Executive Summary: Evaluation of Listen to Families

Evaluating the Listen to Families patient and public voice (PPV) service working across London prisons

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Thank you to everyone who gave their time to share their views and experiences of the Listen to Families service: family members, healthcare providers, NHS England commissioners and Listen to Families team members.

"If everyone can change a little bit of the world then we can change the world together." (Family Team Member)

Introduction

"It's just like being parachuted into a battlefield. You don't know what side you're on, who you can trust, where you are, who to ring, what to do. Your emotions are everywhere. Your instinct is to help your loved one as much as you can. But you can't get to them." (Family member)

NHS England (NHSE) has been responsible for commissioning health services in prisons since 2013. A central principle of healthcare in the justice system is that it is equitable to that in the community in terms of availability, accessibility and acceptability. In London, Oxleas NHS Foundation Trust, Practice Plus Group and Central and NW London NHS Foundation Trust are commissioned to provide healthcare services across the prison estate.

Families and carers have long been recognised as valuable partners in promoting the health and wellbeing of their loved ones. NHS England's Strategy for Health Services in the Justice System (2016-20) identifies families and carers as 'vital sources of intelligence' and states that 'where it is appropriate and they can, families and carers should be involved'.²

NHS London have a statutory duty, under Section 13Q of the Health and Social Care Act, to involve and listen to lived experience voices in the design, delivery, and ongoing performance of their commissioned health services.

In responding to this duty, NHSE commissioned Pact to pilot the very first independent Families & Carers Lived Experience (PPV) service across eight London prisons: HMP Belmarsh, HMP Brixton, HMPYOI Feltham, HMP YOI Isis, HMP Pentonville, HMP Thameside, HMP Wandsworth and HMP Wormwood Scrubs. The pilot was commissioned for an initial two years between 1st July 2022 and 30th June 2024. Pact named the service 'Listen to Families'.

The Listen to Families service

The vision of the Listen to Families programme 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 mechanisms and opportunities for families to be heard and influence how healthcare services are delivered and developed.

The service has the following aims:

- 1. To improve families and carers' experiences of health and justice services.
- 2. To ensure that key themes in the needs of families and carers are identified, consulted on and met by commissioners and providers.
- 3. To 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.

¹ HM Government and NHS England (2019) National Prison Healthcare Board Principle of Equivalence of Care for Prison Healthcare in England, p2

² NHS England (2016) Strategic Directions of Health Services in the Justice System 2016-2020, NHS England

4. Provide assurance that any identified service changes will be consulted on with families and carers, implemented and addressed confidentially.

This evaluation, undertaken by an independent evaluator, reviewed the delivery and impact of the Listen to Families service between January 2023 (when the service started delivery of its listening activities) and April 2024, drawing on the views of families, healthcare providers, NHS commissioners and Pact team members.

Executive summary

Listen to Families is the very first patient and public voice service for families and carers of people in custody. It has been successful in creating a range of communication channels across London prisons that have enabled families and carers to effectively share their views and concerns about prison healthcare.

In the first 12 months of reporting, the service conducted almost 800 interviews with families and carers in prison visit centres, collected 106 paper surveys, engaged 241 families in token-voting on pertinent healthcare issues, conducted nine family/carer coffee mornings and established a mailing list of over 100 family members/carers to share information. In addition to this, they have recruited a Family Team to support the delivery of the service, the team currently includes eleven individuals all of whom have lived experience of supporting a loved one's health and wellbeing in custody.

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. 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 inform the development of recommendations.

As with many new services, particularly those that require collaborative working across multiple agencies, there have been challenges in establishing shared expectations, processes and accountability. The very nature of delivering healthcare in a demanding, under-resourced and frequently un-healthy prison environment, has served to only enhance these challenges. It is to the merit of all the stakeholders, including families and carers, that these challenges have, for the most part, been translated into learning opportunities, and as a result, Listen to Families has had a tangible impact – both on individuals and London prison healthcare.

Family team members report that the service has had a significant positive impact both on them as individuals and on their wider families: increasing access to peer support, reducing isolation, enabling them to feel valued and respected, developing their knowledge and understanding about justice healthcare, providing a sense of empowerment and agency, developing resilience and restoring trust. Crucially, family members also report that their engagement has enabled them to support their loved one in custody more effectively. The development of an escalation process has also enabled families with a loved one in custody to share immediate concerns about their family members' wellbeing with healthcare providers, via the Listen to Families team.

Stakeholders acknowledge that there is still a significant way to go to embed families and carers into prison healthcare practice, and progress is slow (given the current challenges on the prison system); however, families, providers and commissioners alike recognise that there has been a marked shift in how justice healthcare are considering the role of families and carers as a result of the Listen to Families service.

While the implementation of recommendations falls outside of Listen to Families' direct remit, the service has played a considerable role in supporting the delivery of key actions. The co-development of a Families and Carers' Charter has been a significant output and 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. In addition, information for families about prison healthcare services and how to navigate the system is being developed. Every family member or carer with whom the service has contact in visit centres is given an information booklet, and improved signposting and promotion has significantly increased family use of the Call PHILL service (Prisoner Health Information and Liaison Line).

Recommendations

The following **recommendations** were identified by families, Listen to Families (Pact) team members, healthcare providers and NHS London.

- Sustain the Listen to Families service across London prisons: families and carers play
 an integral role in the development and delivery of effective healthcare provision
 for individuals in custody, the Listen to Families service provides the mechanism
 that enables this role to be realised.
- 2. Increase the promotion of Listen to Families: service promotion amongst families and carers as well as healthcare providers is essential. Extending promotion into the courts will ensure that families have access to information as early as possible.
- 3. Continue to develop relationships with healthcare providers: the relationship between Listen to Families and healthcare providers is fundamental to realising the full potential of the service. Partners should build on established relationships and reflect on lessons learnt to strengthen collaborative working.
- 4. Work more closely with other Patient and Public Voice (PPV) services: there is potential value in Listen to Families working more closely with other PPV services across London bringing together the voices of individuals in custody as well as families and carers in the community.
- 5. Engage families and carers in improving practice regarding serious incidents: healthcare staff and commissioners identified a need to improve practice with regards to family and carer engagement in serious incidents. Listen to Families can play a role in supporting families/carers to inform practice development.

- 6. Provide Family Team members with additional training opportunities: Family Team members would welcome the opportunity to access further training to support them in their roles, including 'setting boundaries' and 'safeguarding'.
- 7. Shift focus to supporting implementation: the whole prison system, including healthcare, is currently under acute pressure and as a result, healthcare teams require support to implement Listening Report recommendations. Listen to Families can play a valuable role in supporting implementation, specifically the utilisation of the Carers Charter and the ongoing development of improved information about healthcare for families and carers.
- 8. Continue to evaluate the impact of the service: Listen to Families is a pilot project and should be routinely evaluated to monitor and understand the impact of the service – for example, how far has the Carer's Charter impacted on healthcare provision?
- **9. Extend the Listen to Families provision to other areas:** families identify the significant value of the Listen to Families service and are keen that carers and family members across the estate have access to similar PPV services.