

# Listening Report

*Listen to Families*  
Q1 2023/24

May 2023



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

- ➡ E-mail [listenstofamilies@prisonadvice.org.uk](mailto:listenstofamilies@prisonadvice.org.uk)
- ➡ Visit [prisonadvice.org.uk/healthcare](https://prisonadvice.org.uk/healthcare)
- ➡ Use the QR code below

**Pact**





## Vision

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 prisoners improve as a result.



## Purpose

The purpose of 'Listen to Families' is to **create mechanisms and opportunities for families to be heard and influence** how healthcare services are delivered and developed.



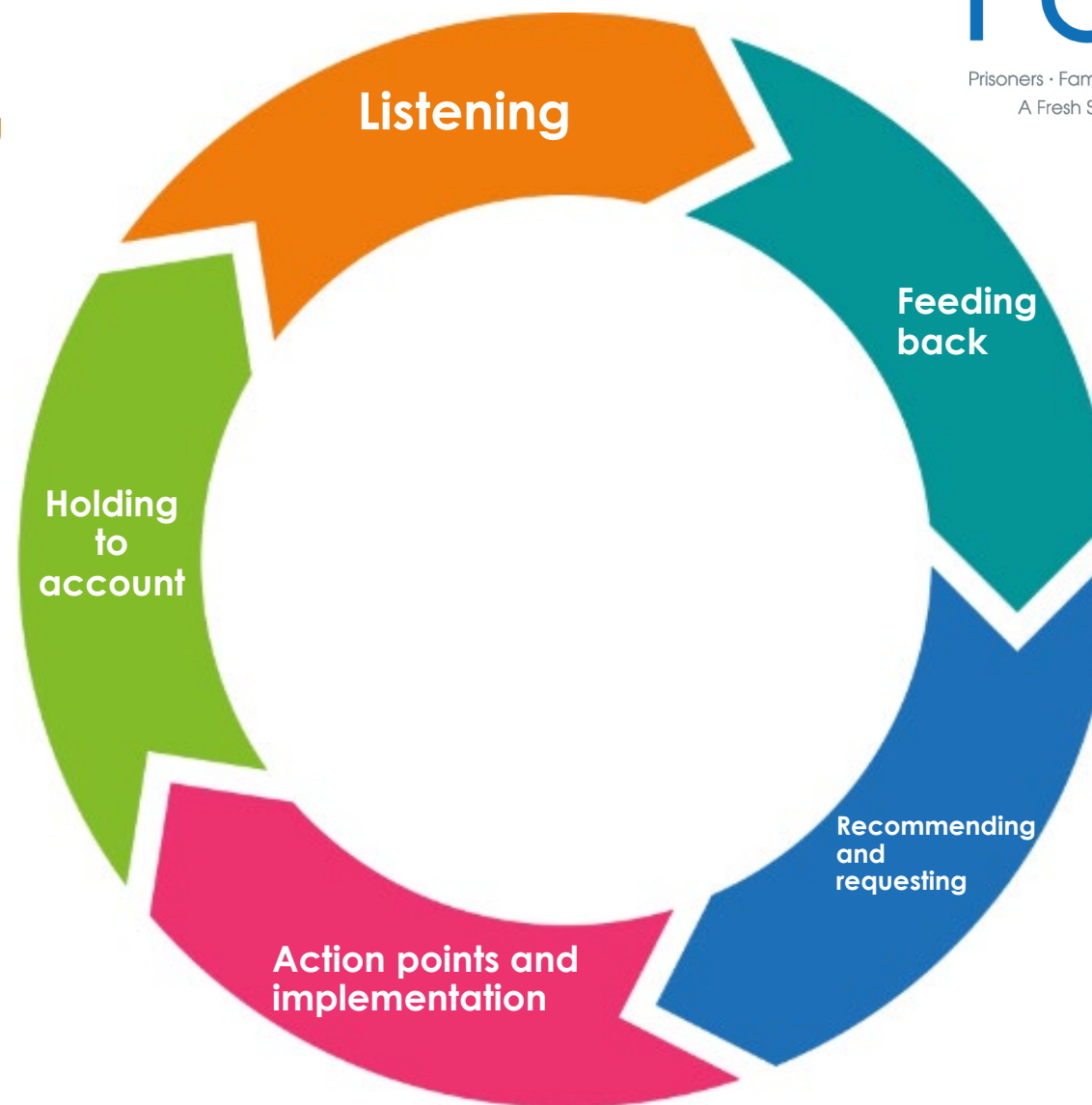
## Aims and objectives

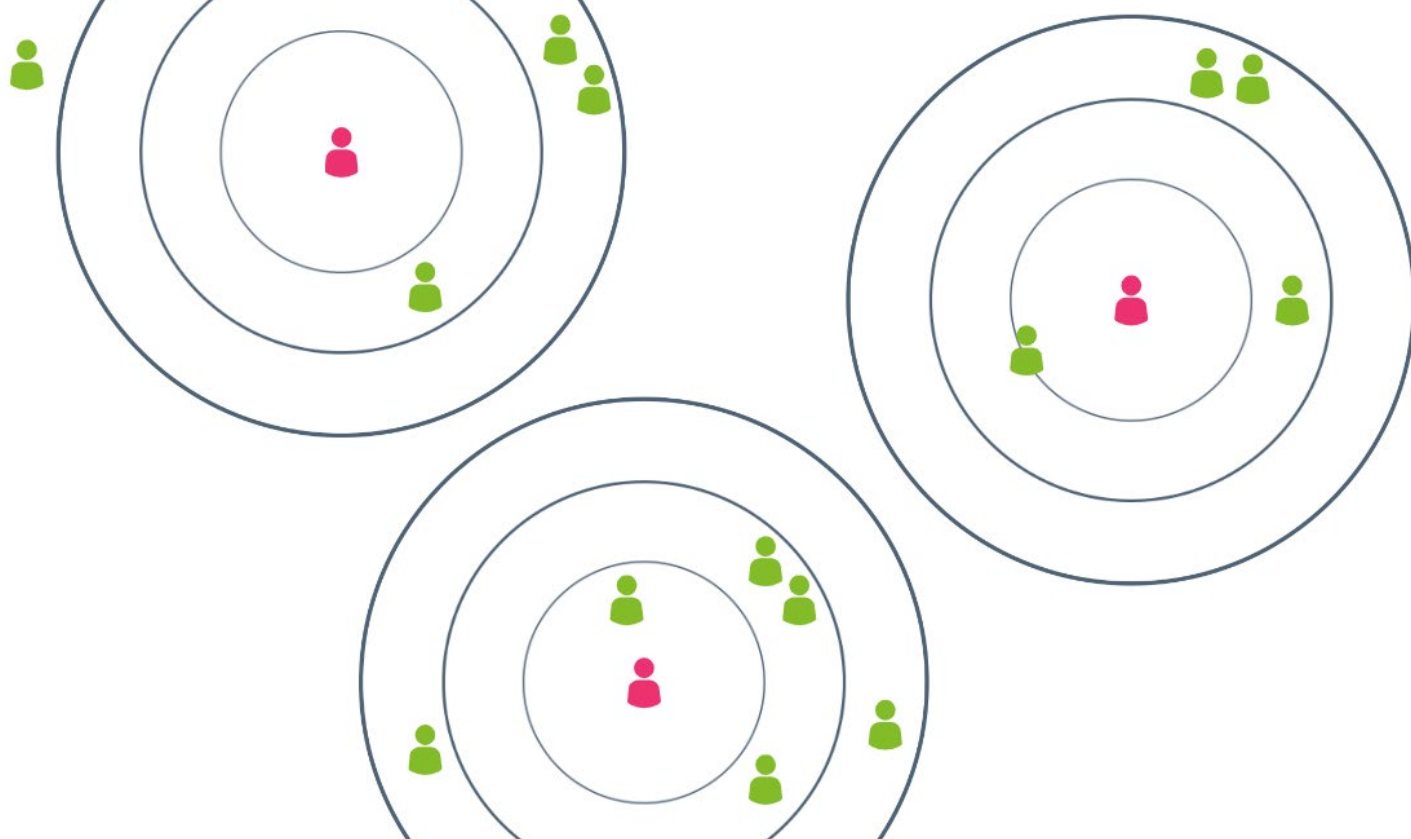
1. To **improve families and carers' experiences** of health and justice services.
2. To ensure that **key themes in the needs of families and carers are identified, consulted on and met** by commissioners and providers.
3. To **listen to the voices of families and carers** and **address their experiences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

## Our quarterly process with NHS London and healthcare providers

- Every quarter, *Listen To Families* does an array of **listening activities with families and carers** who have a loved one in a London prison.
- *Listen to Families* **feeds back** what we've heard through a **quarterly seminar** and discuss NHS London and healthcare providers.
- On the basis of these discussions, we develop **recommendations and requests** that are included in our **quarterly Listening Report**.
- NHS London and healthcare providers consider these requests, **decide on action points for themselves and lead on implementation**. *Listen to Families* keeps an actions log.
- *Listen to Families* **facilitates accountability** by giving NHS London and healthcare providers an opportunity to provide a **written response** to the Listening Report, the actions they have taken (or not) and the reasons.
- *Listen to Families* **closes the loop** by passing this update to families, listens to their responses and enables them to comment back to NHS London.

**Note:** *Listen to Families* may also make recommendations and requests to other Pact services, who then take on implementation tasks in their roles as public health service providers. *Listen to Families* doesn't lead on implementation ourselves.





The 7000+ people held in London prisons all have **different types of relationships**.

- Some have family and friends who are part of their 'inner circle', whilst some would say they have nobody.
- Often, **it's complicated**.
- HMIP research suggests **16% of prisoners** don't receive visitors whilst they are in prison (HMIP 2016), whilst others estimate that this figure is as high as 50%.

We hear predominantly from family, friends and carers who are closest to prisoners – **their "fam"**.


We're mindful that any system changes need to make sense for the full range of relationships. We use **Ecins**, Pact's family case-notes system, to give us broader peripheral vision.





# Our Family Team Members


- We are **building a team of family members and carers** who are taking a larger role in *Listen to Families*.
- **Ten individuals have been offered these roles so far**, and they are currently going through Pact's onboarding process.
- Collectively, our family Team Members have experienced having loved ones across the **full spread of the London prisons**.
- The team also has expertise in building family forums, sharing lived experience, and a link to Pact's board of trustees.



Register for job alerts [Recruitment agencies click here](#)

## Listen to Families: team member (Casual)

📍 Homebased - London  
📍 Prison and community-based service  
🕒 Part time  
📄 Casual



**Paid Opportunity:**  
*Listen to Families* Team Member

**Summary**  
A *Listen to Families* Team Member role is a flexible, paid position designed for people who have a loved one in a London prison, or whose loved one has been released from a London prison. Pact is working with the NHS to improve healthcare in prisons – helping them understand the issues that come up again and again for families and carers, and looking at what improvements could be made. We are doing this by piloting a new service, *Listen to Families*. As a Team Member of *Listen to Families*, you'll play a crucial role in enabling families and carers to get their voices heard. Playing your part in the team typically takes between 4 and 8 hours a month. Team Members usually combine their work for Pact with other employment or caring responsibilities. You can choose to work more hours or fewer hours, depending on your preferences and the opportunities available at any given time.

**Apply now**

**About us**  
Pact (the Prison Advice & Care Trust) is a pioneering national charity that provides caring and life changing services to men and women in prison, to people with convictions on release and in the community, and to their children and families.

Pact's vision is of a society in which justice is understood as a process of restoration and healing, in which prisons are used sparingly and as places of learning and rehabilitation, and in which the innate dignity and worth of every human being is valued. We work for the common good of Society, taking a public health-based approach. We work at the intersection of criminal justice, child and family welfare, mental health, wellbeing provision and health & social care.

Our volunteers and staff can be found in courts, prisons, probation services, and in communities across England & Wales. We are a diverse, inclusive, modern, and collaborative charity. We build effective partnerships and sustainable

## Q1 Listening Activities



Listening activities since January 2023	No. engaged	Notes
Families and carers share their experiences in <b>semi-structured interviews</b> at Visiting Centres.	227	Interviews at all visiting centres, 25 visits in total.
Families and carers <b>vote on a key question using tokens</b> during their visits to Visit Centres.	159	Available at HMP Brixton.
<b>Paper surveys</b> are completed by families and carers at Visit Centres.	44	Available at HMP Brixton.
People share their experiences in a safe space with others in the same boat at <b>family forums</b> .	1	First coffee morning in April, one attendee and one drop-out.
Families and carers <b>send an email to our functional mailbox</b> .	10	7 unsolicited emails, plus 3 emails responding to our messages.
Families and carers <b>book online for a 1:1 video call</b> with the team.	7	Mostly regarding Team Member opportunities.
Family and carers have representation at <b>monthly 'Listen to Families' team meetings</b>	1	A Pact family trustee attended every month.
Referrals from <b>specialist VSOs</b> for more marginalised and disadvantaged groups	1	Via Spark2Life.
<b>Total engagements</b>	<b>450</b>	
<b>Total on mailing list</b>	<b>78</b>	

## What we've heard in Q1



### 1. Families have a lot to say.

- Families and carers are **generally forthcoming and happy to speak about healthcare**. Only on one occasion (out of 227 approaches in visiting centres) has someone said they didn't want to speak to us.
- We can do approximately **10 interviews per prison visiting slot**. People often arrive early to maximise time with their loved ones, so can usually talk whilst they wait.
- Just over **half of interviewees** have significant experience to share.
- With a few weeks of notice, **it would probably be possible to fill focus groups to a brief** – for example, families whose loved ones are neurodiverse, have mental health difficulties, are from a particular prison etc.
- The Pact lanyard is important, but **pent-up demand to be heard** often overrides the usual barriers for interviews.



## What we've heard in Q1

## 2. Many families are desperately worried

How does it feel to be in your shoes...?



**John\***

"I sleep with one eye open. Always, when the phone rings, I think it's because my son has died."

## What we've heard in Q1

### But it's not all bad...

- We do encounter positive stories, where families and carers report feeling **satisfied and assured** that their loved ones are being looked after.
- **Simple things can make a big difference to families** – for example, people remembering their names, getting back to them to return messages or helping them understand how the system works.
- Several families have valued our thank you emails with signposting information **"it was really lovely to felt heard and appreciated in feedback. Thank you for the useful information."**
- When they understand what's going on, families are **grateful and appreciative** of healthcare teams' efforts.
- There is a lot of **pragmatism** and positivity about **small steps forward**.

#### Shahida's story

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

## What we've heard in Q1



### 3. Approximately half of family members and carers who visit prison want to be more involved

Through token voting in HMP Brixton visitor centre (2nd March – 2nd April), **50% of visitors said they don't feel involved enough in their loved one's healthcare in prison**, wanted to be more involved and get more information.

24% said they felt involved enough and 26% said it wasn't necessary for them to be involved.

Corresponding with the fact that half of interviewees have substantial experience to share, we might estimate that the potentially resource of healthcare support from families is roughly half of those who attend visits, plus an unknown amount of those who don't attend.

**The token voting system has worked well.** Where practicalities allow, we can facilitate quantitative data gathering of a closed question with three options.

## What we've heard in Q1



### 4. There are communication challenges

- Families report a **lack of communication between themselves, healthcare staff, prison staff, between different prisons and with patients**. As a result, families can feel left in the dark and unable to contribute to their loved ones' care.
- **There is even a lack of communication around the initiatives designed to improve communication**. Awareness of the "Call Phill" service is very limited – there is a lack of promotional materials in relevant visit centres, and families are unable to find online materials that are aimed at them. It's not on the prison's gov.uk pages and the PPG webpage seems to be targeting a professional audience.
- **Many families were unaware that the consent of the patient might be a barrier to them receiving updates on their loved one's care**. They did not know what process their loved one could follow to have their permission for recognised.
- There is some scepticism about whether consent is genuinely the issue, rather than staff time and the power advantages of keeping silent: **"They hide behind data protection and privacy, but actually they are only interested in us if it's a case of serious injury or death."**

#### Sonia's story\*

"My 18 year old son has autism, severe learning disabilities, ADHD – and also a heart condition. He can't read or write. He's got nobody inside. His food is stolen from him and he's sharing with a cellmate who won't let him touch anything in the cell and plays loud music at all hours.

He can't use the kiosks – it's a struggle for him to apply to see a doctor. He had to wait three months to get an infection in his foot seen to, and he's at risk of blood clots which could mean his heart fails.

He can't remember appointments on his own, but now that he's 18 they won't tell me anything. They won't let me help."

## What we've heard in Q1

### Secondary data on communication problems

The **Prisoners' Families Helpline** collects data on how many cases it escalates on behalf of families who can't get through to the prison. These vary across prisons and over time.

This might indicate differences in promotion of the helpline service. They could also indicate the extent to which families are listened to by different prisons.

There was a peak in Q2 last summer. Perhaps the heatwave? Or summer staff shortages? We will continue to analyse this data to see if it is possible to identify trends.

	Q4 21-22	Q1 22-23	Q2 22-23	Q3 22-23	Q4 22-23
Belmarsh		1	1		
Brixton	1		1	2	
Feltham					
Isis				1	1
Pentonville	3	6	6	3	5
Thameside	2	6	16	5	7
Wandsworth	1	6	6	12	10
Wormwood Scrubs	1	3	2	1	5
<b>TOTAL</b>	<b>8</b>	<b>22</b>	<b>32</b>	<b>24</b>	<b>28</b>



## What we've heard in Q1



### 5. Delays can become intolerable

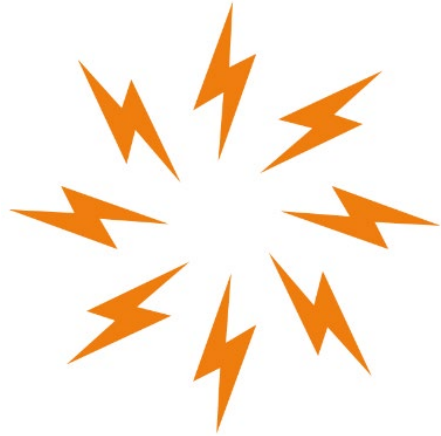
- Many families reported that their loved ones had faced **long delays in receiving healthcare services**.
- Families and their loved ones reported being **in the dark about how long they would have to wait** and what was going on, which added to their stress levels.
- Families said that their loved ones' **health has deteriorated because they have had to wait so long**.
- Those who transferred from one prison to another reported going **back to the bottom of the list** in the new prison, and long delays in medical records being transferred.
- Families reported that **failure to coordinate** with security and visiting teams had meant that long-awaited hospital appointments and operations had been missed.
- Some families said that their loved ones had **resorted to desperate measures** to improve their chances of receiving services.

#### Hazia's story\*

"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.

I wrote letter after letter; I wrote to our MP. But in the end, things only changed when he took it to extremes."

## What we've heard in Q1



### 6. Families report that pain isn't taken seriously

- A commonly reported issue from families was **their loved one not being believed or taken seriously when they were in pain.**
- Whilst many families acknowledge the resourcing issues that prisons and healthcare teams face, often their only information about prison healthcare is gov.uk, which states: "*Prisoners get the same healthcare and treatment as anyone outside of prison*".
- **Families have almost no information about why dispensing and prescribing may be different in prison than on the outside.** They are often at a loss as to why certain decisions have been taken, which makes it harder for them to support their loved ones.
- **Families can play a role in helping patients cope with pain and lack of treatment.** They describe offering comfort and emotional support, as well as practical assistance such as doing breathing exercises or meditation on the phone.
- Families stress that the lack of responsiveness poses **major safeguarding risks.**

#### Jennie's story\*

"My partner nearly died of a ruptured appendix. He was in agony in the cells but nobody believed him. He asked for paracetamol, and they said to put it on his canteen which would come in a week's time.

His cellmate raised the alarm and managed to get medical attention. He was taken out of the prison for emergency surgery but I wasn't told. They said it wasn't an emergency – but it was a life or death situation. It might not have become so serious if they had believed him to start with."

## What we've heard in Q1



## 7. Disrespect and lack of human decency

- Many families describe **being "treated like criminals" themselves** - spoken to rudely, judged and belittled.
- Some families describe feelings of being **fobbed off and lied to** by prison and healthcare staff - being given explanations that don't make sense, or expected to follow processes that they perceive as dysfunctional.
- Some families describe being **seen as the enemy** when they are trying to help their loved ones, with healthcare staff treating them as a problem to be managed rather than an asset to be drawn on. Some people have felt intimidated when they raised difficult questions or asserted themselves.
- A number say that their loved ones are being treated like animals, for example with 23 hour lock-up or lack of medical care. They describe how inhuman treatment makes reoffending more likely: **"They treat him like a dog. And if you keep poking a dog, eventually it is going to bite you"**.
- Family members describe how they **help their loved ones feel more human** again, reminding them of who they are to them - as dads, partners, brothers, husbands etc, beyond their lives in prison.

### Sharon's story\*

"My partner has open sores all over his skin and terrible pain in his teeth too. There are rats in his cell and he hasn't been able to shower for ten days. He's in agony but they told him, "you are going to have to suffer".

I get treated like a prisoner myself – spoken to rudely and shouted at for no reason. When I challenged the rudeness, I was told I would be barred from prison."

## What we've heard in Q1



### 8. Lack of trust

- Families often perceive a mutual lack of trust between themselves and the prison establishment – **they don't trust the prison, and the prison doesn't trust them.**
- For many families, failures around healthcare provision are the latest in **a long line of institutional failures** that contributed to their loved ones being in prison. Having been let down many times, some are resigned to the status quo.
- Some families **can blame themselves** for failing to navigate the system on behalf of their loved ones or don't trust that they will be able to engage successfully. This is more common amongst those who can't speak much English, are more disadvantaged or have limited literacy.
- Most families **don't differentiate** between healthcare teams, prison staff and other professionals when describing their experiences. The language is usually **"they said", "I told them"** etc.
- In this context, there are particularly **delicate relationships to navigate in terms of PPV work.** The readiness of families to engage with *Listen to Families* is underpinned by their experience of the programme as an independent channel for family voice, which isn't part of 'the system' but has a credible chance of bringing about change.

#### Johanita's story\*

"He was stabbed in the neck and taken into hospital – and then from hospital straight into custody. The nurse refused to dress his wounds – she gave him the pads and told him to do it himself. Then when they took him from the police station into prison they forgot to bring his neck brace, his dressings, his paddings – they left all his medical supplies behind.

The prison was asking me to go and get it all from the police station and bring it to him. I said no. I knew I would get the blame for it going wrong.

So much needs to change, but  
**what is the next right thing?**



We welcome NHS London's idea of developing a **Carers' Charter on Prison Healthcare** so that families and carers know the standards they should expect from prison healthcare and can access the information they need.

## 1. The development of a **Carers' Charter on Prison Healthcare**

- We recommend that NHS London kickstarts the process of developing a Carers' Charter on Prison Healthcare and takes the lead on making it happen.
- We recommend that NHS London works to bring the right people around the table to agree the charter's Terms of Reference – including HMPPS, healthcare providers, family representatives from the Listen to Families team and other relevant stakeholders.
- We recommend that the scope of the charter enables families to understand whether the service they have received has met expected standards, with lines of sight to commissioning decisions and quality mechanisms.
- We recommend that the charter is co-designed with the Listen to Families team, comprising families and carers, with a clear delineation of roles and responsibilities.

## Recommendations

Custodial patients should be informed about the fact that **they can give permission for their loved ones to be informed** about health issues. They should be offered opportunities to give consent, so that information can flow with families appropriately.

## 2. Give custodial patients better information and opportunities about **their right to give consent for information to be shared**

- We recommend that healthcare providers add a point of information on their health app forms, and on materials given to people at reception. Suggested text below:

"If you have a family member or friend who is allowed to know about your healthcare issues, please tell the healthcare team. Unless you say it's ok or your health needs are extremely serious, the healthcare team won't tell your loved ones anything."

Or alternatively...

"Did you know? If you think someone from your family needs to be contacted about your health problem, you can suggest this during your appointment with the health team".

- We recommend that Pact family services teams display appropriate information in visits centres, explaining consent issues to families.
- We recommend that Pact family services work with HMPPS to display appropriate information aimed at prisoners in reception and prisoner information desks.
- We recommend that Pact family services and the Prisoners' Families Helpline make their service users aware of consent issues.

We welcome Call Phill (the Prison Health Information and Liaison Line) and want to see it fulfil its potential as a tool for families.

This service should be **better signposted and promoted** so that more families have the opportunity to use it.

### 3. Improve signposting and promotion of the Call Phill service

- We recommend that Call Phill is signposted on the gov.uk webpages for the appropriate prisons (eg. HMP Brixton, HMP Pentonville, HMP Wormwood Scrubs and HMP Wandsworth).
- We recommend that PPG create an online webpage, written for a family and carer audience, that explains the Call Phill service and what it offers families and carers.
- We recommend that the webpage includes a short video, aimed at families and carers.
- We recommend that PPG send posters and flyers about Call Phill to the relevant visits centres, and that Pact staff put these up on display.
- We recommend that Pact family services in the relevant prisons invite PPG to give a briefing about Call Phill for their staff and volunteers to assist them with signposting.

**To hear more about what families have been saying or discuss our recommendations, please get in touch.**

**Amy Pollard**

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Prison Advice and Care Trust (Pact)

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

Our general mailbox is [listenstofamilies@prisonadvice.org.uk](mailto:listenstofamilies@prisonadvice.org.uk)