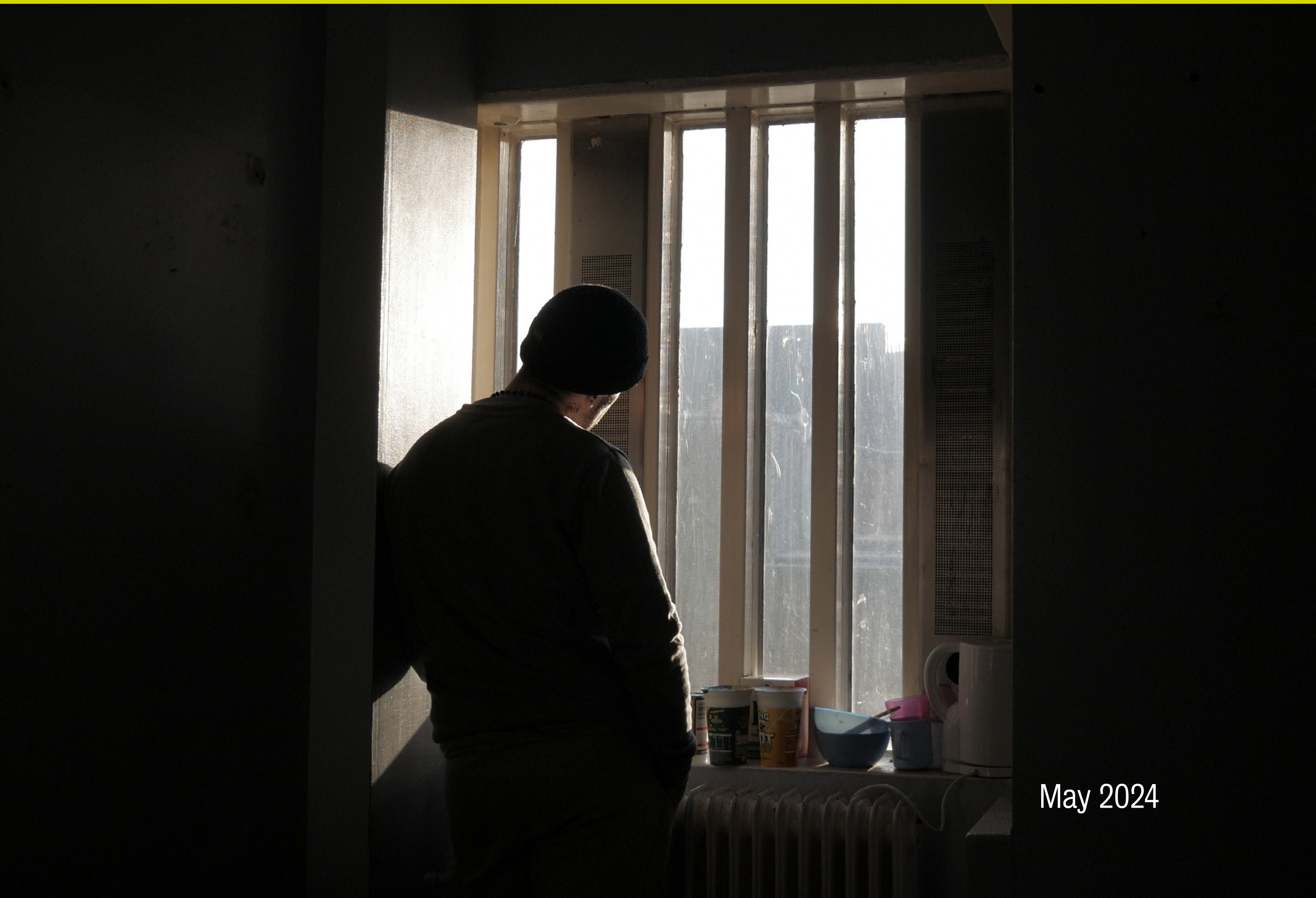
Improving cancer care in prisons



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About the project

> “How is cancer care best provided to patients in English prisons? Assessing the disease burden in the prison population, experiences of diagnosis, treatment and support, and of receiving and providing cancer care”

This research project was funded by the National Institute for Health and Care Research, and ran from 2018 to 2022. It was a mixed method study assessing: disease burden; cost of cancer care; experiences of diagnosis, treatment and support; and experiences of receiving and providing care. It analysed national cancer registration and Ministry of Justice (MOJ) data, National Cancer Patient Experience Survey data (NCPES) and interview data.

The study’s main findings were published in April 2024.[1, 2, 3]

This research project was funded by the National Institute for Health and Care Research (Project number 16/52/53), King’s College London and the University of Surrey. Partners in the study were King’s College London, University of Surrey, University College London, University of Southampton, University College London Hospitals NHS Foundation Trust, the National Disease Registration Service, Revolving Doors and Synergy Theatre Project.

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

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Contents

The challenge

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

This means that cancer care – and patients' experiences of it – in prisons is materially different from cancer care in the community. Efforts to improve care in prisons are hindered by an array of practical and cultural obstacles:

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

In March 2022 we convened a Policy Lab[5] which brought together researchers, professionals from health and prison services, charities, policymakers, and those with personal experience of the relevant issues to reflect on these challenges and develop practical ideas to improve care.

Background

> Cancer burden, treatment, survival, cost of care and experiences of care in prisons are significantly different from community treatment

Our recently published study has found that over the past 20 years, the incidence of cancer recorded in prisons has increased[1]. While it is now much more comparable to the general population, reflecting better diagnosis, incidence in prisons is still generally lower (with the exception of bladder and lung cancers, as well as pre-cancerous cervical cancer, which has a higher incidence among the female prison population than those in the community)[1].

People diagnosed in prison are less likely to receive curative treatment. In comparison to people of similar age, sex, type of cancer and disease stage, receiving a diagnosis in prison is associated with less surgery, but similar levels of radiotherapy and chemotherapy[1]. Adjusting for ethnicity, comorbidity and route to diagnosis explains some of the lower access to treatment with curative intent.

Survival estimates for people diagnosed with cancer in prison versus those in the community are significantly lower at 1-, 2- and 5-years post-diagnosis. This increased risk of death in prison settings can be explained by a combination of comorbidities, route to diagnosis and access to curative treatment[1].

People in prison also report significantly poorer experiences of care than community cancer patients in relation to: pre-diagnosis GP visits, time to referral to secondary care, having the support of family and friends at diagnosis, privacy, receiving adequate information on the potential side-effects of treatment, and contact information upon leaving hospital[2].

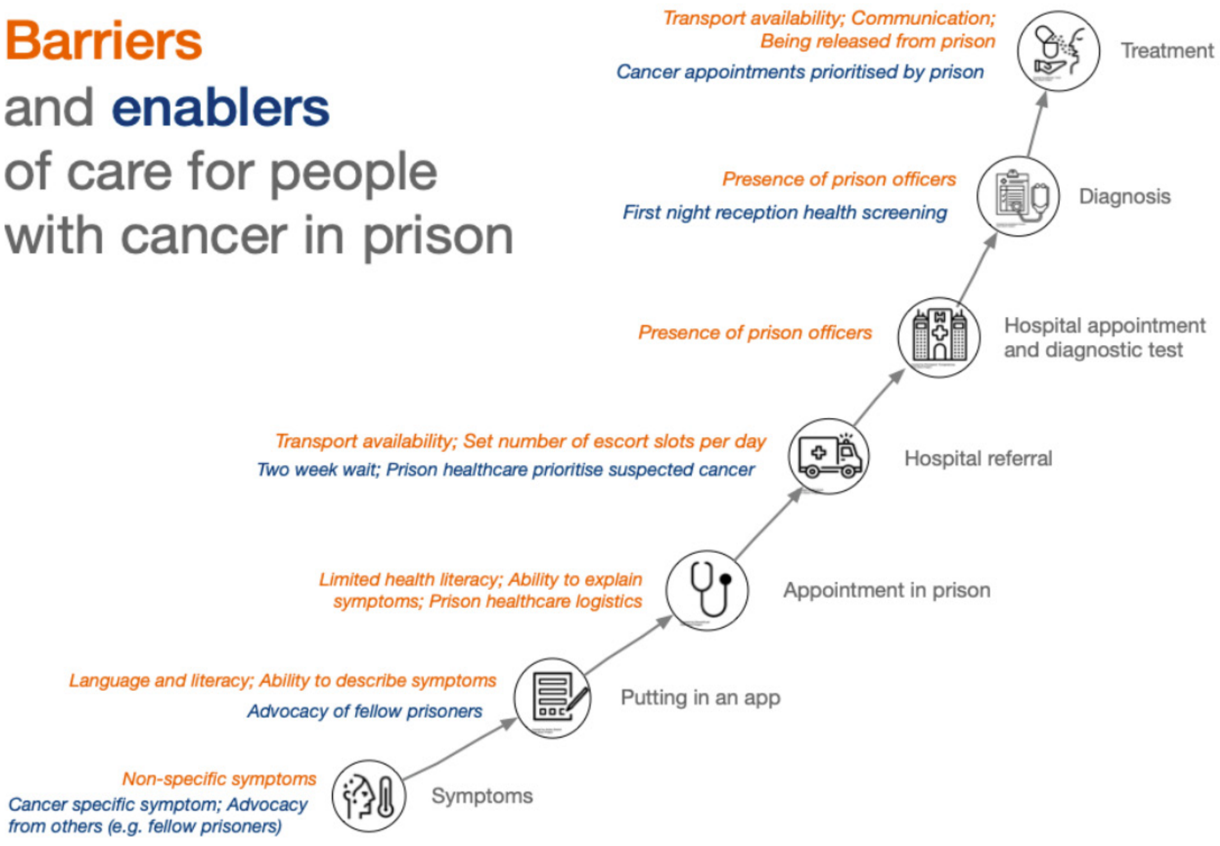
What does cancer care in prisons look like?

Our study identified the pathway to cancer care and the associated barriers and facilitators encountered at each stage, as set out in Figure 1.

Initiating the treatment process needs symptoms to be recognised and an ‘app’ to be submitted (an application for a GP appointment), which is the first step in accessing any healthcare in a prison setting). However, this crucial diagnostic phase is often hindered by a triage process that relies on self-reporting of symptoms that are (i) often non-specific to cancer, and (ii) experienced by people who may lack the literacy and language skills required to effectively describe them and complete the ‘app’.

Key barriers we identified later in the process include limited escort slots to attend hospital appointments, the need for prison officers to be present throughout appointments and lack of access to support networks.

Figure 1: Barriers and enablers for cancer care in prison over the treatment journey



Credits for images: Treatment – Nithinan Tatah from Noun Project (CC-BY); Diagnosis – Amethyst Studoi from Noun Project (CC-BY): Hospital Appointment - Phoniaphat Thongsriphong from Noun Project (CC-BY); Hospital referral - Nawiconm from Noun Project (CC-BY); Appointment in prison – DinosoftLab from Noun Project (CC-BY); Putting in an app – Arslan Shahid from Noun Project (CC-BY): Symptoms – Noun Project (CC-BY)

The Policy Lab

Given this background and the rich evidence generated from our research study, we convened a Policy Lab to address the question:

> 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?

The Policy Lab brought together researchers, professionals from health and prison services, charities, policymakers, and those with personal experience of the relevant issues to:

- Reflect on the evidence and findings emerging from the study
- Understand the barriers and constraints to change
- Develop new ideas and practical approaches to improve outcomes

Through a series of structured, facilitated sessions, participants explored how care is organised and delivered, and were encouraged to think creatively about possible improvements. The practicalities of implementing these changes at a suitable scale were considered, along with the roles of different stakeholders in achieving this.

Proposed improvements in care

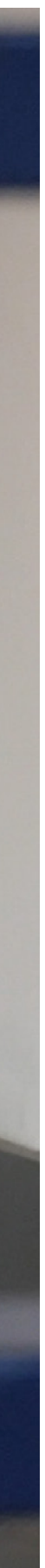
The rich discussions at the Policy Lab covered a wide range of ideas at different points of the care pathway and considered the roles of different stakeholders in supporting improvements in care. These ideas are set out in the following sections, but within these we also asked participants to prioritise a set of concrete proposals, based on both the potential impact they could have over the next three years and how possible they would be to implement. This resulted in four proposed 'top improvements':

- Communicating to clinical teams how the prison system works (as part of work to join different parts of 'the system' and achieve a more integrated approach).
- Coordinating and promoting an effective approach to screening that significantly increases take-up.
- Establishing 'health champions' amongst prisoners to advise and support others.
- Raising health literacy and awareness of symptoms using different media, especially radio, TV and video.

Two further possible improvements were also rated highly for impact, but some considered implementation to be more difficult:

- The provision and use of 'in-cell' technology (eg tablets, two-way phone lines, approved helpline support numbers) to enable prisoners to access support more readily, in a timely way that respects privacy.
- 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.

Other ideas were considered likely to have either a lesser impact (eg patient experience surveys) or substantial barriers to their implementation (eg increasing Clinical Nurse Specialist roles).



More broadly, the ideas emerging from the Policy Lab can be grouped into five themes.

1. The need for a coordinated, standardised approach

2. The need for awareness and effective screening

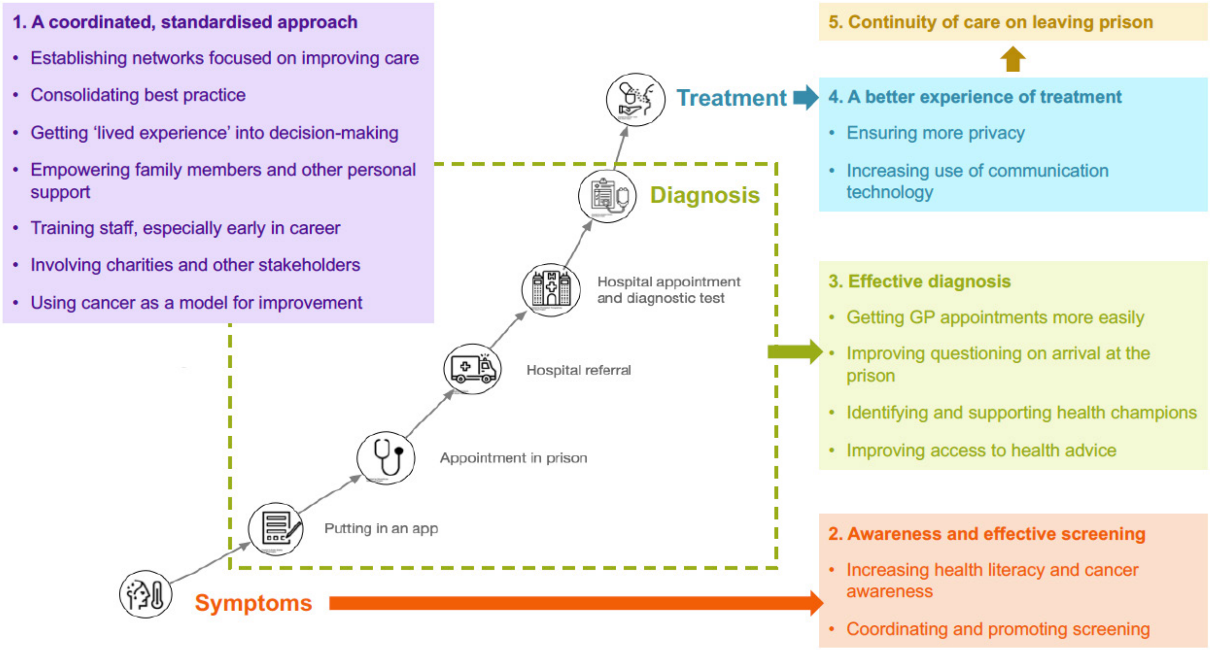
3. The need for effective diagnosis

4. The need for a better experience of treatment

5. The need for continuity of care.

These are summarised in Figure 2 and discussed in more detail in the following sections.

Figure 2. Proposed improvements at each stage of the care pathway



1. A coordinated, standardised approach
- Establishing networks focused on improving care
- Consolidating best practice
- Getting ‘lived experience’ into decision-making
- Empowering family members and other personal support
- Training staff, especially early in career
- Involving charities and other stakeholders
- Using cancer as a model for improvement

5. Continuity of care on leaving prison

4. A better experience of treatment
- Ensuring more privacy
- Increasing use of communication technology

3. Effective diagnosis
- Getting GP appointments more easily
- Improving questioning on arrival at the prison
- Identifying and supporting health champions
- Improving access to health advice

2. Awareness and effective screening
- Increasing health literacy and cancer awareness
- Coordinating and promoting screening

1. The need for a coordinated, standardised approach

Establishing networks focused on improving care

Policy Lab participants strongly agreed that there needs to be more interchange and “cross-talk” between groups that come into contact with and are involved in the treatment of cancer patients within the prison system. This includes, but is not limited to, prison officers, local hospital administration teams, clinical staff, voluntary support organisations and family/personal support networks. Better inter-organisational collaboration would help build mutual understanding of the challenges each group faces and address co-ordination issues that undermine the quality and experience of care (and reduce "passing blame").

While training programmes or clearer reporting lines might help support an integrated approach, finding the willingness, capacity and/or funding to drive this could be difficult. An alternative might be the establishment of informal networks of those with an interest in improving support to people in prison. As noted by one Policy Lab attendee "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?".

There are many people specialising in this area, including prison nurses interested in cancer and some in acute settings with experience and understanding of the challenges in the prison context. Bringing these people together and supporting them to inform and equip their colleagues could be an efficient way of achieving a more coordinated approach.

Some of these networks can be at a local system level where the critical aim is to develop links between oncology services and local prisons that help establish and maintain personal connections amongst those who are empowered or have the authority to make changes. There is also scope for a network at a national level to develop best-practice, share learning and provide a steer to policy. This could bring together both practitioners and policy makers, and should span multiple health disciplines (oncologists, surgical staff, nursing, mental health, etc).

Consolidating best-practice

Prison and healthcare systems have very different organisational structures, meaning that it can be hard to bring together good practice in a way that leads to standardised improvement. Equity across different prison settings and models of healthcare (eg presence or otherwise of a 'prison hospital') can be worked towards by consolidating the development of best-practice to work consistently across both prison and health systems. This could be done through a national network, while it might also be helpful to consolidate some of the resources that can drive improvement at a regional level to support local co-ordination.

Getting 'lived experience' into decision-making

People with lived experience have valuable insights into the reality of navigating the complex prison and healthcare systems and it is important that their voices are integrated into any process to improve services in the future. Policy Lab participants agreed that the different data sources and evidence from the project had come together incredibly powerfully in a short film based on interviews with people throughout the system[4] and that what is recognised anecdotally by many is now becoming evident in the quantitative and qualitative data generated.

Empowering families and other members of a personal support network

Policy Lab attendees agreed that both experience and outcomes can be improved by enabling families and other members of personal support networks to be involved from the early stages of diagnosis and throughout the care process. This helps with retaining information on diagnosis, maintaining mental health, and following treatment plans.

The use of video consultations would make it easier for others to be present. Alternatively, families could be offered the opportunity to meet with healthcare staff separately to discuss plans for care and what they can do – particularly if placement of prisoners also aims, where possible, to ensure that they are physically closer to their support networks. Prison officers who are present during the diagnosis and treatment process could also be trained in how they can help in those conversations.

Some individuals, especially those with longer sentences, do not have established relationships outside of prison and it will be important to provide alternative forms of personalised support to these individuals.

Training staff, especially those early in their career

The Prison Service, like the NHS, faces challenges in terms of staffing. Any improvement that requires seeking more staff could be difficult to achieve in the short-term, so interventions should be based on the resources currently available. Given these constraints, it is also important to work across the prison and health systems, rather than in silos, to make the most of any resource flexibility that exists. An example could be expanding the role of the chaplaincy, given the personal support skills that exist 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 the particular challenges faced by prisoners. A powerful way to do this could be by providing short courses for medical, nursing and prison officer students. Reaching people at this early stage of their careers could be especially effective in helping avoid or tackle misperceptions and stigma, by highlighting the issues prisoners face and the perspectives and challenges experienced by all stakeholders at different points in the system.

The Policy Lab also affirmed the sense that prisons are mysterious places for NHS staff, so connecting professionals from both systems and sharing experiences should be part of learning how the prison system works and how prisoners experience care. While there have been efforts to improve health literacy in prisons, there has been less focus to date on ‘prison literacy’ in healthcare, so that clinicians can understand what is and isn’t possible.

Involving charities and other stakeholders

Charities have a valuable role in the provision of cancer services in prisons, including, for example, nursing posts funded by Macmillan Cancer Support. Voluntary sector organisations can be very effective in acting as confidantes (perhaps particularly where access to family and friends is limited) or training peers in prison to help navigate prison healthcare processes.

However, this support is variable across the country and is not resilient, sometimes being withdrawn because of budget constraints. Anything more that can be done to resource and enable the involvement of these organisations would contribute to the improvement of care.

To support this and – more generally – to highlight the need to improve outcomes for prisoners with cancer, it is important to bring commissioners and provider management into the conversation, sharing research findings and involving them in relevant networks.

Using cancer as a model for improvement

Some of the challenges faced in providing care effectively are not unique to cancer and apply equally to other conditions (eg completing the application for a GP appointment). Although there are a relatively small number of cases, focusing on cancer care in prisons could be a lever for improving care more generally, perhaps by piloting improvements on a small scale and creating learning that can be applied across both other health conditions in prisons and cancer care in other challenging settings. For example, sharing learning and establishing networks that bring together cancer specialists with prison care specialists can test new approaches that improve outcomes for those in prison, but also has the potential to benefit other groups in challenging circumstances such as the homeless population.


NHS
Joanna
Sister

2. The need for awareness and effective screening

Increasing health literacy and cancer awareness

Increasing levels of health literacy amongst both prisoners and staff would help in promoting preventative behaviours and spotting potential symptoms. For example, while prisons have smoke-free policies, smoking cessation still needs to be promoted after release. Good examples of work in this area include Macmillan Cancer Support awareness-raising as a powerful part of the community pathway and the way that Hepatitis C services have proactively been brought into prisons.

Investing in the use of video resources, such as the short film developed by the project, and other material that could be shared via prison TV or radio would be an effective way of conveying important information around health generally and cancer signs and symptoms specifically. This approach could also explain the practicalities of navigating prison healthcare processes. Alternatives to messaging online could include more use of literature, posters and canteen bags.

Coordinating and promoting screening

Early intervention is key to delivering appropriate cancer care and achieving better treatment outcomes. Screening is a key part of this and is especially relevant to catch those that are not yet showing any symptoms. Depending on individual backgrounds and circumstances, prison may also present an opportunity for some to access healthcare that was not available or used before.

Policy Lab attendees reported that the Covid pandemic has hugely impacted the delivery of screening. Efforts are needed to recover services but also to go further in establishing a more effective approach that sees a much higher uptake among the prison population.

Alongside increased information, regular screening sessions should take account of other factors that shape people's routines and which may act as barriers to prevent take-up (eg timings that clash with social and other events in the prison).

In some instances, the reported experience of existing routine screening is good (especially in relation to women's health), but there are often still challenges in progressing from screening to scheduling an appointment to follow up.

3. The need for effective diagnosis

Getting GP appointments more easily

Once someone is concerned enough to seek help, one of the biggest obstacles is successfully completing the written 'app' needed to get an appointment. Many individuals find it difficult to complete these forms because of accessibility issues (eg learning difficulties) or an inability to articulate the relevant issues[2].

It is then common for applications to be rejected. Attempts to follow up with prison staff can be difficult, with individuals sometimes being accused of "causing trouble". This response is part of a broader culture where a lack of trust between prisoners and staff can mean that people are not believed or suspected of seeking drugs.

Improving questioning on arrival at the prison

Policy Lab participants suggested that some symptoms are missed and diagnoses delayed because of the way data is collected at arrival to the prison. This can be improved by asking questions in a variety of different ways on the same questionnaire, by more active listening to 'unpack' what the individual might be experiencing, and by taking time to explore issues (eg why the person has missed an appointment).

Identifying and supporting health champions

Tackling the stigma attached to seeking help and/or going into hospital, especially for men, is a key area for action. Men may be less proactive in accessing healthcare, more worried about "nurses gossiping" and embarrassed to ask for help with very personal issues. Additionally, the fastest growing group of people in prison with cancer are the over 50s, who may not want people to know their background and who have previously experienced stigma in mainstream settings such as hostels. All of this leads to delays in diagnosis.

The establishment of prisoner 'health champions' may be a significant opportunity to help address these issues. Individuals tend to be much more willing to speak to their peers and with care taken over individual privacy can learn from the health champions about symptoms and the process of diagnosis and treatment. Champions can also support in navigating the first steps towards getting a diagnosis.

An advantage of this approach is that it need not necessarily be expensive to implement. While some training would be needed, the group could include both those currently in prison and those who have been released but nonetheless represent “someone like me”.

Improving access to health advice

Individuals should be able to access advice that is relevant and timely. Suggestions to support this include the approval of specific phone numbers for direct communication with oncology services and the increased use of video consultations that remove the need to rely on travel.

Ideally, resourcing should be increased to enable external nurses to work in the prison setting. Very effective examples were discussed in the Policy Lab (eg Macmillan nurses, NHS Clinical Nurse Specialists) where support can be given at appointments, routine visits and in liaising with families. The role of CNSs was felt by many participants to be by far the most useful element in providing care that is personal and helpful (eg helping overcome some of the privacy issues and providing continuity).

However, relying on these roles existing widely and consistently across settings may be risky, due to the potential for their removal because of budget constraints and the large number of vacant posts. Ideas to improve their sustainability include organising them on a regional basis and delivering some of the CNS support using virtual consultations that draw on a bank of staff located nationally.

4. The need for a better experience of treatment

Ensuring more privacy

Interventions should be developed to increase privacy in attending appointments, undergoing procedures, and producing samples for analysis. Very practical examples were suggested in the Policy Lab, such as using a longer chain between the guard and prisoner, or separate consultation spaces. One approach might be to create a working group with key staff and people with experience in prison cancer care to generate a set of ideas which could be reviewed for feasibility and then trialled in different prisons.

Increasing use of communication technology

There was strong agreement among Policy Lab attendees that communication technology has the potential to transform the interaction between prisons and hospitals, but mixed views about how quickly this might be achieved and the potential for variation between different prison settings.

Such technology could help with retaining information from appointments and protecting privacy of conversations, especially if there is good coordination between prisons and hospitals in setting this up. Ideally, the technical capabilities should then remove some of the individual variation currently experienced because of staff taking different approaches. As noted earlier, video consultations would also allow for families and others providing personal support to take part directly in conversations.

However, while the potential for initiatives like virtual consultations already exists, rolling out such technology at scale is complex. It needs an appropriate space in each prison, as well as sufficient uptake of the relevant system across secondary care departments.

The use of ‘in cell’ technology, such as the trialling of tablets, may also present considerable opportunities. This could open up the possibility of using specific apps to address health literacy issues and keep track of treatment. It was also proposed that two-way phonelines in cells be used so that individuals can call out to dedicated support lines (currently, phone lines are often one-way only).

While technology offers many possibilities for supporting improvement, there is a need to guard against it embedding inequalities, either from variabilities in provision (eg between the technology available in modern compared with older prisons) and/or with individuals’ ability to use it (eg digital literacy, accessibility issues).

5. The need for continuity of care

Upon release from prison, there is a need to ensure that care is uninterrupted and patients are able to engage independently with the health system. Policy Lab participants agreed that place-based approaches should be the focus of this. However, in making these work, all of those involved in providing care (including, for example, third sector partners) should 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 through gaps in the care pathway.

Looking to the future

Providing good cancer care for people in prison needs an effective and coordinated approach from two systems which are structurally, operationally and culturally very different. Building from the evidence generated by the project, participants at the Policy Lab were optimistic about the potential opportunities that exist to make a real difference to outcomes and suggested a wide range of ideas that might be effective at different points in the care pathway. Clearly, challenges remain, not least around resourcing and ensuring equity, but there are also promising areas for piloting or scaling up improvements in the relatively short-term.

In the longer-term, there are several areas where further research can address important gaps in our understanding, as well as valuable opportunities to learn from other sectors, geographies and areas of healthcare. Some of these that were raised by Policy Lab participants are set out below.

Questions and options for research

- Implementing individual interventions risks creating or embedding inequities (eg around tech literacy). What is needed – in terms of the variety of approaches offered – to avoid this?
- What can be learned from other areas that have focused on inclusion in health services (eg for sex workers, homeless population, etc)?
- How do new governance structures (eg ICBs, Cancer Alliances) best cater for the needs of the prison population, and would a national mapping exercise of approaches help with understanding this?
- What is driving discrepancies in curative care (eg what contributes from prison, healthcare, and individual perspectives)?
- What is it specifically about prisons that needs to be demystified for oncology services and how can this be done?
- How can self-care be improved in prisons (eg using a form of social prescribing)?
- How can diet and lifestyle advice be implemented in prisons?
- How can relatives be better involved in cancer care and what impact does this have on people in prison and their families?
- What can be learned from the experiences in Scotland, Wales, and Ireland?
- What else works on the experiential side that can be learned from other parts of health and social care?
- How much is currently done by the voluntary sector, and can this be used more?
- Is there scope for some form of performance management, including transparently reporting on variations in health outcomes so that patients can also understand what is/isn't working (eg referral times and other standard measures used across health and prison services)?
- Can we collect better data to determine the prevalence of cancer in the prison population? This should include people who have had cancer in the past as well as those newly diagnosed, undergoing treatment or receiving palliative care.
- Given the time lags in collecting data, it may be hard to track the impact of changes made on longer-term outcomes. What intermediate indicators can we monitor to assess progress?
- How can electronic health record systems be improved so that cancer is flagged to prison health and officers?

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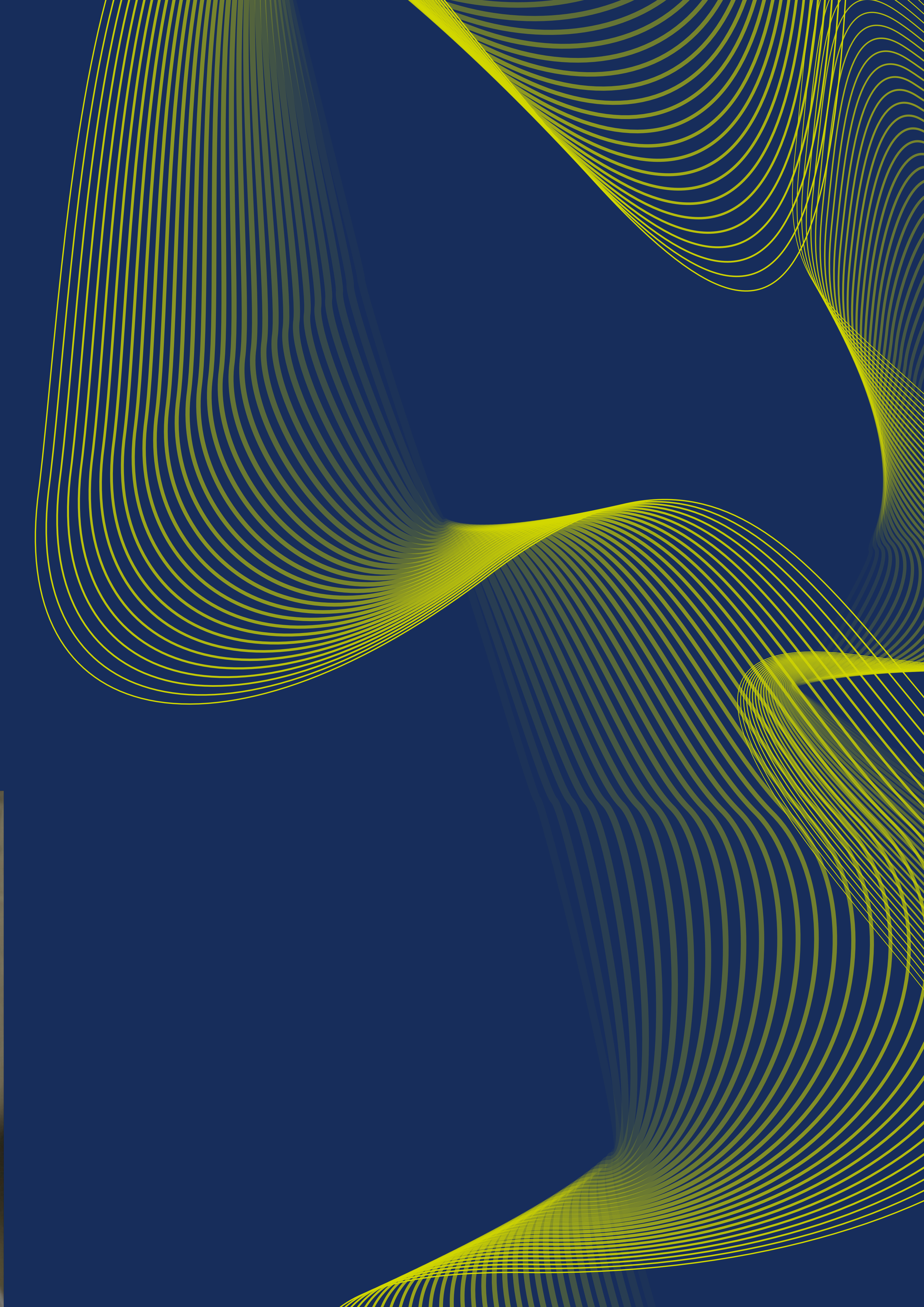

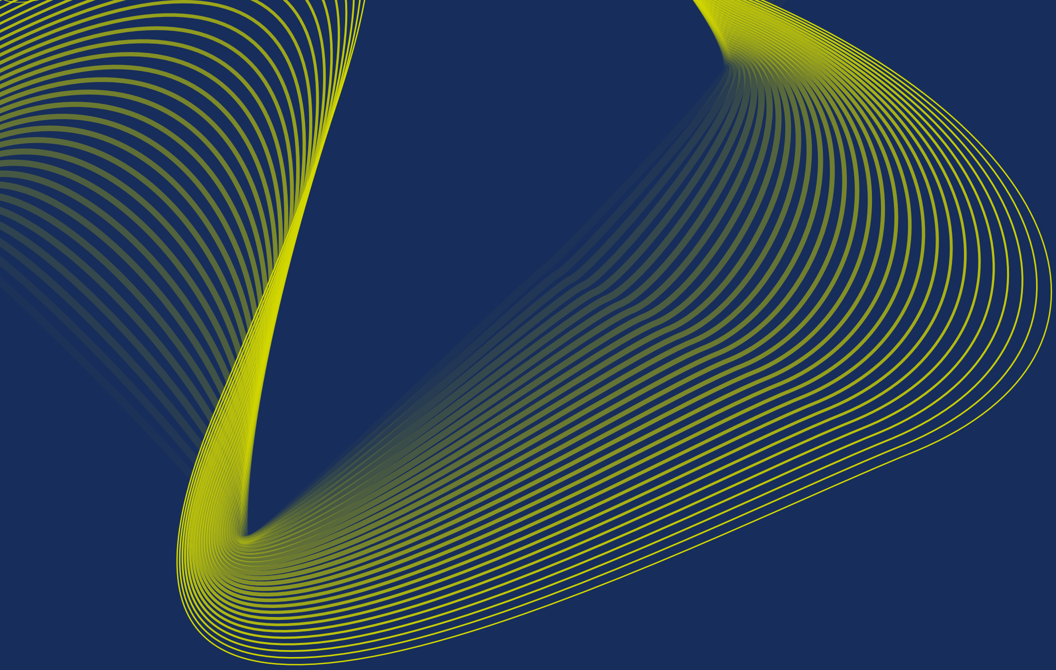

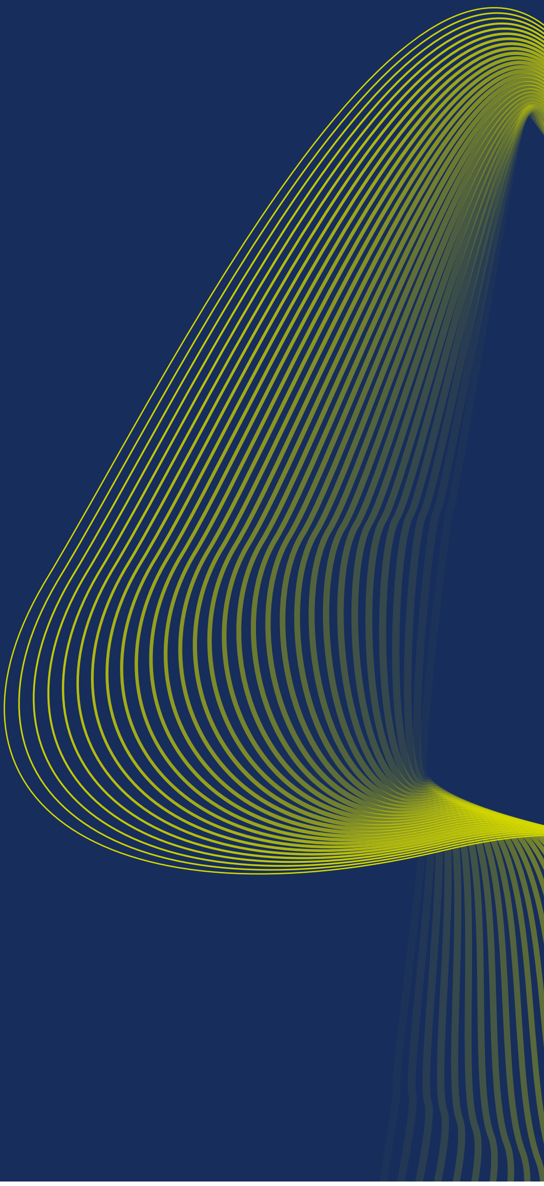

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