

1,500 Voices:

What it's like to support your loved one in prison with health issues

January 2025



Prisoners · Families · Communities
A Fresh Start Together



Executive Summary

Families can play a crucial role in supporting their loved ones when they are unwell. Relationships have long been identified as a key enabler for better health outcomes and are a pillar of the biopsychosocial model of health. However, for families of 90,000 people in custody in England and Wales today¹, the opportunity to engage in their loved ones' care is often taken away.

Pact's Listen to Families service creates opportunities for families and carers to be heard and influence how healthcare services in prison are delivered and developed. As the first Families and Carers Patient and Public Voice (PPV) service in England and Wales, it aims to improve families and carers' experiences of health and justice services.

Listen to Families was commissioned by NHS London as an innovative programme in eight London prisons in 2022 and extended NHS South East to four prisons in the South East region in 2024. It drives improvement in prison healthcare through an ongoing cycle of partnership with families, the NHS and healthcare providers:

Listening via a range of different activities to engage families and carers who have a loved one in a relevant prison.

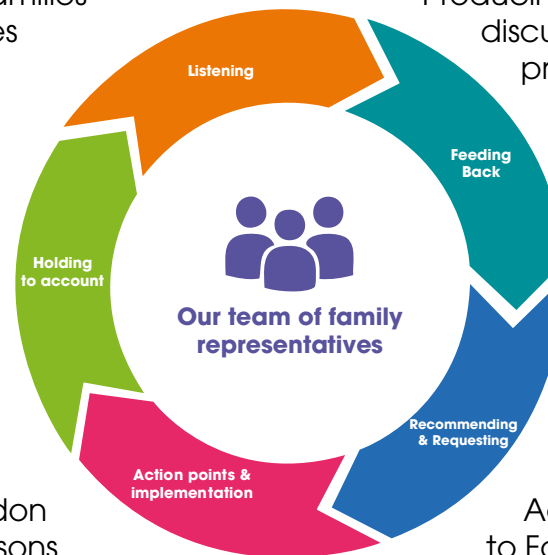
Feeding back to NHS commissioners and healthcare providers via a quarterly seminar and Listening Report.

Producing **recommendations and requests** and discussing these with the NHS and healthcare providers.

Developing **action points** with the NHS and healthcare providers and supporting implementation.

Facilitating accountability by giving NHS London and healthcare providers an opportunity to share updates on the actions they have taken (or not) and the reasons, and close the loop back to families.

Across our London and South East services, Listen to Families has conducted over 1,500 semi-structured interviews with families in prison visit centres. Through these and our other listening channels, we have developed a rich understanding of what it's like for families to support their loved ones in prison with health issues.



¹ See Prison population: weekly estate figures 2024. Available at: Prison population: weekly estate figures 2024 - GOV.UK

What families say about prison healthcare

It can be hard to hear families describe what it's been like for them to support their loved ones in custody. Their experiences often involve high levels of distress, trauma, and a sense of powerlessness.

Nevertheless, **one third of families with experience of prison healthcare have something positive to say**, even if their experiences had been mixed. Families value the positive work that prison healthcare teams do and the care they provide to their loved ones. Seemingly small things can make a very significant difference to families' experiences.

However, almost **half of families share describe wholly negative experiences**. Their concerns involve a wide range of issues from delays, missed appointments and unsatisfactory care to not being believed and lack of adequate pain relief. Prison life impacts on health and wellbeing in multiple ways, and the challenges faced by families and their loved ones often sit across healthcare, prison and community boundaries.

One in six families share safeguarding concerns that require escalation. Many of these families can provide information that adds clinical value and enables healthcare teams to deliver care that improves health outcomes.

Recommendations

Working with our team of family representatives, Pact has developed recommendations that work at the levels of structure, practice, culture and accountability in the health and justice system. These include:

Structure

- Commission Listen to Families across the NHS regions.
- Develop a multi-agency consent passport.
- Build family engagement into reception processes.

Practice

- Improve staff training and family engagement practices.
- Enable dialogue with families before a patient reaches crisis point.
- Commission new programmes to involve families in care planning

Culture

- Recognise and reward staff for family engagement – identifying champions and role models.
- Family-centred goals in staff performance reviews.
- Celebrate and scale good practice.

Accountability

- Broaden signatories to the Family and Carers' Charter for Health and Justice.
- Healthcare providers to report quarterly against Family and Carers' Charter commitments.

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 Pact is building.

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.

We're grateful to NHS London for commissioning Pact to deliver Listen to Families as an innovative programme in London. Without their support, this Patient and Public Voice programme would not exist.

Many thanks to NHS London and healthcare providers for reading and commenting on drafts of this report. Their input and reflection was much appreciated.

Last but by no means least, we are indebted to Pact's team of family representatives who worked alongside us as this report was prepared and co-designed its recommendations with us.

1. Families' role in patient health and wellbeing

Relationships have long been identified as playing a crucial role in patient health and wellbeing, and are a pillar of the biopsychosocial model of health. When a loved one is unwell, it is a natural response to hold their hand, provide a reassuring phone call, send a care package, sit alongside and advocate for them at a doctor's appointment, or help them make sense of a diagnosis or treatment plan. It can cause us to feel anxious, overwhelmed and fearful, and we often rely on healthcare professionals not only to provide treatment, but also to reassure and support both ourselves and our loved ones.

For families of the 90,000 people in custody in England and Wales today², the opportunity to engage in their loved ones' care is often taken away.

“It's really hard because you can't do anything. (You're) just hearing someone broken on the phone.”
Family member”

Families will often know their loved ones best. Many have been their primary carers and life-long advocates, with experience and knowledge of their loved ones' histories, needs and care plans. And yet, for a long time, families have been telling Pact that they feel locked out of a justice healthcare system

and prevented from being able to inform and support the care of their loved one in custody.

Pact is a pioneering national charity who has been supporting prisoners and their families for over 125 years and is committed to making prisons safer and healthier. Pact believes that enabling prisoners and their families to speak truth to power is fundamental in creating change.

“If everyone can change a little bit of the world then we can change the world together.”
Listen to Families Family Team member”

Statutory obligations to involve patients and the public in NHS commissioning have been in place for over a decade³ with NHS England stating that 'families are important to recovery and carers often hold information that allows services to work more effectively⁴. However, whilst community services routinely include Patient and Public Voice (PPV) provision for families and carers, PPV services in custodial settings have historically only involved patients.

² See Prison population: weekly estate figures 2024. Available at: Prison population: weekly estate figures 2024 - GOV.UK. ³ Under section 13Q of the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012), NHS England has a statutory duty to make arrangements to involve the public in commissioning services for NHS patients. (see Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning, NHSE Engage (November 2015)). ⁴ NHS England and University of Central Lancashire (2018) Carer support and involvement in secure mental health services Toolkit.

2. The Listen to Families service

Public engagement has been recognised as crucial to reforming and improving services across the NHS and is at the heart of work to shape the forthcoming NHS 10 Year Health Plan⁵. NHS England's Health and Justice Framework for Integration 2022-2024 states that "the inclusion of voice of (...) families and carers is a vital component of driving quality and improving health and wellbeing outcomes"⁶.

In July 2022, Pact was commissioned by NHSE to deliver the very first Families & Carers Patient and Public Voice (PPV) service across eight London prisons: HMP Belmarsh, HMP Brixton, HMP YOI Feltham, HMP YOI Isis, HMP Pentonville, HMP Thameside, HMP Wandsworth and HMP Wormwood Scrubs. The service is known as 'Listen to Families'.

The service aims to:

1. Improve families and carers' experiences of health and justice services.
2. Ensure that key themes in the needs of families and carers are identified, consulted on and met by commissioners and providers.
3. Listen to the voices of families and carers and address their experiences and concerns of health and justice services, with a view to finding solutions and improving those areas that require modification.
4. Provide assurance that any identified service changes will be consulted on with families and carers, implemented and addressed confidentially.

“ The creation of the family team has been a real standout achievement. It has enabled us to genuinely have the voice of those with lived experience at the heart of our service
Healthcare provider ”

The vision of Listen to Families is that families and carers can support their loved ones to access effective healthcare services in prison, and that health outcomes for custodial patients improve as a result. It achieves this by creating opportunities for families to be heard and influence how healthcare services are delivered and developed.

Pact's Listen to Families London team includes ten individuals all of whom have lived experience of supporting a loved one with their health and wellbeing in London prisons. These Family Team Members are in frequent contact together via a messaging group, attend regular team meetings, contribute to the development of feedback reports, and attend development meetings with justice healthcare professionals.

⁵Press release by Department of Health and Social Care "Government issues rallying cry to the nation to help fix NHS" (Oct 2024). ⁶NHS England. Health and Justice Framework for Integration 2022-2024: Improving lives - reducing inequality. Available at: NHS England » Health and justice framework for integration 2022-2025: Improving lives - reducing inequality

Family and carer insights are collated and analysed on a quarterly basis and presented in Listening Reports which are shared with NHS London and healthcare providers and published on Pact's website for families to access. Families' views and experiences are gathered via a range of communication channels: interviews in prison visit centres, paper surveys, family forums, emails, telephone and video calls. The service has been successful at engaging with a broad cross section of family members/carers. Both Family Team members and families interviewed in visit centres represent a rich diversity of experience, age, religion, nationality and ethnicity, and the Listening Reports publish an 'inequalities spotlight' every quarter to explore how different aspects of intersectional inequality affect families' experiences of justice healthcare.

A robust protocol has been developed to ensure that families' experiences are represented faithfully and with integrity, while giving healthcare providers and commissioners the opportunity to respond and avoid causing unnecessary alarm.



Listening via a range of different activities to engage families and carers who have a loved one in a relevant prison.

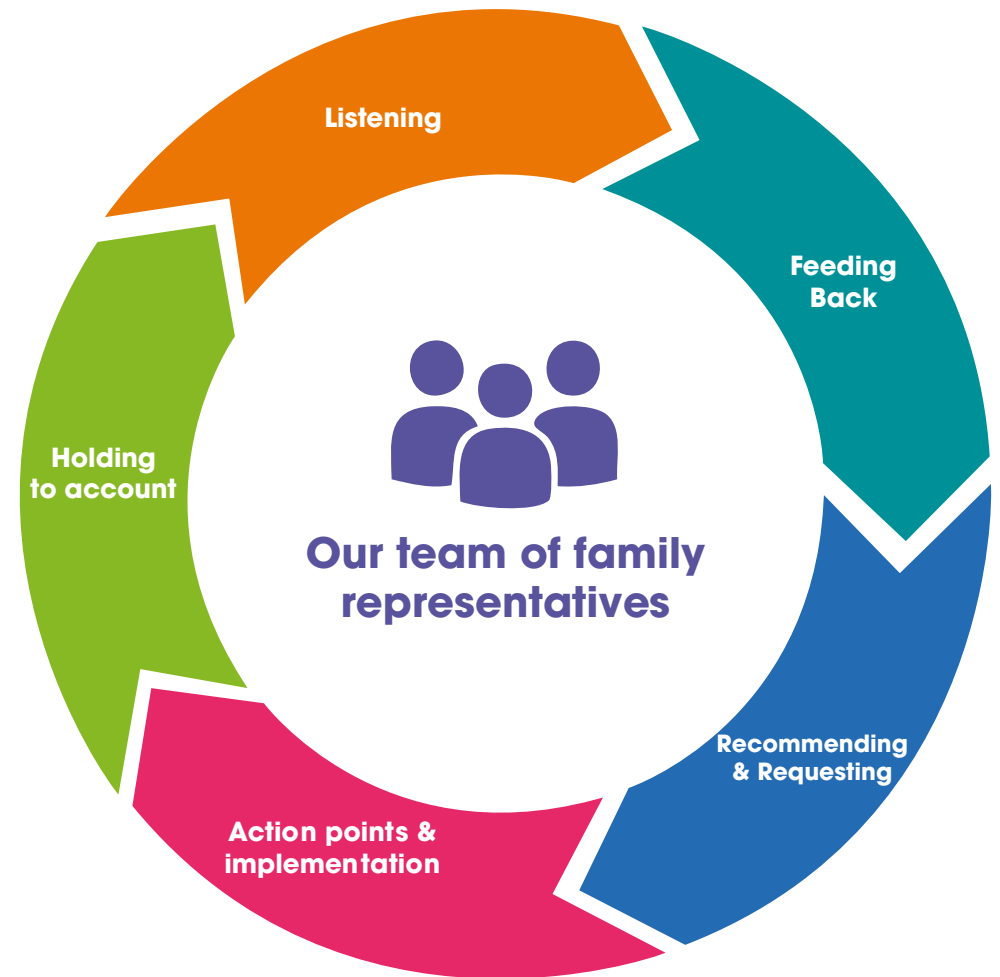
Feeding back to NHS commissioners and healthcare providers via a quarterly seminar and Listening Report.

Producing **recommendations and requests** and discussing these with the NHS and healthcare providers.

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Facilitating accountability by giving NHS London and healthcare providers an opportunity to share updates on the actions they have taken (or not) and the reasons, and close the loop back to families.

In 2024, Listen to Families expanded to four prisons in the South East: HMP Aylesbury, HMP Downview, HMP Elmley and HMP Huntercombe. Here, the service is enriched by Family Link Workers who provide a liaison service between families, patients and healthcare providers. Operating through an integrated PPV / Delivery model, they bring additional capacity to involve families and carers in their loved one's care where all parties agree this will be beneficial to the patient.



3. What families say about prison healthcare

3.1 Families value the positive work that prison healthcare teams do

One third of families with experience of prison healthcare had something positive to say about the care their loved one had received, even if their experience had been mixed.

The label 'something positive to say' includes both 'wholly positive' experiences and those who have at least one positive element to their experience. Experiences categorised as 'something positive' are not necessarily positive on balance.

“

I couldn't get him to go to the dentist before he went to prison - but he has been to the dentist now so that's good.

Healthcare member

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“

On the outside it was hard to get him taking his methadone regularly, but he has done better inside. The structure and the routine have been good for him - it's been a bit of a blessing

Family member

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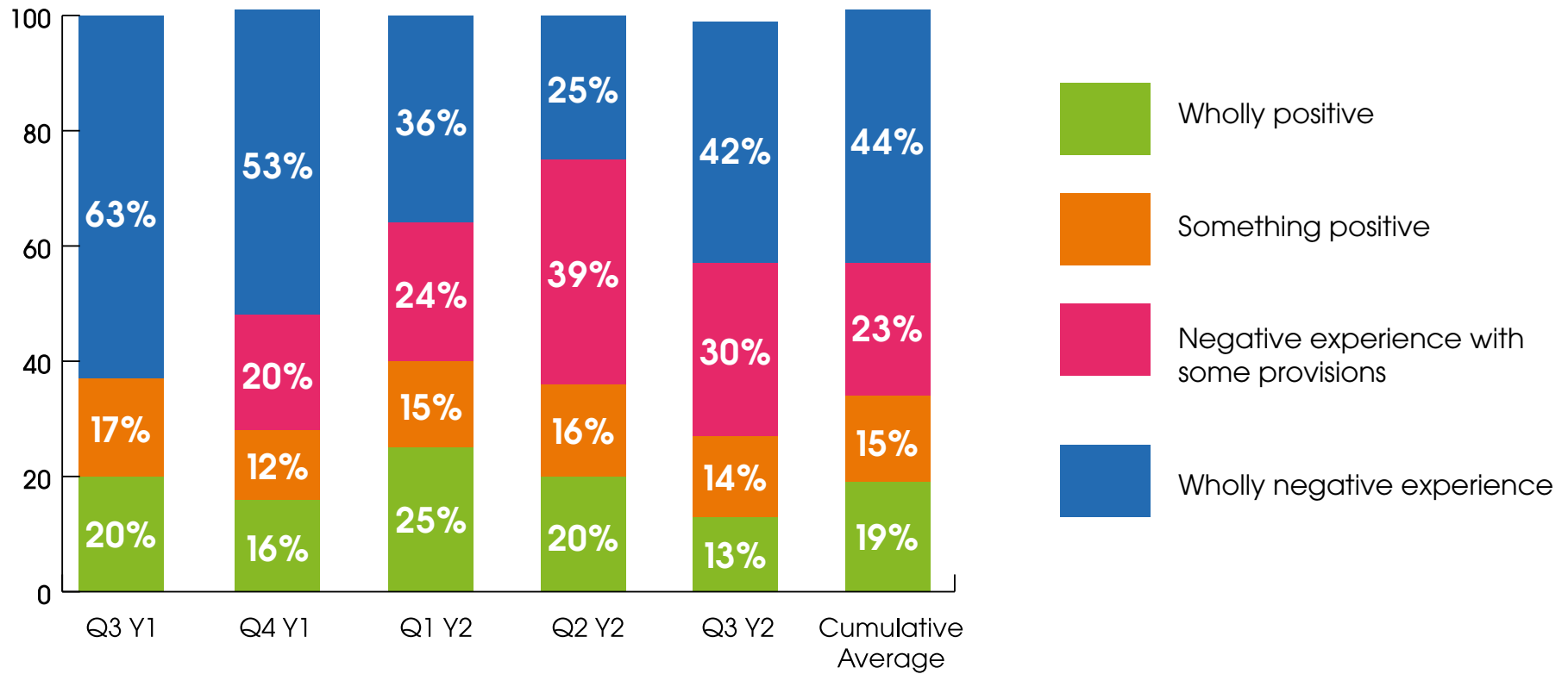
“

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 he is getting.

Family member

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Prevalence of families' positive comments



Families describe how positive experiences of prison healthcare can help to provide reassurance, reduce anxiety and build positive relationships between prison staff, healthcare teams and families (all of which can serve to improve health outcomes for patients in custody). Despite the challenges of the justice healthcare environment, families share positive experiences, including:

- Healthcare teams pro-actively reaching out to family members on the request of patients, so that families can advocate or share information on their behalf
- healthcare and prison staff being responsive to family members who contact them with concerns/to share information
- health assessments and treatment being undertaken in a timely fashion and in response to patient's needs



- treatment and medication effectively following the patient from the community into custody
- structure, daily routines and regular medication within prison regime improving patient health and wellbeing, particularly for patients who had previously struggled with substance misuse and/or found it difficult to engage with healthcare services in the community
- roles such as mental health liaison workers and Listeners providing individuals in custody with a sense of purpose, impacting positively on their own emotional wellbeing.

However...

- **almost half of families share wholly negative experiences** associated with their loved ones' health and wellbeing⁷, and
- **one in six families share safeguarding concerns**⁸ which require escalation.

⁷ Families who have experience of supporting their loved one in custody with their health and wellbeing and who were approached for interview. ⁸ A safeguarding escalation process was introduced to the service in December 2023. This figure is calculated based on the interviews conducted since this was put in place, with families who had experience of supporting their loved one in custody with health and wellbeing.

3.2 Families raise safeguarding concerns

Listen to Families London has escalated 73 safeguarding issues to date, relating to a range of issues.

In some instances, families shared information that was extraneous or already known to the healthcare team, however on a number of occasions families provided information or raised issues that added clinical value and enabled healthcare teams to deliver care that improved health outcomes.

Example:

Safeguarding concern: “(Patient)’s family reports that (patient)’s repeated requests for a mental health assessment have not been responded to. His family says his anxiety and depression are getting worse, and they are concerned for his wellbeing.”

Response from NHS London H&J: “Regarding his mental health, for some reason, the therapies team who received a referral for assessment were under the understanding that he was no longer resident in the prison. Today, (healthcare worker) has raised the referral again on an urgent basis and has explained to the team that he is still here requiring the assessment. So, unclear why this referral was closed or why they had on record that he had moved on. However, as the referral has been raised as urgent, he will be seen within 4 working days.”



3.3 Prison life significantly impacts on health and wellbeing

Families repeatedly highlight concerns regarding the impact of prison on their loved ones' health and wellbeing. We appreciate that many of these issues are not in the gift of healthcare teams to resolve, but include them here in order to faithfully feed back what families tell us about their experiences. For families, it can be challenging to discern from the outside what are 'prison-side issues' versus 'healthcare issues' - and in practice, the challenges faced by families and their loved ones often sit across healthcare, prison and community boundaries.

“

It's a big concern for me. They're not getting to shower or getting clean clothes.

Family member

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Physical environment:

lack of cleanliness, vermin, poor bedding, unhealthy temperatures, damp and mould, broken facilities and limited of access to showers.

Prison regime:

lack of time outside of prison cells, limited access to activities and resources promoting positive wellbeing such as art, music and exercise, and limited access to daylight and outside space.

Prison culture:

prevalence of violence and aggression, discrimination and trauma (amongst both prisoners and staff).

Prison staffing:

inconsistent approaches, lack of training about health, wellbeing and disability, lack of compassion, limited experience amongst new staff, and insufficient staffing to allow time out of cell or access to appointments.

Prison systems

slow and inconsistent responses to in-cell alarms, disjointed working between health and prison staff and poor communication systems creating challenges for families contacting both staff and their loved ones in custody.

Prison transition points:

transfers between prisons, travel between custody and court, movement from the youth to adult estate, or release and resettlement could lead to delays or changes in treatment. Different systems in each establishment also cause confusion and anxiety for patients and their families.

“

I understand they've done something wrong, but they're still human. It's no wonder people in there go insane. You're trapped in a small box all day without a breath of fresh air.

Family member

”

“

The situation with his property is getting him down. He was brought here six months ago but his clothes have only just been approved. He's been cold all through the winter.

Family member

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“

I rang Safer Custody because I was so worried about him, but it took them a week to call me back.

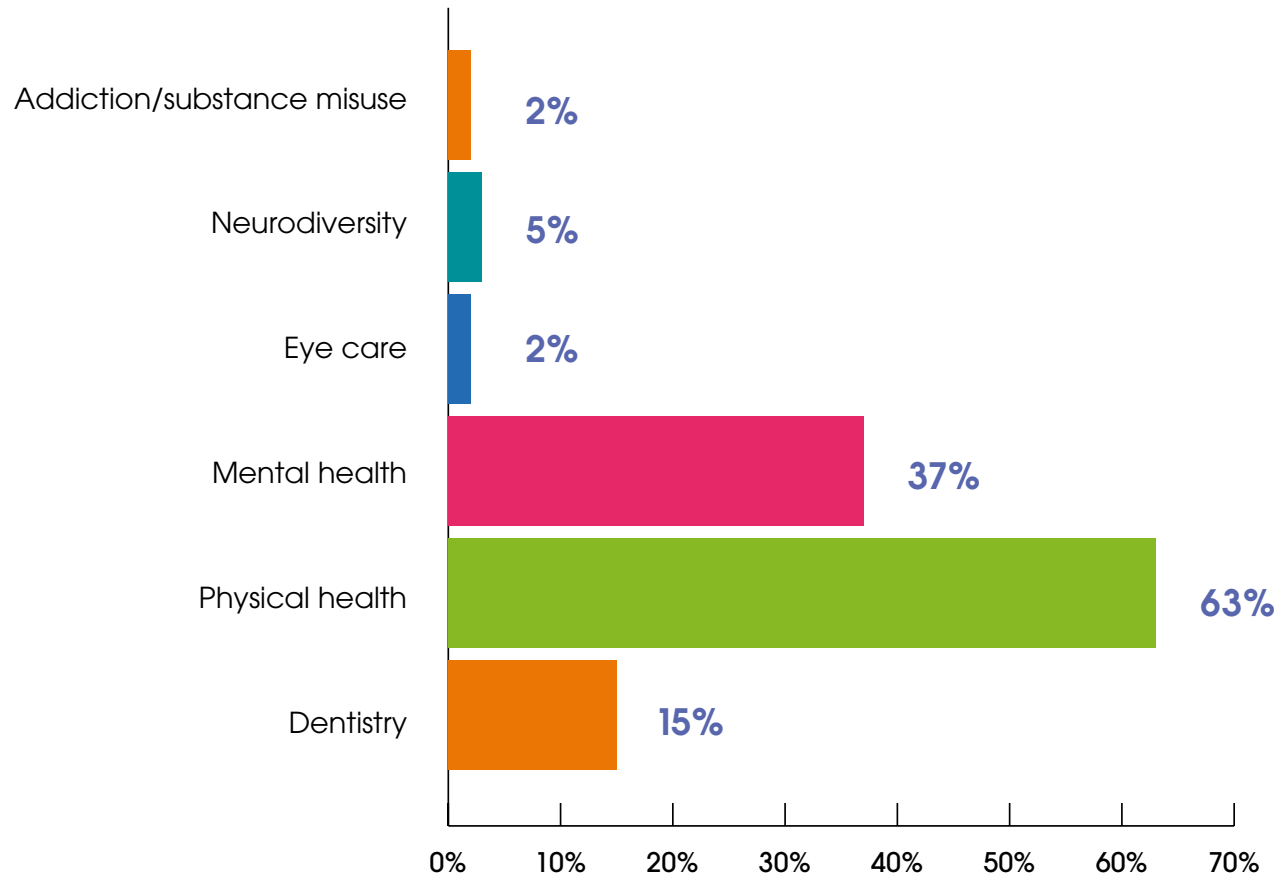
Family member

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3.4 Families are concerned about all aspects of their loved ones' health and wellbeing

Families share insights about all aspects of their loved ones' wellbeing. Many families describe complex, multi-faceted health needs and a long history of trying to enable their loved one to access support via social care, education, mental and physical health services, both in the community and criminal justice systems. Around a quarter of families interviewed describe their loved one in custody as having more than one existing healthcare need. For other families, their loved one has become unwell or injured during their custodial sentence, or families have become increasingly concerned that their wellbeing is at risk.

Healthcare concern shared by family member



3.5 Communication with prison and healthcare staff is challenging

Communication is a frequent challenge raised by families and carers. They report:

- Patients in custody struggling to communicate with, or receive information from, relevant healthcare and/or prison staff. This is particularly challenging for neurodiverse patients or those who do not speak English fluently.

“

They can't understand him. He has severe learning disabilities and doesn't communicate like other people.

Family member

”

- Lack of information, for both patients and families, about how or who to communicate with, with regards to concerns about health and wellbeing
- Inconsistency in information being communicated by prison and healthcare staff
- Consent and data protection acting as a barrier to communication and information sharing.

“

One person says one thing, and another day someone else will say the opposite.

Family member

”

- Poor attitudes and disrespectful behaviour from healthcare and/or prison staff, dehumanising communication heightening anxiety, stress and frustration and exacerbating patient and families' feelings of stigma and isolation

“

I get treated like a prisoner myself – spoken to rudely and shouted at for no reason.

Family member

”

- Prisons frequently failing to return families' calls when they raise concerns or wish to share information
- Disjointed working between community-based healthcare, prison staff and justice healthcare creating communication problems and negatively affecting outcomes

3.6 Families needed information and guidance

Across multiple interviews in 2023-24, families shared their difficulties in accessing realistic and practical guidance to support them in navigating the complex justice healthcare landscape. Families reported how a lack of information serves to heighten anxiety, increase frustration, places more demands on their time, and exacerbates feelings of being 'locked out' and disempowered. They wanted information about: what healthcare services are available in custody and who delivers them, how healthcare services follow patients between the community and criminal justice system, prison rules and regulations, problem-solving advice, services and resources for neurodiverse patients, jargon busters, patients' and carers' rights, consent, confidentiality and information sharing and key policies and guidance governing justice healthcare provision. Families asked that comprehensive public information should be made available that is accessible, aimed at a diverse audience and able to be easily translated.

“

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 okay.

Family member

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This need for greater information was directly responded to with the co-production of 'Your Guide to Prison Healthcare: By families, for families', a new resource which has been available on the Pact website since October 2024.

3.4 Patients in custody often struggle to ask for help themselves

Families highlight that their loved ones in custody can be reluctant or unable to ask for help effectively when they are struggling with their health and wellbeing. This may be for a variety of reasons, including:

- Disillusionment with, and a lack of trust in, healthcare services due to previous poor experiences both in the community and in custody
- Reluctance to be perceived as vulnerable within the prison environment
- Lack of knowledge/awareness about available healthcare services and resources and how to access them
- Communication difficulties (due to language, disability or neurodiversity)
- Mental health difficulties that create feelings of paranoia and distrust

“

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.

Family member

”

When patients are struggling to access services, families emphasise the important role that they can play in advocating for their loved ones, raising concerns with prison staff and sharing information with relevant healthcare teams. By providing families with accurate information about justice healthcare services and how they can be accessed, they can also encourage and support their loved ones to reach out to services when needed.

3.5 Families are concerned about delays and slow responses to healthcare needs

Families share insights about all aspects of their loved ones' wellbeing. Many families describe complex, multi-faceted health needs and a long history of trying to enable their loved one to access support via social care, education, mental and physical health services, both in the community and criminal justice systems. Around a quarter of families interviewed describe their loved one in custody as having more than one existing healthcare need. For other families, their loved one has become unwell or injured during their custodial sentence, or families have become increasingly concerned that their wellbeing is at risk.

“

My partner nearly died of a ruptured appendix. He was in agony in the cells but nobody believed him... His cellmate raised the alarm and managed to get medical attention. He was taken out of the prison for emergency surgery.

Family member

”

Families also report that a lack of information about waiting times and treatment schedules contributes to heightened anxiety amongst both patients and their families. While families often report that they will try and step in when they feel like delays are reaching crisis point, they have also described examples of incidences where their loved ones have resorted to desperate measures to expediate their treatment.

“

He was in so much pain and he had waited so long that he took an overdose just to be seen. He eventually got an outpatient's appointment but he was never taken to it. He just got made to wait in reception and then missed the appointment.

Family member

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“

He has bad asthma and it took ages for them to give him anything... he was really struggling to breathe and it was really scary... Now he's okay, but it took a lot of time and a lot of phone calls to make anything happen.

Family member

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3.6 Families have a diverse range of experiences and protected characteristics can impact on those experiences

Families describe how intersectional inequalities can impact their experiences of the justice healthcare system in a range of ways.

To date, Listen to Families has shone a spotlight on the experiences of racialised communities, Gypsy Roma and Traveller Families, Muslim families, women, and families caring with loved ones who are autistic, have a learning disability or who are neurodiverse. Key themes identified include:

- a lack of knowledge, awareness and sensitivity amongst some prison and healthcare staff to respond to and meet the diverse social, spiritual, cultural, practical and health related needs of patients in custody and their families;
- negative experiences and discrimination in the past leading to distrust and disillusionment amongst families and patients. This can lead to reluctance to engage with healthcare
- a lack of access to resources that support patients' diverse social, spiritual, cultural, practical and health related needs – for example, seemingly small things like hair products or headscarf pins that help people feel comfortable.

“

My son is autistic, but nobody can tell at first glance. He understands things in a very different way than other people, which means he is often misinterpreted, and he often misinterprets others.

Family member

”

- healthcare needs can be misinterpreted or misunderstood due to intersectional inequalities;
- families can play an important role in supporting justice healthcare staff to understand patients' individual needs (whether social, cultural, spiritual, practical or health related) - for example, explaining how a patient may be presenting to staff as less unwell than they are because of cultural differences.

3.7 Families often have important insight and knowledge and want more opportunities to work in partnership with justice healthcare

A survey of 159 visitors to HMP Brixton found that 50% of family members/carers did not feel sufficiently involved in their loved one's healthcare in custody⁹. Families report struggling to share information with either health or prison staff and are often dismissed or struggle to reach the department with whom they want to share information. Few families report healthcare staff pro-actively reaching out to them for information.

When they are given the opportunity to be involved, families greatly appreciate healthcare staff engaging them in care planning and assessment processes, enabling them to provide valuable insight that otherwise would not be available to health practitioners.

“

He has learning difficulties and I've always supported him as his carer. He had a brain scan, but he hasn't got the 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.

Family member

”

“

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.

Family member

”

“

They won't listen to me and they won't believe me. We're not criminals, we know him and we are trying to help.

Family member

”

⁹Token voting survey conducted at HMP Brixton by Listen to Families in 2023

3.8 Supporting a loved one in custody has a significant impact on families and carers

Many of the families describe being stressed, anxious, and overwhelmed with the experience of supporting a loved one in custody. They feel frustrated and disempowered by the lack of information available to them, and helpless in being able to offer the support they so desperately want to provide to their loved one. Many families have lost faith in both justice and healthcare services and are exhausted by the time and resource required to navigate their complex systems. For many family members, having a loved one in custody has resulted in feelings of shame, social isolation and stigma, which is only exacerbated by the lack of compassion and empathy offered to them by the justice healthcare system.

“

There's so much shame and guilt and you know, you feel you've failed your family, you feel helpless, you feel all these huge emotions.

Family member

”

And yet, despite this, families demonstrate significant resilience, strength, pragmatism and determination in continuing to support their loved ones in custody.

“

I think how we approach the whole system defines us as people. The fact that we've been affected by this horrendous setup, all the pain and suffering that's been inflicted upon us and our loved ones, along with all the things that are wrong with it, and yet we're still smiling, still caring and making a difference. It shows the strength we have within us. It's strange how that saying 'what doesn't kill you makes you stronger' is so, so true.

Family member

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4. The impact of the Listen to Families service

4.1 Families' have increased opportunities to have their voice heard

Listen to Families London has engaged families and carers with experience of justice healthcare services via:



1536 interviews in prison visit centres



One of the Pact workers had come up to me on my prison visit and asked me some questions which I actually really appreciated because it was like nobody really talks to you otherwise.

Family member



a mailing list of over 192 family members/carers which shares information about justice healthcare, disseminates the Listen to Families quarterly reports, provides updates on developments and promotes opportunities for engagement



17 coffee mornings where families drop in, share their views and support one another



The coffee mornings are a really simple idea, but it's so effective. They are 100% inclusive. I think the group helps to give them (family members) purpose, they are supporting other people and sharing information... they share ideas and they support one another – it is really positive.

Healthcare commissioner



133 paper surveys completed by family members/carers in visit centres



three co-production workshops with healthcare staff, NHS England representatives and families/carers



56 one-to-one phone or video calls with family members/carers who requested the opportunity to share their story



a family team of 10 family members with lived experience who routinely inform the development and delivery of the Listen to Families service.



(I feel) valued, and feel held... I feel almost honoured as someone special. It's helped me to actually say to people and hold my head up, and not cry, and not feel ashamed.

Family member



While system change in the health justice landscape is slow, healthcare commissioners and providers acknowledge that families' insight and experiences have begun to influence justice healthcare services in London:



It has helped us to shape services and different approaches. Families' voices have been added into processes that have been around for a long time - they are now embellished with new insight.

Healthcare commissioner



We have been more proactive in involving families, for example, we have had a palliative care case recently where we have worked closely with the families and we probably wouldn't have rushed to do that in the past. It has certainly made us start to think about families more.

Healthcare provider



4.2 Family and Carers' Charter for Health and Justice

The Listen to Families service has established the first ever set of standards that explicitly lays out NHS London's and healthcare providers' commitment to families and carers of those in custody. The Charter was co-developed by family members, Pact, healthcare providers and NHS England. All three justice healthcare providers in London, NHS England and Pact have signed up to the Charter.

The Charter can be downloaded [here](#).

“

(The Charter) was collaborative in its very nature, it included suggestions from all our colleagues as well as families and we all agreed on the aims and objectives... we all own it and that's fundamental.

Healthcare provider

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“

(it is) a guide for families by families that genuinely talks to family members. It is about informing and upskilling families so that they know what to do and where to go.

Family team member

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4.3 'Your Guide to Prison healthcare: By Families for Families'

Listen to Families has worked with families and carers to develop a practical online guide to prison healthcare for those supporting someone in prison living with physical or mental health issues. The guide includes short films, text and link to further support and guidance and includes information on:

- What to expect
- Who to contact
- How to communicate effectively
- Templates and resources
- Common challenges and top tips

The guide can be accessed [here](#).



5. Recommendations and calls to action

Improving families and carers' experiences of health and justice services requires a whole system approach that considers both structures, practice, culture and systems of accountability. Our team of family representatives worked with Pact to co-design the following recommendations:

5.1 Structures – resources, policies, frameworks and infrastructure to enable families' voices to be listened to

- **Commission Listen to Families across the NHS regions:** Regional commissioners should commission Pact to roll out Listen to Families within their areas so that this integrated PPV / delivery model is brought to scale and available throughout custodial settings in line with statutory requirements.
- **Develop a multi-agency consent passport:** Healthcare providers should work together to create an integrated system for recording patient consent for family involvement, so that this paperwork can travel with the patient across different custodial settings/providers and between custody and the community.
- **Create a Secure Information-Sharing Portal:** Develop a secure digital system or platform (akin to the

NHS App for a custodial setting) where authorized family members can receive timely updates on their loved one's healthcare, subject to consent. This system could integrate secure messaging with prison healthcare staff for faster communication.

- **Build family engagement into reception processes:** Ensure that reception processes include specific questions about whether the person in prison has family supporting them with their wellbeing as part of a holistic wellbeing assessment. This should record the preferences in terms of ongoing involvement, consent and practicalities such as contact details.
- **Improve escalation pathways:** Ensure that information from families can flow expediently and securely to where it is needed, with quality-controlled processes at national and regional level.

5.2 Practice – the staffing practices/processes/ approaches that pro-actively engage families and promote involvement.

- **Improve Staff Training and Family Engagement Practices** Implement comprehensive training for prison and healthcare

staff on the importance of family involvement in prisoner wellbeing. Training should include strategies for respectful communication, understanding neurodiverse, complex and mental health needs, and fostering a culture of compassion. It should include role plays and scenarios to promote trauma informed communication and cultural competence for serving diverse groups. This proactive engagement can reduce misunderstandings, improve patient outcomes, and support families who feel isolated and stigmatized by the prison environment.

- **Enable dialogue with families before a patient reaches crisis point:** Seek consent for family involvement at an early stage to avoid a situation where a person in crisis is unable to give consent because they lack the capacity to do so. Screening for whether family can act as a protective factor should be a routine part of care for chronic conditions and within ACCT reviews. Assurance processes should ensure that guidance and policies in this area are implemented in practice.
- **Commission new programmes to involve families in care planning** Commissioners should commission new programmes to involve families in care planning. This should leverage the expertise that families and carers can bring to patient care by evolving care planning models, address local, legal, procedural and practical obstacles and embrace family and carer participation as a strategic focus.

- **Commission new programmes to promote cross-boundary working** Commissioners should commission new work to promote system join-up and cross boundary working, through the gate and between health and justice agencies. This should integrate with support to family members to enhance Core20Plus5 health and wellbeing outcomes.

5.3 Culture – promoting attitudes/ethos that supports a ‘Listen to Families’ culture

- **Recognise and reward staff for family engagement – identifying champions and role models** Implement a recognition programme that rewards staff who demonstrate excellence in family engagement and compassionate communication, helping set a benchmark for others.
- **Family-centred goals in staff performance reviews** Integrate family engagement goals into the performance appraisals of healthcare and prison staff. This could involve metrics on response times to family inquiries or participation in family engagement activities such as Family Forums.
- **Include family engagement within job descriptions** Ensure that relevant job roles include an expectation of family engagement or coordination with Family Link Workers so that this is recognised as a core component of appropriate roles. Test competency on family engagement as part of recruitment processes.

- **Celebrate and scale good practice** Regularly identify and lift up examples where family involvement has added clinical value, helped healthcare professionals improve care provision or led to better outcomes. Explore what happened and what enabled this to happen.

5.4 Accountability – promoting mechanisms that hold providers to account, identify and build on good practice

- **Broaden signatories to the Family and Carers' Charter for Health and Justice so this becomes a national standard**
Other NHS regions and healthcare providers should join NHS London, Practice Plus Group, Oxleas, CNWL and Pact in signing on to the Family and Carers' Charter for Health and Justice – a set of commitments for valuing and engaging with families.
- **Healthcare providers to report quarterly against Family and Carers' Charter commitments**
NHS Commissioners should require providers to report on family and carer engagement as part of their regular assurance processes.
- **Integrate the Family and Carers' Charter for Health and Justice commitments into commissioning processes**
NHS Commissioners should include family involvement as part of tendering requirements, so that providers incorporate family engagement as an integrated part of their service plans.



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