

HMP Lewes: residents' experiences of health and care

Published: March 2025

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1. Introduction

Healthwatch East Sussex (HWES) is an independent organisation that aims to ensure that patients' voices are listened to and considered by providers and commissioners of health and care services in the local area.

As residents of East Sussex, we were keen to ensure that the prison population of HMP Lewes had the opportunity to have their voices heard.

1.2 Background

The prison population must receive healthcare that is 'equivalent' to community services, so that, 'people detained in prisons in England are afforded provision of and access to appropriate services or treatment... considered to be at least consistent in range and quality (availability, accessibility and acceptability) with that available to the wider community' (HM Government').

Despite this, the health of prisoners has been reported as poorer than any other population group ⁱⁱ. With an ageing cohort, the prison population has a high prevalence of chronic disease compared to the general population, significant mental health needs, and multiple specific risk factors including high levels of communicable diseases^{iii iv}.

A recent report by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) highlighted that prisoners face a significant reduction to their life expectancy, citing poor health and unreliable access to healthcare as primary factors for this.

1.3 Context

HMP Lewes is a category B reception prison for male adult and young offenders aged over 18, with a maximum capacity of 624.

Healthcare is provided by Practice Plus Group (PPG) within HMP Lewes, including primary care, mental health and substance misuse services, onsite pharmacy, and emergency response team.

Healthwatch East Sussex had previously visited HMP Lewes prior to 2020. Visits stopped during the pandemic, but we were keen to restart our

engagement with the prison population of HMP Lewes and visits recommenced in May 2023.

Prior to our first visit, HMP Lewes had been inspected in 2022 by <u>HM</u> Inspectorate of Prisons (HMIP)^{vi} where a range of concerns were identified, including gaps in patient care, poor communication with prisoners relating to healthcare, ineffective partnership working, and issues related to arranging escorts for health appointments.

Our initial intention was to enable the prison population to access our Information and Signposting service by offering drop-in sessions in the onsite library, to provide the opportunity for residents¹ to share their feedback and raise any concerns relating to their health and care.

As similar themes and concerns were consistently raised through these sessions, we developed some additional targeted engagement to explore these further and to include a wider cohort of residents, with the following aim:

To identify the key concerns residents have relating to their health and care needs, including what has worked well and where changes need to be made to improve their experience of, and quality of care.

1.4 Acknowledgements

We would like to thank HMP Lewes and PPG staff for being supportive of our visits, and the Patient Experience Lead in particular, for enabling HWES to conduct a focus group with residents with additional care needs.

We would also like to thank the library staff at HMP Lewes for accommodating our Information and Signposting sessions, and our colleagues at The Advocacy People for supporting our engagement and contributing to this report.

¹ The prison population are referred to as residents at HMP Lewes. We will therefore also use this term throughout this report.

2. What we did

We initially held seven Information and Signposting drop-in sessions in the prison library, alongside an Independent Health Complaints advocate from The Advocacy People, between May 2023 and February 2024. This allowed the provision of information sharing and signposting to be accompanied with direct support for those wishing to understand how to make a complaint about health provision, either within or outside of the prison.

During this time, we spoke to 29 residents who either wanted to share their experience of accessing and receiving health and care services, or to discuss their concerns relating to accessing appropriate care.

Multiple themes became apparent, including difficulty accessing timely health-related information; lack of communication relating to individual patient needs or concerns; long waiting times for appointments or support; limitation of health services available; issues accessing medication; continuity of care when arriving at or leaving HMP Lewes; role of prison staff in enabling access to healthcare; concerns about effectiveness of the complaints process; and the impact of wider determinants, including prison infrastructure, on health.

During this period, the Patient Experience Lead at HMP Lewes was responding to concerns raised by the 2022 HMIP report, and the residents themselves, and had started to implement new practices aimed at improving health awareness, increasing information and communication pathways and actively responding to patient concerns.

To ensure we captured experiences based upon current practices and processes at HMP Lewes, we used our original insight to develop further engagement to explore residents' experiences of health and care, in two ways:

1) a short survey aimed at the whole prison population, asking for their recent (since January 2024) experiences of health and care services.

We designed a short survey to gather feedback on whether residents receive information to help them access health and care on arrival; if they can easily access help to complete healthcare applications; if they have always been able to access medication appropriately; how long they have waited for healthcare appointments; for those with existing health issues - if their usual treatments or medications continued when entering HMP Lewes; and experience of the complaints process.

 a discussion forum for prisoners with disabilities or additional needs, to hear experiences from those most likely to have additional accessibility and/ or social care needs.

During our drop-in sessions at the library, we heard from several residents who had concerns about accessibility, including problems sourcing batteries for a hearing aid, lack of access to glasses, and from a resident who had a social care package before entering prison, but hadn't been assessed since entering HMP Lewes and didn't know how to access help.

We also became aware there are multiple residents with additional health or social care needs who are unlikely or unable to visit the library. We therefore decided to hold a discussion forum for this group, to allow for an in-depth exploration of their experiences of accessing health and care and managing their conditions at HMP Lewes.

2.1 Limitations

We recognise there are limitations to our research due to the unique environment of HMP Lewes, and the way in which data was collected.

As a remand prison, HMP Lewes has a transient population, making it difficult to follow up on issues and concerns raised with us. There were also limitations in our ability to reach residents from all parts of the prison due to our reliance on using the library as a base for engagement. We spoke to 29 residents during our original Information and Signposting sessions, received 35 completed surveys, and heard from a further nine residents who attended the focus group. We recognise this accounts for a relatively small proportion of the residents at HMP Lewes during this timeframe.

We also recognise that the nature of our engagement is likely to attract responses relating to issues or concerns residents have about their health or care. We found that residents tended not to mention, or elaborate on,

instances where they haven't encountered a problem, or where services and care worked well. The focus on negative experiences in the report reflects what was shared with us and represents the views of residents' who participated in this research.

3. Key findings

This section provides a summary of the key themes we heard whilst engaging with residents of HMP Lewes through a focus group and survey, between July and November 2024.

3.1 Issues of communication and information sharing

Many of the concerns cited by residents related to problems with communication and sharing of information, centering around a lack of understanding about how to access healthcare and frustrations with the application system.

Understanding how to request an appointment

We heard mixed experiences of how effective the initial induction was to inform residents how to access health and care services. Whilst 56% (19) of surveys responded they did receive information on how to request a healthcare appointment, 44% (15) reported that they did not. These residents instead picked information up piecemeal from other residents, or members of staff.



'Just dumped in a cell and had to find out by a cell mate what to do, as first time in prison'

We also heard from residents who thought they probably were told how to access healthcare services, but due to the overwhelming nature of entering prison were not sure, or had been unable to retain the information.



'When I arrived at Lewes I was in shock. I have a vague recollection of being told things, but no recollection of any details. By the time I'd recovered a bit I was in my cell on my own with no idea how anything worked.'

We heard how this lack of information, coupled with residents not knowing who to ask, had a negative impact on accessibility of services and individual health conditions.



'I was feeling ill and wanted to see a doctor, but didn't know how . . . I ended up collapsing and getting taken to hospital.'

Recommendations/ what residents say:

- Ensure all residents have written information on how to access health and care services after initial induction, including in Easy Read format, recognising levels of literacy and specific needs in the prison.
- Ensure there is a clear health and care point of contact, or visible information, on all wings to help orientate new residents.

Application process and notice of appointments

The healthcare appointment system consistently came up as a source of frustration for residents.

Written requests for healthcare appointments (commonly referred to as an 'App' by residents) must be submitted, which are then reviewed by the healthcare provider (PPG) and responded to.

It is recognised that many residents at HMP Lewes have difficulty reading and writing, and eight (23%) of the survey respondents reported they needed help to complete an application, with six of these respondents saying help was hard to access. We were led to understand Orderlies² currently help residents to complete applications where needed, but the limited time out of cells coupled with the multiple activities residents need to complete during this time, hindered some from accessing this help.



'I'm dyslexic so can't fill in forms easily. No help from staff.'

Most residents found it easy to access and complete an application form, but many reported they often heard nothing back.



'It's easy to access via an App. It's the reply that is slow or does not happen.'



'Put App in, get no reply month after month.'

² Residents with various jobs within the prison are referred to as Orderlies.

We heard that there is often little to no communication between submitting an application and receiving a movement slip to attend an appointment. There is no confirmation or acknowledgement that an application has been submitted or indication of expected waiting times. Residents often have to ask or chase about the status of their application with staff, with no information provided in the meantime. This creates anxiety for residents, especially those with an urgent need, and led to a perceived feeling by the residents that staff did not care about their state of health or wellbeing.

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'Put in 5 Apps for mental health and substance misuse and still not seen anyone after 8 weeks.'

Feedback suggested there was no system of documenting applications, and we heard that people had submitted apps and never heard anything back about them. However, as there is no means of tracking them, it is difficult for this to be validated. We heard from some residents about their perception that the feeling was some residents won't be there long, so were not seen as a priority for appointments.

Another frustration was the lack of information on movement slips. Residents told us it would help them to know whether their appointment was booked for the morning or afternoon, so they didn't stay in their cell unnecessarily, and also which clinician the appointment was with. Some residents may have requested multiple appointments, and it would help them to prepare for the appointment if they knew who they would be seeing and about what. One example we heard during our previous dropin sessions, related to a resident who had not been told in advance of their appointment with an audiologist for earwax removal. This meant they didn't use ear drops in advance of their appointment, and subsequently couldn't be treated.

We also heard of occasions when movement slips were not received by the resident in a timely way leading to appointments being missed, and examples of residents who found out that they had appointments booked and were recorded as 'Did Not Attend' (DNA), but had never received a movement slip to inform them they had an appointment or been called to attend it.



'Appointments slip given AFTER date of appointment twice.'

Residents flagged concerns over how appointments missed due to not being collected were recorded by staff: residents had the understanding that if the missed appointment was recorded as a DNA, they would have to resubmit an application putting them at the back of the waiting list. This created confusion over what is expected of the resident, and generated worry about how long they would have to wait for another appointment.

This points to a more pervasive issue around the communication between healthcare and prison staff. There was a feeling from some residents that miscommunication caused many of the delays and blockages they experienced, with paperwork and requests getting lost between the health provider and the prison staff, and each group blaming the other where there were problems and issues. As the application system does not appear to be documented or validated in any way, it is difficult to pinpoint if problems exist, and if so where they lie.

Recommendations/ what residents say:

- A system which acknowledges healthcare applications and provides reassurance of how and when they are being dealt with.
- Putting AM/PM time slots on movement notes, and which clinician they will be seeing, to help residents prepare appropriately for appointments.

Support to navigate the system

We heard that when residents are unsure how to access healthcare services, they mostly rely on asking other residents but do not always get clear answers. We heard multiple experiences from residents that they have found staff unable or unwilling to help.



'It's quite hard to access the help needed as the officers expect you to know the information, because they don't know themselves.'

'The staff don't help at all.'

'If you ask ten different people you get ten different answers.'

We also heard residents were not always clear on the roles and responsibilities of different staff members. Some residents told us they would not approach a staff member for help if they didn't know who they were, due to the uncertainty of whether they will be supportive or not.

Prison staff were felt to be of mixed value in acknowledging and responding to issues. Some were felt to be more helpful than others, and a lack of continuity in the presence of the same individuals was often a hindrance to building a rapport.

These experiences may lead residents to be inclined to wait to engage with friendly or familiar faces, especially with those whose role they are clear on, and who they have had a positive engagement experience with in the past.

Understanding who to go to, when, and about what, could be made clearer and better communicated. Badges or other mechanisms to help residents understand who staff were and their responsibilities, were suggested by the focus group participants as something that may be helpful. Photo charts identifying roles and responsibilities were also suggested as something that may assist residents in being more aware of support, but also who did what within the prison.

The willingness of individual staff members to help was often seen as having the biggest impact or difference to an individual's circumstances. Two members of staff - the Patient Engagement Lead and a member of the pharmacy team on F wing - were named by multiple residents as reliable and invaluable sources of support for helping to orientate residents to healthcare processes. Residents highlighted that there was 'often a queue to talk to [Patient Engagement Lead]' when they visited the wings and prison spaces, and indicated a desire for greater access to support through more regular visits. This indicates the importance of personal relationships and the value of staff able to triage and respond to the needs of individuals.

Recommendations/ what residents say:

- Use of name badges or a photo board to help residents know who members of staff are and their roles and responsibilities.
- Increased access (longevity/regularity) to the Patient Engagement Lead, and when not available, access to other named member of staff with similar responsibilities.

3.2 Access to and quality of care

Residents were mostly positive regarding the quality of care and treatment once they were seen by a clinician, however, concerns were raised around timely access to appointments and a lack of service availability.

Issues of facilitation to attend healthcare appointments

As well as the issue of not knowing about, or being collected for, healthcare appointments provided within HMP Lewes, access to external health appointments was raised as a frequent challenge. We heard accessing hospital appointments was often problematic, with residents arriving late, and not able to be seen by healthcare professionals, causing their appointment to be cancelled and rescheduled.

Residents told us a range of reasons for this, including: not receiving adequate notice or not being collected with enough time to prepare; transport not arriving with enough time to make the appointment; or the wrong type of transport being booked – so people with needs for wheelchair transport couldn't travel, and by the time a replacement arrived it wasn't possible to meet the appointment timescale.

One example was shared where an individual was repeatedly late for multiple radiotherapy appointments which resulted in them missing some treatment. In another example, an acute hospital repeatedly provided outpatient appointments at a time residents were unable to attend, despite being informed this made attendance impossible. These examples not only impact residents but create inefficiencies in the health services they are seeking to access.



'I was left to negotiate between healthcare and the prison, who could not agree on how to get me to an [external healthcare] appointment on time – still waiting.'



'I am due to have an MRI at a local general hospital, appointments have been cancelled at the last minute. The latest one was caused by Lewes prison having an argument with the taxi driver and he just drove off.'

Feedback on experiences of care from The Advocacy People Case Study

A resident was scheduled for a scan, but residents are not informed of their appointment times in advance for security reasons. The resident was taken from their cell to begin the process of leaving the prison. However, before they could go through security at the main gate, they needed a specific HMP Lewes staff member to sign them out. Unfortunately, the staff member was not at their post and could not be located. By the time the resident was signed out, they were already late for their appointment. Although the resident proceeded to the appointment, they were informed upon arrival that they could not be seen. A taxi had been waiting for the resident, with the meter running, from when they were supposed to leave the prison. This situation occurred twice more. As a result, the resident was discharged from the NHS service and told they would need to be re-referred.

This is one example of how poor communication and planning leads to negative patient outcomes.

Complaints submitted by The Advocacy People (TAP) on behalf of residents have concerned similar themes of issues with communication between HMP Lewes, PPG and the resident, resulting in delayed treatment.

Recommendations/What residents say:

- Improved communication between healthcare providers and prison officers.
- Improved planning and co-ordination to enable residents to attend external healthcare appointments.
- Improved awareness amongst NHS services of the access limitations imposed on prison residents when organising appointments i.e. times when it is feasible to attend.

Long waiting times and limited services

Whilst a range of health and support services are available in the prison, residents indicated they feel these vary in how and when they are

available. Of the residents who completed our survey, 66% (23) reported delays to care or treatment that were negatively impacting on their healthcare condition as well as their general health and wellbeing.



'I need to see a dentist. Two weeks I've been waiting in pain. Can't sleep, mad anxiety from it.'

Concerns about length of waiting times were heard relating to all clinical areas, but problems accessing mental health support, dentistry, podiatry and physiotherapy were most cited.

We heard specialists only come in for a few sessions, rather than being based in the prison, making them hard to access due to long waiting lists. Many residents reported waiting between two to six months to see a dentist and optician when a medical need was apparent, and one resident indicated having to wait 15 months for access to podiatry. Whilst there was recognition that waiting lists are currently long outside of prison, there doesn't appear to be an equivalent to the urgent, emergency, and community services available to those outside of prison with urgent and/or out-of-hours needs.

We heard concerns during the focus group about access to mental health and psychological support in the prison. Residents indicated that people often arrive at prison in acute distress and may receive very limited support. People with known or recorded issues outside the prison setting don't appear to be well supported despite their known problems.

This was reflected by the survey results where seven (20%) respondents raised the issue of having been unable to access mental health support or treatment due to lack of access to suitable mental health services.



'I haven't been able to access any medication without seeing a therapist on the inside which is taking ages . . . it has been affecting my daily life and how I focus.'



'There is no crisis mental healthcare access at all - I suffered an autistic meltdown/severe suicidal ideation incident on August 20th...

asked multiple staff for help... completed a form... no one came until early September.'

Whilst waiting for mental health support, residents have access to the Samaritans helpline or other residents who have been trained as 'Listeners' to provide confidential emotional support to their peers. Listeners were valued by the residents we heard from as a port-of-call for sharing concerns or issues, but they are only available during the very limited free time, and are of limited number, which meant not all wings have an onduty Listener available. This can limit timely access to them, which was a source of frustration.

Being unable to access medication was a key concern amongst residents, with 60% (21) of survey respondents reporting they experienced problems accessing medication at some time. Waiting for a healthcare appointment was cited as a key reason for this, particularly on arrival to HMP Lewes, which suggests a barrier to effective continuity of care for new arrivals, even if they had been transferred from another prison. Other reasons included prescriptions running out on a weekend, residents being told medications are not available or cannot be prescribed in the prison, but not told why, and frustrations that prescriptions for the same resident weren't synchronized, to save them having to queue on multiple days for their medicine.



'Took 3 weeks to get diabetic meds and blood pressure medication.'



'I was asking staff about my meds and putting in apps every day about meds, Took 38 days for appointment.'

Recommendation/ what residents say

- Shorter waiting times to be seen by clinicians.
- Better communication to explain changes to medication or prescriptions.
- Improved mental health support services, especially to support patients while waiting for an appointment with a psychiatrist or on arrival at HMP Lewes.

Quality of care

Despite the challenges we heard around attending appointments, when successfully attended the quality of care was considered to be generally good.



'Once you get seen I feel they do their best.'



'Mental health [care] is good, psychology counselling is good.'

We did hear some incidences from residents reporting poor standards of care. These cases mostly related to a lack of timely treatment causing conditions to deteriorate in the meantime. One example we heard included delays to a resident being taken to hospital for treatment of a broken hand, leading to the hand needing to be rebroken in order to properly treat it.

3.3 Social care needs and issues of accessibility

A focus group was held with nine residents with additional care and/or mobility needs from F wing. They were asked what they felt worked well, where improvements could be made, and what mattered most to them about their health and care. The majority of feedback in this section relates to the focus group discussion.

Accessing social care support

Focus group participants raised concerns about getting social care assessments. We heard from a resident who had a social care package before entering prison that had not been implemented at HMP Lewes. They were unclear what should have happened – whether it should have carried over, if a new assessment should have been completed on their arrival or once their needs were known, or who to contact to request an assessment for support. Healthwatch staff saw no information in any part of HMP Lewes with information about adult social care eligibility or how to request an assessment.

An issue was raised around getting social care assessments, with one individual giving an example of Adult Social Care and Health (ASCH) failing

to attend two scheduled appointments to complete the process. This is frustrating given the short duration of some residents' stay at the prison, which means that care is not assessed or put in place in a timely way before they move on.

One resident told us it had taken four months to get an assessment that allowed appropriate care to be set up for them. During that period the lack of suitable adaptations had meant that they were unable to have a shower. It was unclear whether the delay was due to HMP Lewes actioning and pursuing the request, ESCC Adult Social Care and Health (ASCH) responding, or a combination of the two.

Residents appear to currently have no way to directly contact ASCH to report concerns, and are reliant on prison staff to liaise with ASCH to report how delays are impacting on the resident's ability to complete basic tasks of daily living, such as maintaining personal hygiene.

The inability to directly contact ASCH also means residents are currently unable to access the feedback and complaints process. The residents we spoke to, some of whom are also social care service users, were unclear about the pathway for ASCH complaints, which meant they weren't sure how to leave feedback with those services.

Residents indicated challenges in using the prison phone service to contact support and complaints providers. All calls to such numbers require approval from the Prison Service, and that process can take a long time to be completed. It was unclear to residents why some service numbers had been centrally cleared (e.g. Samaritans) whilst others hadn't been and therefore needed to be requested on multiple occasions.

A further concern was raised by a Disability Orderly, a resident who works to help other residents with care needs with tasks of daily living, including moving them around the prison. They expressed concern that there are steep inclines in some areas of the prison which are difficult to push heavy men in manual wheelchairs up. They did not feel they had the right equipment to ensure they didn't injure themselves. There are currently no electric wheelchairs in the prison.

Recommendations/ what residents say:

- Ensure information on adult social care eligibility criteria and how to request an assessment is available to residents.
- Consider how users of ESCC ASCH can access the complaints and feedback pathway, including when waiting for an initial assessment.
- Explore training and manual handling needs for Disability Orderlies.

Accessibility of health and well-being services

The HMP Lewes site is awkward for many residents, especially those with disabilities, due to the inclines, gates, doors and steps, which make it challenging and time-consuming to navigate. We heard that residents with disabilities and mobility issues often faced particular challenges in receiving and getting to appointments.

Residents shared their perception that prison officers were less willing to support the journey between F wing and the health centre for those with mobility needs, as this involved a long and complicated journey. Other barriers raised included the availability of wheelchairs for residents to use, the willingness of staff to use them to assist people, and whether staff appropriately trained in lifting and handling were available.

The perception from residents is that this leads those with disabilities to be more likely to miss healthcare appointments, and we heard from one wheelchair user that they had been unable to attend healthcare appointments as no suitably trained staff were available to take them. Residents indicated that in the past health staff would make visits to those with disabilities and mobility issues on the wing, but these no longer seemed to occur.

Poor infrastructure added to barriers for residents with mobility needs. We heard how lifts were broken at the time of our visit making access to video link equipment inaccessible, which is sometimes used to facilitate health consultations with external departments.

Further accessibility issues reported included a lack of access to glasses due to a combination of not being allowed to receive glasses from home and long wait to see an optician at HMP Lewes, and a lack of suitable adaptation for people's needs in health, care and other meetings,

impacting on their ability to raise their concerns, express their needs and understand what would happen as a result. For example, we heard about a resident with a hearing impairment who didn't receive any support in the meeting to ensure he was able to fully participate.

Recommendations/ what residents say:

- Opportunity for some health appointments to be delivered on the wing for people with specific needs or limited mobility or have not attended health appointment due to a lack of escort.
- Deal with multiple access issues for disabled residents within HMP Lewes estate.
- Reinstate the Disability Forum (that used to run in 2023) to allow issues regarding disability and accessibility to be discussed and communicated to staff.
- Ensure appropriate support is provided for residents with communication needs.

3.4 Wider determinants of health and wellbeing

Nutrition

Food and drink portions were of concern for some residents, who questioned whether provisions were adequate to maintain and support good health, with a particular concern for elderly residents who may be more vulnerable to nutritional deficiencies. This reflected the comments of a resident we had spoken to during our previous visits to the library, who considered himself lucky that he had a job in the prison and could afford to supplement food rations by buying fruit and vitamins.

One participant of the focus group noted they had raised concerns that food portions had become smaller and felt this had contributed to increased aggression and frustration they had witnessed amongst residents.

We also heard concerns that dietary requirements due to medical conditions, such as type 2 diabetes, were not always catered for, leading to frustration and anxiety for those affected.

Physical and mental activity

A common response when residents were asked what one change they would make to support their health, was more time out of their cell, with a particular focus on the ability to spend more time outside and more opportunities to engage in meaningful activities. The lack of opportunities to engage in mental, physical and social activities was cited as a key contributor to poor mental health and increased stress, as well as fears physical health will be similarly impacted.



'People are getting depressed because we are confined to our cells too much . . .'



'More activities and fresh air to improve our mental health.'



'More access to the gym. More access to fresh air. Being confined in a cell for most of the day is not conducive to good physical and mental health.'

Elderly and disabled residents voiced concerns about the deterioration of coordination and cognition, and indicated that having stimuli to keep them physically and mentally active and engaged would be immensely beneficial.

The lack of potential for movement and exercise for residents with disabilities was highlighted as a specific problem. We heard there is a lack of accessibility to use the gym for some disabled residents. It has previously been suggested that gym instructors could come to the wing to deliver alternative exercise activities that may better meet their needs, but this had not happened due to a lack of Prison Officers to act as escorts. This leaves residents with disabilities or mobility issues with limited opportunities for exercise.

Building and facilities

The impacts of the age of the building and the extremes of temperature in the winter and summer were raised, especially on elderly residents, those at-risk or with specific health conditions. Barriers in changing this were

acknowledged, but it was felt adaptations to better cater for it could be explored to minimise the potential detrimental impact on health.

The cleanliness of facilities was also raised as sometimes problematic, particularly in shared areas.



'Cleanliness of facilities i.e. showers, sinks and toilets to promote personal hygiene standards'

Recommendations/ what residents say:

- Increase the amount of time residents can spend out of their cell, including more access to outdoor areas.
- Enable disabled residents who cannot access the gym to participate in alternative exercise, including through on-wing activities.
- Regular reviews of the nutritional intake to be undertaken and combined with regular opportunities for feedback on food and drink.

3.5 Healthcare complaints

Many residents did not seem aware that there is an official process to make a complaint about health services within or outside of the prison, and that verbally expressing a concern to a member of staff may not be treated as an official complaint that would ensure a response. There was also a lack of knowledge about how to escalate a complaint if they were unhappy with the initial response.

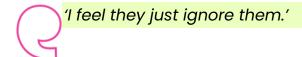


'Not complained yet - can't find the form'

Residents indicated a general lack of responsiveness to healthcare complaints. Even if replies were received, which didn't always appear to be the case, residents reported they usually weren't very detailed or clear in explaining how any decisions were arrived at. Residents didn't indicate whether there was any support provided to people to help them understand the outcome.



'Put in complaint but did not get a reply'



A general feeling was expressed that there was little value in escalating or making complaints if the responses were of little value, or if no changes were likely as a result. This dissuaded residents from following up on things that happened to them. Some participants felt staff became defensive when a complaint is raised and can be reluctant to accept there's a problem.



'Nothing would change even if I made a complaint.'

The value of the Patient Experience Lead was highlighted by participants of the focus group as a constructive means of both leaving feedback, but also in obtaining support to resolve complaints and issues. Residents highlighted there was 'often a queue to talk to her' when she visited the wings and prison spaces and indicated a desire for greater access to support through more regular visits.

Some residents had approached the Independent Monitoring Board (IMB) with their concerns and felt they had been responsive even if their desired result hadn't been achieved. One resident fed back they had swiftly helped to resolve his concern related to medication.

Feedback on the complaints process from The Advocacy People

The following section is written by a staff member from The Advocacy
People who provide the Independent Health Complaints Advocacy
(IHCA) service for residents of East Sussex, and outlines their
experience of supporting residents of HMP Lewes to make complaints
about healthcare.

The Advocacy People (TAP) have been visiting HMP Lewes for several years to make the statutory right to access Independent Health Complaints Advocacy (IHCA) available to the prison's residents. The visiting service stopped due to the pandemic but was reinstated in January 2023.

When TAP resumed the IHCA service in 2023, several challenges were encountered when complaints were submitted to PPG on behalf of residents:

- PPG's complaint process was not aligned with the formal NHS complaints process. The Independent Monitoring Board (IMB) indicated that complaint figures submitted to NHS England may be misleading due to how PPG categorised complaints made by residents. All complaints may have been recorded as 'Concerns' (Informal Complaints).
- 2. PPG staff at HMP Lewes were generally unaware of the statutory IHCA service.
- Prison residents were unfamiliar with the formal NHS complaints process or their statutory right to independent advocacy when making complaints about NHS-funded healthcare.
- Communication challenges prevented residents from contacting professionals or statutory organisations outside the prison.

Through discussions with PPG staff, particularly the Patient Experience Lead, a revised process for handling complaints was agreed. When meeting with residents, TAP would explain that they could either.

- Ask the Patient Experience Lead to visit them on the wing to explore informal ways of resolving their complaint (Informal Complaint).
- Submit a formal complaint on their behalf for PPG to investigate and respond to.
 - Or file a formal complaint on their behalf with NHS England.

Additionally, based on the feedback received from TAP, PPG improved the complaint form that residents must complete when submitting an internal complaint. The updated form clarified that residents could submit formal or informal complaints directly to PPG. However, it still did not inform residents that they could also submit a formal NHS complaint directly to NHS England.

It is difficult for residents to contact NHS England directly. They do not have access to the internet and cannot make phone calls where they need to navigate automated menus due to the prison's phone system. While residents can write letters to organisations, this is a barrier for those who cannot read or write or who are not confident in writing formal letters. Additionally, the back-and-forth nature of communication through the postal system can cause delays, often leaving complaints unanswered, because HMP Lewes is a remand prison and has a high turnover of residents.

Some formal complaint responses received from PPG caused concern about the impartiality and effectiveness of the system. In one example, the medical professional being complained about had conducted the investigation and provided the response. This raised doubts about the investigation's objectivity and undermined the resident's trust in the system.

Recommendations/ what residents say

- A dedicated private space for patient engagement on the wings was felt to be needed, to support confidentiality and security for those seeking to raise issues and reduce concerns about others overhearing or being aware of their issues.
- Clear communications on the different complaints processes and escalation pathways available to residents, including the option to complain to NHS England.
- Improved awareness amongst prison and healthcare staff of the different complaint pathways, and the rights of residents to access these
- Greater availability of information on how to access support with complaints, either within the prison or independently (e.g. advocacy provision).

4. Conclusions

The feedback we received from residents described multiple individual concerns and situations, but they often featured a common theme of issues relating to communication and collaborative working practices, whether between HMP Lewes, PPG, the resident, or external partners, resulting in frustration and worry for the resident, and sometimes poorer patient outcomes and inefficient use of resources. Concerns with waiting times were also added to by lack communication to both reassure that requests had been actioned, and establish realistic expectations for residents about whether their experience aligned with the standards they should expect.

The quality of relationships and effectiveness of collaborative working practices appear key to enabling residents to use health and care services. Accessing services can be a complex process, including multiple stages and the involvement of various teams, increasing the risk for errors to occur. The difficulty of tracing this process to solve or understand issues can further add to the frustration for residents.

Feedback also highlighted how the prison regime and environment has a significant impact on enabling healthcare and supporting or impacting on the overall health and well-being of residents. Alongside the effectiveness of collaborative working with PPG, this was seen through issues of accessibility, and the extent to which opportunities or support were available for residents to manage their health conditions and general well-being.

Since engaging with residents at HMP Lewes we have been updated by Practice Plus Group (PPG) of changes to practices and improvements to services with the hope that this will benefit the patient experience.

We have been told:

 The Patient Experience Lead now meets new arrivals to orientate them to healthcare and ensure they have a healthcare information sheet.

- PPG are focusing on building relations with prison staff to increase understanding of the importance of their role in enabling healthcare appointments. They report they are starting to see a decrease in appointments missed due to issues of facilitation.
- Waiting times have improved for all services, with the exception of opticians.
- A regime change was implemented at HMP Lewes in November 2024, which has enabled increased time out of cells for residents. PPG report this seems to have had a positive impact on general mental health and well-being of residents.

PPG also told us they recognise there have been issues regarding residents receiving messages from healthcare in a timely manner and are actively working with prison staff to find a workable solution to this.

Healthwatch East Sussex welcome these developments and recognise they begin to address some of the concerns identified by the feedback presented in this report.

5. Recommendations

Practice Plus Group

- Explore training residents as Health Champions to support the Patient
 Experience Lead to assist residents in understanding health and care
 processes, provide basic health and self-care advice, and supporting
 the completion of tasks such as completing healthcare applications.
- Implement a process to acknowledge and track healthcare applications (Apps) so residents are aware whether applications have been successfully received.
- Review mental health provision in HMP Lewes and pathways for access to external mental health services to determine their effectiveness in meeting resident's needs.
- Undertake an accessibility audit for the healthcare provision in HMP
 Lewes and explore opportunities to maximise access for those with the most significant support requirements.
- Develop channels of communication with ESCC and NHS Sussex so that emerging themes and issues can be regularly discussed and addressed.
- Update movement slips to specify the time referred to (AM/PM) and the healthcare service the appointment relates to and ensure these are provided to residents well in advance of appointment times.

HMP Lewes

- Collaboration with the healthcare provider (PPG) to explore
 opportunities for services to be delivered on wings in order to maximise
 accessibility and reduce barriers to attendance.
- Photo charts identifying the roles and responsibilities of staff to be made accessible on all wings and in all settings, and badges to identify staff roles.

 Consider how residents can have direct communication with ESCC adult social care department to request an assessment and/or raise concerns.

NHS Sussex

- Staff to be made aware of the limitations around appointment times for prison residents to better support the take-up of appointments and reduce 'Did Not Attends' (DNAs).
- Clear contact information to be provided to PPG and HMP Prison Lewes staff to support changes to medical appointments.

East Sussex County Council

- Ensure accessible information on adult social care services, including eligibility and assessment processes, is provided to residents.
- Ensure there is an accessible complaints and escalation pathway, and information available to both health and social care users about how to access this.
- Consider how residents can have direct communication with ESCC adult social care department to request an assessment and/or raise concerns.

Healthwatch East Sussex

- Continue to share healthcare feedback and experiences of HMP Lewes residents with PPG, HM Prison Service, NHS Sussex, East Sussex County Council, Care Quality Commission and NHS England.
- Continue to offer Information and Signposting support and monitor feedback on healthcare services from Lewes Prison residents to support understanding on their effectiveness, equity and accessibility.
- Share insight and reports on healthcare services in Prison settings with Healthwatch England and NHS England to support national intelligence on this theme.

6. Response to our report

Practice Plus Group (PPG) and HMP Lewes provided a joint response to our report and its findings:

"We would like to thank Healthwatch and The Advocacy People for the work they do in supporting the patient voices of those residing at HMP Lewes.

We view all feedback as an opportunity for us to learn and improve the service we offer and are particularly grateful for the feedback we receive through this independent collaboration which we understand is unique to HMP Lewes.

Our focus is in providing safe, quality and timely care for everyone, regardless of their background and am pleased to say that we are already actively addressing some of the issues raised.

We look forwards to meeting with Healthwatch and The Advocacy People more regularly in future to share our progress and to create the space to hear more about where we can improve further through regular independent feedback"

February 2025

7. References

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Healthwatch East Sussex
Unit 31
The Old Printworks
1 Commercial Road
Eastbourne
BN21 3XQ

- www.healthwatcheastsussex.co.uk
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