: We compared cancer diagnoses made in prison between 1998 and 2017 with those made in the general population using a cohort comparison. We then used a cohort comparison approach to patients' treatment, survival, care experiences and costs of care between 2012 and 2017. We also conducted qualitative interviews with 24 patients diagnosed or treated in prison, and 6 custodial staff, 16 prison health professionals and 9 cancer professionals. Findings were presented to senior prison and cancer stakeholders at a Policy Lab event to agree priority recommendations.

Results: By 2017 cancer incidence in prison had increased from lower levels than in the general population to similar levels. Men in prison developed similar cancers to men outside, while women in prison were more likely than women outside to be diagnosed with preinvasive cervical cancer. In the comparative cohort study patients diagnosed in prison were less likely to undergo curative treatment, particularly surgery, and had a small but significantly increased risk of death. They also had fewer but slightly longer emergency hospital admissions, lower outpatient costs and fewer planned inpatient stays. While secondary care costs were lower for patients in prison, when security escorts costs were added, emergency care and total costs were higher. Control and choice, communication, and care and custody emerged as key issues from the qualitative interviews. People in prison followed a similar diagnostic pathway to those in the general population but experienced barriers arising from lower health literacy, a complex process for booking general practitioner appointments, communication issues between prison staff, surgical, radiotherapy and oncology clinicians and a lack of involvement of their family and friends in their care. These issues were reflected in patient experience survey results routinely collected as part of the annual National Cancer Patient Experience Survey. The four priorities developed and agreed at the Policy Lab event were giving clinical teams a better understanding of the prison system, co-ordinating and promoting national cancer screening programmes, developing 'health champions' in prison and raising health literacy and awareness of cancer symptoms among people in prison.

Limitations: We could not identify patients who had been diagnosed with cancer before entering prison.

Conclusion: Healthcare practices and policies both within prisons and between prisons and NHS hospitals need to be improved in a range of ways if the cancer care received by people in prison is to match that received by the general population.

Future work: Evaluating new policy priorities.

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.

Contents

List of tables

List of figures

List of abbreviations

A&E	accident and emergency
EbE	experts by experience
GP	general practitioner
HES	Hospital Episode Statistics
HMPPS	His Majesty's Prison and Probation Service
HRG	Healthcare Resource Group
ICD-10	*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision
MOJ	Ministry of Justice
NCPES	National Cancer Patient Experience Survey
NDRS	National Disease Registration Service
ONS	Office for National Statistics
OPCS-4	Classification of Interventions and Procedures
PPI	public and patient involvement
RDA	Revolving Doors Agency

Plain language summary

Background

Information on the diagnosis of cancer and experience of cancer care in prison is sparse both in the United Kingdom and globally. This is the first national study to investigate this topic with the aim of informing English prison cancer practice, policy and research.

Methods

We analysed English cancer data for the years 1998–2017 and previously collected National Cancer Patient Experience Survey data. We also interviewed 24 patients receiving cancer care in prison, and 32 prison and health professionals. Findings were analysed and presented at a half-day ‘Policy Lab’ attended by people with lived experience of being in prison, and professionals working to develop health services in prisons and National Health Service cancer care services. The aim was to develop and agree priority recommendations for healthcare practice and policy for patients with cancer in English prisons.

Results

Cancer diagnoses in the prison population were initially lower in 1998 but increased to levels comparable to those in the general population by 2017. Men in prison were diagnosed with similar cancers to those outside, while women in prison were more commonly diagnosed with precancerous cervical changes. Patients in prison were less likely to undergo treatment to cure their cancer, particularly surgery to remove the tumour, and had a small but significantly increased risk of death, half of which was explained by treatment differences. People in prison had fewer but slightly longer emergency hospital admissions than the general population, and the cost of National Health Service hospital care was lower in the first 6 months due to fewer outpatient attendances and planned inpatient stays. However, once emergency care and security escort costs were added, the overall hospital care costs for people in prison were higher. Three core themes were identified from the interviews: control and choice, communication, and care and custody. People in prison followed similar diagnostic pathways to those outside but experienced barriers including lower health literacy (the ability to obtain and understand information about health and the services needed to make health decisions), a complex process for booking general practitioner appointments, and communication issues both between prison staff and with National Health Service clinicians involved in cancer care. These findings were largely confirmed by a separate analysis of National Cancer Patient Experience Survey data. At the Policy Lab event, the lived experience and policy and practitioner stakeholders gave priority to providing clinical teams with a better understanding of the prison system, co-ordinating and promoting national cancer screening programmes within prisons to increase uptake, developing the role of ‘health champions’ and raising health literacy and awareness of cancer symptoms among people in prison.

Conclusions

Healthcare practices and policies both within prisons and between prisons and National Health Service hospitals need to be improved in a range of ways if the cancer care received by people in prison is to match that received by the general population.

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.

Chapter 1 Introduction and rationale

Context and literature review

There is limited understanding worldwide of how cancer affects prison populations. It is well known that people in prison frequently have multiple and complicated health problems, often with worse outcomes than those residing in the community.[1,2] However, so far attention has focused on communicable diseases, with little being known about the diagnosis and treatment of non-communicable diseases, which are currently thought to be neglected.[3] Studies do reveal that people in prison are diagnosed with cancer,[4–6] and that there is growing awareness of the importance of offering cancer screening to people in prisons.[7,8] Yet, little is known about the process by which people in prison are diagnosed and treated for cancer, how they experience their health care and how the cost of their care compares with that of care for people in the general population.

His Majesty's Prison and Probation Service (HMPPS) is responsible for prisons in England and Wales, and this prison population has doubled in size since 1990, remaining steady at around 85,000 persons over the past decade.[9] It can be anticipated that within this growing and ageing prison population more and more people will experience a cancer diagnosis. Currently, the health care provided in prisons is commissioned and funded by NHS England and includes services provided by both the NHS and private contractors. Prison Ombudsmen Reports have already highlighted the lack of care systems and planning for the management of non-communicable diseases that will affect this ageing population.[10] It is therefore important to understand how cancer is currently detected in prisons, and how diagnosis, treatment, follow-up care, outcomes and costs compare with those of the general population and may need to be improved for those residing in English prisons.

This is, to our knowledge, the first study to examine the entire population of cancer patients within the English prison population, patients' experiences of cancer care and how professionals caring for people in prison with cancer view their role in the patient's cancer journey. Our initial scoping review identified that no studies have previously examined the experiences of people with cancer in prison. Studies investigating cancer in the prison population are predominantly quantitative accounts, such as retrospective cohort studies,[4,6,11] studies on screening[7,8,12–15] and studies on health literacy.[16] Most studies were conducted in the USA, with the cancer most often researched being cervical cancer. No qualitative studies were identified that aimed to understand the impact of cancer on people in prison.

Studies of people's experiences of health care in prison have shown tensions around identities of being 'a prisoner', 'a patient' or even 'a person'.[17] While there is a move towards 'health-promoting prisons', it has been suggested that prisons have been deliberately designed to limit choice, therefore hindering the decision-making of people with health problems in prison.[18]

Previous studies of health care in prison have shown that prison officers can find it difficult to adopt a caring role,[19] and often there is a tension between care and custody in secure environments.[20–22] Health professionals both inside and outside prison need to work with the constraints put in place to mitigate the 'security risk' posed by patients who reside in prison. One recent interview study found that security often over-rode heath care needs, with patients reporting public humiliation and fear, difficulty and delayed access and reduced autonomy when they attended NHS hospitals.[23] Guidance proposes that people in prison are entitled to the 'equivalence of care' received by those residing in the community.[24,25] In 2018 the Royal College of General Practitioners defined equivalence of care for those in secure environments as follows:

> *'Equivalence' is the principle by which the statutory, strategic and ethical objectives are met by the health and justice organisations (with responsibility for commissioning and delivering services within a secure setting) with the aim of ensuring that people detained in secure environments are afforded provision of, or access to, appropriate services or treatment (based on assessed need and in line with current national or evidence-based guidelines) and that this is*

> *considered to be at least consistent in range and quality (availability, accessibility and acceptability) with that available to the wider community in order to achieve equitable health outcomes.*
>
> *Royal College of General Practitioners*[24]

In summary, it is known that providing health care in prison is complex and that cancer care is complicated. This study therefore explores what happens when these two issues intersect for people residing in English prisons and sets out the barriers to and facilitators of good cancer care for these patients.

Research objectives

These were approached in three phases.

Phase 1: describe the burden of cancer within English prisons by examining those aspects of its epidemiology and potential cost of direct relevance to commissioning NHS cancer care services, including –

1. Comparative national trends (1998–2017) for cancer incidence in young people and adults aged > 18 years serving a prison sentence with the English general population.
2. Comparative disease stage at diagnosis, pathways to diagnosis and treatment, treatments received, days spent in hospital, 1- and 5-year survival rates and cause of death for patients in prison with the most common cancers compared with other English residents with these cancers.
3. Estimates of the prevalence of cancer among the prison population including all cancers diagnosed in patients during a prison sentence and pre-existing cancers requiring further treatment or care, including follow-up, in prison.
4. Comparative cost (burden) of cancer in prisons and to (1) the cost of care in the community and (2) the cost of alternative pathways of cancer care in prison.

Phase 2: describe experiences of diagnosis, treatment, care and support from the perspectives of patients in prison and prison staff and clinicians by presenting –

1. Qualitative analyses of experiences described in individual interviews of people diagnosed or receiving treatment and support during a custodial sentence and of staff and clinicians caring for patients in prison.
2. Comparative analyses of National Cancer Patient Experience Survey (NCPES) results (2012–8) for patients in prison with those reported for all English cancer patients and a qualitative analysis of the additional survey comments of people in prison to identify aspects of care that require further investigation.

Phase 3: develop priorities and recommendations to improve quality of cancer care in prisons, care of prisoner-patients in hospital and the policy underpinning the commissioning of cancer services, including –

1. Develop scenarios from data generated in phases 1 and 2 above to present in workshops with key patient and clinician stakeholders to map experience and the delivery of cancer care against expected standards.
2. Present scenarios to an expert panel to develop priorities and recommendations for practice, policy and future research.
3. Consult with participants to refine the recommendations and identify areas in the care pathway for interventions.

Chapter 2 Methodology

In this study, we took a mixed-methods approach to data collection and analysis. Our aim was to extract and analyse the existing but unreported epidemiological, health economic and quantitative survey data from within national cancer systems for the first time. Simultaneously, we collected new qualitative data during interviews with patients with cancer in prison and a range of professionals caring for them, working closely with individuals who have lived experience of being in prison or caring for patients with cancer in prison. The work on phases 1 and 2 was conducted simultaneously and we synthesised the findings iteratively as we proceeded to build a comprehensive picture of how cancer occurs and how people are treated and cared for in the English prison population. This final picture then informed the development of priorities and recommendations in phase 3 of the study.

Phase 1: quantitative data

Epidemiological data sources

Comprehensive cancer registration records are made by the National Cancer Registration and Analysis Service (NCRAS) following the receipt of monthly electronic pathology and clinical data from NHS hospitals and death certificate data from the Office for National Statistics (ONS).[26]

Comparative cancer incidence between the prison and the community population data

From the cancer registry closedown of 2017, we identified all diagnoses of primary invasive cancers, excluding non-melanoma skin cancer [*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10) C44], and diagnoses of cervical cancer in situ (ICD-10 D06) diagnosed in persons with a known gender aged between 18 and 120. All cancer diagnoses during the 1998–2017 period were considered for cancer incidence.

We used publicly available prison postcodes, and time periods in which they were active, to identify all cancer diagnoses made for persons registered at a prison postcode at the time of their diagnosis. This pragmatic method of identifying patients in prison had previously been tested in a study of cancer patients in London undertaken by a cancer registry and most recently in national studies of hospital admissions undertaken by the Nuffield Trust. It is not yet possible to identify remand patients.[4,27] The total number of cases found was counted as the numerator in subsequent calculations of cancer incidence in prison.

We used ONS population tables to calculate incidence rates for general population, whereas for the prison cohort we used the England prison population (excluding immigration removal centres) mid-year estimates for 1998–2017 that were provided by the Ministry of Justice (MOJ). Data were stratified by year, gender and age groups 18–20, 21–24, 25–29, 30–39, 40–49, 50–59, 60–69, 70–79 and ≥ 80 years. Owing to differences in age bands with the European Standard Population, categories of 18–20 and 21–24 years were created using the rectangular assumption. Age-standardised rates were calculated using the European Standard Population. To compare the incidence rate of cancers diagnosed in prison with cancers diagnosed in the general population, we calculated age-standardised incidence rate ratios for the 20-year period, with 95% confidence intervals (CIs) using Byar's approximation.[28]

Length of hospital stay, treatment and survival

To carry out comparative analyses on length of hospital stay, curative treatment receipt and survival, we identified the prison cohort as adult persons with a first primary cancer diagnosed in prison between 2012 and 2017 and excluded the cervical cancer in situ diagnoses, as well as 'death certificate only' cancer registrations. We adopted a matched comparative cohort model, where for all persons with cancer diagnosed in prison (n = 883), we randomly selected individuals from the NCRAS cancer registry who were not diagnosed at prison postcodes (i.e. the general population) in a ratio of 1 : 5, matched on 5-year age group at diagnosis, gender, year of diagnosis, cancer site (three-digit ICD-10 code) and disease stage at diagnosis. There were four prison cancer cases where no matching control could be identified, and these were excluded from further analysis. There were 22 cases with fewer than five matching patients.

Thirty-two patients in prison were further excluded from analysis due to vital status data issues, along with their matched cases. The final numbers for analysis of length of stay, treatment and survival are 847 prison cases and 4165 general population cases.

Length of stay

Length of stay was calculated as the number of bed-days for any hospital admission with an admission date that fell within the period of 31 days before and 183 days after the date of diagnosis with a matching cancer diagnosis.

Treatment data

Linkage to the Hospital Episode Statistics (HES) admitted patient care data was carried out using a matching algorithm based on NHS number, date of birth, gender and postcode at diagnosis.

The HES linked data were used to derive information on surgical resections with curative intent. Any surgical procedure recorded between 31 days before and 183 days after diagnosis and with an OPCS-4 (Classification of Interventions and Procedures) code identified as major surgery was used in the analysis. This meant that for one-fifth of tumours no curative surgery could be identified, affecting both prison patients and their matched cases.

Linkage to the radiotherapy data set was carried out using a matching algorithm and ICD-10 code. Any radiotherapy attendance with a start date from 31 days before to 183 days after date of diagnosis and recorded as having curative intent was included in the analysis.

Linkage to the systemic anti-cancer therapy data set was carried out using patients' NHS number and matching to the ICD-10 code of their tumour. Any systemic anti-cancer therapy with an earliest drug cycle, regimen or administration start date from 31 days before until 183 days after date of diagnosis and recorded as having curative intent was included in analysis.

Confounding factors

Finally, Charlson comorbidity scores were derived from the diagnosis fields of the inpatient HES data from 27 to 3 months prior to diagnosis, using the ICD-10 codes and scoring derived from Quan.[29]

Ethnicity is recorded in the cancer registry data from different data sources and takes the most frequently reported ethnicity. We used the following main ethnicity groupings in our analyses: white, mixed, combined Asian and Chinese, black, other and missing.

Routes to diagnosis are based on cancer registration, cancer waiting times and HES data, and defined as screen detected (flagged by cancer registry as detected via breast, bowel or cervical screening programme), 2-week wait [urgent general practitioner (GP) referrals with a suspicion of cancer], GP/outpatient referral (routine and urgent referrals where the patient was not referred under the 2-week wait referral route), other outpatient (an elective route starting with an outpatient appointment that is a consultant-to-consultant referral, other referral, self-referral, dental referral or unknown referral), inpatient elective (where no earlier information can be found prior to admission from a waiting list, booked or planned), emergency presentation [an emergency route via accident and emergency (A&E), emergency GP referral, emergency consultant outpatient referral, emergency transfer, emergency admission or attendance], or unknown (no data available from inpatient or outpatient HES or from cancer waiting times or screening).[30]

We also identified all data on comorbid psychiatric diagnoses in HES data for each population. After careful consideration of data quality, we decided that the diagnosis and reporting of these conditions was likely not to be made in similar ways for each population. We therefore decided not to include these data in our analyses.

Prevalence data

We intended to carry out a new linkage of national MOJ data held within prison clinical systems with cancer registration data held within NCRAS. This would have allowed us to determine not only the incidence of new cancers diagnosed while in prison but also the numbers of previously diagnosed cancers made in the general population before admission to prison. These data would tell us how many people in prison are living with a cancer diagnosis and give us a fuller picture of the burden of cancer within this population compared with the general population. This would, however, have been a labour-intensive exercise for staff working on prison data systems, and we decided that it was not feasible to pursue in the context of the COVID-19 pandemic. This remains, however, an important objective for future research.

Health economic data

We used the same linked patient-level data, patient cohorts and timelines as above, namely patients with an invasive cancer diagnosis identified in NCRAS for the most recent years 2012–7, with prison cases identified based on prison postcode. However, the cohort in this analysis differs slightly, in that patients with inconsistencies in date of death and other recorded dates are not excluded as they are from the survival analysis. HES data included inpatient and outpatient data only. A&E data were not included given the challenges of identifying cancer-specific A&E care for both sets of patients. HES resource use covers 6 months from diagnosis.

Costs

Unit costs were obtained from NHS Reference Costs 2010–1 to 2018–9[31] and applied to Healthcare Resource Groups (HRGs) reported in the sample, using the most recent costing year for which HRGs are available. Unit costs for inpatient stays were converted to an average cost per bed-day to capture the cost impact of differences in length of stay. These were applied to inpatient bed-days for emergency versus elective (non-emergency) costs. The relevant unit costs were also applied to day cases and regular day or night admissions. For HRGs that ceased to exist prior to 2018–9, costs were inflated to 2018–9.[32] Outpatient attendances were costed from 2018 to 2019 unit costs and based on service code and assuming consultant-led service.

In 2009 the costs of escorts and bed-watches were transferred to the NHS, making the NHS responsible for covering the cost of a prison officer escorting a prisoner to hospital attendances, with some exceptions, such as extended lengths of stay. Escort and bed-watches for prison patients were costed as £168 per hospital attendance and £2232 per bed-day, respectively. This is a weighted estimate based on the average time per appointment and the number of prison officers from a 2006 study of escorts and bed-watches[33] uplifted to 2018–9 costs using the Services Producer Price Index.[34] The costs of escorts and bed-watches may be overestimated given that we do not know if people were released and in the community during the 6 months from diagnosis, or if they were in the approximately 5% of the prison estate who are eligible for release on temporary licence and hence can apply to attend appointments without an escort. As a result, this analysis should be interpreted with caution, representing an estimate only.

Phase 2: patients' experiences of cancer care

We adopted an exploratory sequential mixed-methods approach comprising two elements: a qualitative exploration of the experiences of diagnosis and care of people with cancer in prison; and an analysis of NCPES data. In this design the quantitative data are secondary and supplement the qualitative data.

Qualitative interview data

Participants were invited to take part in a one-off semistructured interview.

Sample and setting

We employed purposive sampling to recruit a sample reflective of the current prison population (by age and region). Therefore, we aimed to recruit fewer women, as most (96%) people in prison are men.[35]

In practice, patients who had a diagnosis of cancer were identified and approached by prison healthcare services in six prisons. These services provided patients with a copy of the information sheet and a verbal outline of the study's aims and what it involved. The patient's understanding of the aims of the study and methods for data collection were checked before they signed the consent form. Limited information was provided to the interviewees about the interviewers due to time constraints within the prison setting. Their consent form allowed them to assign their gender. Professional participants were recruited using snowball invitations, mailing lists, newsletters and social media. Interviews were conducted either face to face or over the telephone. Professionals provided written consent to participate.

Interviews

Phase 2 comprised qualitative interviews with (1) people with cancer in prison, (2) oncology practitioners, (3) prison healthcare staff and (4) prison custodial staff. All patient interviews were conducted face to face, and professional interviews were conducted either face to face or over the telephone. Professional interviews were conducted by Renske Visser, who was unknown to the participants. Patient interviews were conducted either one to one by Renske Visser, or two to one by Renske Visser and an Expert by Experience (EbE) or fellow researcher Jo Armes. All interviewers were female except one EbE who was male. Both Renske Visser and Jo Armes have PhDs and are experienced in undertaking qualitative interviews. Renske Visser and Jo Armes provided training (6 hours) to the EbE who co-conducted interviews, which included a discussion about their interest in the topic and the potential biases each might bring. Training was augmented by debriefing and mentorship after each interview.

Interview guide and information sheets

For each participant group a separate interview guide and information sheet was developed. Experts from each group were invited to comment on the interview guides to make sure that all relevant topics were covered. Particularly with the patient group, patient and public involvement (PPI) was paramount, and EbE from Revolving Doors Agency (RDA) were involved in designing the information sheet and interview guide to ensure that relevant information was presented in the right tone and at the right literacy level.

Experts by experience

As part of our approach to PPI, three peer researchers with lived experience of prison were involved in various stages of the research. They advised on the practicalities of doing research in a prison environment, commented on information sheets and interview guides, co-conducted interviews and contributed to the analysis of the interviews. This collaboration was instrumental in asking the right questions and setting priorities in our project. The EbE involvement in the study was supported by RDA. For a reflection on this collaboration, see our published article.[36]

National Cancer Patient Experience Survey data

The NCPES contains around 70 questions covering different aspects of cancer care experience. The survey also allows individuals to assign their own gender. For the analysis included here, NCPES data from 2012 to 2018 were used. People with cancer diagnosed in prison were identified from the national cancer registration based on postcode of residence at diagnosis. Linkage with NCPES is based on patient and tumour identifiers. A matched population approach was adopted to compare the cancer experience of persons diagnosed with cancer while in prison with the experience of persons diagnosed with cancer in the community. Controls were randomly sampled from the NCPES responders not diagnosed in prison and were matched in a 1 : 5 ratio on gender, age group and NCPES data year. Matching was not performed on tumour site, but control sampling was restricted to tumour sites present in the prison cases, excluding males with breast cancer. The final population included 78 cases and 390 controls. Answers to NCPES questions were dichotomised according to preferred answers versus other. Missing answers were excluded. Logistical regression modelling was adjusted for the matching variables and ethnicity and tumour stage to control for potential confounding.

During the initial part of the study, the national process for obtaining additional anonymous qualitative comments made by patients as part of their NCPES responses was put on hold due to a general review of confidentiality. By the time the new application process for these data had moved from the survey provider to NHS England, the three EbE working with us had helped to define the qualitative interview schedule and we had begun using this to collect rich new data. We therefore decided not to pursue an application for the qualitative comments but to compare the quantitative survey results with the themes emerging from our new interviews.

Ethics approval

The National Disease Registration Service (NDRS) has approval from the Confidentiality Advisory Group of the NHS Health Research Authority to carry out surveillance using the data it collects on all cancer patients under Section 251 of the NHS Act 2006. All analyses of national data were undertaken by Jennie Huynh and Margreet Lüchtenborg, who worked within NDRS. Therefore, separate ethics approval was not required for the phase 1 epidemiological, health economic, or phase 2 survey analyses.

The qualitative interview study in phase 2 received favourable research ethics approval from the Health Research Authority (REC 19/LO/1073) and HMPPS (reference 2019-306) on 3 October 2019.

The methods used in the development of recommendations, including the development of a film, co-design groups and the Policy Lab event in phase 3, received approval from King's College London Research Ethics Committee (reference MRA-20/21-22403) on 23 July 2021.

Modes of analysis/interpretation

Epidemiological data

To assess the trend over time in the male prison population, we calculated the incidence rate ratio per year for the period 1999–2017 with 1998 as the baseline, using Poisson regression adjusted for age. Age was imputed as a continuous variable, providing age-adjusted incidence rate ratio averaged over the 19 years in comparison with baseline.

The Wilcoxon rank-sum test was used to compare the median length of stay between patients diagnosed with cancer in prison and those in the community.

Logistic regression was performed to investigate the likelihood of the patients in prison receiving curative treatment compared with the patients in the general population. Ethnicity, comorbidity and route to diagnosis were considered as confounding factors, but only route to diagnosis was found to improve the model fit with use of the Akaike information criterion. Logistic regression models were adjusted for matching variables (age, gender, disease stage and year of diagnosis) and additional potentially confounding factors (route to diagnosis).

Survival time was calculated from date of diagnosis or date of the start of curative treatment for those undergoing treatment with curative intent until date of death or latest tracing with ONS (February 2019). Survival estimates for the prison cases and population cases were compared using the Kaplan–Meier methodology.

Cox proportional hazards modelling was used to investigate the relative risk of death in the prison population compared with the community population. Cox models were adjusted for matching variables and extended to include stratification for the receipt of any treatment with curative intent to assess the impact of such treatment. The same models were further adjusted for route to diagnosis. The Cox proportional hazards assumptions were assessed by visual inspection of the log–log plots, and scaled Schoenfeld residuals. Assumptions were met for matched variables but not for the receipt of treatment with curative intent, which is why models included stratification for curative treatment.

Health economic data

Descriptive statistics were calculated for the proportion of patients who used each resource use type. Means and standard deviations (SDs) were calculated for attendances and bed-days for patients who used that resource only. Logistic regression was used to calculate the odds ratio (OR) of patients accessing the resource in prison compared with in the community.

As the distribution of costs was unlikely to be normal, we prespecified testing cost differences between prison and comparison patients using general linear models. The suitability of using a log-link was tested for using the link test. The family (normal, Poisson, negative binomial or gamma) was chosen based on Akaike information criteria.[37]

All ORs and general linear models were adjusted for matching factors (age group, gender, year of diagnosis, cancer type and disease stage) as well as Charlson comorbidity score and ethnicity as a binary of white compared with non-white. Adjusted costs and cost differences were obtained using margins.

Analyses were conducted in Stata v15 (StataCorp LP, College Station, TX, USA).

Sensitivity analysis

The main analysis included patients with unknown NHS numbers. It is possible that incorrect linking was done for these patients and hence they are excluded from a sensitivity analysis. There were also a few HRGs where either we were unable to find the cost or the cost obtained for the HRG was 0. A sensitivity analysis was conducted for HRGs where the cost was unknown or 0 was imputed as the mean cost of all known HRGs > 0.

Qualitative interview data

We conducted 55 interviews and, of these, 53 were recorded and transcribed verbatim by a professional transcription service. On one occasion, the recording device was not permitted in the prison and so the researcher (RV) took notes. Fifty-four interviews were conducted in English and one was conducted in Dutch (by RV). Patient interviews lasted, on average, 60 minutes, while interviews with professionals were shorter, lasting approximately 30 minutes. Interviewers were encouraged to keep written field notes on their experience of conducting the interviews. All patient interviews took place in a separate room in the healthcare facility in each prison. Most professional interviews were undertaken over the telephone.

We used reflexive thematic analysis,[38] as this supported an experiential orientation whereby precedence is given to the meaning ascribed by the participant. Initially Renske Visser and Jo Armes inductively coded the interviews. Subsequently our EbE (SW, AX, AB) reviewed transcripts and identified additional codes. Coding continued in NVivo 12 (QSR International, Warrington, UK) and then we reviewed the codes to develop and refine them into themes and subthemes. Analysis of each participant group was undertaken separately, and themes and subthemes were subsequently compared across groups. All analyses were reviewed by the wider research team and our EbE and any necessary refinements were made. The analysis was done both individually by the researcher (RV) and as a wider group with Jo Armes and the EbE from RDA. We held online analysis meetings to discuss common themes. These meetings deepened the analysis as on occasion researchers and EbE interpreted the same data differently. However, after extensive group discussions, consensus was reached on the three core themes. These themes were (1) communication, (2) care and custody and (3) control and choice. As we were specifically interested in cancer diagnosis and management, the themes were mapped to the generic cancer pathway to identify its similarities to or differences from that experienced by cancer patients residing in the community.[39]

Phase 3: creation of scenarios and public engagement film and development of recommendations

Creation of scenarios and public engagement film

The qualitative interview findings were used to create scenarios depicting the differing perspectives of patients, health professionals in prison and the NHS, and prison professionals. Our aim was to present these to both the co-design and expert groups to enable them to develop their recommendations for improving care based on these and their own experiences. We used a method described by Jones *et al.*[40] to develop vignettes representing the experiences of Black African and Black Caribbean women with breast cancer symptoms in the general population. The steps were as follows:

1. Define the target audience to whom they would be presented.
2. Collate and analyse the qualitative data, basing the vignettes on interview findings attained through iterative analysis of the transcribed interviews.
3. Develop a framework for each vignette – these frameworks were provided by the themes generated in the analysis of interviews.

4. Identify and justify quotations – verbatim quotations from the interviews illustrating key themes were incorporated alongside a tabulation of the rationale for their inclusion. This systematic process contributed to their representativeness.
5. Create vignettes – these were constructed around themes, associated quotations and 'alternative viewpoints'. Consideration was paid to length, and presentation was made in the first person. During this process the vignettes were reviewed by the EbE and revisions were made based on their comments.
6. Pilot vignettes – this was undertaken to determine whether modifications were needed to the process of introducing and discussing them during the workshops.
7. Refine the process of using the vignettes.
8. Select narrators – ensuring that each voice sounded authentic to the role being played – and audio-record vignettes.

We partnered with Synergy Theatre Project, an organisation that works towards rehabilitation and resettlement with prisoners, ex-prisoners and young people at risk of offending through theatre and related activities. Synergy Theatre Project identified actors for each part and produced the audio vignettes.

Due to the COVID-19-related lockdown restrictions and work pressures on NHS and prison staff during the pandemic, it was not possible to recruit patient and clinical stakeholders to the co-design workshops that we had planned and designed to develop initial recommendations from the qualitative study findings. Instead, using the vignettes we worked with Synergy Theatre Project and a scriptwriter to develop the audio scenarios directly into a film script that the company then produced as a short 8-minute 'talking heads' film entitled *Cancer Cells* (https://www.surrey.ac.uk/research-projects/how-cancer-care-best-provided-patients-english-prisons-assessing-disease-burden-prison-population#news; accessed November 2024). This was presented during the Policy Lab event as an additional summary of the main qualitative findings and to gain feedback from a wider audience on its strength and tone as a public engagement and dissemination output from the project.

Development of priorities for policy and care recommendations

A Policy Lab is a method designed by the Policy Institute at King's College London to bring key stakeholders together to consider new data or policy options. This approach recognises that robust evidence is only one ingredient in the development and uptake of new policy and practice based on new evidence. The engagement approach develops aims to provide a forum for open and honest conversations around a policy topic, creating new networks for the synthesis of evidence into an accessible format.[41]

The event was initially planned as an all-day in-person event, but due to pandemic restrictions and the pressure of work on NHS and prison staff it was designed by the Policy Institute and the research team as an online half-day event and held during March 2022. The event was attended by expert stakeholders from the NHS, MOJ, HMPPS and cancer charities, as well as prison healthcare professionals, EbE, PPI cancer experts and the research team. Invitees were chosen for their personal experience of prison health care and cancer care and for their experience of and potential influence on informing future prison policy planning and development. One week before the event, all attendees received a summary pack of the key epidemiological, health economic, and qualitative and quantitative patient experience findings. In addition, a series of key challenges and barriers identified from the research findings were distilled and outlined. Participants were encouraged to reflect on the evidence and findings emerging from the project, understand the barriers and constraints to change, and develop new ideas and practical approaches to improve outcomes. The key question presented for those at the meeting to answer was 'What could be the top three improvements to benefit those with cancer in prisons that are achievable in the next three years, given the practical obstacles?' Participants were enabled to explore how care was organised and delivered and encouraged to think creatively about possible improvements. The practicalities of implementing these changes at a suitable scale were considered, as were the roles of different stakeholders in achieving this.

Chapter 3 Epidemiological results

Some text in this chapter has been reproduced with permission from Lüchtenborg *et al.*[42] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The text below includes minor additions and formatting changes to the original text.

Cohort study of cancer incidence

The prison population increased in size during the 20-year period, with the number of men in prison increasing from 60,252 in 1998 to 77,825 in 2017. The number of women in prison is much lower overall but also increased from 3139 to 4007 (a 28% increase) during the same period. The proportion of male and female prisoners over 50 years of age doubled from 17% and 17% in 1998 to 34% and 35% in 2017, respectively. The number of malignant and pre-malignant tumours diagnosed in prison increased sixfold from 19 in 1998 to 171 in 2017. We identified 2015 tumours in 1964 adult persons in prison during the 20-year period, of which 1556 were diagnosed in men and 459 were diagnosed in women. More than half of cancers in men are made up of prostate (19%), lung (15%), colon and rectal (9%), testis (7%) and bladder (4%) cancer. Most diagnoses in women are cervical cancer in situ (76%), whereas cervix and breast cancer account for 5% of all diagnoses each and 20% and 22% of invasive tumours, respectively.

The age-standardised incidence rate of cancer for men in prison was lower than that for men in the general population during the early study period but increased towards the end of the study period to a level similar to the general population (*Figure 1*). Poisson regression showed that during the study period the incidence of invasive cancer for men in prison increased [incidence rate ratio per year 1.05, 95% CI 1.04 to 1.06, during 1999–2017 compared with 1998].

The incidence rate ratios in *Figure 2* show that over the 20-year period the cancer incidence was lower in both women and men in prison, although not statistically significantly so for women. Incidence rate ratios for the most common male cancers showed statistically significantly lower rates of colon, rectal, prostate and testis cancer in the prison population, but no differences in bladder and lung cancer incidence. Invasive cancers are relatively rare in women in prison, but it is striking that cervical cancer in situ is diagnosed around twice as often in prison as in the general population.

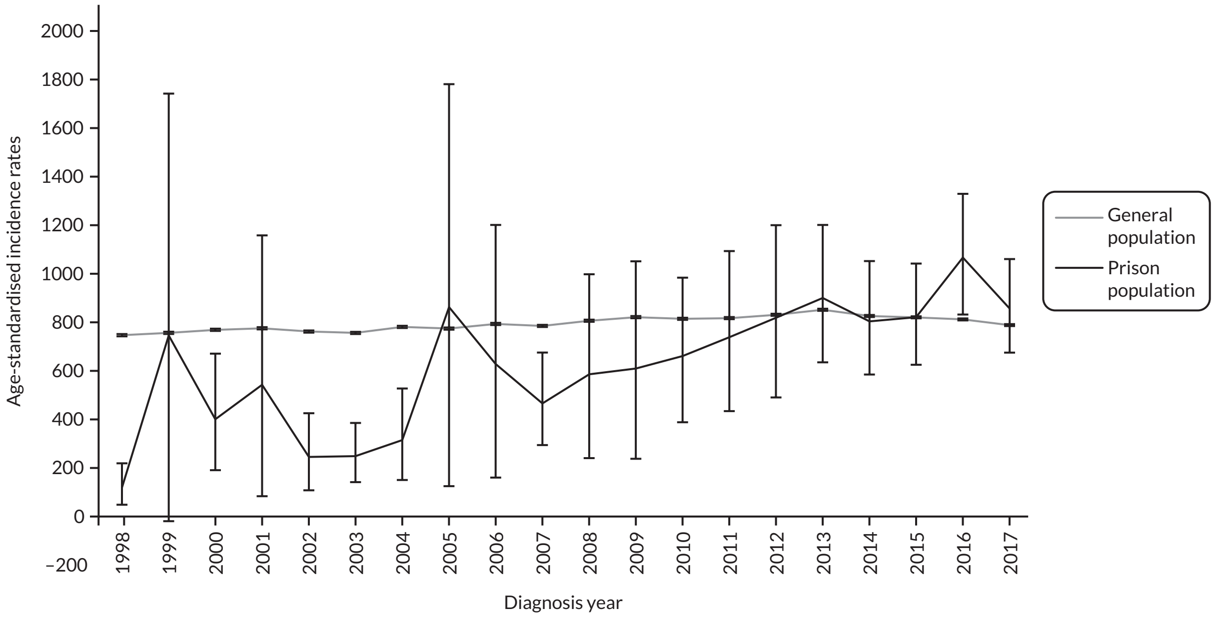

FIGURE 1 Age-standardised incidence rates (per 100,000 person-years) for cancer in men in the general and prison populations in England by diagnosis year.

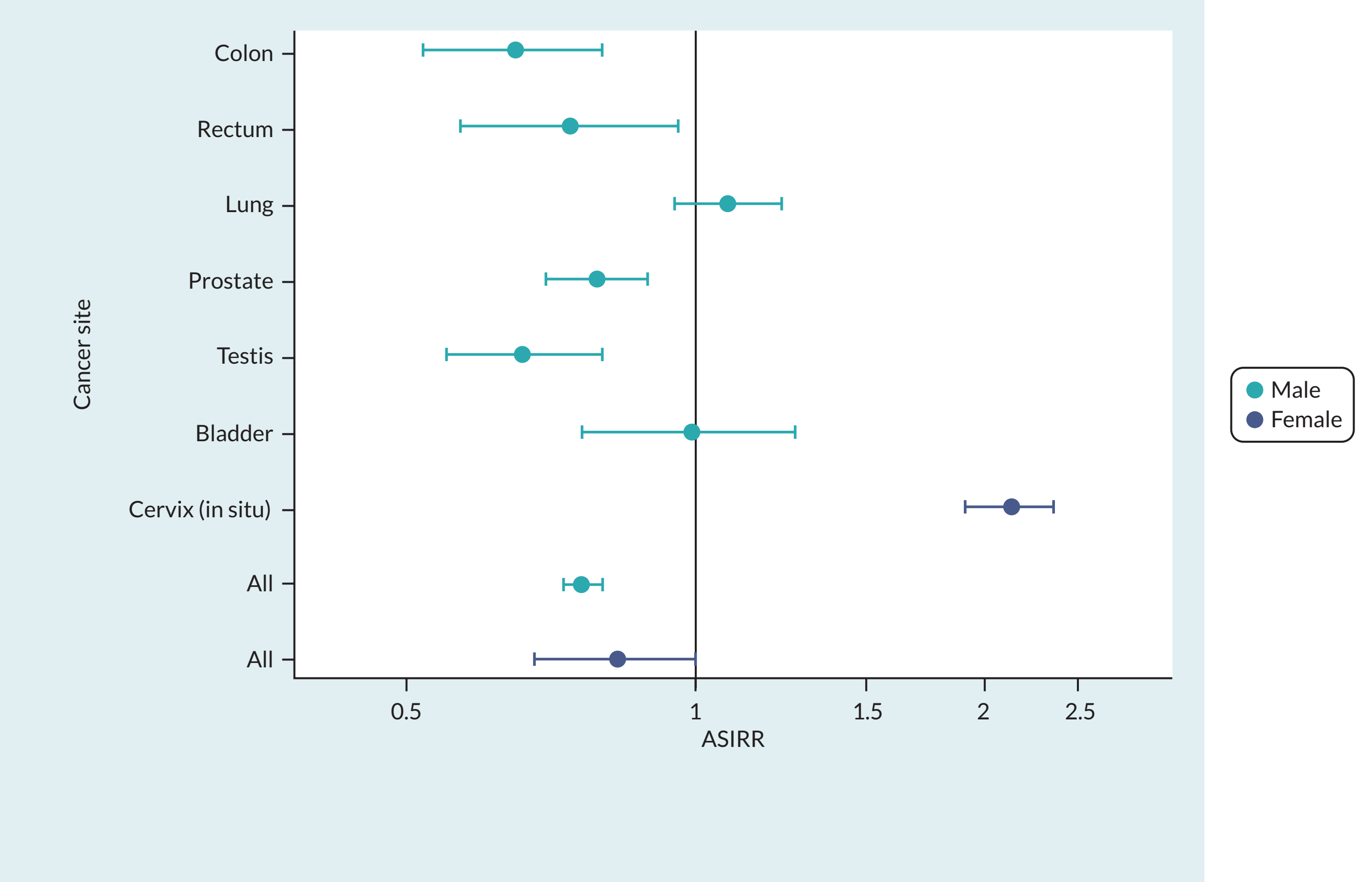

FIGURE 2 Age-standardised incidence rate ratios for common cancer and for all cancers combined in English prisons compared with the general population by gender between 1 January 1998 and 31 December 2017.

Matched cohort study of treatment and survival

Table 1 gives an overview of the prison cohort and matched general population cohort. It shows that the matching on age, gender, tumour stage and diagnosis year worked well. There were differences in ethnicity, with fewer individuals with an Asian ethnicity and more with a black, mixed or other ethnic background in the prison cohort than in the general population controls. No significant difference in levels of comorbidity was found. Individuals diagnosed with cancer in prison were far less frequently diagnosed via screening than were matched general population cases. In an analysis where we randomly matched prison cases to cases from the general population on age, gender, tumour site and diagnosis year, but not tumour stage, we found no significant difference between the frequency of stage IV tumours among people diagnosed in prison and that among the general population (28% vs. 26%; $p = 0.067$).

Hospital admissions

Excluding day cases and regular night and day attenders, we found that fewer patients among those diagnosed with cancer in prison had HES recorded hospital admissions than among those diagnosed in the community (40% vs. 46%; $p < 0.001$). When admitted, prison patients had slightly longer admissions using the same definitions than community controls, where the median bed-days for prison cases was 8 (interquartile range 3–17 bed-days) compared with 6 (interquartile range 3–13 bed-days) among community controls ($p = 0.024$).

Curative treatment

Table 2 shows the OR of the receipt of any treatment with curative intent, curative surgery, radiotherapy and systemic anti-cancer therapy of people diagnosed with cancer in prison compared with those in the general population. The prison population is less likely to undergo treatment with curative intent than the general population (OR 0.63, 95% CI

TABLE 1 Characteristics of patients diagnosed with cancer in English prisons compared with matched patients in the general population, 2012–7

	Patients with cancer in the general population, *n* (%) (*N* = 4165)	Patients with cancer in prison, *n* (%) (*N* = 847)	*p*-value
Gender			0.94[a]
Male	3931 (94.4)	800 (94.5)	
Female	234 (5.6)	47 (5.5)	
Age in years, median (IQR)	58 (48–68)	58 (47–67)	0.15[b]
Ethnicity			< 0.0001[a]
White	3588 (86.1)	672 (79.3)	
Mixed	19 (0.5)	14 (1.7)	
Asian and Chinese	132 (3.2)	13 (1.5)	
Black	96 (2.3)	39 (4.6)	
Other	63 (1.5)	26 (3.1)	
Missing	267 (6.4)	83 (9.8)	
Cancer stage at diagnosis			1.0[a]
I	994 (23.9)	201 (23.7)	
II	524 (12.6)	106 (12.5)	
III	660 (15.8)	135 (15.9)	
IV	1172 (28.1)	235 (27.7)	
Missing	815 (19.6)	170 (20.1)	
Diagnosis year			1.0[a]
2012	500 (12)	101 (11.9)	
2013	617 (14.8)	126 (14.9)	
2014	677 (16.3)	138 (16.3)	
2015	719 (17.3)	146 (17.2)	
2016	842 (20.2)	171 (20.2)	
2017	810 (19.4)	165 (19.5)	
Treatment with curative intent			< 0.0001[a]
No	2437 (58.5)	573 (67.7)	
Yes	1728 (41.5)	274 (32.3)	
Charlson comorbidity score			0.086[a]
0	3489 (83.8)	684 (80.8)	
1–2	499 (12)	117 (13.8)	
≥ 3	177 (4.2)	46 (5.4)	
Route to diagnosis			< 0.0001[a]
Two-week wait	1536 (36.9)	228 (26.9)	
Emergency presentation	712 (17.1)	179 (21.1)	

TABLE 1 Characteristics of patients diagnosed with cancer in English prisons compared with matched patients in the general population, 2012–7 (*continued*)

	Patients with cancer in the general population, *n* (%) (*N* = 4165)	Patients with cancer in prison, *n* (%) (*N* = 847)	*p*-value
GP or outpatient referral	1131 (27.2)	210 (24.8)	
Inpatient elective	109 (2.6)	25 (3)	
Other outpatient	444 (10.7)	103 (12.2)	
Screen detected	65 (1.6)	4 (0.5)	
Unknown	168 (4)	98 (11.6)	

IQR, interquartile range.
a *p*-values based on chi-squared test, excluding missing or unknown categories.
b *p*-values based on Mann–Whitney *U*-test.

Note
Stages I–IV indicate progressive spread of cancer throughout the body from localised within the tissue of origin (stage I) through regional (stages II and III) to distant spreading or metastatic cancer.

TABLE 2 Likelihood of receipt of treatment with curative intent for patients diagnosed with cancer in English prisons compared with matched patients in the general population, 2012–7

		Any treatment		Surgery		Radiotherapy		Systemic anti-cancer treatment	
	Total number	Number of patients (%)	Adjusted OR (95% CI)	Number of patients (%)	Adjusted OR (95% CI)	Number of patients (%)	Adjusted OR (95% CI)	Number of patients (%)	Adjusted OR (95% CI)
General population	4165	1728 (41.5)	1 (ref)	1228 (29.5)	1 (ref)	486 (11.7)	1 (ref)	303 (7.3)	1 (ref)
Prison population (model 1)	847	274 (32.3)	0.63 (0.53 to 0.75)	187 (22.1)	0.64 (0.53 to 0.78)	80 (9.4)	0.78 (0.60 to 1.01)	51 (6.0)	0.79 (0.57 to 1.08)
Prison population (model 2)	847	274 (32.3)	0.72 (0.60 to 0.85)	187 (22.1)	0.73 (0.60 to 0.88)	80 (9.4)	0.85 (0.65 to 1.10)	51 (6.0)	0.85 (0.62 to 1.17)

Note
Logistic regression models adjusted for cohort matching variables (gender, age category, disease stage and diagnosis year) in model 1, and additionally adjusted for route to diagnosis in model 2.

0.53 to 0.75), but the difference is most pronounced for major resections (OR 0.64, 95% CI 0.53 to 0.78). Adjusting the analyses for route to diagnosis in the model attenuated the association (OR 0.73, 95% CI 0.60 to 0.88).

Survival

The survival of patients diagnosed with cancer in prison is lower than that of patients diagnosed with cancer in the community. One-year survival was 71% (95% CI 68% to 74%) among prison diagnoses compared with 74% (95% CI 73% to 76%) among community diagnoses. Five-year survival estimates were 54% (95% CI 50% to 58%) and 56% (95% CI 55% to 58%), respectively.

Table 3 shows the results from the Cox proportional hazards analysis. 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, model A]. Stratification by treatment with curative intent showed that differences in treatment explained almost half the increased risk (adjusted HR 1.09, 95% CI 0.97 to 1.23, model B). Further adjustment for diagnosis route attenuates the association further (HR 1.05, 95% CI 0.94 to 1.18, model D).

TABLE 3 Risk of death for patients diagnosed with cancer in English prisons compared with matched patients in the general population, 2012–7

	Number of deaths; person-years	Model A: adjusted HR (95% CI)	Model B: adjusted HR (95% CI)	Model C: adjusted HR (95% CI)	Model D: adjusted HR (95% CI)
Population					
General population	1626; 10,944.2	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Prison population	347; 2021.9	1.16 (1.03 to 1.30)	1.09 (0.97 to 1.23)	1.09 (0.97 to 1.23)	1.05 (0.93 to 1.18)
Route to diagnosis					
Two-week wait				1 (ref)	1 (ref)
Emergency presentation	N/A			3.05 (2.72 to 3.43)	2.76 (2.45 to 3.10)
GP or outpatient referral	N/A			1.03 (0.91 to 1.17)	0.98 (0.86 to 1.12)
Inpatient elective	N/A			1.34 (1.02 to 1.77)	1.22 (0.93 to 1.61)
Other outpatient	N/A			1.34 (1.14 to 1.57)	1.31 (1.11 to 1.54)
Screening	N/A			0.34 (0.15 to 0.77)	0.38 (0.17 to 0.86)
Unknown	N/A			1.19 (0.95 to 1.50)	1.03 (0.82 to 1.30)

N/A, not applicable.

Note

Cox proportional hazards modelling, adjusted for cohort matching variables (gender, age category, disease stage and diagnosis year) in model A; for cohort matching variables and stratified by treatment with curative intent in model B; for cohort matching variables and route to diagnosis in model C; and for cohort matching variables and route to diagnosis, stratified by treatment with curative intent, in model D.

Chapter 4 Health economic results

Some text in this chapter has been reproduced with permission from Hunter *et al.*[43] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The text below includes minor additions and formatting changes to the original text.

Demographic characteristics for the prison and general population cohorts are reported in *Table 4*. Patients diagnosed with cancer in prison were less likely to attend outpatient appointments (OR 0.31 95% CI 0.25 to 0.39) and have

TABLE 4 Demographics for HES analysis data set for patients diagnosed in prison compared with the matched general population cohort

	Place of diagnosis				
	General population		Prison		
	n	%	*n*	%	*p*-value[a]
Patients	4326	100	879	100	
Sex					0.94
Men	4082	94	830	94	
Women	244	6	49	6	
Age category (years)					1
18–20	29	1	6	1	
21–24	57	1	12	1	
25–29	109	3	26	3	
30–39	341	8	70	8	
40–49	693	16	140	16	
50–59	1078	25	216	25	
60–69	1144	26	231	26	
70–79	723	17	146	17	
≥ 80	152	4	32	4	
Stage					1
I	1014	23	205	23	
II	534	12	108	12	
III	676	16	138	16	
IV	1262	29	253	29	
Missing	840	19	175	20	
Diagnosis year					1
2012	505	12	102	12	
2013	662	15	135	15	

continued

TABLE 4 Demographics for HES analysis data set for patients diagnosed in prison compared with the matched general population cohort (*continued*)

	Place of diagnosis				
	General population		Prison		
	n	%	*n*	%	*p*-value[a]
2014	697	16	142	16	
2015	775	18	157	18	
2016	867	20	176	20	
2017	820	19	167	19	
Ethnicity					< 0.001
White	3737	86	698	79	
Mixed	19	0	14	2	
Asian and Chinese	134	3	13	1	
Black	101	2	40	5	
Other	63	1	27	3	
Missing	272	6	87	10	
Charlson comorbidity score					0.07
0	3622	84	708	81	
1–2	518	12	124	14	
≥ 3	186	4	47	5	

a *p*-values based on chi-squared test, excluding missing or unknown categories.

planned inpatient attendances (OR 0.75 95% CI 0.64 to 0.88) than the matched cohort of patients diagnosed in the general population (*Table 5*). Among all patients who had any outpatient appointment, 20.8% (*n* = 275) of people diagnosed in prison had a 'did not attend' recorded for an outpatient appointment compared with 13.0% (*n* = 448) of the matched general population cohort. This represents a significantly higher likelihood of a 'did not attend' for patients diagnosed in prison (OR 1.79 95% CI 1.51 to 2.11).

Based on link tests, Akaike information criteria, log-link and negative binomial family were chosen for all general linear models to test for significant differences in costs. Six months from diagnosis and 31 days prior to the diagnosis costs for secondary care for patients diagnosed in prison are significantly lower than for the matched cohort diagnosed in the general population (−£1216, 95% CI −£1638 to −£795), with outpatient and planned inpatient care costing significantly less for patients diagnosed in prison (*Table 6*). Emergency care costs £497 (95% CI £375 to £619) more per patient diagnosed in prison. When the cost of bed-watches and escorts is added to the total cost of secondary care cancer treatment, patients diagnosed in prison cost significantly more per patient than the matched general population cohort.

The results for the sensitivity analyses are reported in *Appendix 1*. If patients with unknown NHS number are excluded from the analysis, the results remain the same as for all other analyses.

TABLE 5 Resource use 6 months post cancer diagnosis with means and SDs reported only for patients with an attendance

	General population (*n* = 4326)	Prison (*n* = 879)	OR[a] (95% CI)
Outpatient			
Proportion (%)	93.39	82.25	0.31 (0.25 to 0.39)
Attendances,[b] mean (SD)	11.97 (11.90)	8.86 (10.96)	
Elective (planned) inpatient care			
Proportion (%)	35.99	29.82	0.75 (0.64 to 0.88)
Attendances,[b] mean (SD)	1.38 (0.93)	1.41 (1.02)	
Bed-days,[b] mean (SD)	8.25 (10.78)	8.61 (11.08)	
Day cases			
Proportion (%)	45.28	36.86	0.69 (0.60 to 0.81)
Attendances,[b] mean (SD)	4.51 (5.55)	3.63 (4.15)	
Emergency inpatient care			
Proportion (%)	16.10	14.79	0.90 (0.73 to 1.11)
Attendances,[b] mean (SD)	1.32 (0.68)	1.32 (0.72)	
Bed days,[b] mean (SD)	13.92 (19.03)	17.22 (21.77)	
Any inpatient care			
Proportion (%)	69.05	60.18	0.68 (0.58 to 0.79)
Attendances,[b] mean (SD)	3.99 (5.12)	3.25 (3.76)	
Bed-days,[b] mean (SD)	10.49 (15.19)	10.73 (15.38)	

a Adjusting for age groups, sex, year of diagnosis, cancer type, disease stage, Charlson comorbidity score and ethnicity.
b Participants with values > 0 only.

TABLE 6 Total cancer healthcare costs in 2018–9 GBP

	General population (*n* = 4326)	Prison (*n* = 879)	Difference[a] (95% CI)
(1) Outpatient			
Cost,[b] mean (SD)	1651 (1693)	1209 (1541)	
Adjusted[a] total cost, mean (SE)	1544 (24)	981 (33)	−563 (−643 to −483)
(2) Elective (planned) inpatient care			
Cost,[b] mean (SD)	9382 (9902)	9424 (10,633)	
Adjusted[a] total cost, mean (SE)	3414 (57)	2919 (101)	−495 (−715 to −275)
(3) Day cases			
Cost,[b] mean (SD)	1516 (1639)	1224 (1160)	
Adjusted[a] total cost, mean (SE)	685 (11)	455 (16)	−230 (−267 to −193)
(4) Emergency inpatient care			
Cost,[b] mean (SD)	7473 (12,840)	8766 (12,729)	
Adjusted[a] total cost, mean (SE)	1153 (21)	1650 (63)	497 (375 to 619)

continued

TABLE 6 Total cancer healthcare costs in 2018–9 GBP (*continued*)

	General population (*n* = 4326)	Prison (*n* = 879)	Difference[a] (95% CI)
Total inpatient care (2–4)			
Cost,[b] mean (SD)	7619 (11,144)	7589 (10,803)	
Adjusted[a] total cost, mean (SE)	5234 (82)	4601 (157)	−634 (−977 to −291)
Total health care costs (1–4)			
Adjusted[a] total cost, mean (SE)	6784 (106)	5568 (190)	−1216 (−1638 to −795)
Total healthcare costs (1–4) including escorts and bed-watches			
Adjusted[a] total cost, mean (SE)	6784 (106)	17,085 (582)	10,301 (9145 to 11,456)

SE, standard error.

[a] Adjusting for age groups, sex, year of diagnosis, cancer type, disease stage, Charlson comorbidity score and ethnicity.

[b] Patients with values > 0 only.

Chapter 5 Patient experience results

Some text in this chapter has been reproduced with permission from Armes *et al.*[44] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The text below includes minor additions and formatting changes to the original text.

Qualitative results

We conducted 55 semistructured interviews with 24 patients from 6 prisons, 6 custodial staff, 16 prison healthcare staff and 9 oncology specialists. Patients were recruited from six prisons from across England. We aimed to recruit more people from 10 prisons in total; however, recruitment was suspended in March 2020 due to the COVID-19 pandemic. *Table 7* shows the personal and clinical characteristics of patient participants and *Table 8* shows those of professionals. As intended, most participants were men, and the most common diagnosis was prostate cancer in men and breast

TABLE 7 Patient personal and clinical characteristics (*n* = 24)

	n
Age bands (years)	
20–39	2
40–59	9
60–79	10
≥ 80	3
Cancer diagnosis	
Breast	3
Gastrointestinal	1
Haematological	5
Head and neck	4
Lung	2
Skin	1
Urological	8
Place of diagnosis	
Community	7
Prison	17
Treatment received	
Surgery	3
Systemic anti-cancer therapy	10
Radiotherapy	4
Hormone therapy	1
None	7

continued

TABLE 7 Patient personal and clinical characteristics (n = 24) (*continued*)

	n
Residence during treatment	
Community	6
Prison	18
Treatment status at time of interview	
On treatment	6
Follow-up	14
Palliative care	1
No treatment received	3

TABLE 8 Professional participants (N = 31)

Job title	Setting	*n*
Consultant oncologist	Hospital	2
Surgeon	Hospital	1
Clinical nurse specialist	Hospital	2
Chemotherapy scheduler	Hospital	1
Radiographer	Hospital	1
GP	Prison	5
Prison officer	Prison	4
Specialist nurse	Prison	3
Head of health care	Prison	3
Clinical nurse	Prison	4
Social care	Prison	1
Custodial manager	Prison	2

cancer in women. There was significant variability in place of diagnosis, place of treatment and treatment type. Thus, while 16 patients/participants were diagnosed and treated in prison, others (n = 6) were diagnosed and treated in the community and a small proportion (n = 2) were diagnosed in the community but treated while in prison.

In reporting our results, we draw on all participant groups to highlight the particular complexities of cancer care when a patient resides in prison. Three core themes were developed inductively: (1) communication, (2) care and custody and (3) control and choice. For each theme and subtheme, we summarise the findings, which we support by quotations presented in *Table 9*. *Figure 3* depicts the generic pathway to a cancer diagnosis,[39] adapted to reflect the experiences of people in prison. This pathway starts with a person experiencing symptoms, and in prison they put in an application ('app') to get an appointment with a GP and potentially have diagnostic tests (blood tests). If cancer is suspected, they are referred to an external hospital for further diagnostic tests, receive a diagnosis and are subsequently treated for cancer. *Figure 3* also summarises the enablers and barriers at each point in the pathway, which we discuss in more detail below in relation to our themes.

TABLE 9 Participant quotations

Patients	Oncology specialist	Custodial staff	Prison health care
Communication			
Between patients and GPs			
Getting a referral You've got to write out paper apps to see a doctor. That can take time, so you've got all that, playing up there, thinking, 'Oh God, I need to get this sorted out straight away.' But you can't because it's out of your hands; there's nothing you can do until you get that appointment with the doctor *Man, 50s, haem cancer* But if I ever have something I'm not too sure about, I'll just write, 'I've got a pain here, but due to my [cancer] history …' and they're going to need to look at that, you do get looked at a lot quicker *Man, 80s, multiple cancers* Every day I was telling them, and they just kept telling me that they'd got booked appointments. Then they [healthcare] told me 'Oh, you've got a cold, it's a gland,' and then it wasn't a gland, it was a thyroid. 'We're booking him in to have it operated on, it's just your thyroid.' But it turns out it wasn't a thyroid, it was cancer *Man, 20s, haem cancer* It took around 5 months for the doctor to send me to hospital to get diagnosed. I'd never been ill up until this really, like normal illness and stuff but nothing serious. And I was going to the doctor a lot with just being extremely tired *Man, 20s, haem cancer* **Post-prison move** I was first diagnosed when I was in [different prison], with all the blood tests they do when you go into prison. And then I was referred to [local hospital] and seen a consultant there, and I was just diagnosed with CLL *Man, 50s, haem cancer*	**Post-prison move** We are quite often asked to see people who have been transferred to a prison that is local to us who are not a local resident. They might be in one prison, then moved to a different prison and there is a complete lack of continuity of care (…) We were the third specialist bladder cancer team that were meeting this patient within 6 months *Surgeon*		**Getting a referral** It could be a patient who self-presents, who puts an app in, 'I've found a lump', otherwise we wouldn't know, and that gets the ball rolling with the initial investigations, scans. Or it could be an incidental finding, so they've come for something else but then through either doing blood sampling or a thorough examination they've found something else *Lead nurse* **Malingering** The other bit that happens is malingering. Malingering happens; people tell you they are bleeding, say bleeding in the urine and bleeding in the rectum and things like that, and then you find out that the episode happened to be the day before their court case *GP* **Mental health and substance abuse** To be honest, a minority of them are people who have got physical health diseases. The majority of them is medication review, mental health review, but the most difficult or challenging consultations are those around substance misuse and the issuing of prescriptions which are potentially abusable within the prison service *GP* I mean, as much you build up relationships with prisoners because you see the same ones in and out quite a lot, it's not the same thing. Unfortunately, a lot of prisoners are not interested in their health, they are interested in other things. And the problem is that by the time they are interested in their health, they have got serious problems and an awful lot of time and money in prisons is dedicated to their substance misuse problems and their mental health problems *GP*
Between patients and the oncology team			
I tried to get in touch with some organisations, but that was so difficult because I think I was the first person. Like Macmillan. By the time	All patients are given a phone number to ring if they are in that situation [of developing a fever or infection].		

continued

TABLE 9 Participant quotations (*continued*)

Patients	Oncology specialist	Custodial staff	Prison health care
they'd allowed me to have the freephone number and an extended amount of time on the telephone so that you can wait to get through to all the right channels, then I was actually over all the treatment *Woman 60s, breast cancer*	That is clearly not straightforward if you are on your own in prison *Oncologist* The problem was more that once we finished the consultation, and then if we had to follow it up with a phone call, how we are doing, that was not possible *Medical oncologist*		
Between professional groups			
	it is just really hard communicating when the prison healthcare system seems pretty thin on the ground and stretched. It's difficult to get hold of people to discuss and to try and make a plan *Clinical oncologist* it's a bit more of a logistics one just to try to keep on top of the communication with the case workers at the prison, to make sure they're aware of our rules and we're aware of their rules, and they're aware of when the patient needs to attend and what they're coming for *Chemotherapy scheduler* A lot of the discussions we have with the prison is, '*What are you able to deliver?*' The problem is he has to be in a prison because he is in detention, but then what is the situation when they can't deliver? Does he end up staying in hospital, which also isn't the best place? With this particular case, that was some of the challenges Specialist registrar I think his contact with us and his contact as an inpatient when things were not as good was probably prolonged because of where he was going to have to go back to when he was discharged from hospital *Specialist registrar*	**Medical confidentiality** I believe you do get a bit of a brick wall sometimes [from prison healthcare] and you're not getting the full picture. Or things are delayed from the outside hospital with information, and I get to hear the information from the prisoner before it comes from the hospital to the prison *Prison officer* But we wouldn't have been sat down and been told about the diagnosis with them, it would just filter through to us, and then we would start putting things into place for them *Prison officer* I've almost got to go and get a piece of paper signed each time for them to information share. Sometimes, if we had the full picture at the beginning, it would help me with my position, especially if there is going to be that risk of that person falling into that palliative care. If I'm prepared for it, then I'm prepared to be able to support them in a better way *Prison officer*	**Medical confidentiality** I think sometimes the nurses in the hospital can be quite difficult to communicate with us. They've very reluctant to communicate with us, even when we've had to set passwords up and things like that for them to communicate with us, they will only give us the bare information, the minimum *Nurse* Some of the NHS are really funny about it, they won't send stuff to [prison healthcare e-mail] but if you've got an NHS [e-mail], they'll e-mail you to an NHS *Senior staff nurse* I just send a letter to the officers on the wing to say, 'Look, he's on this treatment, these are the side effects. Please be aware. These are the phone numbers to call should he have anything.' So, they keep that in their office, so they've got all that *Clinical nurse specialist* A lot of the time they [patients] won't have anybody else with them. So if they're being bombarded with information, we [healthcare] don't know what information has been given because obviously the prison officers don't come back and tell us *Clinical nurse practitioner*

TABLE 9 Participant quotations (*continued*)

Patients	Oncology specialist	Custodial staff	Prison health care
Control and choice			
Preparation for appointments			
No, I know when I'm going. I'm not meant to, do you know what I mean? It's every 21 days they have to do it *Man 20s, head and neck cancer* I didn't know I was going. I hadn't written my questions down. I keep asking odd questions [in the hospital] *Man, 80s, head and neck cancer* Quite simply, my operation is at 7 : 30, I have to be in [hospital], so I've got to leave here at 6:30. They require me to have washed my hair before I go. It's very difficult for prisoners to wash their hair in the prison. I need to do it the night before, but will I be told that I'm going to [hospital] the following morning? Probably not *Man, 70s, multiple cancers*	I don't know this for 100 per cent sure, but I think when booking appointments the bookings team liaise with the prison. They don't tell the prisoner, to try and de-risk anything from that point of view *Specialist registrar* *Information-giving to patients* I think information-giving is really difficult because you always feel slightly constrained, you are saying to them, 'We will give you chemotherapy every 3 weeks.' And you are thinking, 'Can I say that?' Because they are not supposed to know when they are coming *Clinical nurse*	They are not allowed to know when they are going, but they'll have an idea when they're going. We'll take the gentleman for his chemotherapy appointment, he'll have his chemo, he'll come away. The hospital will then write to the prison with the new date for the next session. And he won't know when he's having the next one *Prison officer*	Well, usually patients can't know when they're going out to hospital because there could be a security breach. So there's the element of surprise when they may or may not know they're going and that morning they get up and have to go to hospital. If they need to be nil by mouth they may know the night before, but that's rare *Senior healthcare manager*
Treatment			
Chemotherapy I have three lots of chemo; every 21 days I have to go and have it done. It's only once every 21 days, but I'm on three different types. I don't know what they're called *Man 20s, head and neck cancer* **Radiotherapy** Well, it is cancer because I am having radiotherapy, possibly some time this month. I don't know when because they don't tell you. *Man, 80s, lung cancer* **Hormone therapy** I'm on tablets now. They've not said anything about any further treatment or whatever, or anything. I don't think they tell you if they've received anything from the specialist; they only tell you what they want you to know *Man 70s, urological cancer* **Surgery** All I had was operations, operations, operations *Man 50s, head and neck cancer*	**Equivalent treatment plans** The patient, depending on their diagnosis, stage, things like that, would be offered the best treatment for them. Any cancer patient, regardless of whether they are a prisoner or not, will be discussed in a multidisciplinary team meeting – a group of professionals who then come up with what they think is the best treatment option for that patient Radiographer Cancer is very much a standardised treatment based on evidence so we try to do all we can. I think in terms of his treatment, it wasn't any different to what it would have been *Specialist registrar*		**Communicating about treatment** So, we've got a guy who's on chemotherapy tablets in the prison at the moment, so I just send a letter to the officers on the wing to say, '*Look, he's on this treatment, these are the side effects. Please be aware. These are the phone numbers to call should he have anything*.' So, they keep that in their office so they've got all that *Clinical nurse specialist* So usually if they are going to start active treatments, we liaise with wherever they're going to if they were going to have a course of chemotherapy, we'll get all those dates prior to it and then admin will clear them all with security, because they're only allowed so many patients out a day, we triage that list so that patient then becomes priority. So if there's other people on the list that day, they'll be taken off and moved elsewhere. So we plan ahead so it doesn't affect their chemotherapy or radiotherapy or whatever treatment they're having *Lead nurse*

continued

TABLE 9 Participant quotations (*continued*)

Patients	Oncology specialist	Custodial staff	Prison health care
Managing treatment side effects			
I have suffered very severe side effects from the radiotherapy. This is not necessarily relevant to having that treatment from prison, but it's difficult to have side effect management in prison. All night sweating you can cope with, but anal bleeding is not easy to handle, and I have that every day *Man, 70s, multiple cancers* Obviously, they've got to kill my immune system and then try and rebuild it. In here, you're just open to infections. Plus, staff come in with coughs and colds, and it's just a dirty environment *Man, 20s, haem cancer* I've not had any side effects at all. But no, some lads on the wing do have side effects, and sometimes they'll go, 'I'm not going to air today, I don't feel too well,' or this sort of stuff *Man, 80s, multiple cancers*	He had two episodes of febrile neutropenia and actually he felt that his first one was ignored (...) So actually getting him to hospital as an emergency was probably quite difficult and it must have been difficult for them [the prison] to facilitate *Clinical nurse specialist* I don't think that [being in prison] would necessarily change my approach to explaining side effects to them, because my assumption would be that, if they have a prison doctor and the prison doctor is completely aware of a patient and the management plan that they're undergoing *Clinical oncologist* You have to explain everything because he still needs to be treated as a normal patient. If you have any new symptoms, if you have any new worries, if you have any new concerns, you ring the hotline. Then again it is back on the prison. '*He has rung and we want to see him. You have got to arrange for him to come up*.' If a person rang me from [place], say, and they were ill, I would tell them to go to A&E *Specialist registrar*	I believe if someone was given anything like that [chemotherapy], healthcare would generally come and give us some sort of handover, saying, '*This person's having this therapy, and these are going to be the side effects*' *Prison officer* One [patient] had a brain tumour (...) he was going up to hospital either every day or every couple of days for treatment (...). But it was *the actual prisoner who lived with him* who came and told me if he was struggling. I don't think staff are fully aware of what to look out for *Prison officer*	We've had other patients where we've been managing their side effects from their cancer treatment, or explaining their diagnosis to them because they don't really understand it because they don't take it in when it's told to them in hospital, or because they can't read very well – that kind of thing *Clinical nurse specialist* There's a protocol in place, around chemotherapy and around blood transfusions as well, with escalation plans in place if someone's bloods are indicating a neutropenia or something like that, what to do. That's shared with both prison staff and with the clinical staff so they know exactly what the contingency plan is, if XYZ happens *Senior healthcare manager*
Managing emotions			
I'll have the chemo, and as the days go on, you feel bad for the first few days, then you start feeling a bit better again. But it's your emotions; it plays with your head, badly. I just have to keep telling myself I'm going to get better, but it does play with your emotions. I had it going last Monday, and then Monday night they didn't give me my medication that they're meant to give me, and I just flipped. I knew when I was doing it that I was just doing			

TABLE 9 Participant quotations (*continued*)

Patients	Oncology specialist	Custodial staff	Prison health care
it because I was kicking off for no reason, but I couldn't control it; your head just goes *Man, 20s, haem cancer* I've been told that I've got a really aggressive cancer, and I'm not being given any time to process it. I'm a man, I want to go and cry in my cell on my own, just have a night where I try and get my head around everything *Man, 20s, haem cancer* When you're vulnerable or unwell, or mentally vulnerable, the officers will all decide, they'll have a little sit down and a chat with you and work out things that they can do to help you, people you can see, and how many times they'd like to check on you so that you're still alive. So, they did that, and I didn't really need that *Woman, 60s, breast cancer*			
Care and custody *Getting to hospital*			
Missing appointments The main thing I think that sometimes breaks down is getting people to the hospital when they need to be. That's the only thing where mine went wrong *Man, 60s, urological cancer* **Missing scans** I've never missed a chemo appointment. The one [doctor] was really cross about was the scan. I was supposed to have had one before the last appointment and I haven't and she said, 'Why not?' and I said, 'I don't know'. That's like blaming the prisoner for not having a key *Woman, 40s, breast cancer*	**Missing appointments** They don't turn up to an appointment and we end up trying to chase it up, phone the original prison, and they say 'No, they're not there.' I've spent hours trying to track people down in the past, not being willing to tell me where somebody is *Clinical oncologist* **Escorts – arranging appointments** It still has been quite hard work, negotiating with the prison and actually getting him into appointments. I've gone to the trouble of trying to liaise with our X-ray department for him to have the ultrasound scan on the same day he comes to see me, to help the prison out so that he's only [needed] one trip under escort out *Clinical oncologist*	**Missing appointments** Unless something has gone catastrophically wrong, they will never miss their appointment. And obviously because we know they're going off for chemo, we know how important that is. So no, they should never, in an ideal world, miss their appointments *Prison officer* **Hospital escorts** It's about making sure that a diagnosis is reached quickly, and that's about us communicating to the medical staff, the medical staff communicating to the relevant oncology department, making sure that we've got staff available to escort *Custodial manager*	**Hospital escorts** Now, the challenge with that is, the prison has capacity issues and resource issues about taking anybody out for any healthcare appointment. So, the prison currently allows three outside appointments in a day, which means that you are often the people who pick and choose who goes out *Prison health care*

continued

TABLE 9 Participant quotations (*continued*)

Patients	Oncology specialist	Custodial staff	Prison health care
Handcuffing It's a bit of a thing at the minute, because I'm 80 years old, when you go for the scan, they lock the door, nobody can go in anyway, but they still insist on being cuffed *Man, 80s, multiple cancers* [When going for] a scan they have to take your handcuffs off and put plastics on (…) They're plastic handcuffs, and they haven't got anything to open them with they have to use this prehistoric tool to open it *Man, 50s, GI cancer* I don't get handcuffed when I go to the hospital. There is a list of a few of us that don't; we just go down with two prison officers *Man, 70s, urological cancer*	**Handcuffing** But yes, typically, they are handcuffed when we see them. Obviously if you need to examine the patient, often there is some arrangement to allow that. But it's not ideal *Clinical oncologist* It is so obvious when they [patients from prison] walk into the department handcuffed to two burly [prison officers] … Everyone looks then. How can we try and reduce some of the stigma attached to that? *Radiographer*	**Handcuffing** [I]f they are cuffed, we are sensitive to that and we don't parade them round and bark orders at them in the hospital. We're sensitive to their needs and the public needs, because we're the face of the prison service when we're out there *Custodial manager* **Public safety** But we've also got to be aware that these people are a risk to the public, so we've got our job to do there in protecting the public. And we try to just blend in as much as two prison officers and a prisoner handcuffed together can blend in *Prison officer*	**Handcuffing** They obviously will go out in handcuffs with two officers *Senior healthcare manager* And I think 98% of our cancer patients are not cuffed when they go to their appointments either. I've got a list of 36 patients that are not cuffed *Clinical nurse specialist*
Prison officers in consultations			
Presence of prison officers The chance to sit and talk to a specialist without somebody else in the room [would be great]. While they [the officers] might be sympathetic, it's not their treatment. Because there are questions I would like to ask my consultant but I don't feel comfortable *Woman, 40s, breast cancer* You have to have an enema every time you have radiotherapy and having an enema with prison escorting officers is difficult. There were different escorting officers each time *Man, 70s, urological cancer*	**Presence of prison officers** It is always challenging, and you always ask permission from the patient [for the prison officers to be present]. I don't understand the ins and outs of the law. I presume that whoever is in charge of bringing him has to be there. *Specialist registrar* She [a patient] was a young woman who was really, really frightened about losing her fertility. So there was a lot of discussion about that and that was all done in the presence of strangers *Clinical nurse specialist* *Ignoring presence of prison officers* We try to blank it out [the presence of prison officers], so when you have a patient in front of you, whether you have a prison officer	**Presence of prison officers** I've also been on escorts where they've gone out for their treatment, their chemotherapy. And obviously you're on a ward with other people who are suffering from cancer and having treatment and you're there with a closeting chain sometimes. It's not great *Prison officer* *Trying to absorb information* We'll go, we'll try and absorb some of the information to him, just in case he misses something, so we can tell him 'They said that and said this,' just try and make it as comfortable as we can for them	

TABLE 9 Participant quotations (*continued*)

Patients	Oncology specialist	Custodial staff	Prison health care
	or whether they are handcuffed or not handcuffed, you try to just have an absolutely normal conversation as much as you possibly can *Medical oncologist*	Prison officer *Zoning out during consultations* So obviously we know we're hearing stuff that is for him. Me, personally, when stuff goes on between him and his doctor, I try not to listen unless the doctor will ask questions like, at the prison is this available to them *Custodial manager*	

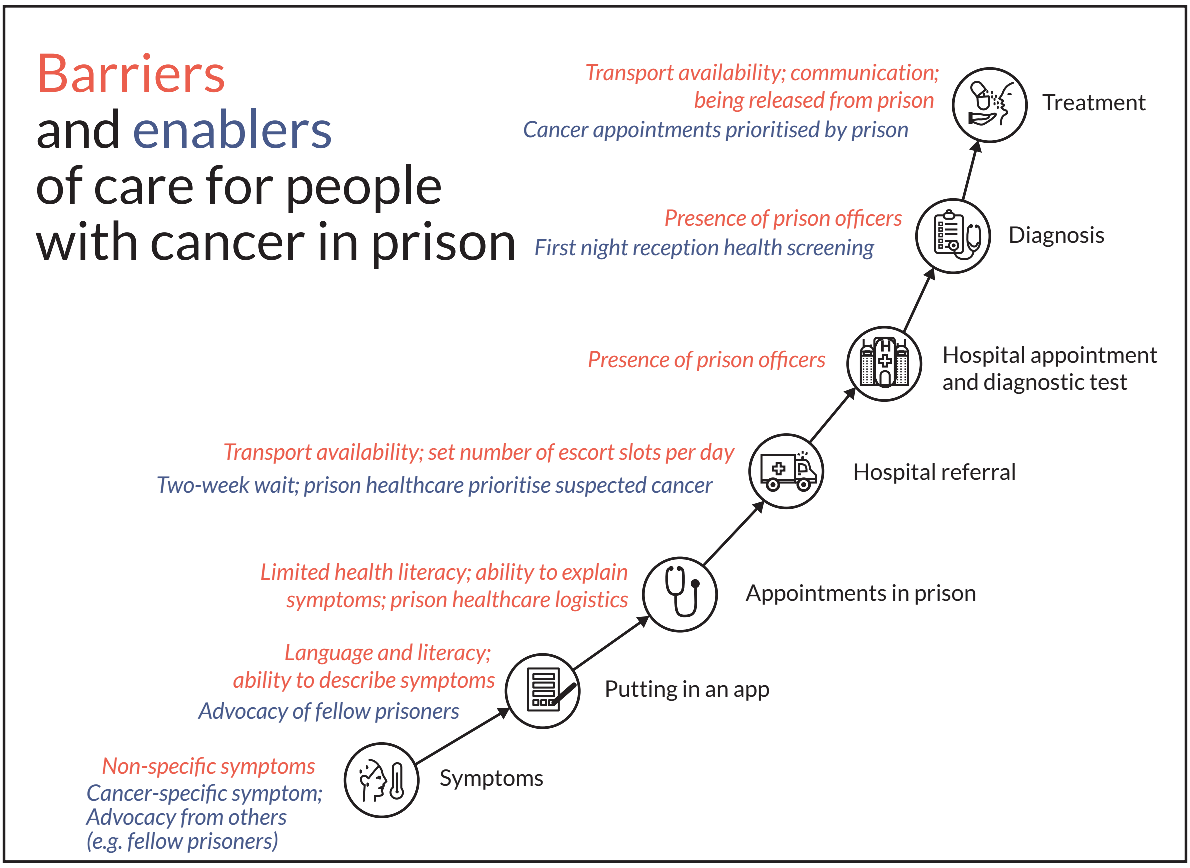

FIGURE 3 Barriers to and enablers of care for people with cancer in prison. Images reproduced with permission: treatment – Nithinan Tatah from Noun Project (CC-BY); diagnosis – Amethyst Studoi from Noun Project (CC-BY): hospital appointment – Phoniaphat Thongsriphong from Noun Project (CC-BY); hospital 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).

Getting a diagnosis

Cancer patients in prison are a diverse group, and we identified three different pathways to diagnosis.

1. Pathway 1: people diagnosed and treated in the community who need follow-up care in prison (*n* = 6).

This group were diagnosed and treated prior to going to prison but required ongoing anticancer medication, monitoring and follow-up care.

2. Pathway 2: people diagnosed in the community and treated in prison (*n* = 1).

One participant completed all diagnostic tests shortly before being sentenced but underwent treatment in prison, highlighting the blurring of boundaries and overlaps between prison and community settings.

3. Pathway 3: people diagnosed and treated in prison (*n* = 17).

Pathway 3 included various ways of being diagnosed. Some people were diagnosed via the health check that occurs during the first-night intake ('reception screening'), while others were diagnosed through national screening programmes offered in prison. Some participants were asymptomatic and were diagnosed secondary to other health interventions. By contrast, some, particularly younger participants with non-specific symptoms, experienced a prolonged route to diagnosis. Oncology professionals reported that being moved between prisons could delay diagnosis. This was corroborated by a man in his 50s who was diagnosed with leukaemia via reception screening but moved to another prison where staff were unaware of this diagnosis and repeated the diagnostic process.

Three core themes that were developed inductively – communication, care and custody, and control and choice – will now be outlined in more detail.

Communication

A major barrier in providing or receiving good care is communication. This includes communication between patients and clinicians and between professional groups.

Between patients and general practitioners: getting a referral

Typically, if a person experiences symptoms in prison, they 'put in an app [application]' to be seen by prison health care. This can be paper-based or electronic but is triaged by a prison health professional who decides which patients will see a prison GP, and how quickly. Only patients and prison healthcare interviewees spoke about the 'app' system. Using the 'right' language on an application was key; one person commented that he always wrote 'due to my history with cancer …' to ensure that he was seen promptly. Others reported putting in daily 'apps' for weeks or months before they received an appointment. Some not only filled out 'apps' for themselves but also helped fellow prisoners for whom literacy was a challenge. This system of 'putting in apps' is thus the first barrier that some people in prison needed to overcome to access health care.

'Malingering' and trust

The main difficulty in detecting cancer from a prison healthcare perspective was differentiating between people with physical healthcare problems and those with mental health and substance abuse issues. Prison doctors reported that the risk of 'malingering' was high. While patients reported the challenge of 'not being believed' by health professionals and custodial staff, this was not simply unwillingness on behalf of professionals but, instead, a complicated dynamic between understaffing and limited healthcare appointments, combined with a complex patient population and low cancer awareness. The implication is that people in prison may have to convince the prison GP that further investigations are warranted. In the study there were several patients in their 20s who struggled to get a diagnosis as they experienced vague symptoms and were labelled as 'lazy' or 'attention seeking'.

The NCPES data corroborated these findings in that people with cancer diagnosed in prison were significantly less likely to report that 'they saw their GP less than three times' before being referred to hospital (OR 0.32, 95% CI 0.18 to 0.59) or that they were seen by a hospital doctor within 3 months (OR 0.33, 95% CI 0.19 to 0.59) (*Table 10*).

Communication between patients and cancer professionals

Oncology specialists became involved only when a patient was referred to hospital, and this was the only time patients in prison could ask them questions about their cancer. Patients could not communicate directly with specialists from prison, as it was generally not possible to add the phone numbers to their approved numbers in a timely fashion. Thus, for patients in prison, preparing questions for these visits was crucial. Oncology professionals reported offering 'the same' kind of information regarding reporting side effects, despite acknowledging that people with cancer in prison may struggle to contact cancer services using the telephone hotline and that this may result in poorer side-effect management. It was generally accepted by patients that they had limited access to cancer specialists. Some tried to access information through Macmillan Cancer Support, a UK cancer charity. But just as patients could not easily add the number of their cancer specialists to the list of phone numbers they were permitted to call, it was equally difficult to contact charities. In some prisons, Macmillan professionals visited cancer patients regularly, but this service was based on available funding, and thus some patients and professionals reported how Macmillan 'used to visit'.

These communication challenges were reflected in the NCPES findings (see *Table 10*). People diagnosed with cancer in prison were almost as likely as those in the general population to respond that the way the possible side effects of treatment(s) were explained was easy to understand (OR 0.90, 95% CI 0.51 to 1.61) and much less likely to report that written information was easy to understand (OR 0.22, 95% CI 0.09 to 0.56). Likewise, people diagnosed in prison were 90% less likely to report that they were told who to contact if they were worried about their condition or treatment after leaving the hospital (OR 0.10, 95% CI 0.04 to 0.23) (see *Table 10*).

Communication between professional groups

All three professional groups reported that communication with each other was difficult. Oncology specialists reported finding it hard to communicate with prison health care, while prison health care reported that oncology services were reluctant to share information with prison health care. The interviews with oncology professionals revealed that they found prisons mysterious places, and their narratives included many questions around what was available to patients in prison, and who to speak to. Prison officers reported being constrained by the notion of medical confidentiality, and this was highlighted by the fact that they were often not informed about a prisoner's cancer diagnosis. When prison officers tried to acquire information, prison health care were reluctant to share information due to medical confidentiality constraints. Prison officers noted that people in prison might inform them about their diagnosis, but as 'malingering' was considered a big issue in prisons, prison officers often wanted to verify this information. The study revealed that patients were unaware of the ways hospitals and prisons communicated about their health care, but they were affected by miscommunication or non-communication between oncology specialists and the prison.

Responses to NCPES showed a similar finding, whereby people diagnosed with cancer in prison were far less likely to report that their GP was given enough information about their condition and the treatment received at the hospital (OR 0.15, 95% CI 0.06 to 0.36) than those diagnosed in the general population (see *Table 10*). Moreover, they were around half as likely to say that the GPs and nurses at their general practice did everything they could to provide support during cancer treatment (OR 0.46, 95% CI 0.26 to 0.83) (see *Table 10*). In addition, people diagnosed in prison were more likely to respond that their GP was not involved ($p = 0.011$, data not shown).

Control and choice

People in prison had limited control of and choice about decisions regarding their own health, and there were various structural barriers that hindered access to health care. While these barriers impact the everyday lives of people in prison the most, prison health care and custodial staff were also constrained by their working environment and the role divisions within prison. Oncology services, by contrast, aimed to empower patients to self-manage their illness, for example, through exercise and healthy eating, but the prison environment provided limited opportunities for doing this.

TABLE 10 Likelihood of preferred responses to CPES questions on cancer care among persons with a cancer diagnosed in prison compared with those diagnosed in the general population

Number	Question	Question heading	Preferred answer	OR	95% CI
1	Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Pre-diagnosis GP visits	Saw GP no more than twice before referral to hospital	0.31	0.16 to 0.57
3	How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?	Time to secondary care	Seen in less than 3 months	0.33	0.19 to 0.57
11	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Family or friend on first visit	Yes	0.14	0.07 to 0.27
14	When you were told you had cancer, were you given written information about the type of cancer you had?	Written information about cancer	Yes, and it was easy to understand	0.66	0.37 to 1.17
17	Were the possible side effects of treatment(s) explained in a way you could understand?	Possible side effects of treatment explained	Yes, definitely	0.98	0.56 to 1.72
18	Before you started your treatment, were you given written information about the side effects of treatment(s)?	Written information about side effects of treatment	Yes, and it was easy to understand	0.35	0.14 to 0.88
26	Did hospital staff discuss with you or give you information about the impact cancer could have on your work life or education?	Information on impact on work or education	Yes	0.51	0.24 to 1.10
48	Were you given enough privacy when discussing your condition or treatment?	Privacy	Yes, always	0.20	0.09 to 0.42
54	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Contact information after leaving hospital	Yes	0.10	0.04 to 0.25
55	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Information on care passed on to someone close	Yes, definitely	0.27	0.14 to 0.50
63	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Enough information given to GP	Yes	0.17	0.07 to 0.40
64	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	GP support	Yes, definitely	0.46	0.25 to 0.84

Note
Multivariable logistic regression models, adjusted for survey year, age, gender, tumour stage and ethnicity.

Preparing for appointments

Cancer treatments are generally given at regular intervals, with clear scheduling information given to patients. Because of security concerns, this information is not provided to people in prison who have cancer. Patients often deduced when their next appointment was likely to be, yet oncology professionals were discouraged by prison officers from openly discussing timeframes for treatment plans. This impacted the consultation with oncology specialists. It was important that people in prison were as prepared as possible to ask the right questions about side effects, treatment and follow-up care. If patients were not prepared, or forgot to ask questions, they missed their chance to ask any questions and had to wait until the next appointment.

Treatment

Oncology professionals reported that treatments for patients residing in prison should not differ from those for patients residing in the community. Yet patients in prison reported that they had less access to information about their specific cancer, and, as family and friends were typically absent from the diagnostic process, they made decisions about treatment on their own and on the spot. Some participants were diagnosed prior to entering prison and so their family were involved in the decision-making process. Typically, treatments such as radiotherapy and chemotherapy were provided only in hospital. Oral chemotherapy could be offered 'in-house', and a few participants in the study were 'on tablets' to treat their cancer.

Again, these findings are reflected in the NCPES results (see *Table 10*). People with cancer in prison were significantly less likely to report that they were told they could bring a family member or friend with them when they were first informed about their cancer (OR 0.17, 95% CI 0.09 to 0.32), and that family or someone close to them was given all the information they needed to help care for them at home (OR 0.49, 95% CI 0.25 to 0.98) (see *Table 10*). Further inspection of the data not included in the modelling for the latter question (data in Supplementary Table) revealed that far more people diagnosed in prison indicated that no family or friends were involved ($p < 0.0001$, data not shown).

Managing treatment side effects

It can be difficult to manage side effects in prison. Oncology specialists reported the challenge of getting patients to hospital if they experienced side effects that necessitated immediate medical attention. Furthermore, their accounts revealed that they were not sure who was responsible for monitoring patients in prison. Patients reported a range of experiences; some did not experience any symptoms, while others experienced severe and ongoing side effects. The physical prison environment was noted to be 'dirty', which was particularly concerning for immunosuppressed patients. Prison health professionals reported that there were specific protocols in place to manage side effects. As prisons had individual responses to managing cancer care, it was unclear whether these protocols were developed locally or nationally.

Managing emotions

Prisons are emotionally complicated places both for people in prison and for staff. Patients and prison officers reported that showing vulnerability was avoided in prison. A prison sentence is already emotionally challenging, and a cancer diagnosis adds to this. Yet, as one participant reported, 'This is not a place to have a mental breakdown'. Patients in prison tried to save face and keep their emotions to themselves, for example, when they heard their prognosis and bad news in front of prison officers. One person was hospitalised at the time of diagnosis and received his diagnosis while under 24-hour surveillance. He reported longing to return to his cell so he could cope with this news on his own.

Care and custody

For both prisons and healthcare organisations safety is a top priority, but their focus differs; for health care the focus is the safe delivery of care, while for prisons the emphasis is on ensuring the safety of prisoners and protecting the public from them. Tensions that were identified between care and custody largely derived from these different foci for ensuring safety. Interviews with the professional groups showed that those working in the criminal justice system were not always sure whether their role was to provide care or custody. Prison officers found it particularly difficult to reflect on their role in the care of people in prison, despite, for example, being instrumental in getting people in prison to hospital appointments. Cancer patients in prison moved between the identity of ‘cancer patients’ and ‘prisoner’ both within the prison walls and during their out- and inpatient hospital appointments.

Getting to hospital

Transporting people from prison to hospital requires careful logistical planning. Each prison can convey a limited number of people (prisoners) to hospital appointments each day, based on the prison officers available for escort duty. Typically, two prison officers escort the patient and are only told on the day of duty. The study showed that cancer was considered urgent within prisons, and patients needing to attend treatment or appointments were prioritised over others. Before diagnosis, people in prison are at risk of their diagnostic appointments being cancelled or replaced by others. Patients also reported missing appointments or being late when transport did not show up. Staff shortages and emergency situations within prisons could also result in missed appointments if escort officers were asked to cover other jobs within the prison.

The tension between care and custody is made visible as people in prison are handcuffed to an escorting prison officer. Prisons, however, adopted individual strategies to manage the issue of handcuffing. One prison did not require patients aged > 65 years to be handcuffed if their security risk allowed it. In another, people with cancer were not handcuffed. This decision was based on the risk they posed to the public. For patients, not being cuffed helped minimise feelings of shame, as they looked less like a prisoner. The use of handcuffs was a barrier to accessing care and was a reason why patients refused a hospital appointment.

Presence of prison officers in medical consultations

Interview data highlighted that the tension between security and autonomy for patients, prison officers and health professionals was amplified by the presence of prison officers during medical consultations. Oncologists reported trying to ignore the prison officers, and prison officers reported various coping strategies during consultations, ranging from ‘trying to absorb some information’ to ‘zoning out’. Patients had diverging opinions about the presence of prison officers; some said they did not mind it, while others reported that they would not ask certain medical questions (e.g. about impact on fertility) or raise concerns in front of the officers. Reasons for this ranged from being embarrassed to being wary that officers might feedback personal information to others in the prison.

Likewise, results from NCPES showed that those diagnosed in prison were far less likely than those diagnosed in the general population to respond that they were always given enough privacy when discussing their condition or treatment (OR 0.20, 95% CI 0.10 to 0.41) (see *Table 10*).

Chapter 6 Developing stakeholder policy recommendations

Some text in this chapter has been reproduced with permission from Pollitt *et al.*[45] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 3.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/3.0/. The text below includes minor additions and formatting changes to the original text.

The briefing pack for the Policy Lab participants presented the key results in graphical and written form, showing that patients in prison have significantly poorer cancer outcomes than the general population, controlling for age, sex and comorbidity, and that they report fewer positive experiences of care.

Factors underlying this situation were explained as including:

1. lack of awareness of symptoms and how to seek help
2. problems with accessing clinicians for diagnosis, problems accessing care, lower level of treatment (for a variety of reasons)
3. no or limited access to other support (e.g. online or phone)
4. limited access to or availability of after-care.

Improving this situation was explained as requiring a range of obstacles to be overcome, including:

1. a culture of control and incarceration which can clash with a culture of care
2. limited budgets
3. mental health and addiction issues tend to dominate when presenting with symptoms (e.g. suspicion that someone is seeking access to drugs)
4. the systems in place and the skills of staff tending to focus on mental health rather than physical symptoms
5. a lack of privacy (e.g. when receiving bad news, giving samples)
6. staff lacking the practical skills and experience needed to support patients
7. security and other prison policies acting to prevent patients finding support from others
8. prisons being ‘mysterious places’ for external teams to interact with.

Summary of proposed ‘top improvements’

The discussions at the Policy Lab identified four proposed ‘top improvements’ in terms of both how much impact these would have over the next 2–3 years and how possible they would be to implement:

1. communicating to clinical teams on how the prison system works (as part of efforts to join different parts of ‘the system’ to achieve a more integrated approach)
2. co-ordinating and promoting an effective approach to cancer screening that significantly increases take-up
3. having ‘health champions’ among prisoners to advise and support others
4. raising health literacy and awareness of symptoms in prison using different media, especially TV and video.

Two other, and related, possible improvements were also rated highly for impact, but some participants considered implementing these to be less feasible:

5. providing and using ‘in-cell’ technology (tablets, two-way phone, approved helpline support number) to enable prisoners to access support more readily in a timely way that respects privacy

6. using video consultations for outpatient and treatment-related interactions, which could also be extended to involve families and other members of personal support networks in the process of diagnosis and care.

Figure 4 shows the overall scoring from 16 Policy Lab participants across 12 different improvements that emerged from the discussions at the workshop.

The scoring of impact and feasibility across Policy Lab participants varied for some possible improvements more than others, reflecting the experience or evidence that each person was drawing on. It does mean that, for these improvements, some individuals gave much higher (and some much lower) than the average shows (*Table 11*).

The remainder of this document sets out the ideas that emerged from the Policy Lab under several themes:

- the need for a co-ordinated and standard approach
- the need for awareness and effective screening
- the need for effective diagnosis

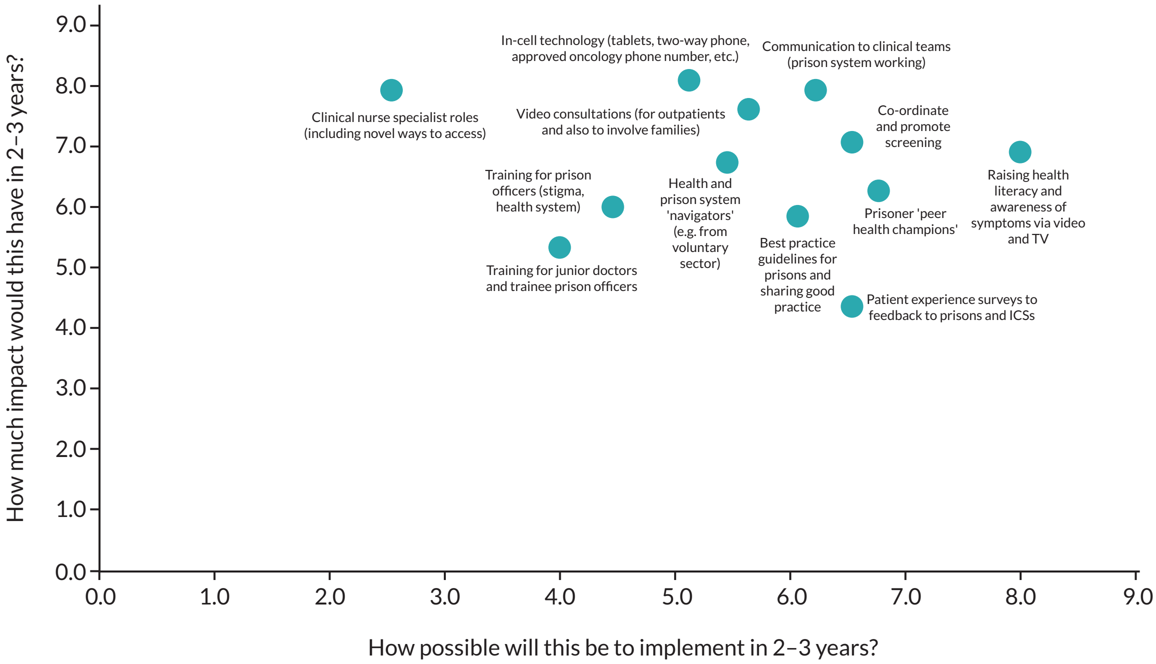

FIGURE 4 Summary scores of Policy Lab participants based on impact and feasibility.

TABLE 11 Variability in scoring potential recommendations

Most variability in scoring of impact	Most variability in scoring of implementation feasibility
Training for junior doctors and trainee prison officers	Prisoner 'peer health champions'
In-cell technology (tablets, two-way phone, approved oncology phone number)	Best practice guidelines for prisons and sharing good practice
Video consultations (for outpatients and to involve families)	Patient experience surveys to feedback to prisons and Integrated Care Systems (ICS)
Communication to clinical teams (prison system working)	Clinical Nurse Specialist roles (including novel ways to access)

- the need for a better experience of treatment
- the need for continuity of care.

It then concludes by listing a set of questions/options for further research.

The need for a co-ordinated and standard approach

The use of networks focused on improving care

It was strongly agreed that more interchange and 'cross-talk' is needed between groups who come into contact with people with cancer and are involved in the treatment of cancer patients within the prison system. This includes, but is not limited to, the prison officers and staff, local hospitals' administrative teams, cancer treatment clinicians, voluntary support groups and family/personal support networks. This would help address some of the lack of mutual understanding and co-ordination issues that undermine the quality and experience of care. Better interorganisational collaboration would also improve mutual understanding that there are challenges across all groups involved and hopefully address these issues rather than 'passing blame'.

While training programmes or clearer reporting lines might be actions to tackle the challenges in offering an integrated approach, it was felt that finding the willingness, capacity and/or funding to drive this could be hard. An alternative might be support for the establishment of informal networks of those with an interest in improving support to those in prison. This would address one question posed, namely 'there are a lot of individuals with a lot of heart and a lot of care – how do we connect these people who make an effort to join things up?'

Many people specialise in this area, including nurses in prison interested in cancer and some in acute settings who understand the rules in relation to prison (e.g. prisoners not knowing when appointments are). Bringing these people together and supporting them to inform and equip their colleagues could be an efficient way of achieving a more co-ordinated approach.

Some of these networks could be established at a place or system level where the critical aim is to develop links between surgery, radiotherapy and oncology services and local prisons that help establish and maintain personal connections among those who are empowered/have the authority to make change. There is also scope for a network at a national level to develop best practice, spread learning and provide a steer to policy. This could bring together all relevant stakeholders, both practitioners and policy-makers, and would span multiple health disciplines (medical staff, surgical colleagues, nursing, mental health).

Consolidating best practice

Whereas prison systems are quite centralised, health care tends to be much more localised. Given these very different organisational approaches, it can be hard to bring together best practice in a way that leads to standardised improvement. To create equity across different prison settings (e.g. in terms of security level) and models of health care (e.g. presence of 'prison hospital' or not), it might help to consolidate the development of best practice to ensure that this works consistently across both the prison and the health systems. It might also help to consolidate some of the resources that can drive improvement at a regional level as this could support co-ordination at a place level.

Getting the 'lived experience' into decision-making

People with lived experience have valuable insights, and it is important that their voices are integrated into any process to improve these services in the future. It was agreed that the different data sources and evidence from the project had come together incredibly powerfully in the film (*Cancer Cells*). What had previously been heard anecdotally now appeared to be borne out by the detailed quantitative and qualitative data.

Empowering families and other members of a personal support network

It was agreed that both experiences and outcomes can be improved by enabling families and other members of personal support networks to be involved from the early stages of diagnosis throughout the care process. This helps with retaining information on diagnosis, maintaining mental health and following treatment. The use of video consultations could help with this, or families could be offered the opportunity to meet with clinical staff separately to discuss what is happening and what they can do. Prison officers could also be trained so they know what they can do to help in those conversations. It was noted that the placement of prisoners so that they are physically closer to families would help with involving these support networks.

Of course, some individuals, especially those with long-term sentences, do not have established relationships outside prison, and it will be important to provide them with alternative forms of personalised support.

Training staff, especially those early in their career

It was emphasised that, like the NHS, the prison service is challenged in terms of staffing and in recovering from the disruptions resulting from the COVID-19 pandemic. Any improvement that is based on seeking more staff could be difficult to achieve in the short term, so interventions should be based on the resources available. Given these constraints, it is also critical to work across the prison, justice and health systems, rather than in silos, to make the most of any resource flexibility. An example here could be expanding the role of the chaplaincy, given the personal support skills they have established in areas, such as bereavement counselling.

As with most areas requiring improvement, specific training should be considered, especially if this can focus on improving mutual understanding of the different systems and raising awareness of specific lived experience challenges faced by prisoners. It was suggested that a particularly powerful way to do this would be by providing short courses for both medical and prison officer students. Reaching people at an early stage of their careers could be especially effective in helping avoid or tackle misperceptions and stigma by highlighting the issues prisoners face and what they may be experiencing.

The Policy Lab also affirmed the real sense that prisons are ‘mysterious places’ for NHS staff, so connecting staff from both systems and sharing lived experience stories should be part of educating them about how the prison works and how prisoners experience care. While quite a lot has been done to improve health literacy in prisons, less has happened with regard to prison literacy in health care, so that clinicians understand what is and is not possible.

Involving charities and other stakeholders

The very valuable role of charities was underlined by several examples, including experiences of Macmillan Nurse-funded posts. Voluntary sector organisations can be very effective in acting as confidantes (perhaps covering for the lack of family and friends) or training prisoner peers to bridge the gap between individual and health settings and navigate prison processes. However, this support is very variable across the country and is also not resilient, often being withdrawn because of budget constraints. Anything more that can be done to resource and enable the involvement of these organisations is likely to contribute to the improvement of care.

To help with this, and generally to flag the need to address the outcomes for prisoners with cancer, it is necessary to bring commissioners and provider management into the conversation, sharing the findings of the research and involving them in relevant networks.

Using cancer as a model for improvement

Some of the challenges faced in providing care are not unique to cancer and apply across other conditions too (e.g. completing the application to get a doctor’s appointment). Although there are a relatively small number of cases, it was suggested that cancer care can be a lever for improving care more generally, creating learning that can be used across the whole system. This could involve piloting improvements in small areas to see what works.

So, for example, sharing learning and establishing networks across the systems can bring cancer specialists together with prison care specialists to understand each other’s worlds, which would benefit not just patients in prison but also other groups, such as homeless people.

The need for awareness and effective cancer screening

Increasing health literacy and cancer awareness

Increasing levels of health literacy among both prisoners and staff would help with adopting preventative behaviours (e.g. improved diet) and spotting potential symptoms. Good examples of work to generally improve this include Macmillan Cancer Support awareness raising as a powerful part of the community pathway and the way Hepatitis C services have proactively been brought into prisons.

It was agreed that investing in the use of videos, such as that developed by the project, and messages that could be broadcast on prison TV or radio would be a great way of getting important messages across about health generally and cancer signs and symptoms specifically. This could also be used to communicate the practicalities of going through the healthcare process. Alternatives to messaging online could include greater use of literature, posters and canteen bags.

Co-ordinating and promoting cancer screening

Early intervention is key to appropriate cancer care and better treatment outcomes. Many participants emphasised that screening is a key part of this and is especially relevant for detecting disease in individuals with breast, cervical and bowel cancer who are not yet showing any symptoms. Given the individual backgrounds of people in prison, prison can also be an opportunity to access health care that was not used before.

It was suggested that the COVID-19 pandemic has hugely impacted the delivery of screening and that efforts are needed to recover from this but also to go further in establishing a more effective approach that sees a much higher proportion of eligible individuals take up the offer of screening.

Alongside increased information, there should be regular screening for these cancers as in the community that take account of the external factors that shape people's routines and that may act as barriers to prevent take-up (e.g. timings that clash with social and other events going on in the prison).

There are examples of the reported experience of routine screening being good (especially in relation to women's health), although there are often problems moving from the screening result to the next stage of getting a follow-up appointment.

The need for effective diagnosis

Getting appointments

As shown by the qualitative findings, once someone is concerned enough to seek help, one of the biggest obstacles is successfully completing the application forms to get an appointment. Many individuals find it difficult to complete these forms because of accessibility issues (e.g. dyslexia) or an inability to articulate the issues.

It is then common for applications to 'go missing', and attempts to follow up with prison staff can be tricky, with individuals being accused of 'causing trouble'. This response is part of a broader culture where trust between prisoners and staff is a major issue such that prisoners are not believed or there is suspicion of a hidden agenda.

Better questioning at reception

It was suggested that some diagnoses are missed because of the way questions are asked at reception. This can be improved by asking questions in a variety of ways on the same questionnaire, by listening more actively to 'unpack' what the individual might be experiencing, and by taking time to explore issues (e.g. why the person has not turned up at certain appointments).

Identifying and supporting health champions

Tackling the stigma attached to seeking help and/or going to prison health services or NHS hospitals, especially for men, was seen as a key area for action. Men may be less proactive in accessing health care, more worried about 'nurses gossiping', and embarrassed to ask for help with very personal issues. In addition, the fastest-growing group of people in prison with cancer are the over-fifties, who may not want people to know their background and who often have experienced stigma in mainstream settings, such as hostels and psychiatric care. All of this leads to delays in getting a diagnosis.

The use of prisoner ‘health champions’ was seen as a large potential opportunity to help with this. Individuals could be much more willing to speak to their peers and could learn from the health champions about symptoms and the process of diagnosis and treatment. They can also support people in prison in completing the application to get an appointment.

This intervention has the advantage of not necessarily being expensive to implement. The group could include those currently in prison but also those who have been released and are happy to return for visits and who nonetheless represent ‘someone like me’.

Accessing advice

Individuals should be able to access advice that is relevant and timely. Suggestions to support this include having approval of specific phone numbers in place so that individuals have a direct line to oncology services and increasing the use of video consultations that remove the reliance on escort services.

Ideally, resourcing should be increased to enable external nurses to work in the prison setting. Very effective examples were cited (e.g. Macmillan Nurses, NHS trust clinical nurse specialists) of support that can be given at appointments, at routine visits and in liaising with families. The role of clinical nurse specialists was felt by many participants to be by far the most useful in providing care that is personal and helpful (e.g. helping overcome some of the privacy issues and providing continuity).

However, these roles being relied on as widely available was questioned by some as they can be removed because of budget constraints. Ideas to improve their sustainability included organising them on a regional basis and delivering some of the clinical nurse specialist support using virtual consultations that draw on a core team of staff who are located nationally.

The need for a better experience of treatment

Ensuring more privacy and dignity

It was agreed that interventions to increase privacy in attending appointments, undergoing procedures, and producing samples for testing should be developed. Very practical examples were suggested, such as using a longer chain between the guard and the prisoner or having separate consultation spaces. One approach might be to create a working group with key staff and people with experience of prison cancer care to generate a list that could be reviewed for feasibility and then trialled in different prisons.

Increased use of communication technology

There was strong agreement that communication technology has the potential to transform interactions with hospitals, but views were quite mixed about how quickly this might be achieved and about potential variation between different prison settings.

It is evident that such technology could help with retaining information that is communicated and with protecting privacy of conversations, especially if there is good co-ordination between prisons and hospitals in setting up this technology. Ideally, the technical capabilities should then remove some of the variation experienced because of individual staff behaving in different ways.

However, while the technology to provide virtual consultations already exists, providing access to such consultations is complex. It is necessary for the prison to have an appropriate room to house the technology and for the system to be used by the relevant departments in secondary care. As noted earlier, video consultations would also allow families and others providing personal support to take part directly in conversations.

There was considerable interest in the use of 'in cell' technology, with the example given of the trialling of tablets in cells. This could open the way to using specific apps to help address health literacy issues and keep track of treatment. It was also proposed that two-way phone lines in cells be used so individuals can call out to dedicated support lines. Currently the phone lines are often one-way only.

Although technology offers many possibilities for supporting improvement, there is a need to guard against it embedding inequalities, from either variation in provision (e.g. between the technology available in modern prisons and the lack of it in older prisons) and/or the individual's ability to use it (e.g. digital literacy, accessibility issues).

The need for continuity of care

Because of the relatively lower levels of health literacy among people in prison, providing continuity of care post imprisonment is especially important if treatment is to be sustained and the best outcomes achieved. For example, when people are released from prison, it is important to ensure that they are provided with their health records and the date and time of their next appointment and that they are able to engage independently with their healthcare provider.

There was again agreement that place-based approaches should be a focus of this. However, in making these work, all those providing care who might be able to play a role (e.g. charities) need to be encouraged to think creatively about how best to support such complex cases and need to be aware of the potential risks of people falling between the gaps in the care pathway.

Questions and options for research

The Policy Lab concluded by identifying further questions and/or options for further research work to consider:

- How do new NHS governance structures (e.g. ICS, Cancer Alliances) best cater for the needs of the prison population, and would a national mapping exercise of approaches help with understanding this?
- What can be learnt from the experiences in Scotland, Wales and Ireland?
- What else works on the experiential side that can be learnt from other parts of health and social care?
- How much is currently done by the voluntary sector, and can this be used more?
- What is the potential learning from other areas in the inclusion agenda for health services (e.g. for sex workers, homeless populations)?
- How can self-care be improved in prisons (e.g. using social prescribing)?
- Implementation of individual improvement interventions risk creating or embedding inequities (e.g. around technological literacy) – what is needed in terms of a multiplicity of approaches to avoid this?
- What is driving discrepancies in curative care (e.g. what contributes from prison, health care and individual perspectives)?
- As people travel through the system, to what extent are they let down by care in the community?
- Is there scope for some form of performance management around this group, including transparently reporting on variations in outcomes so that patients can also understand what is/is not working (e.g. around referral times and other standard measure used across health service)?
- Given the long lags in getting data, it may be hard to track the impact of improvements on outcomes, so what would be the intermediate measures we can look at?

Chapter 7 Discussion

Summary of main findings

In line with the growing and ageing prison population, our epidemiological analyses found an increasing number of cancers diagnosed in English prisons between 1998 and 2017. The age-standardised incidence rates showed that cancer incidence among people in prison increased from lower levels than among the general population towards similar rates by the end of the study period. Given the higher prevalence of risk factors in the prison population, notably a higher smoking prevalence than in the general population, this increase probably reflects improved awareness and diagnosis.

Although we found a slightly higher stage distribution among the cancers diagnosed in prison, the difference from the general population was not statistically significant. However, there was a clear difference in the route to diagnosis, with cancers diagnosed in prison being less likely to result from an urgent '2-week wait' referral or through screening than those in the general population. We also found significantly lower odds of curative treatment for patients diagnosed in prison than for patients diagnosed with comparable cancers in the general population. Survival from cancers diagnosed in prison was also lower than in the general population. Although some confounding seems to arise from other factors, such as route to diagnosis, half of the survival discrepancy can be explained by fewer among the prison population receiving treatment with curative intent.

Our health economic analyses show that the secondary healthcare cost of cancer care for patients diagnosed in prison is £1284 less per patient on average than that for their peers diagnosed in the general population. This is predominately due to fewer attendances for planned inpatient care and outpatient appointments. The cost of emergency care for patients diagnosed in prison was on average £1018 higher per patient than for the matched general population cohort. This finding fits with the epidemiological findings of poorer access to care and poorer outcomes. This poorer care also comes at the additional cost of escorts and bed-watches for people in prison, a cost that is covered by the NHS.

Our qualitative interviews with patients and health and prison professionals showed that cancer care in prison is complex, not least because people in prison move between a hospital and a prison environment. People in prison follow a similar pathway to diagnosis to those in the community, but with several specific barriers to diagnosis including health literacy, the process of 'putting in an app' before seeing a clinician and the logistics and routines of both prisons and hospitals. We found that there were tensions between control and choice in prison health care that impact patients' experience of cancer care in terms of symptom management, accessing information about their cancer, and family involvement in their care. Communication between professionals within and out of the prison was also disjointed and significantly impacted the care experiences of people with cancer in prison. These interview findings were also reflected in the findings from analyses of previously collected NCPES results. Here patients returning surveys reported worse experiences of cancer care than matched controls from the general population. In interviews we found that oncology professionals took pride in providing 'the same' care to people in prison as they did to those in the community. This may, however, unintentionally disadvantage people in prison, as in prison patients have limited access to information and support. The Royal College of General Practitioners warned in 2018 that 'equivalence of care' in secure environments should not mean 'the same', so more training needs to be provided to healthcare professionals to ensure equity in access to health care.[24]

Based on all the findings above, four initial policy priorities were identified by stakeholders in the Policy Lab that might be reasonably implemented within the next 2–3 years. Participants' collective choices were based on the likely feasibility and impact of interventions using their knowledge and experience of working in prison and/or cancer policy. The first was to increase communication to clinical teams in hospitals about how the prison system works. This was seen as being undertaken as part of efforts to join up different parts of 'the system' to achieve a more integrated approach for patients. Co-ordinating and promoting an effective approach to cancer screening that significantly increases take-up was the second priority. The third concerned supporting people in prison by developing peer health champions from the prison population who could advise and support others, and the fourth was to devise ways of raising health literacy and increasing awareness of symptoms using different media, especially TV and video, in prison.

Robustness of the results and their limitations

Because in our epidemiological analyses we matched individuals diagnosed in prison on age, sex, diagnosis year, tumour site and disease stage with those in general population settings, we could not investigate the actual influence of these factors, most notably stage of disease, on treatment and survival. There may therefore have been residual confounding that would explain the survival deficit we found. The prison population is also more likely to include individuals from lower socioeconomic backgrounds – a factor that is known to be associated with poorer survival. We were not able to assess the impact of this or of other factors associated with higher levels of deprivation as in England we would normally do so using an individual's postcode of residence to calculate the Index of Multiple Deprivation. In this study the prison postcode was used to identify the place of diagnosis, which is not reflective of the person's usual socioeconomic status.

One of the main treatment modalities for curative intent is surgery. We could not identify potentially curative surgical procedures for all cancers in this study. This means that for the 19% of cancers for which relevant OPCS-4 codes have not been identified, potentially curative treatment is missing from the analysis. However, as we matched on cancer site, this affects both the prison and the comparison general population and may attenuate overall findings. We were not able to consider palliative treatments.

While we were able to identify cancers diagnosed in prison, the total burden of cancers in prison is likely to be higher. To estimate the prison cancer prevalence, work will need to be undertaken to match clinical data from SystmOne and MOJ to the cancer registry to determine those diagnosed with cancer before arriving in prison and who therefore may be living with active or recurrent cancer that could require treatment.

Our health economic study is limited to including only secondary care contacts and does not include primary care or prison healthcare costs. Further work is required to understand the quantity and cost of prison health care for patients diagnosed with cancer in prison. The equivalent would also need to be undertaken for a matched cohort in the community. We were also unable to include accident and emergency data and hence additional costs of these attendances could have been missed, particularly for patients in the community. The cost of appointments that patients did not attend was also excluded from the analysis. This is due to the issues associated with estimating such costs, particularly the cost implications for prison compared with the community.

The use of routine data is a strength of this study as research in prisons is notoriously difficult to conduct, and loss to follow-up is common.[46] Using routine data reduces the bias inherent in prison studies, but people in prison can still be commonly missing from routine healthcare data.[47] Routine data are also known to contain some errors, particularly when calculating costs.[48] These errors should have been equal across both groups, so although the total costs might not be correct, the difference in costs should be close to the true value.

While we sought to calculate the costs for people diagnosed in prison, some of the patients diagnosed in prison may have been released into the community during the 6 months after diagnosis and their contact with care may have changed. People who are released on temporary licence may also not have escort and bed-watches costs, although they make up only 5% of the prison population. As a result, the cost of escorts and bed-watches might have been overestimated and should be interpreted with caution. When looking at costs it is also important to look at outcomes and potentially conduct a full economic evaluation to fully quantify the inefficiency of providing cancer care in prison. This was not possible given that, other than on mortality, we had limited outcome data. The number of different cancer sites and potential outcomes would have made any decision modelling or estimation of outcomes prohibitive.

Owing to the COVID-19 pandemic we had to stop our qualitative interviews early; nevertheless, the 55 interviews conducted provided detailed information from a broad range of participants on the main themes. One-off interviews offer a snapshot of people's lives, and follow-up interviews and a longitudinal approach could have offered even greater insight into the lived experiences of people with cancer in prison and those who care for them. However, as this is the first study to explore this issue, our interviews already offer ample evidence of how cancer care is experienced and potentially could be improved. This is the first time that NCPES data have been analysed for patients in prison, and we do not know how representative the patients responding are of all those diagnosed in prison. We also know that patients from lower socioeconomic groups are less likely to respond to surveys and that the lower literacy levels among the prison population would likely decrease the response rates further. We were not able to match patients' CPES response on tumour site.

Finally, it is possible that a different group of practitioner stakeholders attending a second Policy Lab might have viewed the study findings in different ways and chose different policy priorities as a result.

Review of evidence

This study is the first to use comprehensive NDRS data to reliably establish cancers diagnosed in English prisons, based on postcode of residence for the two decades 1998–2017. As far as we can determine it is also the first study worldwide to consider an entire national population of patients diagnosed with cancer in prison, quantify the cost of cancer care for a national population of people in prison, particularly compared with those in the community, offer an in-depth multiperspective account, including the prisoner-patient voice, and report stakeholders' priorities based on findings that demonstrate the complexity of cancer care in custodial settings.

We identified several barriers to and enablers of getting a diagnosis and treatment. Not all the barriers we found are specific to patients in prison, with some (i.e. late diagnosis) experienced by people residing in the general population, but these are exacerbated by the prison environment. Prisons are designed to take away elements of control and choice,[18] yet hospitals aim to be inclusive and empowering. The overlap and tensions between the social roles of 'prisoner' and 'patient' have been documented[17] and were also present in the study as the professional groups used a range of terms, including 'prisoner', 'patient', 'prisoner/patient' and 'the men and women in our care'.

While surgeons, radiotherapists and oncologists might treat people in prison 'the same', this sameness can unintentionally lead to further disadvantage. We also found that each prison adopts its own way of caring for its prison population. National guidance and the sharing of best practice could therefore improve cancer care. Better methods for communicating within and between institutions could also improve cancer care and specifically the patient experience. Our results support findings from other studies on health care in prison showing that there is awareness of the disadvantages and structural barriers to care for those residing in prison.[17,18,23] With a growing and ageing prison population these barriers need to be addressed in both policy and practice to ensure good patient care.

Recommendations for future research

At a health system level there is a need to map and understand how NHS governance structures in England, including ICS and Cancer Alliances, currently operate for cancer patients in prison. In addition, at this level an assessment is needed of how previously unanalysed data on people in prison, currently held by NHS and used in this study, could be used to routinely report cancer outcomes for patients in prison and explore variations in referral and outcomes. Because of the complexity of obtaining prison healthcare medical records, patient data for people in prison have not been used to monitor quality of care. Further work with MOJ, prison health providers and commissioners is required to explore how these data could be accessed with the aim of conducting data linkage studies to give a complete picture of the burden of cancer in this population. As there may be time delays in reporting these data, more real-time measures that might be used to track the impact of any planned improvements on outcomes should also be explored. The cost implications to the NHS of escorts and bed-watches could also be better quantified using linked data.

To design new interventions more could be learnt from health and cancer care systems in Scotland, Wales and Northern Ireland, which were not included in this study. Some models of care already applied in other parts of health and social care, and the voluntary sector around health inclusion and decreasing health inequalities, may be relevant. For example, there may be lessons learnt for cancer care for people who are sex workers, homeless or refugees that could be applied to prison care. As far as the development of specific interventions in cancer care are concerned, more work is needed to understand barriers to achieving equivalence in treatment and care. These may be related to the organisation of clinical care, restrictions in the prison system due to security measures, the availability of personnel, communication between health professionals within the prison system and hospitals, communication between health professionals and prison staff, or patient choice affected by availability of information. It will also be important to determine as far as possible the reasons for the lower rates of curative treatment and survival and to determine where these are amenable to change. Technological solutions including remote consultations and access to online information are potentially attractive for improving co-ordination of care between the NHS and prisons, but they do potentially risk creating or embedding further inequities relating to technological literacy, and a multiplicity of approaches may be needed. Finally, there is a need to know what happens to cancer care for patients once they leave prison and the kind of ongoing support that these patients may need. This would include data from primary care and over a longer time horizon to obtain a better understanding of long-term community care.

Implications for decision-makers

This study provides new knowledge about the cancers that most commonly affect people in English prison and the areas on which prevention and national cancer screening programmes should focus. Prisons have been smoke-free since 2006, but the effect of previous exposure will endure for many years, and lung and bladder cancer will remain a significant issue for this population. National screening programmes currently exist for three cancers – breast, cervical and bowel cancer – and need to be both effective and monitored. The use of cancer data already within the system needs to be extended for reporting and used much more actively to monitor incidence, prevalence, and patients' experiences and their outcomes routinely.

Although the secondary care component of cancer care costs less for patients diagnosed in prison than for their peers diagnosed in the community, this comes at a significant cost in terms of outcomes, such as increased emergency attendances and reduced survival. It also comes at the additional cost associated with escorts and bed-watches. Further work is needed to improve access to planned care following a cancer diagnosis in prison. It is important that any future evaluations of interventions to improve access to cancer care in prisons take account of the impact of costs as well as attempting to quantify the health benefits of the intervention. Equity considerations also need to be explicitly considered as investments should be made such that outcomes for people in prison begin to better reflect those for people in the community, which may require significant additional investment.

Several barriers to and enablers of getting a diagnosis and treatment exist within the prison setting and between prisons and NHS services. Limited guidance is available on care provision for this group and so national guidance and the sharing of best practice could help drive improvements in cancer care. As communication processes are disjointed, better methods for more seamless communication within and between institutions could improve cancer care, the patient-prisoner experience and understanding among clinical teams in hospital of how the prison system works. Co-ordinating and promoting an effective approach to cancer screening that significantly increases take-up and effective follow-up and treatment would assist with earlier diagnosis of cancer in the prison population, particularly in relation to cervical screening in women's prisons. Psychological support of people with cancer in prison could be improved by developing peer health champions from the prison population who could advise and support others. Finally, raising health literacy levels and increasing awareness of cancer symptoms using different media, especially TV and video, in prison, could help detect cancer at an earlier stage.

Equality, diversity and inclusion

The composition of the research team remained almost entirely female throughout the study, with one male research manager, five senior female researchers at reader, professorial or director levels, and three female researchers at lecturer or earlier career stages. One male EbE was also involved in interview data collection and analysis throughout the study. He helped to design the interviews and our approach to patients in prison. He also led the initial interviews and was involved in the qualitative analysis and the Policy Lab event. The male–female balance for both the Project Advisory and Independent Steering Groups was 50 : 50, and 25 : 75 for the Policy Lab event which was facilitated by one male individual. Diversity by ethnicity, however, was limited across each group involved in the study.

Patient and public involvement

Patient and public involvement was considered at every stage of the design, delivery and presentation of this research project. Members of the NCRI Consumer Forum who had experience of being diagnosed with cancer and of working in prison were included in designing the initial study proposal. After the project was shortlisted for funding, this element was expanded to include RDA, which has specific experience of working with EbE (people who have experience of being in prison). RDA advised on involving EbE in the co-design of the interviews with all parties, and their delivery and analysis. Once the proposal was successful in being funded, RDA engaged and supported three EbE who had experience of cancer in prison to work with us on these elements of phase 2 work package as well as to attend meetings as members of the Project Advisory Group. A paper describing the very positive benefits of this collaboration was the first study output to be published.[33] The interview findings were then used to develop a 'talking heads' film, *Cancer Cells*, in collaboration with Synergy Theatre Project. This organisation works with people who have been in prison as part of their rehabilitation to develop films and plays that portray issues of justice. Once the script had been produced, EbE advised members of the research team about whether some sensitive details about taking a sample should be included in the script. Several members of the Synergy Theatre Project cast had been in prison themselves, which we believe led to the development of a film that was seen as hard-hitting but very realistic by stakeholders attending the Policy Lab. We have so far received very positive feedback about this element. The three EbE also attended the Policy Lab event and contributed to discussions, and they have been positive about their involvement. Two of the EbE were also present at the launch of its findings and the Synergy Theatre Project film *Cancer Cells* at the House of Lords in May 2024, where they also presented their experience of being involved in the study. No analysis of economic benefit has been undertaken, but our experience is that this kind of PPI is essential to any future study of the experiences of people in prison.

Conclusions

Cancer incidence in English prisons rose between 1998 and 2017 to reach similar levels to those in the general population. However, patients diagnosed in prison have fewer but longer 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 security escorts. This is alongside evidence of poorer experiences of care reported both in detailed interviews with patients and using an established national survey. Cancer care in prison is complex, not least because people in prison move between a patient and a prison environment. Tensions between control and choice in prison healthcare impacted patients' experiences of cancer care in terms of the diagnostic process, symptom management, accessing information about their illness, and the involvement of family in their care. The initial policy priorities identified by prison and cancer stakeholders based on these findings are to improve understanding between prison and cancer clinical teams to improve patient care, develop the role of 'health champions' in prison, and raise health literacy and awareness of both cancer screening and cancer symptoms in prison.

Additional information

Contributions of authors

Elizabeth A Davies (https://orcid.org/0000-0003-2325-0849), Professor in Cancer and Public Health at King's College London, led the overall study, edited each chapter, wrote the abstract, drew together the findings, wrote *Chapter 7* and co-ordinated report development.

Margreet Lüchtenborg (https://orcid.org/0000-0001-8694-4819), Lecturer in Cancer Epidemiology at NDRS, NHS England and Honorary Lecturer in Cancer Epidemiology at King's College London, designed and checked the epidemiological analyses and wrote *Chapter 3*.

Rachael Maree Hunter (https://orcid.org/0000-0002-7447-8934), Professor of Health Economics at University College London, designed and supervised the health economic analyses and wrote *Chapter 4*.

Renske Visser (https://orcid.org/0000-0002-6086-5837), Research Fellow at Surrey University, designed, undertook and analysed the qualitative interviews and drafted *Chapter 5*.

Jennie Huynh (https://orcid.org/0000-0003-1232-4152), Research Assistant in Cancer Epidemiology at King's College London, helped to design and undertake the epidemiological and health economic analyses, helped to write *Chapters 3* and *4*, and reviewed all the figures and references.

Ross Pow (https://orcid.org/0009-0005-0951-9970), Director, The Power of Numbers Ltd, designed and facilitated the Policy Lab event and wrote *Chapter 6*.

Emma Plugge (https://orcid.org/0000-0002-8359-0071), Professor at University of Southampton, and Consultant in Public Health, Health Equity and Inclusion Health, UK Health Security Agency, helped to design and interpret the qualitative study and reviewed and edited the full report.

Rachel M Taylor (https://orcid.org/0000-0002-0853-0925), Director of the Centre for Nurse, Midwife and Allied Health Profession Research, helped to design the Policy Lab event and reviewed and edited the full report.

Jo Armes (https://orcid.org/0000-0002-7994-0796), Professor of Cancer Care at the University of Surrey, designed and analysed the qualitative study, helped write and revise *Chapter 5* and reviewed and edited the full report.

Acknowledgements

We thank Josefien Breedvelt, Ruth Jack, Paula Harriott, and Jeremy Whelan for their help with the design of this study, and Philomena Bredin of King's College London for her administrative support throughout. We thank members of our Project Advisory Group, chaired by Baroness Delyth Morgan, and our Independent Steering Group, chaired by Mr Richard Stephens, for their support and advice throughout the project. Finally, we thank Revolving Doors Agency research managers Ann Hanrahan and Philip Mullen and Experts by Experience Alyce-Ellen Barber, Sue Wheatcroft and Anthony X for their involvement in and support of this project.

Funding was also received by Elizabeth A Davies from King's College London and by Jo Armes from University of Surrey – Strategic Priorities Fund (SPF) Allocation 2019/20.

Data-sharing statement

Data for the epidemiological, health economic and CPES analyses are collated, owned, maintained and quality assured by the NDRS within NHS England. The authors do not own these data and are therefore not permitted to share or provide these data other than in scientific communication format. Other data requests should be submitted to the corresponding author for consideration. Access to some anonymised data may be granted following review.

Ethics statement

The National Disease Registration Service (NDRS) has approval from the Confidentiality Advisory Group of the NHS Health Research Authority to carry out surveillance using the data they collect on all cancer patients under section 251 of the NHS Act 2006. All analyses of national data were undertaken by Jennie Huynh and Margreet Lüchtenborg, who worked within NDRS. Therefore, separate ethical approval was not required for the phase 1 epidemiological, health economic or phase 2 survey analyses. The qualitative interview study in phase 2 received favourable research ethics approval from the Health Research Authority (REC 19/LO/1073) and HMPPS (reference 2019-306).

The methods used in the development of recommendations including the development of a film, co-design groups and the Policy Lab event in phase 3 received approval from King's College London Research Ethics Committee (reference MRA-20/21-22403).

Information governance statement

King's College London is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, King's College London is the Data Controller, and you can find out more about how it handles personal data, including how to exercise your individual rights and the contact details for its Data Protection Office here: https://www.kcl.ac.uk/research/research-environment/rgei/research-governance

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/HYRT9622.

Primary conflicts of interest: Elizabeth A Davies reports Irish Cancer Society review of proposals (November 2021), Singapore government review of proposals (May 2021), and Emory College Summer School lectures (July 2019). Emme Plugge was a mem ber of the Systematic Reviews National Institute for Health and Care Research (NIHR) Cochrane Incentive Awards. Rachel M Taylor reports Margaret Spittle Fellowship, NIHR, NCEL ICS, UCLH Charity and Sarcoma UK (all payments to institution); travel to present a keynote lecture in Toronto, ON; being a member of the RCN Research Society Steering Committee; being a member of Teenagers and Young Adults with Cancer (TYAC) Professional Education Group; being a member of TYAC Research Advisory Group; being an ambassador for Sarcoma UK; and leading the patient outcome work package for the FOSTER (European osteosarcoma) consortium.

References

1. Sturup-Toft S, O'Moore EJ, Plugge EH. Looking behind the bars: emerging health issues for people in prison. *Br Med Bull* 2018;**125**:15–23. https://doi.org/10.1093/bmb/ldx052
2. World Health Organization. *Prisons and Health*. Copenhagen: WHO; 2014. URL: www.who.int/europe/publications/i/item/9789289050593 (accessed 17 October 2024).
3. Alves da Costa F FN, Berdzuli N, Kluge H, Davies E, Hamad M, Neufeld M, *et al*. Non-communicable diseases are being left behind in prisons during the COVID-19 pandemic. *BMJ Opin* 2021. URL: https://blogs.bmj.com/bmj/2021/09/10/non-communicable-diseases-are-being-left-behind-in-prisons/ (accessed 17 October 2024).
4. Davies EA, Sehgal A, Linklater KM, Heaps K, Moren C, Walford C, *et al*. Cancer in the London prison population, 1986–2005. *J Public Health (Oxf)* 2010;**32**:526–31. https://doi.org/10.1093/pubmed/fdq009
5. Puglisi LB, Winkelman TNA, Gross CP, Wang EA. Cancer prevalence among adults with criminal justice involvement from a national survey. *J Gen Intern Med* 2020;**35**:967–8. https://doi.org/10.1007/s11606-019-05177-2
6. Renault L, Perrot E, Pradat E, Bartoli C, Greillier L, Remacle-Bonnet A, *et al*. Concerns about lung cancer among prisoners. *Lung* 2018;**196**:115–24. https://doi.org/10.1007/s00408-017-0066-6
7. Blagden S, Simpson C, Limmer M. Bowel cancer screening in an English prison: a qualitative service evaluation. *Public Health* 2020;**180**:46–50. https://doi.org/10.1016/j.puhe.2019.10.024
8. Escobar N, Plugge E. Prevalence of human papillomavirus infection, cervical intraepithelial neoplasia and cervical cancer in imprisoned women worldwide: a systematic review and meta-analysis. *J Epidemiol Community Health* 2020;**74**:95–102. https://doi.org/10.1136/jech-2019-212557
9. UK Prison Population Statistics. *House of Commons Library Briefing Paper Number CBF-04334*. London: UK Prison Population Statistics; 2020.
10. Prisons and Probation Ombudsman. *Prisons & Probation Ombudsman Independent Investigations: Annual Report 2018–2019*. London: Prisons and Probation Ombudsman; 2019.
11. Harzke AJ, Baillargeon JG, Goodman KJ, Pruitt SL. Liver cancer mortality among male prison inmates in Texas, 1992–2003. *Prev Med* 2009;**48**:588–92. https://doi.org/10.1016/j.ypmed.2009.03.011
12. Brousseau EC, Ahn S, Matteson KA. Cervical cancer screening access, outcomes, and prevalence of dysplasia in correctional facilities: a systematic review. *J Womens Health (Larchmt)* 2019;**28**:1661–9. https://doi.org/10.1089/jwh.2018.7440
13. McConnon A, Fung K, Lofters A, Hwang SW, Kouyoumdjian FG. Colorectal and breast cancer screening status for people in Ontario provincial correctional facilities. *Am J Prev Med* 2019;**56**:487–93. https://doi.org/10.1016/j.amepre.2018.11.011
14. Plugge E, Fitzpatrick R. Factors affecting cervical screening uptake in prisoners. *J Med Screen* 2004;**11**:48–9. https://doi.org/10.1177/096914130301100111
15. Ramaswamy M, Simmons R, Kelly PJ. The development of a brief jail-based cervical health promotion intervention. *Health Promot Pract* 2015;**16**:432–42. https://doi.org/10.1177/1524839914541658
16. Valera P, Mackey D, Cropsey K. A pilot study of cancer 101 for incarcerated male smokers. *Behav Med* 2020;**46**:112–9. https://doi.org/10.1080/08964289.2019.1588219
17. Plugge E, Douglas N, Fitzpatrick R. Patients, prisoners, or people? Women prisoners' experiences of primary care in prison: a qualitative study. *Br J Gen Pract* 2008;**58**:630–6. https://doi.org/10.3399/bjgp08X330771
18. Woodall J, Dixey R, South J. Control and choice in English prisons: developing health-promoting prisons. *Health Promot Int* 2014;**29**:474–82. https://doi.org/10.1093/heapro/dat019

19. Tait SA. Typology of prison officer approaches to care. *Eur J Criminol* 2011;**8**:440–54. https://doi.org/10.1177/1477370811413804
20. MacDonald R, Parsons A, Venters HD. The triple aims of correctional health: patient safety, population health, and human rights. *J Health Care Poor Underserved* 2013;**24**:1226–34. https://doi.org/10.1353/hpu.2013.0142
21. Pont J, Stover H, Wolff H. Dual loyalty in prison health care. *Am J Public Health* 2012;**102**:475–80. https://doi.org/10.2105/AJPH.2011.300374
22. Turner M, Payne S, Barbarachild Z. Care or custody? An evaluation of palliative care in prisons in North West England. *Palliat Med* 2011;**25**:370–7. https://doi.org/10.1177/0269216310393058
23. Edge C, Stockley MR, Swabey ML, King ME, Decodts MF, Hard DJ, Black DG. Secondary care clinicians and staff have a key role in delivering equivalence of care for prisoners: a qualitative study of prisoners' experiences. *EClinicalMedicine* 2020;**24**:100416. https://doi.org/10.1016/j.eclinm.2020.100416
24. Royal College of General Practitioners. *Equivalence of Care in Secure Environments in the UK*. London: Royal College of General Practitioners; 2018.
25. United Nations. *The United Nations Stanvdard Minimum Rules for the Treatment of Prisoners (the Nelson Mandela Rules)*. 2015. URL: www.unodc.org/documents/justice-and-prison-reform/GA-RESOLUTION/E_ebook.pdf (accessed 17 October 2024).
26. Henson KE, Elliss-Brookes L, Coupland VH, Payne E, Vernon S, Rous B, Rashbass J. Data resource profile: National Cancer Registration Dataset in England. *Int J Epidemiol* 2020;**49**:16. https://doi.org/10.1093/ije/dyz076
27. Davies M, Keeble E, Hutchings R. *Injustice? Towards a Better Understanding of Health Care Access Challenges for Prisoners*. Nuffield Trust; 2021. URL: www.nuffieldtrust.org.uk/files/2021-10/1634637809_nuffield-trust-prisoner-health-2021-final.pdf (accessed 17 October 2024).
28. Rothman KJ, Boice JD Jr, editors. *Epidemiologic Analysis with a Programmable Calculator*. Bethesda, MD: U.S. Department of Health, Education, and Welfare, Public Health Service, National Institutes of Health; 1979.
29. Quan H, Sundararajan V, Halfon P, Fong A, Burnand B, Luthi JC, *et al*. Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data. *Med Care* 2005;**43**:1130–9. https://doi.org/10.1097/01.mlr.0000182534.19832.83
30. National Cancer Intelligence Network. *Routes to Diagnosis: NCIN Data Briefing*. 2010. URL: http://digital.nhs.uk/dat-and-information/publications/statistical/routes-to-diagnosis/2018 (accessed 17 October 2024).
31. NHS England. *National Cost Collection for the NHS*. 2020. URL: www.england.nhs.uk/national-cost-collection/#ncc1819 (accessed 2 June 2021).
32. Curtis LA, Burns A. *Unit Costs of Health and Social Care 2020*. Canterbury: PSSRU, University of Kent; 2020. https://doi.org/10.22024/UniKent%2F01.02.84818
33. Department of Health and Social Care. *A Twelve-Month Study of Prison Healthcare Escorts and Bedwatches*. London: Department of Health and Social Care; 2006.
34. Office for National Statistics. *Services Producer Price Index*. 2019. URL: www.ons.gov.uk/economy/inflationandpriceindices/bulletins/servicesproducerpriceindices/januarytomarch2019 (accessed 4 August 2021).
35. Ministry of Justice. *Prison Population Statistics*. URL: www.gov.uk/government/collections/prison-population-statistics
36. Visser R, Barber AE, X A, Wheatcroft S, Mullen P, Armes J. Collaboration with people with lived experience of prison: reflections on researching cancer care in custodial settings. *Res Involv Engagem* 2021;**7**:48. https://doi.org/10.1186/s40900-021-00284-z
37. Barber J, Thompson S. Multiple regression of cost data: use of generalised linear models. *J Health Serv Res Policy* 2004;**9**:197–204. https://doi.org/10.1258/1355819042250249

38. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health* 2019;**11**:589–97. https://doi.org/10.1080/2159676X.2019.1628806

39. Richards M, Corner J, Maher J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. *Br J Cancer* 2011;**105**:S1–4. https://doi.org/10.1038/bjc.2011.416

40. Jones CE, Maben J, Lucas G, Davies EA, Jack RH, Ream E. Barriers to early diagnosis of symptomatic breast cancer: a qualitative study of Black African, Black Caribbean and White British women living in the UK. *BMJ Open* 2015;**5**:e006944. https://doi.org/10.1136/bmjopen-2014-006944

41. Hinrichs-Krapels S, Bailey J, Boulding H, Duffy B, Hesketh R, Kinloch E, *et al*. Using Policy Labs as a process to bring evidence closer to public policymaking: a guide to one approach. *Palgrave Commun* 2020;**6**:101. https://doi.org/10.1057/s41599-020-0453-0

42. Lüchtenborg M, Huynh J, Armes J, Plugge E, Hunter RM, Visser R, *et al*. Cancer incidence, treatment, and survival in the prison population compared with the general population in England: a population-based, matched cohort study. *Lancet Oncol* 2024;**25**:553–62. https://doi.org/10.1016/S1470-2045(24)00035-4

43. Hunter RM, Huynh J, Lüchtenborg M, Armes J, Plugge E, Taylor RM, *et al*. 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;**72**:102575. https://doi.org/10.1016/j.eclinm.2024.102575

44. Armes J, Visser R, Lüchtenborg M, Huynh J, Wheatcroft S, X A, *et al*. Cancer in prison: barriers and enablers to diagnosis and treatment. *eClinicalMedicine* 2024;**72**:102540. https://doi.org/10.1016/j.eclinm.2024.102540

45. Pollitt A, Pow R, Moxham-Hall V, Davies EA, Taylor R, Armes J, *et al*. *Improving cancer care in prisons*. London: The Policy Institute, King's College; May 2024. URL: http://openresearch.surrey.ac.uk/esloro/outputs/report/improving-cancer-care in prisons/99883666302346

46. Quinn C, Byng R, Shenton D, Smart C, Michie S, Stewart A, *et al*. The feasibility of following up prisoners, with mental health problems, after release: a pilot trial employing an innovative system, for engagement and retention in research, with a harder-to-engage population. *Trials* 2018;**19**:530. https://doi.org/10.1186/s13063-018-2911-1

47. Ahalt C, Binswanger IA, Steinman M, Tulsky J, Williams BA. Confined to ignorance: the absence of prisoner information from nationally representative health data sets. *J Gen Intern Med* 2012;**27**:160–6. https://doi.org/10.1007/s11606-011-1858-7

48. Thorn JC, Turner E, Hounsome L, Walsh E, Donovan JL, Verne J, *et al*. Validation of the hospital episode statistics outpatient dataset in England. *PharmacoEconomics* 2016;**34**:161–8. https://doi.org/10.1007/s40273-015-0326-3

Appendix 1 Healthcare costs sensitivity analysis

TABLE 12 Total cancer healthcare costs in 2018–9 GBP: excluding unknown NHS numbers

	General population (*N* = 4192)	Prison (*N* = 852)	Difference[a] (95% CI)
Outpatient			
Adjusted[a] total cost, mean (SE)	1545.589 (24.90668)	1008.12 (34.8716)	−537.469 (−620.429 to −454.509
Elective (planned) inpatient care			
Adjusted[a] total cost, mean (SE)	3377.641 (57.19538)	3023.497 (106.8898)	−354.144 (−583.577 to −124.711)
Day cases			
Adjusted[a] total cost, mean (SE)	672.9136 (10.96276)	468.2676 (16.3743)	−204.646 (−242.45 to −166.842)
Emergency inpatient care			
Adjusted[a] total cost, mean (SE)	1164.324 (21.54516)	1684.888 (64.70555)	520.5636 (394.5648 to 646.5623)
Total inpatient care			
Adjusted[a] total cost, mean (SE)	5188.937 (82.27267)	4731.648 (164.0583)	−457.289 (−813.371 to −101.207)
Total healthcare costs			
Adjusted[a] total cost, mean (SE)	6739.039 (106.6988)	5728.353 (198.1954)	−1010.69 (−1447.96 to −573.408)
Total healthcare costs including escorts and bed-watches			
Adjusted[a] total cost, mean (SE)	6739.017 (106.5665)	17,584.11 (608.5001)	10,845.09 (9638.346 to 12,051.84)

SE, standard error.

[a] Adjusting for age groups, sex, year of diagnosis, cancer type, disease stage, Charlson comorbidity score and ethnicity.

TABLE 13 Total cancer healthcare costs in 2018–9 GBP: imputing HRGs with 0 cost with mean HRG costs

	General population	Prison	Difference[a] (95% CI)
Outpatient			
Adjusted[a] total cost [mean (SE)]	–	–	–
Elective (planned) inpatient care			
Adjusted[a] total cost, mean (SE)	3771 (100)	3213 (146)	−558 (−854 to −261)
Day cases			
Adjusted[a] total cost, mean (SE)	747 (16)	505 (21)	−242 (−290 to −193)
Emergency inpatient care			
Adjusted[a] total cost, mean (SE)	1251 (37)	2567 (152)	1316 (1043 to 1589)
Total inpatient care			
Adjusted[a] total cost, mean (SE)	5268 (110)	4752 (201)	−515 (−936 to −95)
Total healthcare costs			
Adjusted[a] total cost, mean (SE)	6936 (138)	5624 (232)	−1312 (−1817 to −807)
Total healthcare costs including escorts and bed-watches			
Adjusted[a] total cost, mean (SE)			

SE, standard error.

[a] Adjusting for age groups, sex, year of diagnosis, cancer type, disease stage, Charlson comorbidity score and ethnicity.

EME
HSDR
HTA
PGfAR
PHR

Part of the NIHR Journals Library
www.journalslibrary.nihr.ac.uk

Published by the NIHR Journals Library