

Families' experiences of dental and oral healthcare in prison

Q2 24-25 Listening Report

6th October 2024

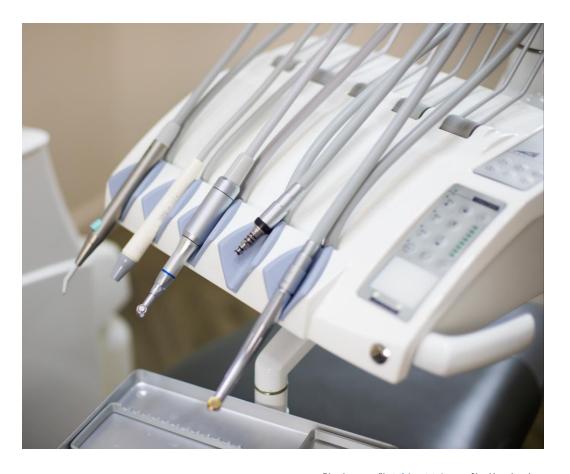


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About this report

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.



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.

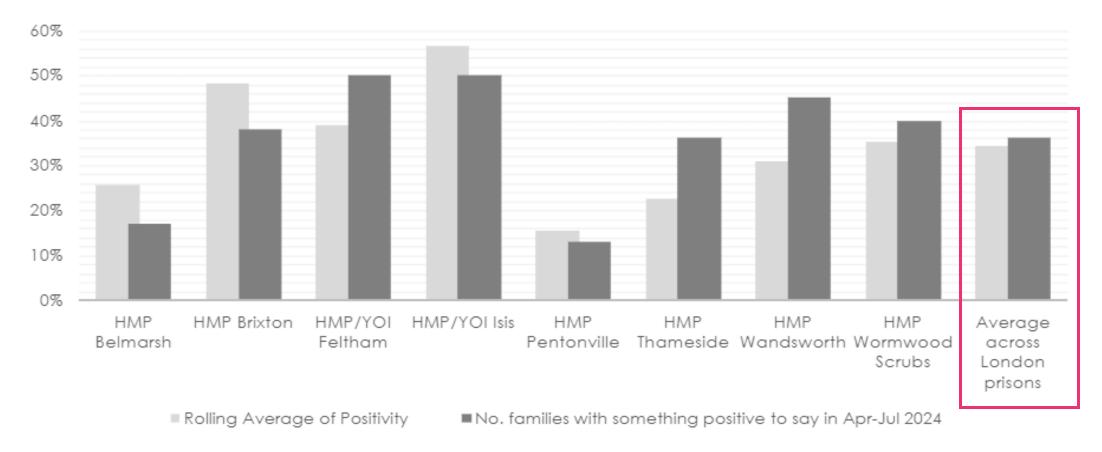
Listening activities 29th April 2024 – 29th July 2024	No. engaged	Notes
Family Team Members take an active part in shaping the service, including through our active Telegram group.	11	11 Family Team Members (FTMs) consulted throughout the quarter
Families and carer community members who share experiences on an ad-hoc basis	9	Members of our wider community
Semi-structured interviews at Visiting Centres.	207	Interviews at all visiting centres. 17 visits in total.
People share their experiences in a safe space with others in similar situations at family forums .	21	Coffee mornings in May, June and July
Families and carers send an email to our functional mailbox.	24	5 unsolicited emails, 19 emails responding to our messages
Families and carers book 1:1 online video calls or request phone calls with the team.	6	Bookings initiated by families
Family and carers have representation at 'Listen to Families' team meetings.	21	Family Team Member attendance at monthly online meetings.
Family Team Members contribute to the drafting of quarterly Listening Report	7	At in-person team day and reviewing drafts
Paper surveys are completed by families and carers at Visit Centres.	4	1 from HMP Wormwood Scrubs, 1 from HMP/YOI Feltham, 1 from HMP/YOI Isis and 1 from HMP Belmarsh
Total engagements for quarter	310	
Mailing list	168	Plus 26 where our emails bounce back



Prevalence of positive comments: Variations by prison

In the last three months, out of the families we interviewed who had experience with prison healthcare, **just over a third (36%)** had something positive to say about their experience. This is slightly higher than the average across all our data so far (34%).

The label 'Something positive to say' includes both 'wholly positive' experiences and those who had 'Something positive' to say (at least one positive element to 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.



Q2 Inequalities Spotlight: When women are assertive

In each of our Listening Reports, we shine a spotlight on how a different aspect of intersectional inequality affects families' experiences of prison healthcare and the criminal justice system. This quarter, we're focusing on gender – and in particular, the challenges that women can face when they are being assertive on behalf of their loved ones.

Women are over-represented as carers

- 70% of the family members Pact have interviewed at visits centres have been women. (see note 1)
- 100% of our current Family Team Members are women.
- The 'primary carer' role is more frequently played by women than men women family members we interview tend to be better informed and more closely involved with their loved one's care in prison.
- In London, where there is an all-male estate, the most common scenario is of a woman family member supporting a man in prison.

Being a carer involves being assertive

- Advocating for a loved one is a core element of the role that most families and carers play.
- To advocate effectively in a prison setting, carers must be assertive in the context of steep power-dynamics.
- Women can face additional barriers when it comes to being assertive. The mind-map on the right shows real-life challenges that our team has faced.

Recommendation:

• If you receive communication from a woman that comes across to you as aggressive or overly-emotional, ask yourself whether it might feel any different coming from a man.



Some women also face additional barriers due to other aspects of inequality – for example, racism, ageism, class prejudice, Islamophobia, ablism etc. Different forms of discrimination may add up and compound one another.



Dental health care: A range of experiences

Families report a wide range of experiences when it comes to dental and oral health care – these run on a full spectrum from negative to positive.

Josh*

"He applied to see the dentist, but had to wait so long he took matters into his own hands. He [...] did home surgery on himself." Yara*

"He cracked his tooth six months ago and it still hasn't been dealt with."

Helen*

"It took a while to get the dentist appointment - but it takes everyone a while for that" Maisam*

"He had an issue but was able to get it sorted."

Sheli*

"He's doing great. He just had his teeth done!"

Matty* "He has a fake tooth that broke. He waited so long to get a new one that he started supergluing it in."

Carole*

"He needs to take his braces off - it's been over a vear and still isn't sorted out."

Nicky*

"He waited to see the dentist the first time. Now he needs a followup appointment and he's waiting again."

Adia*

"He saw a dentist. I'm happy with his care -I give it 6 out of 10."

Alexia*

"He is in severe pain and losing his teeth."

Lucvna*

"He needs all his teeth removed; the whole of his mouth. He's been waiting [over three months] and is in pain when he eats." (see note 1)

Natasha*

"He can't get a dental appointment. It's been over a year and he still hasn't seen anybody"

Kerry*

"He seeing the dentist he's had no issues with that"

Marie-Louise*

"He was in terrible pain with his teeth but was told - 'you are going to have to suffer."

Maxy*

"He is having to go to sleep in a lot of pain."

Montell*

"He has a follow-up appointment scheduled and is going to get dental surgery"

Kim*

"He had an issue but it's sorted now - an orthodontist on the outside helped him get the moulds he needs."

Cristy*

"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."

Jody*

"He was in agony [with tooth pain] but was only given paracetamol."

Jade*

"His teeth need looking at because he has an abscess - he has been waiting a long time."

Note 1: This case was escalated in March 2024. No update has yet been received.



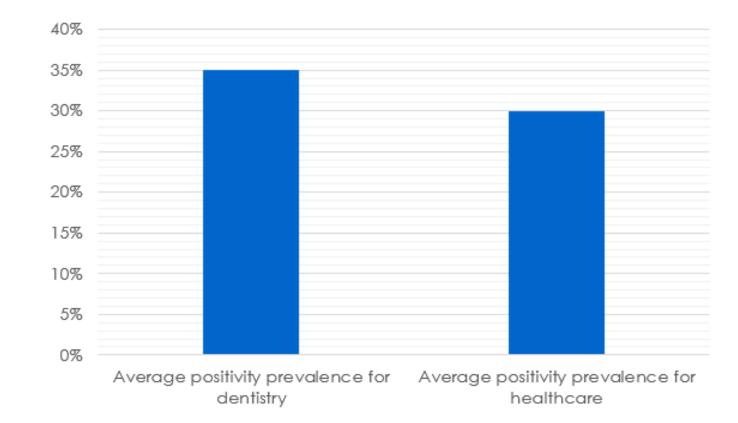
Dentistry Special: Positivity Prevalence

The prevalence of positive comments on prison dentistry is similar to the prevalence of positive comments on prison healthcare generally. It is slightly more common for families and carers to say something positive about prison dentistry than prison healthcare overall.

On average, just over a third (35%) of families and carers have something positive to say about dentistry services in prison.

This is higher than the rolling average positivity prevalence for general healthcare services across London prisons (30%), but only slightly.

This means that, whilst it's slightly more common to find positive comments about dentistry than other services, nearly two thirds of families have negative experiences.







Dental health: Common issues

There are themes in the issues raised by families. A number of concerns came up several times across different prisons. These have been organised by descending frequency.

Lack of access to care (53%, n=50)

- Over half of families mentioned during interviews that their loved ones had difficulties accessing dental care.
- Report issues include long waiting times; lack of access to dental care in emergencies; issues with continuity of care between prison and the community; poor care coordination; being unable to get a new appointment that had been scheduled at another prison when transferred.
- Some families report that their loved ones are reluctant to apply for dental care because they have low expectations.
- Two patients reportedly were not able to get a dentist appointment for over a year.

Issues with pain management (33%, n=31)

- A third of families mentioned during interviews that their loved one had issues with pain management for dental issues.
- Reported issues include not receiving adequate pain medication in time, or at all – or only being given paracetamol for serious pain.
- Some families report that their loved ones aren't believed when they report pain or are expected to put up with it.

Positive resolution of substantive dental issues (21%, n=16)

- Several families reported satisfaction with their loved one's dental care and were relieved that complicated issues had been dealt with.
- These issues included receiving dental surgery, fixing a cracked tooth, tooth extraction, receiving antibiotics, getting braces removed, getting moulds from an orthodontist and getting spare retainers.



Dissatisfaction with care (15%, n=14)

- Several families mentioned during interviews that their loved ones were dissatisfied with the care they had received.
- Reported issues include facing barriers to making apps and attending appointments; receiving minimal care; feeling dismissed; being unable to get follow-up care or appointments; recurrent infections and long waiting times for antibiotics.

Issues for families trying to support (9%, n=8)

- Several families mentioned during interviews that they
 had experienced challenges when trying to support their
 loved one.
- Reported issues include being 'fobbed off'; being treated rudely by staff; not being able to get through on the phone; being misinformed about whether they can send patient's dental records to the prison.

Some of these concerns may be in the gift of dental healthcare providers and the NHS to address, whilst others may not be. These issues are a part of families' experiences, nevertheless.



Conclusion and recommendations

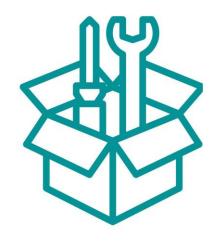
We appreciate that family and carers' experiences represent only one piece of the jigsaw puzzle, and that a number of other data sources are required to build a comprehensive picture of prison dentistry and oral healthcare. Given the pressures and challenges that dentistry services face across the NHS, we are aware that some healthcare professionals compare prison dentistry services favourably with those in the community.

We support NHS London's Dental Commissioner for Health and Justice in her call for a nuanced approach to such comparisons, and agree with her that additional information and context can help elucidate the distinct challenges faced by prison healthcare professionals and people in prison alike (pers comms, meeting, 19th Sept 2024).



- 1. To embed a culture of curiosity where dentistry providers and commissioners explore issues that may sit underneath quantitative assurance data, in light of feedback from patients and the public.
- 2. To put more information about prison dentistry in the public domain so that families and carers can understand the systems and support their loved ones more effectively.
- To support reflective practice and ongoing learning.

We thank NHS London for their engagement with families and took forward to progressing mutually agreed actions over the coming months.





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.



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, no amendments were made to the text. There were no redactions.

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



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

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You can directly book a diary slot

Our general mailbox is listentofamilies@prisonadvice.org.uk

Appendix available on request:

If you would like to see a more detailed quantitative analysis of our positivity prevalence data, please get in touch.