

Q4 2023/24

Listening Report:

The opportunity of the Family and Carers' Charter for Health and Justice

9th April 2024



Do you have a loved one in prison?
We want to hear your views about
their healthcare.

- ⇒ E-mail listenstofamilies@prisonadvice.org.uk
- ⇒ Visit prisonadvice.org.uk/healthcare
- ⇒ Use the QR code below





About this report

Pact's quarterly Listening Reports give families a public voice. These reports share what families have told Pact about their experiences of supporting their loved one with health needs in London prisons in the previous three months. They reflect what families have said to us and are written in partnership with our team of family representatives.

We follow a process to make sure we represent families' experiences faithfully and with integrity, without spreading misinformation or causing unnecessary alarm. When an alarm does need to be raised about something families have told us, Pact and NHS London do this immediately through our safeguarding channels. We work collaboratively (rather than in a wholly independent way) with a view to improving outcomes wherever we can. You can find more information about [how we work](#) on our webpage.

Families' comments are not, as standard, subject to independent verification where they relate to reported actions or inactions of third parties. There is a process in place to ensure that clinically serious cases that are raised by family members are escalated, corroborated and reviewed where possible.

In almost all cases, we have limited the issues raised in the report to those that are in the direct remit of healthcare providers and NHS London. However, on occasion, broader issues have been included. Whilst we appreciate these are not in the direct control of healthcare providers, these have been included to provide broader context about what families are telling us about the health of their loved-ones.

All names have been changed. Case studies are reconstructed from notes.

Foreword

This report summarises what Pact heard from families from late Autumn 2023 into the New Year (28th October 2023 – 28th January 2024). During this period, families were separated from their loved ones at Christmas, and many healthcare and prison staff worked across the festive period.

The New Year marked the first anniversary of the Listen to Families programme becoming operational. London prisons were already overcrowded when our programme started but grew to population of 7,778 people by the end of 2023 – an annual rise of 6%. This has exacerbated the structural pressures on healthcare services, as well as for HMPPS colleagues, and made prison life more challenging for those inside. Such factors, alongside many others, mean that improving health outcomes is not wholly in the gift of health professionals.

Seemingly small things make a big difference to families, and the positive experiences they share are encouraging. However, it is sobering to hear many of their accounts. Time and again, families describe delays and inadequate treatment, inhumanity, lack of information and desperate worry. There is a bleak, painful quality to many of the accounts, which can make them hard to read.

And yet, there have been steps forward. In December 2023, a new escalation pathway was agreed to enable Pact to raise safeguarding cases directly to NHS London and healthcare providers, so that family concerns have an additional chance of being addressed.

Another key milestone was an in-person workshop in December 2023, which brought together families, NHS London and the healthcare providers for London prisons. Here, we jointly co-designed a Family and Carers' Charter for Health and Justice. A first-of-its-kind document, the Charter sets out a series of steps that would improve the experiences of patients and their families and carers.

This quarter's Listening Report focuses on demonstrating the opportunity of the Family and Carers' Charter. Drawing on what we've heard from families over our latest reporting period, it aims to show how the commitments of the Charter correspond to what families tell us on the ground and highlights its potential for improving outcomes.

We are delighted that NHS London, Practice Plus Group, Oxleas NHS Foundation Trust, Central and North West London NHS Foundation Trust and Pact have now formally signed on to the Charter. By making these commitments, these health and justice organisations have pledged to take actions that will make a difference to families and carers. This is a landmark on our journey towards improving prison healthcare, and we look forward to working in partnership to ensure the commitments are delivered.



The signing of the Family and Carers' Charter is a landmark in our journey towards improving families and carers' experiences of prison healthcare.

Our Listening Activities

Each quarter, we listen through many different channels of communication so families and carers can share their experiences in a way that works for them.



Listening activities 29th October 2023 – 29th January 2024	No. engaged	Notes
Family Team Members take an active part in shaping the service, including through our active Telegram group.	19	Consulted throughout the quarter: 12 Family Team Members (FTMs). 3 new FTMs onboarded during quarter. 4 Community Members on Reserve.
Semi-structured interviews at Visiting Centres.	199	Interviews at all visiting centres. 19 visits in total.
People share their experiences in a safe space with others in similar situations at family forums .	15	Coffee mornings in November, December & January
Bespoke outreach to target more marginalised and disadvantaged groups .	6	Via London Gypsies and Travellers
Families and carers send an email to our functional mailbox .	17	5 unsolicited emails, 9 emails responding to our messages, and 3 unsolicited emails to Amy directly
Families and carers book 1:1 online video calls or request phone calls with the team.	18	Bookings initiated by families
Family and carers have representation at ' Listen to Families ' team meetings.	34	Family Team Member attendance at monthly online meetings.
Paper surveys are completed by families and carers at Visit Centres.	16	8 from HMP Brixton, 7 from HMP/YOI Isis, 1 from HMP Wormwood Scrubs
Total engagements for quarter	324	
Mailing list	123	Plus 24 where our emails bounce back

What we're hearing: Positive stories

We hear families express relief as they describe times when their loved ones' health needs have been met in prison.



Families and carers have told us that their loved ones have received care including:

- Asthma inhalers
- Dentist appointments
- Sexual health checks
- Therapy appointments

And have been able to:

- Stay active during time outside the cell
- Switch their mattress to relieve back pain
- Keep in positive spirits due to family visits

Freya*

'He has diabetes and is checked regularly. It took him a while to get a dental appointment (which he hasn't had yet), but it takes everyone a while for that- even on the outside. As far as I'm aware, everything is going quite well... I give healthcare here 9/10, which is better than I expected.'

Colin*

'He had a heart attack before he came to prison, and he's being looked after really well since he's been here. He's getting all his tablets and everything he needs.'

Jodie*

'He has now been given protein shakes, is in therapy, and has had a medications review. He has everything he needs care-wise now.'

Brian*

'He has a spare set of retainers for his teeth now, which is really good. It took a while to get them but, luckily, he got a good orthodontist who was really helpful.'

Carole*

'My partner has had problems with headaches since he has been [in prison] but has had positive things to say about the pain relief he's been getting. He feels he has had quite quick access to painkillers. No complaints.'

What we're hearing: A good practice story

Our colleagues at a prison outside London have shared how a Deputy Head of Healthcare engaged with June*, the wife of a patient with dementia. Whilst this case study comes from outside London, it encapsulates how small steps by healthcare staff can make a big difference.



Our Pact colleagues described:

"The reason that I feel the need to share this is because this is what Family Forums are about and can achieve.

June* is such a timid lady that attends the visits centre regularly to see her husband, Ray, who has dementia. As you can imagine, not knowing how he is coping or how he presents himself, is he on the right medication, do they even know how bad he is are just some of the anxieties that June and other families are going through. June regularly contacts the at-risk line because he hasn't called her, when he does call he has been extremely confused about what he is doing, where he has been, or saying he doesn't think he has eaten or showered.

I think that the biggest thing that has been achieved is having the Deputy Head of Healthcare come into the visits centre and speak to June, one to one, to explain what they have done what they are doing and how they can support Ray moving forward. He has emailed June, but the face-to-face meeting was much more personal where she was able to ask more questions that had deemed too silly or personal to mention in an email. If we ever needed evidence that Family Forums work, then this is it.

[The Deputy Head of Healthcare] mentioned to a few of his work colleagues that he was coming out to see me and a prisoner's wife and they were horrified! He went to his manager who absolutely agreed with him to go. The Family Forums help families and prisoners, but we also need them to help the prison staff have greater understanding of what we can all achieve if we work together."

Email from June* to Pact:

"Thank you so much for your kind intervention on Ray's* behalf and mine yesterday and for arranging the interview with [the Deputy Head of Healthcare]. **It was fantastic to have the opportunity to voice my concerns in a way and a place where I was taken seriously and where I felt I was heard.**

It has been hard to know what to do as I watch Ray's health deteriorate and it is particularly good to have the prospect of being able to report those occasions when Ray is audibly unwell or very confused because I hope it will help those caring for him to build up a more complete and informed picture of him, especially should he need medication.

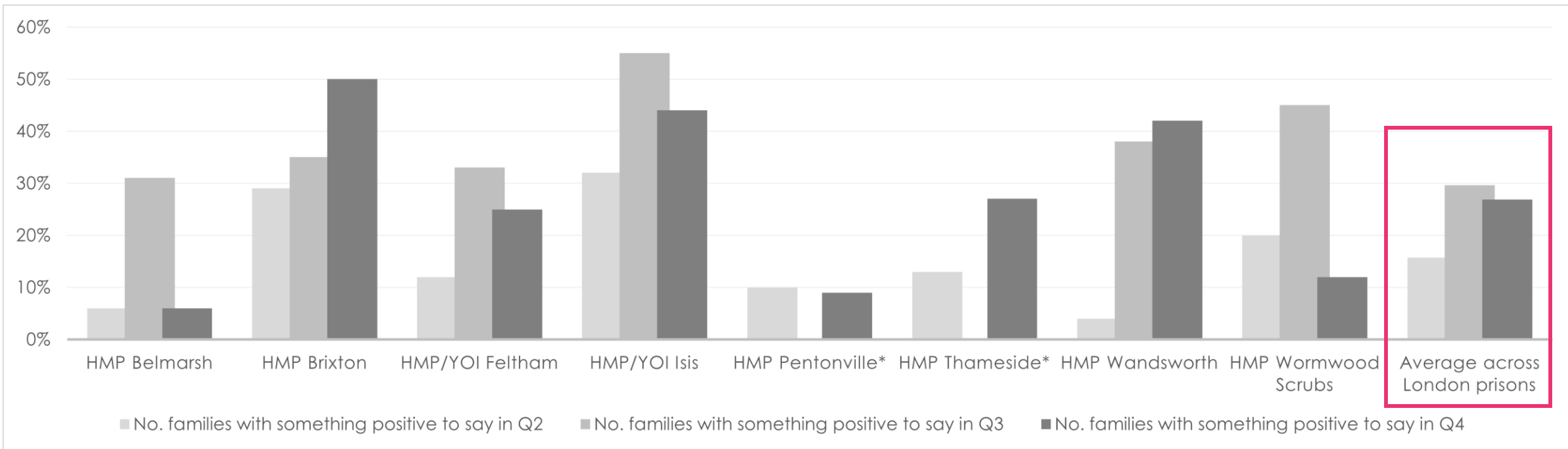
I am grateful, of course, for Ray's sake - but I don't think I had recognised just how much anxiety I had built up, especially at times like the present when Roy is having one of those 'episodes' when he is very confused and vulnerable and when he forgets to phone I cannot help him. **After speaking with you and [the Deputy Head of Healthcare] I feel much less stressed about the situation - which is stressful by its very nature.**

Thank you again. I hope you have a lovely Christmas with your family.'

Prevalence of positive comments: Variations by prison

Of the families we interviewed who had experience with prison healthcare, more than a quarter (28%) had something positive to say about their experience in Q4, which is slightly lower than in Q3 (30%).

The label 'Something positive to say' includes both 'Wholly positive' experiences and those who had 'Something positive' to say (at least one positive element) about their experience. Experiences categorised as 'something positive' are not necessarily 'positive on balance'.



The data represents subjective experiences and is not an overall assessment of prison healthcare quality. Differences in positivity scores are likely affected by the scheduling of wing visits, as well as a range of other factors. Please see the appendix for further data and methodological notes.

*Q3 figures at these prisons are anomalies due to small sample sizes. Listen to Families Visits have since been scheduled to ensure equal coverage of prisons.

The opportunity of the Carers' Charter:

1) Families benefit from clear, user-friendly information to guide them through the system

We hear families express confusion as they describe the challenge of knowing what to do, and their need for accessible guidance.



Key themes:

- Accurate, up-to-date information enables families to knock on the right door and avoids placing strain on the system.
- Clear, practical instructions about solving common problems let families know their next steps for helping their loved ones.
- Information on what to expect, their rights and responsibilities helps families get prepared for different stages in their loved one's journey through custody.

James*

'I'm confused about what exactly the prison healthcare team does and doesn't do. My son is getting out around Christmas time, and I want us to be prepared... When he gets released, are we responsible for registering with a GP, or will they do that for him?'

Khadeejah*

'I'm frightened and I don't know what to do.'

Catalina*

'He's having problems with his glasses. He puts in an app, and nothing happens. We don't know if we are allowed to bring them in for him or not.'

Shannon*

'My partner has bowel cancer. *[There have been a series of issues with his treatments, including several missed appointments.]* I've been ringing all the helplines and calling the prison over and over to get information and try and get things sorted. I found Call PHILL helpful, but it took me 35 phone calls before someone gave me their number.'

Rachel*

'He has spinal cord compression and needs a better mattress. I phoned the prison to raise it with them but was told I have to write to the healthcare providers.'

Nazaat*

'My son has a health condition that means he needs vitamin supplements, but we don't know how to get them to him. The process of finding out information is hard and takes a long time – you get bits and pieces, but there is no clear, solid information available, and it's hard getting through to services when you finally do know who to call. No one has been able to advise us confidently or give us proper information, even for the basics.'

Plestia*

'He hasn't been to the dentist for years. Is he entitled to an ordinary check-up? We would like information about his rights.'

The opportunity of the Carers' Charter:

2) Helping families to be involved, where possible, can ensure patients have more support

We hear families express a desire to help, as they describe their experience and insight as carers, and their need for connection with their loved ones.



Key themes:

- Whilst involving families may not be helpful in all circumstances, there are many times when families could assist with practical tasks and provide greater emotional support to their loved ones.
- Being involved can strengthen family bonds and enable family members to continue playing their roles as carers.
- Families know their loved ones best and may have valuable insights into their wellbeing and needs.

Linda*

'He has learning difficulties and I've always supported him as his carer. He had a brain scan at [a previous prison] but he hasn't got the test results back. It's hard not knowing. I don't mind if he gets the results or I do, we just want to support him.'

Janet*

'My son has long-term mental health conditions – he's been diagnosed with psychosis and personality disorder and has been unwell since the age of 10. Safer Custody have been fantastic, and he's been given colouring things and elastic bands to use if he feels like self-harming, which is good.'

I know there is no tablet or magic wand to make it better, but I feel he's on his own a lot and that he'd benefit from talking therapy. He does talk to us – he cries on the phone to me and says things to his sister that he doesn't say to other people.'

Sadé*

'My godson can't see. He's been trying to get glasses for a long time. I want the prison to send me his prescription so I can order glasses for him privately, but they won't do it. I don't know why.'

Haniya*

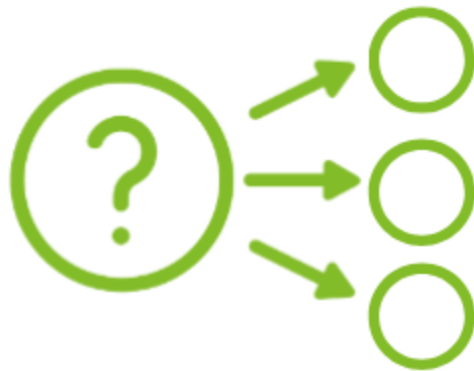
'His mental health has improved a lot since he was taken out of prison and spent time in hospital – the doctors were amazing for him there. I'm concerned about his health deteriorating now that he's been transferred back to prison.'

It doesn't make sense to me that I can't access information about him as his mother. Ruling out family involvement because he's an adult doesn't make sense – he can't always be in the right state of mind. There has to be a method of communication.'

The opportunity of the Carers' Charter:

3) Explaining why information cannot be shared can help families cope with not knowing

We hear families express feeling powerless, as they describe receiving responses that don't make sense to them (or none at all), and their need for understanding.



Key themes:

- When families are given meaningful explanations about why certain information can't be shared, they may develop greater confidence in prison healthcare systems.
- Setting realistic expectations with families can help them know where they stand and mitigate the impact of disappointment.
- Even if families don't agree with the reasons for information being withheld, an explanation gives families something to work with and can be helpful in terms of maintaining family relationships.

Shannon*

'He is told nothing about his appointments. I understand that for security reasons he can't be told when the appointments are, but I think he should be told that something has been booked. He has missed several appointments and had them cancelled [due to regime issues], despite having been put on an urgent referral. Right now he has prostate cancer, bowel cancer and a serious heart condition – we're worried that he's probably gone from stage 2 to stage 3 since he's been here.'

It would help just to know that appointments have been organised, even if he can't know when they will be. The officers dismiss him when he asks for help – they assume he feels anxious simply because he's in prison.'

Valentina*

'I once received a call from a prison psychiatrist. We spoke for a long time, and he asked me for a lot of information, but I wasn't able to ask him for any information back.'

I wish I knew more information. I wish I knew how the prison treated people with mental health problems. I wish I knew he was ok. We want to know what's going on and be included – that's normal for family, you care about your family members.'

The psychiatrist was called away and he said he would call me back to finish the conversation – but he never did.'

Angie*

'I just get stonewalled everywhere'

The opportunity of the Carers' Charter:

4) Supporting staff can help them work with families and carers competently and confidently

We hear families express fear, as they describe variation in the quality of care their loved ones receive, and their need for high-quality patient engagement.



Key themes:

- Care can be improved when managers respond to concerns and speak with their staff to address issues.
- Some of the issues that families raise appear to stem from simple misunderstandings of rules or guidelines by staff, that could potentially be smoothed out.
- Staff who are secure and confident can listen to both patients and families and take their points on board, without feeling that their own expertise is being undermined.

Olivia*

'To start with, he wasn't being properly cared for, but things are sorted now. He is a Type 1 diabetic, but they weren't giving him enough insulin. They were saying he was given enough, but he's done one of the top diabetic programmes on the outside, and he knew he needed more. When he said this to the nurse she said 'go away' and was rude to him. They refused to listen to him.

It was so serious and life-threatening, and our whole family were so worried - we had to act on his behalf and get it sorted. We tried to complain directly but it was very difficult. We kept trying to call but they just cut you off. We never got a response.

So I emailed his diabetes consultant on the outside and asked her to complain on our behalf. She contacted the prison and let them know everything he needed. Then the management must have stepped in - it seems like they spoke to the nurse. Since then, the nurse has been nothing but nice and very accommodating. He is getting what he needs now.'

Angie*

'He's only 20, and he's having blood tests to query leukaemia and autoimmune disease. He won't show it, but I know he's afraid. He doesn't understand what's happening, what to expect, what he has to do or what questions to ask.

The healthcare team won't let him see his own medical records - they told him: "We don't have to share that information with you". I've always supported him with his health and been his advocate - I'm a nurse myself and I know the system. He has a right to see his own medical records.'

The opportunity of the Carers' Charter:

5) Being non-judgemental, polite and kind can build more trusting relationships

We hear families express frustration, as they describe the long-term impact of negative experiences, and their need for respect.



Key themes:

- Treating families and their loved ones with compassion creates a positive feedback-loop where people are more likely to engage well with services.
- Families and their loved ones feel safe to speak-up if they feel they will be believed and protected from any negative reactions.
- Polite, non-judgemental treatment by staff makes it more likely that families and patients will behave politely and non-judgementally too.

Jide*

'He has requested appointments and made medical teams aware of his issue, but nobody has attended to him.'

I understand that people inside sometimes cry wolf, but [if you don't believe people when they say they need help] it means people who actually do need medical attention don't get any.'

Ella*

'He has given up asking questions because once he asked the same question twice to the officers and they gave him a warning. Now he's afraid to ask.'

Edvina*

'He once rang the bell in the night [...]. A doctor came and said: 'Well, if you aren't dead already, then you aren't going to die'. Even though he is a prisoner he is still a human being – it's shocking for him to be spoken to like that.' (see note 1)

Note 1: In December 2023 the relevant healthcare provider offered to investigate this incident, however this wasn't possible due to lack of information about which staff member was involved.

Melanie*

'He has panic attacks and mental health issues. Yesterday I asked for a welfare check and they said he had been seen, but then I spoke to him and he wasn't. They said they would ring me back and they didn't. They lie. We had to speak to the senior officer, and he just said he was new in the job and that they were sorting it out - but they didn't.'

The opportunity of the Carers' Charter:

6) When families are enabled to share information about their loved ones, healthcare teams can be better informed

We hear families express anxiety, as they describe their knowledge of case history and symptoms, and their need to communicate.



Key themes:

- Families who have cared for their loved ones for many years have knowledge that could be useful for health professionals.
- They may be able to provide details of medical history or case notes that their loved one isn't able to access or recall.
- Families and their loved ones may be able to piece together a pattern of symptoms, using their experience of dealing with the same health issue previously.

Donna*

'My son has a complex, longstanding eye condition, that started when he had an eye infection as a child that led to glaucoma. I'm not sure if the prison are even aware of it.'

He has partial vision and needs glasses to read – but he doesn't have any glasses with him, so he is having trouble with reading.

He has a tube fitted at the back of his eye that releases the build-up of pressure, and since he was 8 years old, we've been taking him to Moorfields Eye Hospital to get the pressure regularly checked. I've said to him that he needs to let the prison healthcare know that he should have a specialist appointment so they can check the pressure.'

Chibuike*

'He has been very sick with sickle cell disease. He has had it for many years, and it is on his medical records, but it seems like they didn't look at the notes. He had symptoms and he knew he was getting sick – he asked for help, but they didn't take it seriously.'

He became very ill and was taken to hospital. It will take a long time for him to get better and process it all.'

Faith*

'My partner was brought in two weeks ago with broken legs. He requires pins and has no medical help. I want to hire solicitors to help me navigate this issue, but I can't afford it. I'm worried about him healing wrong before he can get his next round of surgery. He's in excruciating pain. I've been trying to get something done, but no one really wants to help.' (see Note 2)

Note 2: This concern has been reviewed by the healthcare provider, who stated that in the weeks following our interview with Faith*, her partner attended a hospital appointment; was provided with a range of support; and now has other appointments either booked or in progress. A complicating factor had been delays in the healthcare team receiving medical records from the hospital that treated Faith*'s partner prior to prison.

The opportunity of the Carers' Charter

7) Efforts to include everyone can improve access for all communities and backgrounds

As we've seen in previous Listening Reports, intersectional inequalities play a significant role in families' experience of prison healthcare. This quarter, our Inequality Spotlight focuses on GRT families.

Q4 Inequality spotlight: Gypsy, Roma and Traveller families

Our partners, London Gypsies and Travellers, conducted a series of interviews with families and provided us with insights into GRT experiences of prison healthcare.

Key themes:

- Healthcare staff can see past the stereotype of GRT men being 'tough', 'rough' and able to cope well in prison by being aware of the prevalence of mental health issues and suicide in these communities.
- By breaking up public information about healthcare into small, modular units, videos and easy-read versions, healthcare providers can overcome challenges with literacy and take advantage of the strength of GRT WhatsApp groups and social media networks.
- Where healthcare staff recognise the particular importance of family in GRT communities (for example, the traditional reliance on family for survival, the significance of attending funerals and the role of GRT men in protecting the family), they can understand their patients more fully, provide better person-centred care, and foster better relationships with the community as a whole.

The discrimination and prejudice that GRT communities face on the outside is often also experienced in prison.

Irish Traveller men are seven times more likely to die by suicide than the general population, and 11% of all deaths of Irish Traveller men are due to suicide.

It may be more accurate to assume that GRT prisoners are struggling [with mental health] than to assume they are fine. Mental health manifests in complex ways with this group, and increased monitoring and in-depth assessment may be beneficial.

GRT families often have insight into how their loved one is faring and the healthcare needs they have in custody – especially given the stigma around mental health for GRT men.

LONDON GYPSIES & TRAVELLERS

Being locked up may feel particularly claustrophobic for those used to travelling and being outdoors.

It's common for members of whole GRT families to assist in an individual's affairs, so a wide range of family members may play a carer role.

The opportunity of the Carers' Charter:

8) Working in partnership with other agencies brings multiple benefits

We hear families express concerns, as they describe how disconnection between services causes challenges, and their need for joined-up care.



Key themes:

- Good coordination between healthcare teams, HMPPS and community services enables patients and their families to benefit from greater continuity of care.
- Effective partnerships can ensure that each stage in the patient journey goes smoothly, and care is more person-centred.
- When services link up effectively, families can maximise the support they offer at the transition points.

Beverley*

'He had a really bad toothache and had been waiting for months to have his tooth extracted. Eventually he had the procedure, but that same day he was moved [to a new prison].

They should have coordinated and organised themselves, so the two things weren't both happening on the same day.'

Zaynab*

'He has mental health issues and every six to eight weeks he gets very ill – on the borderline of a psychotic episode. He rings his mum every day and she can sense where his mental health is at.

He can be reluctant to engage with services on the outside, but it is a different situation inside. We'd like to support him with his release and make sure he is well set up when he's on the outside.'

Michael*

'He had trouble with back pain and his mattress, and they sorted that for him and changed the mattress. I haven't heard any complaints, and he seems to be in good spirits now.'

Devesh*

'He has eczema, cataracts, and a number of other conditions that require medical attention. It always takes a long time to receive care, and when he does get taken outside to hospital he often misses the appointment because they are late to bring him over.

He has been given contact lenses, but now he needs to have contact solution so the lenses don't irritate his eyes. When he requested this, he was told they are out of stock, and he won't get it for over a month.'

Conclusion

This Q4 Listening Report has described how the experiences that have been shared by families between 29th October 2023 – 29th January 2024 correspond to the commitments in the Family and Carers' Charter for Health and Justice.

Taken together, they confirm the validity of the Charter as a step towards better meeting family and carers' needs.

By signing on to the Charter, NHS London, Practice Plus Group, Oxleas NHS Foundation Trust, Central and North West London NHS Foundation Trust and Pact have demonstrated that they hear what families are saying.

When they deliver on their commitments, these health and justice organisations will have demonstrated that they listen to families. We look forward to supporting them to do this in the months ahead.

The Family and Carers' Charter for Health and Justice

We value the important role that families and carers play in their loved ones' healthcare and are committed to listening to them.

This Charter has been developed by families and carers of people in prison, NHS England and justice healthcare providers working together in partnership.

As signatories to this charter, we pledge to undertake the following actions:

1. We will provide families and carers with clear information in a user-friendly way, to help guide them through the health and justice healthcare system.
2. We will be transparent with families and carers, helping them to be involved with their loved one's healthcare where it is possible.
3. When we are not able to share information with families or carers, we will explain why in a timely and meaningful way.
4. We will encourage all our staff to value the role of families and carers, and support them to develop their skills and knowledge to work with families and carers competently and confidently.
5. We will treat families non-judgementally and be polite and kind to build trusting relationships.
6. We will make sure that all families and carers are able to share information with us about their loved one's health needs.
7. We will be accessible to families and carers from all backgrounds and communities in our effort to include everybody.
8. We will work in partnership with other agencies who promote the health and wellbeing of people in prison.
9. We will continue to review and build this charter together, so it is meaningful for families and carers.

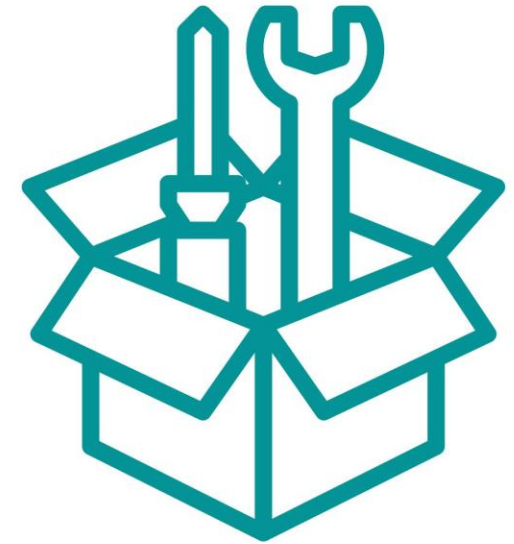
We are committed to all our staff taking small steps to make big changes that make a real difference to our patients and their families and carers.

To sign up to the charter, please email listenstofamilies@prisonadvice.org.uk

Recommendations

Now that the Family and Carers' Charter for Health and Justice has been signed, our focus moves towards putting tools, support and resources in place to facilitate delivery of the Charter commitments.

1. **We recommend that Heads, Deputy Heads of Healthcare and frontline staff work with us to co-design an offer of support and resources that facilitate the delivery of the Charter commitments.**
 - a. Attend focus group workshops with us in April and May 2024 to map existing engagement, barriers and identify appropriate support.
 - b. Attend a face-to-face event on 4th June to co-design resources and support.
2. We recommend that NHS London work with colleagues to publish the Family and Carers' Charter on the NHS England website, to ensure transparency and accountability to families.
3. We recommend that NHS London and healthcare providers involve Listen to Families and our family representatives in discussions regarding a website to share information with families and carers.



Acknowledgements and thanks

We are grateful to all the family members who shared perspectives with Pact and have entrusted us with their stories.

Whilst this report only reproduces a fraction of the experiences that families have shared, everything we've been told has added to the depth of our understanding. Some family experiences have been fed back in private (rather than publicly), and all data has been recorded, in line with GDPR, and contributes to the picture that *Listen to Families* is building. We're grateful to London Gypsies and Travellers, who contributed additional listening activities to serve GRT communities.

On several occasions, listening to families led to immediate action to improve outcomes for families and people in custody. A big thank you to colleagues who responded to safeguarding incidents, and to the visits centre staff who facilitated our data collection.

Many thanks to NHS London and healthcare providers for reading and commenting on drafts of this report. In response to their written input, two amendments were made to the text. There were no redactions.

We're grateful to NHS London for commissioning this pilot programme and attending an online meeting to share their thoughts on 4th March 2024. Without NHS London's support, this Patient and Public Voice programme would not exist.



To hear more or to discuss this report, please contact:

Dr Amy Pollard

Head of Family and Carer Voice (Prisoner Healthcare)
Prison Advice and Care Trust (Pact)

amy.pollard@prisonadvice.org.uk

You can directly [book a diary slot](#)

Our general mailbox is listenstofamilies@prisonadvice.org.uk

Appendix:

Measuring positivity prevalence

Positivity Prevalence: Methodological notes



Each quarter, we measure the prevalence of positive comments regarding healthcare at each London prison.

We review our qualitative interview data for the period and code the interviews as **'Wholly positive'**, **'Something positive to say'**, **'Negative experience with some provision'**, or **'Wholly negative'**.

Having 'Something positive to say' does not indicate that the experience is 'positive, on balance'. Where feedback is a mixture of positives and negatives, we count the interviewee as having something positive to say (rather than giving wholly negative feedback) if they describe a significant positive or satisfactory element to their experience.

Having a 'Negative experience with some provision' indicates that, while a patient received some degree of treatment or accommodation for their healthcare needs, the overarching experience from their families' perspective was negative.

Whether or not a case study was classified as 'Something positive' or 'Negative experience with some provision' is peer reviewed and deliberated within the Listen to Families team.

The statistics represent data points from Q2, Q3 and Q4. We expect to iterate our methodology and build a richer picture over future quarters.

Caveats:

- Our dataset represents the experiences of family members. This is not an overall assessment of the quality of prison healthcare, which would require a wider range of data sources.
- We believe people who have had 'unremarkable' experiences may say less to us during interviews than those whose experiences have been either very positive or very negative.
- Communication issues in prison may mean that families aren't always aware of the resources available or care that has been offered to their loved ones.

'Wholly positive' versus 'Something positive' experiences

Interviews were coded as: 'Wholly negative', 'Wholly positive', 'Something positive' and 'Negative experience with some provisions'. 'Something positive' means the interviewee described at least one positive or satisfactory element to their experience. We excluded interviewees who reported having no experience to share.

Together, 'Wholly positive' and 'Something positive' reviews make up the population of family members who had 'something positive to say' about their experiences with the prison healthcare system.

Similarly, reviews labelled as 'Wholly negative' and 'Negative experience with some provisions' make up the population of family members who had a predominantly negative experience with the prison healthcare system.

Category of Experience	No. of interviewees	%
Wholly positive experience	19	16%
Something positive to say	14	12%
Negative experience with some provisions	24	20%
Wholly negative experience	63	53%
Total	120	100%
Wholly positive + Something positive	33	28%

Prevalence of families' positive comments

Comparison table

It is more common to find families reporting positives at some prisons than at others:

Prison	No. Families interviewed in Q4	No. Families with healthcare experience in Q4	No. Families with something positive to say in Q3	No. Families with something positive to say in Q4
HMP Brixton	26	18 (69%)	8 (35%)	9 (50%)
HMP/YOI Isis	24	18 (75%)	6 (55%)	8 (44%)
HMP Wandsworth	24	12 (50%)	3 (38%)	5 (42%)
HMP Thameside	25	11 (44%)	0 (0%)*	3 (27%)
HMP/YOI Feltham	25	16 (64%)	1 (33%)	4 (25%)
HMP Wormwood Scrubs	26	17 (65%)	9 (45%)	2 (12%)
HMP Pentonville	26	11 (42%)	0 (0%)*	1 (9%)
HMP Belmarsh	23	17 (74%)	5 (31%)	1 (6%)
Total London Prisons	199	120 (60%)	32 (37%)	33 (28%)

Overall, more than half of the families we interview at visiting centres have experiences with prison healthcare.

Of these, more than a quarter (28%) had something positive to say in Q4, which is slightly lower than in Q3 (30%).

*Figures from Q3 are anomalies due to small sample sizes. Listen to Families Visits have since been scheduled to ensure equal coverage of prisons.

Prevalence of families' positive comments

Feedback type across London prisons in Q4

