

Q3 2023/24 Listening Report:

Building trust and transparency

19th January 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 prison 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 covers what Pact heard from families from the height of Summer 2023 into the middle of Autumn (28th July – 28th October). This was a challenging period for London prisons, with a prisoner escape from HMP Wandsworth in September adding media scrutiny to systems that were already under significant pressure.

We understand from healthcare colleagues that there was a ramp up of focus on reception, release and transfer during this period – which hit healthcare teams quite hard and pulled focus into these parts of the patient journey. Additionally, we're told that the increased prisoner flow and movement through the system made meaningful healthcare input more of a challenge.

At the start of Q3 data-gathering, Listen to Families had been operational for just over six months. It was a time of consolidation for the programme – where we onboarded our team of family representatives, made progress towards our recommendations, and gained insights into how our prototype service model has been working in practice.

One of these insights is worth flagging: Listen to Families has been designed to optimise constructive feedback from families, rather than to direct blame. Our task is to identify cross-cutting themes and issues that come up again and again for families, rather than scrutinise individual cases or provide an indirect complaints function – and this is reflected in our methods. Our interest is in working with NHS London and healthcare providers to identify positive steps forward, ensure that the needs of families are better met, and serve our shared goal of improving prison healthcare.

As the first PPV programme for family and carers in the NHS Health and Justice space, our work is on a journey. Whether you are reading this report as a family member, NHS staff, a healthcare or criminal justice professional, we invite you to travel with us.



**Our key message to
healthcare
professionals is:**

**Thank you for doing
your jobs**
Don't leave!
We know it's hard

A wide-range of listening activities

We have many different channels of communication so families and carers can share their experiences in a way that works for them.



Listening activities 28th July – 28th October	No. engaged	Notes
Family Team Members take an active part in shaping the service, including through our active Telegram group.	14	Consulted throughout the quarter. 1 Community Member on Reserve onboarded during quarter.
Semi-structured interviews at Visiting Centres.	152	Interviews at all visiting centres, 19 visits in total.
People share their experiences in a safe space with others in the same boat at family forums .	11	Coffee mornings in August, September and October
Families and carers vote on a key question using tokens during their visits to Visit Centres.	0	Currently on hold at HMP Brixton
Bespoke outreach to target more marginalised and disadvantaged groups .	10	Via Zahid Mubarak Trust
Families and carers send an email to our functional mailbox .	9	2 unsolicited emails, plus 7 emails responding to our messages.
Families and carers book online for a 1:1 video call with the team.	3	Bookings initiated by families
Family and carers have representation at monthly 'Listen to Families' team meetings .	28	Family Team Member attendance at monthly online meetings.
Paper surveys are completed by families and carers at Visit Centres.	22	21 from HMP Brixton and 1 from HMP Pentonville.
Total engagements for quarter	249	
Mailing list	110	Plus 18 where our emails are bouncing back

What we're hearing: Positive stories

The little things can make a big difference to both prisoners and their families.

Key themes:

- Communication, where possible, with both patients and their family members sets both parties at ease and helps things run more smoothly.
- Timely responses to medical issues can build a sense of trust among patients and their families.
- When their loved ones are receiving appropriate healthcare, families say they feel more human.

Family team member:

'When a family member has a positive experience with the system it leaves us feeling a little bit in control of our loved ones life.

This positive feeling has a ripple effect on the prisoner as the family member can comfort and reassure the prisoner, which then leaves them in a better mental state.'

Michael*

'He's been out to hospital regularly and we [his parents] have been kept up to date about what is happening by our son. We are very happy with the support that he's getting.

I was in prison before, and my son's experience has been much better than mine.'



Sarah*

'He is on an ACCT for his mental health [...] They engage with him brilliantly and everything I ask about they action in some way. They found that one of his friends' dads was at [the prison], so they put him in the cell next door so they could have a hug and he could get some support.'

Kimberly*

'He's been really well taken care of. He's getting medications and getting appointments.

This is my first visit, and we don't have a complete idea of how the healthcare system works here, but we have been really pleased so far. I'd give the healthcare system here an 8 out of 10.'

What we're hearing: Comprehensive public information would make a big difference

There is a particular value to general public information about prison healthcare, given the limits to communication regarding a specific loved one's care.

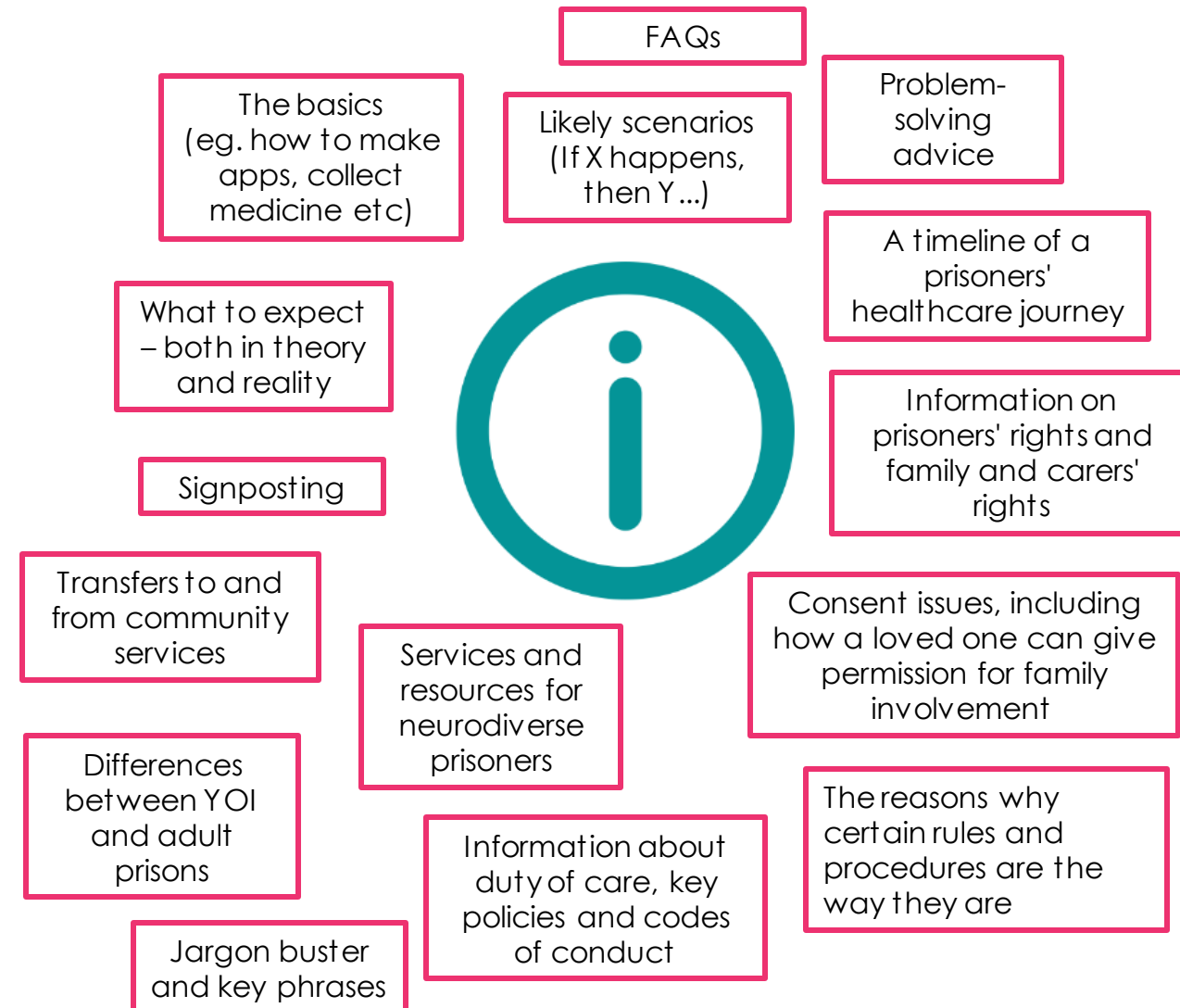
Key themes:

- Families need online information about how prison healthcare works and how they can navigate the system.
- Information should help them problem-solve given **what actually happens** in reality – it shouldn't depict what should happen on paper (or what professionals are aiming for) as if this always occurs in practice.
- Information should be accessible, aimed at a diverse audience (including those with literacy issues) and integrated with Google translate for non-English speakers.

Family team member discussion:

'It shouldn't be a glossy magazine, trying to stop people worrying about their loved ones when in reality, almost none of that is available to them.'

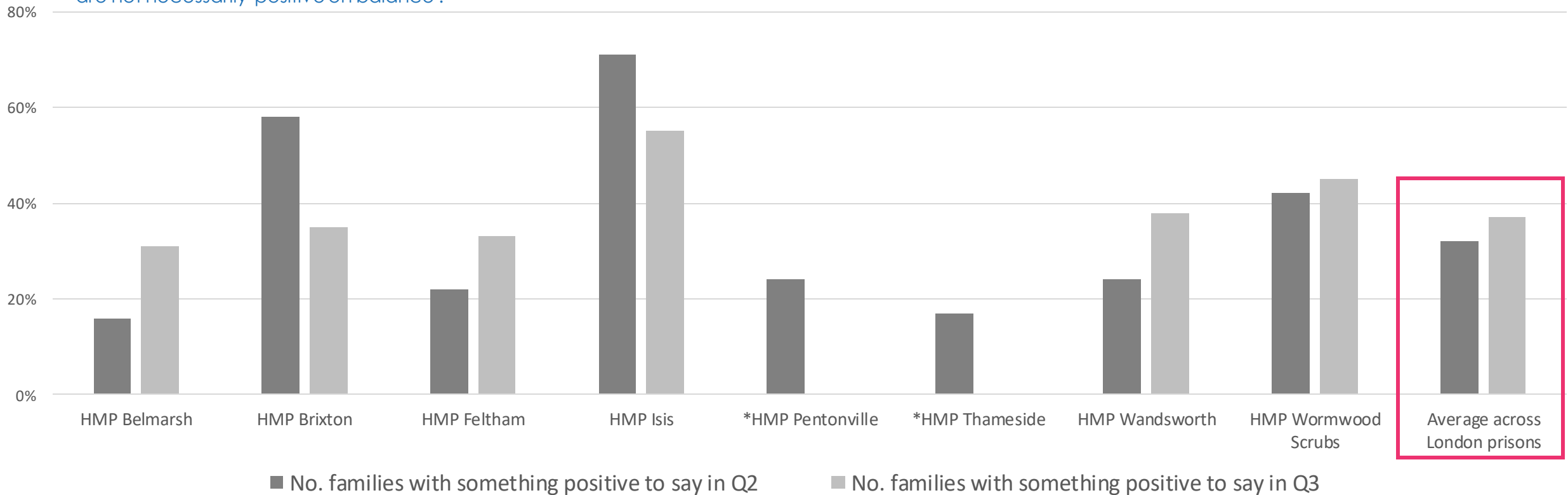
'That just brings more disappointment, anger, anxiety...a rollercoaster of emotions because we feel duped.'



Prevalence of positive comments: Variations by prison

Of the families we interviewed who had experience with prison healthcare, **over a third (37%) had something positive to say in Q3**, which was higher than in Q2 (32%).

'Something positive' includes both wholly positive experiences and those who had a mixed experience with at least one positive element. Mixed experiences are not necessarily 'positive on balance'.



The data represents subjective experiences and is not an overall assessment of prison healthcare quality. Please see the appendix for further data and methodological notes.

*These figures are anomalies due to small sample sizes. Future Listen to Families Visits will be scheduled to ensure equal coverage of prisons.

What we're hearing: Families appreciate proactive outreach and would like more

Some families have been led to understand that their involvement is only considered necessary in cases of 'serious incident or death'. Is this view accurate? If so, what counts as serious? Providers are commissioned to deliver community equivalence, but what should this look like in practice? Whose responsibility is proactive outreach, in different circumstances?



Key themes:

- Families appreciate proactive outreach by healthcare staff, especially when something serious has happened to their loved one.
- Families often feel that a wider range of incidents should count as appropriate for family outreach.
- Where proactive outreach from healthcare teams or the prison is not forthcoming, the prison grapevine sometimes fills in the gaps.
- It would help families to know when they can expect to be contacted, and when they won't be.

Dominic*

'My son was attacked while in prison and taken to hospital, and our family was never told. I found out through the grapevine from prisoners at other prisons who took the time to reach out to me. [...] That's the only reason I know what happened to my son.'

Chloe*

'He's a paranoid schizophrenic and he was in psychosis when he got sent to prison. He was too ill to call me, so I didn't know where he was for three months.

Eventually, someone took pity on him and called me. I sobbed down the phone – I needed to know he was safe.'

Victoria*

'My partner has issues with his mental health and self-harming. [...] When he got sentenced, they cut off his calls for three days. We were never told, and I was very worried.'

What we're hearing: Families find that some healthcare professionals engage with them better than others

Families' experiences vary considerably depending on which staff members they are dealing with.

Key themes:

- From a family perspective, it feels like some staff are more knowledgeable and confident about engaging with families than others.
- Sometimes it appears that the system is effective on paper but isn't always being implemented in practice.
- The importance of treating families with politeness and compassion cannot be underestimated.



Bella*

'He has bad asthma and it took ages for them to give him anything. I phoned up many times, but nothing happened and he didn't get treatment for two months. He was really struggling to breathe, and it was really scary. Now he's ok, but it took a lot of time and a lot of phone calls to make anything happen.'¹

Marie*

'I was worried about his welfare [...] so I called and eventually got hold of someone. [...] Whoever was on the phone with me was incredibly helpful. She went to go check on him, told him to reach out to me, and then called me back to tell me how it went. She also followed up later to see if he had reached out to me yet. [They were] really kind and helpful.'

Nicole*

'I've reached out several times on behalf of my son because I'm concerned about his mental health. I leave a message and they're supposed to get back to me within 48 hours, but I've only ever gotten a response once.'

¹

In November 2023, healthcare providers initiated an investigation into this reported incident.

What we're hearing: Some families are skilled in interpreting their loved ones' behaviour and understanding their needs

Some family members hold an important piece of the jigsaw puzzle. Their knowledge could be an asset for healthcare staff.

Key themes:

- Some family members have been longstanding carers for their loved ones and have extensive knowledge of their medical history; what works and what doesn't; and the issues that may lie behind a patient's presentation.
- Where healthcare professionals give patients the opportunity to give consent for family involvement, they maximise the chances of families being able to offer their knowledge and skills.
- There can be particular benefits to involving families whose loved ones face language barriers or where cultural differences make misunderstandings more likely.

Carol*

'My son is diagnosed as schizophrenic. He fasts for religious reasons, but this interferes with his medication because he refuses to take his meds while he's fasting. This causes more problems for him with his symptoms and behaviour. He has become quite institutionalised and takes a lot of convincing to do what he doesn't want to do or to deal with change.'

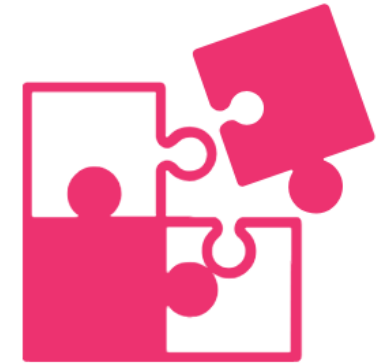
Atiqq*

'He is suffering from hallucinations and delusions – in particular, that the insects and pests in prison are speaking to him. He has stopped eating, gives his food to the rats, and has lost approximately a quarter of his body weight.'

The staff have misunderstood his lack of eating – they think he is fasting for religious reasons, but it's actually to do with his mental health problems.'

Yvonne*

'It would have helped him to have a better explanation of the times when he wasn't given the medication. He didn't know why, he was just in the dark and it made him more stressed [...] I don't think he understands what he is taking or how long he needs to take it for.'



Q3 Inequality Spotlight: Racialised communities

Many of the themes we hear from family members of colour are also reported by white family members, however people of colour can face additional and distinct challenges.

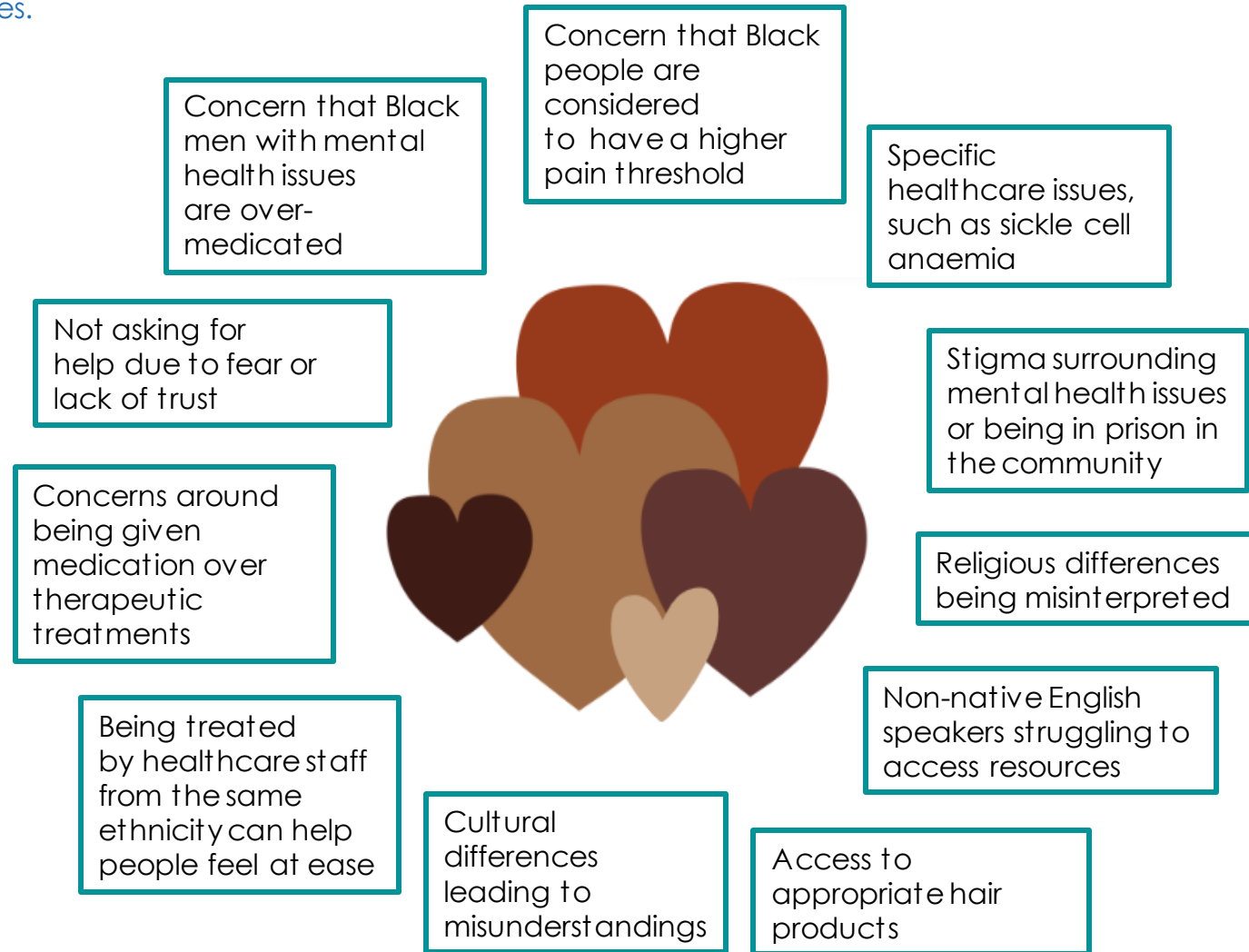
Key themes

- Families from racialised communities often describe a lack of trust in the system or share the view that the system will not be able to help them even if they ask.
- There can be a reluctance to advertise vulnerability within the system.
- Some families report not being understood by prison and medical staff due to perceived religious differences, cultural differences or language barriers.
- Some families describe additional barriers due to the stigma of being in prison and/or of mental health issues within their communities.

Nearly half (47%) of the family members we interviewed in Q3 were people of colour.

Of those family members of colour, over half (60%) were Black.

Additional listening activities were undertaken by Zahid Mubarek Trust to enrich our work in this area. Input from ZMT has been integrated in these slides.



What we're hearing: Lack of trust can mean people stay silent about health needs

Families from all demographics describe a lack of trust in the system, however this is particularly pronounced for Black families and people of colour. Whilst we recognise it can be challenging to work with patients who don't wish to engage, sometimes this is an area where trusted family members can help.

Key themes:

- Many families describe how their loved ones believe that there's no point in asking for healthcare support because nothing will be done for them.
- Families often say their loved ones are reluctant to advertise vulnerability in the system – but sometimes trusted family members can hold crucial information about what's going on.
- Trust can be built when families are involved in helping get a positive outcome; or encourage their loved one to seek help which is then forthcoming.

Fatima*

'There should be a wider structure for families to be more involved. Sometimes a loved-one *[who has mental health difficulties]* can't judge for themselves what they need. *[Family]* would be able to give some insight into what has gone on in their life more than what our loved one will probably say to the medical people.'

Dave*

'He says there's no point in bothering *[making an app for pain relief]* because they won't help anyway.'



Marcia*

'My son needs glasses and I have been trying to persuade him to put in an app for them. He is refusing because he doesn't think they will do anything - he would rather know he has nothing than put himself in a position where other people can let him down.'

He gets paranoid on the wing because he can't see who's around him due to his vision. The paranoia is quite bad. He's not quite delusional yet - but I can see him heading that way.

If he loses touch with reality, will they give him glasses or will they just give him drugs?'

In summary

The Q3 Listening Report has described:

- A slight increase in the prevalence of positive comments compared to Q2, with 37% of interviewees having *something* positive to say (including those whose experiences were mixed).
- Comprehensive public information about prison healthcare would be highly valued by families, especially if this helped them navigate what actually happens in practice.
- Families find that some healthcare professionals engage with them more than others.
- Families appreciate proactive outreach and would like more of it.
- Some families are skilled in interpreting their loved ones' behaviour and understanding their needs.
- Those from racialised communities can face additional and distinctive barriers.
- Lack of trust can mean people stay silent about health needs; something that can particularly affect the Black community.



Families have described instances where they have been able to help gain positive outcomes for their loved ones by working together with healthcare professionals.

When they are given the information they need; treated with compassion; and engaged through respectful dialogue; families and carers can be a valuable asset for improving prison healthcare.

Recommendations:

Family and Carers' Charter

We were delighted to work with NHS London and healthcare providers to co-produce a draft of the Family and Carers' Charter for Health and Justice on 4th December 2023. We recommend that this work is taken forward over the coming months.



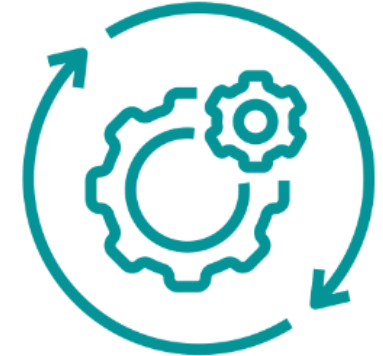
1) **NHS London, Healthcare Providers and Pact to review drafts, agree text and then sign on to the Family and Carers' Charter once this is finalised.**

2) Once finalised, NHS London to publish the text of the Family and Carers' Charter on their website, together with a list of signatories.

Call Phill

We are also pleased that Practice Plus Group have commenced work to improve the signposting and promotion of Call Phill. We recommend that the following actions are prioritised:

- 1) Ensure that Call Phill is signposted via gov.uk for the relevant prisons.
- 2) Change the outgoing voicemail message so that it is clear and welcoming for a family and carer audience.
- 3) Amend the existing news page on the Practice Plus Group website so that it is up-to-date and written for a family and carer audience.



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 Zahid Mubarek Trust, who contributed additional listening activities to serve racialised 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, and for attending a seminar to share their thoughts. In response to their written input, six amendments were made to the text. There were no redactions.

We're grateful to NHS London for commissioning for this pilot programme. Without NHS London's support, this Patient and Public Voice programme would not exist.



To hear more or 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 this period and code the interviews as either wholly positive, wholly negative or mixed (ie. with *something* positive to say).

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 at least one positive or satisfactory element to their experience.

The statistics represent data points from both Q2 and Q3. 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 mixed experiences

Interviews were coded as: "Wholly negative", "Wholly positive", and "Mixed", meaning they 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 "Mixed" reviews make up the population of family members who had *something positive to say* about their experiences with the prison healthcare system.

Category of Experience	No. of interviewees	%
Wholly negative experience	54	63%
Wholly positive experience	17	20%
Mixed experience (at least some positive)	15	17%
Total	86	100%
Positive + Mixed Experience	32	37%

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 Q3	No. Families with healthcare experience in Q3	No. Families with something positive to say in Q2	No. Families with something positive to say in Q3
HMP Belmarsh	28	16 (57%)	3 (16%)	5 (31%)
HMP Brixton	25	23 (92%)	7 (58%)	8 (35%)
HMP Feltham	8	3 (38%)	2 (22%)	1 (33%)
HMP Isis	26	11 (42%)	5 (71%)	6 (55%)
HMP Pentonville	3	3 (100%)	5 (24%)	0 (0%)*
HMP Thameside	4	2 (50%)	1 (17%)	0 (0%)*
HMP Wandsworth	22	8 (36%)	4 (24%)	3 (38%)
HMP Wormwood Scrubs	36	20 (56%)	5 (42%)	9 (45%)
Total London Prisons	152	86 (57%)	32 (32%)	32 (37%)

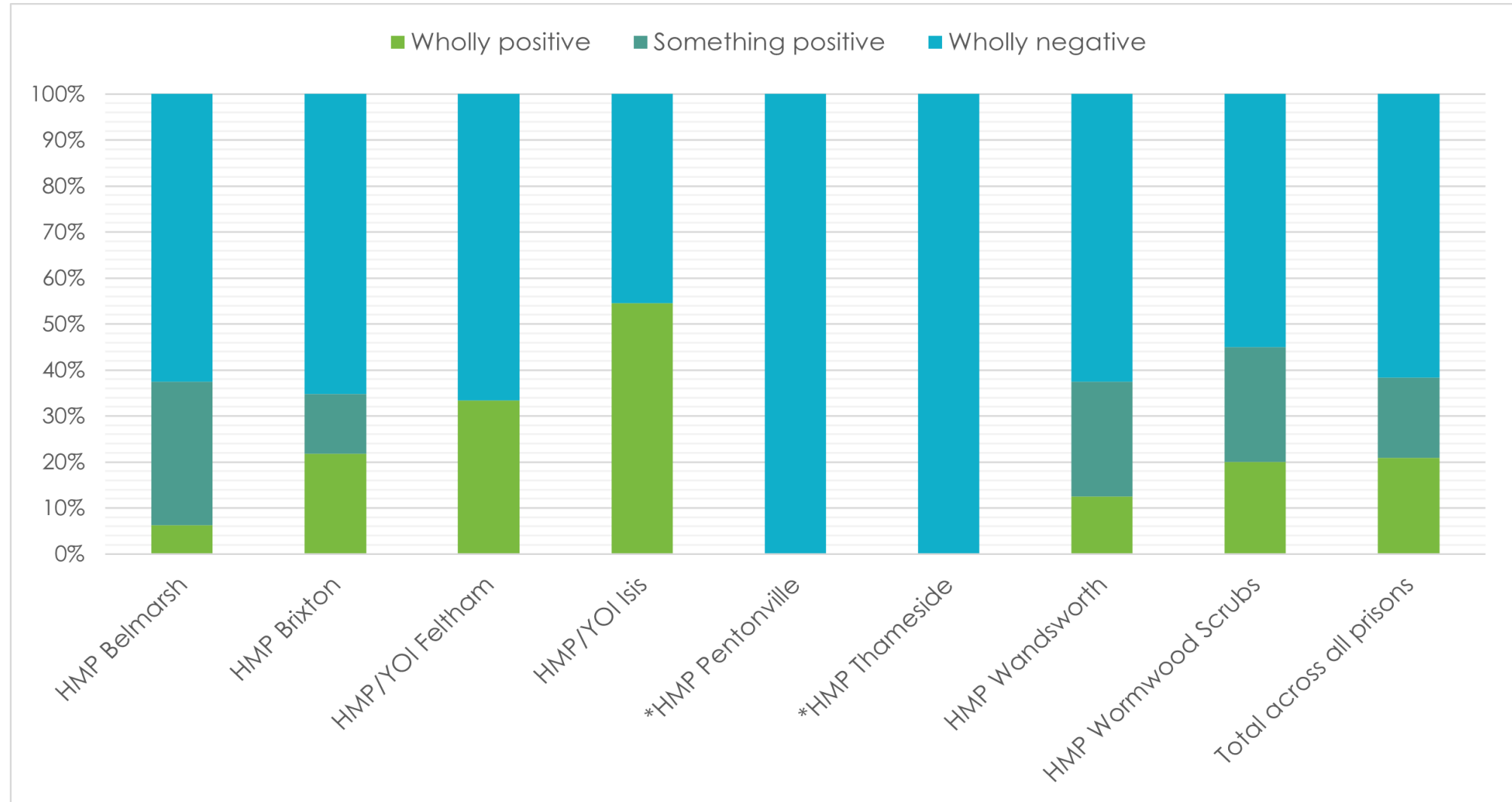
Overall, slightly more than half of the families we interview at visiting centres have experiences with prison healthcare.

Of these, over a third (37%) had something positive to say in Q3, which is higher than in Q2 (32%).

*These figures are anomalies due to small sample sizes. Future Listen to Families Visits will be scheduled to ensure equal coverage of prisons.

Prevalence of families' positive comments

Feedback type across London prisons in Q3



*These figures are anomalies due to small sample sizes. Future Listen to Families Visits will be scheduled to ensure equal coverage of prisons.