



Nobody's Listening

What families say about prison healthcare

January 2023



Prisoners · Families · Communities
A Fresh Start Together

Acknowledgements

What has clearly shone through in undertaking this research is the immense love, dedication and perseverance shown by family members in a system where they feel 'locked out'. We want to thank the families who gave their precious time to share their experiences and insight in the hope that their voices might improve the experiences of families in the future.

Thanks to the organisations and individuals who contacted families on our behalf and supported them to take part. We would also like to thank Graham Beech of Communitatis Ltd for the expertise and guidance that he brought to this research project.

This research was undertaken, in collaboration with families,
by Polly Wright (P. Wright Consultancy).

'People recover better when their family are involved if you cut that off then you are just creating a revolving door because you are not going to find the right solution.'

'No disrespect, but we don't need more projects and reports we need things to change now.'

About Pact

Pact is a pioneering national charity that supports prisoners, people with convictions, and their children and families. We provide caring and life-changing services at every stage of the criminal justice process: in court, in prison, on release, and in the community.

Pact's vision is of a society that understands justice as a process of restoration and healing, uses prisons sparingly and as places of learning and rehabilitation, and values the innate dignity and worth of every human being. 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 and social care.

Our volunteers and staff offer support in courts, prisons, probation services, and communities across England and Wales. We are a diverse, inclusive, modern, and collaborative charity. We build effective partnerships and sustainable solutions based on our well-established understanding of the systems in which we work and on our historic values and ethos developed through our 120+ years of service delivery.

Foreword

Juliet Lyon CBE,

Chair of the Independent Advisory
Panel on Deaths in Custody

This report is worth listening to. It puts a rock-solid case for enabling families to provide support to, and improve the health and wellbeing of, people in prison. Drawing in depth on the experience and views of parents and partners of prisoners, its author explores the importance of, as well as current barriers to, family contact. Pact's clear calls to action set out the practical changes necessary to create a far healthier system.

There is a long way to go to achieve equivalence in healthcare. Government figures referenced in this report identify a marked disparity between the health and wellbeing of prison and general populations. In 2021 the Independent Advisory Panel on Deaths in Custody (IAPDC) report with the Royal College of Nursing (RCN) on the prevention of natural deaths in custody, identified high prevalence of underlying health conditions, respiratory and cardiovascular, among prisoners, making people in prison more vulnerable to the effects of COVID-19.

This report is timely. COVID, and the prolonged period of extreme imprisonment and isolation in the face of it, has had a profound impact on prisoners' mental and physical health. HM Chief Inspector of Prisons, cited in the Justice Select Committee report on mental health in prisons (September 2021) made this plain:

"The most disturbing effect of the restrictions was the decline in prisoners' emotional, psychological and physical wellbeing... In our fieldwork we saw a sense of hopelessness and helplessness becoming engrained."

Since the onset of the pandemic, more than 40,000 prisoners and over 42,000 members of staff across England and Wales are recorded as having contracted COVID-19. Of these, it is not known how many are suffering from Long

COVID – screening, diagnosis and treatment are still needed. This is a period of painstaking recovery: at least an effort to get back to pre-pandemic regime activity and staffing levels; at best an opportunity to evaluate what matters most and to drive forward reform, including measures set out here and in Lord Farmer's seminal reports.

Closer integration between health and justice is in prospect. The draft Mental Health Bill revises the Mental Health Act and sets out to avoid the misuse of prison as a place of safety for people in need of healthcare and treatment. The rapid introduction of in-cell telephony early in the pandemic is an undoubted advance and provides a vital link to family and friends. There are important stepping-stones in the expansion of Pact services and further support for Samaritan Listeners.

The punishment of imprisonment is loss of liberty not loss of identity, hope and connection. We know that imprisonment involves separation and loss which in turn carry risks to health and wellbeing. We know that institutions institutionalise – leading to helplessness and hopelessness – the best staff in the best establishments learn to swim against the institutional tide. Communication with family can help immeasurably here.

What stands out from this report is the resilience of families and their determination to make things better – not only for their loved ones but also for others. There is so much to learn from them and their experience. We should applaud their courage and generosity of spirit. From my IAPDC perspective, I am convinced that communication with families supports government and the prison service to meet their obligations to take active steps to protect lives.

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About this report

The health and wellbeing of individuals involved in our criminal justice system is a pressing public health concern. As the World Health Organisation states 'by addressing the health needs of individuals during their time in prison, it is possible also to have a positive impact on the health of their families and wider communities upon release'¹. For Pact, as an organisation that seeks to support the needs of both individuals in the criminal justice system and their families, promoting health and wellbeing is fundamental to our practice.

Lord Farmer's 'landmark' reviews for both the male (2017) and female (2019) estates identified family practice as an essential element of rehabilitation that should run as a 'golden thread' through all aspects of prison delivery – including in the provision of healthcare and safeguarding practice:

***'Prisons should be able to show evidence that family or other supportive relationships play a role in intelligence gathering regarding a prisoner's mental health, drug use (prescription and illicit), propensity to violence and risk to self.'*²**

The Government has committed to ensuring a 'whole prison approach' is established in delivering prison health³. This approach, endorsed by the World Health Organisation, should involve all aspects of prison that touch on the wider determinants of health – positive family and significant other relationships are both important for physical health and psychosocial wellbeing.

For the majority of individuals, the justice system is a transitory setting in the course of their lives, while the support of friends and/or family is often a constant feature. Pro-social

relationships have long been identified as playing a crucial role in patient health and wellbeing and this role is even more vital when a loved one moves into the criminal justice system. The prison service guidance for the use of 'Assessment, Care in Custody and Teamwork' (ACCT) processes states that 'an individual's family or significant other may well be in a better position to know when something is wrong, and to spot signs of improvement. They can also offer insight into past behaviour, what is 'normal' for that individual and what support has helped in the past'⁴. This is supported by NHS England, who states, 'families are important to recovery and carers often hold information that allows services to work more effectively'⁵. Family engagement is therefore not only beneficial for patients, but also for the wider systems. It reduces pressure on the NHS by enabling services to meet patient needs more effectively; contributes to safer and more stable prison regimes for prisoners and staff alike; and helps to build safer communities by reducing the likelihood that prison leavers will reoffend.

Individuals in our criminal justice system represent some of the most vulnerable people in our communities and contrary to prison providing an opportunity to address health inequalities, evidence suggests that it often has a significant detrimental impact on health and wellbeing⁶. Families and significant others can play a critical role in both supporting continuity in care, as well as informing assessment and care planning processes for those most vulnerable of patients.

This role can only be realised however, if we understand how we can better support families and significant others. Family member imprisonment can have a detrimental impact on all aspects of family life: social, emotional,

financial and practical, and when coupled with the anxiety associated with the ill health of a loved one, the impact can be devastating. Supporting families to support their loved ones is therefore critical.

practitioners and patients, there have been few opportunities for families to share their experiences of supporting a loved one's health and wellbeing in the criminal justice system.

While the discourse regarding health and justice has often provided a voice for both

This report draws on the views of 33 family members who collectively have over 50 years of experience in supporting patients in custody. It presents families' insight into the impact of the criminal justice system on health and wellbeing, shines a light on the role that families play in supporting patients and identifies how systems, processes and services might be developed to unlock the potential of family support. We present 10 'calls to action' which we believe will contribute to essential wider benefits across health, justice and social care systems, as well as society more broadly, by:

improving health outcomes for both patients in custody and their families

reducing demand on both NHS and HMPPS systems by enabling patients' needs to be met more effectively

supporting the delivery of safer, more stable prison regimes for prisoners and staff alike

creating safer communities by reducing reoffending.

Executive Summary

For the purposes of this report we refer to the individual in custody as the 'patient', as their experiences are considered in terms of their health and wellbeing needs.

1 Families' experience of the impact of the criminal justice system on the health and wellbeing of patients

Messages from families

Care not custody required

Many of the families consulted felt that their loved ones' involvement in the criminal justice system was as a result of persistent, systemic failure of services (education, social care, health and/or criminal justice) to meet their needs. Almost a third of families described their loved one as having an acute mental health crisis immediately prior to their contact with the criminal justice system. While families acknowledged patients had committed a criminal offence, many felt that the criminal justice system had failed to effectively consider alternative diversionary treatment appropriate to the patients' needs.

Potential for positive health outcomes

Families acknowledged that when the criminal justice system works well, positive health outcomes can be achieved and for some patients, contact with the criminal justice system had had a positive impact as it had provided:

- + consistent access to ongoing support
- + the opportunity to receive mental health diagnosis and treatment that had not been forthcoming in the community
- + removal of risks associated with previous lifestyle
- + quicker access to healthcare
- + access to peer support.

Custody as a barrier to positive health outcomes

The majority of families witnessed a significant decline in their loved ones' mental and physical health during their custodial sentence. They attributed this to numerous and inter-related systemic factors including: the prison environment, lack of joined up working, delays in healthcare provision, lack of health promotion, a security rather than wellbeing-led regime, ineffective use of ACCTs⁷, staff skills, knowledge and experience, and limited opportunities for patients' or families' voices to be heard.

Call to action

1

Where patients present complex and/or significant mental health needs, alternative diversionary treatment should be more readily considered (in line with Public Protection requirements). This should be informed by all agencies currently working with the patient, as well as their family/significant others (where appropriate).

Messages from families

Lack of recognition.

Families rarely felt that their role (as carers, advocates, sources of information or vital support) was valued or understood by the criminal justice and health systems, and reported a lack of recognition for the role they had played prior to their loved ones' incarceration, particularly where the patient was a young adult, neurodiverse or had chronic mental or physical health needs.

The vital role of families/significant others

Families described their role as vital in promoting their loved ones' health and wellbeing in custody. This involved: providing regular contact with the outside world (via letters, emails, visits and phone calls); emotional support; provision of resources, tools and information to support wellbeing; raising safeguarding concerns; advocating for and

sharing case histories; challenging practice and seeking alternative medical advice/support on their loved ones' behalf.

Barriers to family engagement

Families identified numerous challenges in supporting loved ones' health and wellbeing in custody with 'lack of communication' underpinning them all. The majority of families stated that communication between themselves and the prison had been 'very poor'. Families' engagement was restricted by: fear of repercussions and a lack of trust, challenges associated with maintaining contact, lack of recognition or response from prisons, patient confidentiality, judgement and discrimination, lack of information and inconsistency in prison practice.

Call to action 2

Families' knowledge and experience must be recognised, valued and acted upon in the pursuit of better health outcomes (in line with NHS England's Strategy for Health Services in the Justice System). The NHS national Patient and Public Voice (PPV) framework should be extended to include the families/carers of patients in prison to provide the mechanism for them to have a voice in the development and delivery of justice healthcare services.

Call to action 3

The new HMPPS National Regime Model should be developed in line with Lord Farmer's recommendation that family and significant other involvement be integral to all aspects of prison delivery. Barriers to that engagement, particularly regarding the health and wellbeing of patients, should be addressed at local and national levels.

3 Creating opportunities for families to support health and wellbeing

Messages from families

While policy and guidance regarding family involvement in healthcare provision and criminal justice routinely highlights the value of relationships, families' experiences demonstrate that once a patient moves into the criminal justice system their ability to be heard and play a role in supporting the health and wellbeing of their loved one is often severely restricted. Patients lose access to 'relationships' as a tool in promoting good health at a point at which they are often at their most vulnerable, and families are locked out at a time when they too are often at their most anxious.

Proactive family engagement throughout the criminal justice journey

Families emphasised the need for criminal justice and healthcare staff to pro-actively involve them at key points: at arrest and in police custody, during the judicial process, at point of reception or early days in custody, pre and/or post prison transfer, when a patient's health needs changed and at the point of release and during resettlement.

Family engagement in ACCTs

A third of the families consulted reported that their loved one had been on an ACCT during their custodial sentence. Only one of the 11 families had been informed by the prison that their loved one had been put on an ACCT (families had either been informed by the patient or by the family engagement worker) and only one had been invited to contribute to the ACCT assessment process.

Development of staff knowledge, skills and awareness

Families suggested that in order for the criminal justice health systems to realise the potential of families in supporting patients, staff

required additional training knowledge and awareness in: the value and potential impact of family engagement, the impact of the criminal justice system on family wellbeing, the existing policy and guidance regarding family engagement and communication skills that enable empathetic, compassionate and non-discriminatory engagement with families.

Improved Gateway Communication systems

The significant majority of families had experienced difficulties sharing concerns via safer custody teams which included: struggling to find the correct number, lack of reassurance that answer machine messages had been responded to and staff reluctance to share information or offer reassurance. Families called for safer custody lines that: are staffed (rather than an answer machine service), that provide return calls to families to confirm action has been taken and are effectively logged to ensure accountability.

A single point of contact for families and patients

Families suggested that a single point of contact for families would not only improve outcomes for patients (by enabling families to support and inform care), but may also reduce pressure on safer custody teams. Families recommended that the role provide: advocacy for families and patients; a voice to challenge systems and processes on behalf of families/patients; emotional and practical support; a conduit between families, healthcare and prison staff; an independent service embedded within the prison; accessibility and inclusivity; and proactive contact with families to provide updates on patient progress.

**Call to action
4**

Refocus national and local policies, processes and procedures to integrate family at key points in a patient's journey through the criminal justice health system: pre-custody, early days in custody, prison transfers, when health needs change and at release/resettlement.

**Call to action
5**

Encourage staff to 'Think Family' when patients are on ACCTs by: developing staff knowledge and skills about how and why to engage families effectively and establishing effective monitoring (whether family was involved, how they were involved and if not, reasons why) that enables estate wide scrutiny of family engagement and holds establishments to account.

**Call to action
6**

Ensure that staff recruitment, supervision, management and training, across prison and healthcare systems, promotes an inclusive and non-discriminatory 'Think Family' approach.

**Call to action
7**

His Majesty's Inspectorate of Prisons for England and Wales (HMIP) and Operational and System Assurance Group (OSaG) should hold prisons to account for the delivery of effective safer custody hotlines that consistently record, action and respond to concerns from family members/significant others (in line with the HMPPS Strengthening Prisoners Family Ties Policy Framework).

**Call to action
8**

Establish a 'single point of contact' for families within justice healthcare services to inform and empower family/significant other engagement in patient health and wellbeing.

Messages from families

In order that families can continue to support the health and wellbeing of their loved ones they need to remain resilient. It is therefore crucial that consideration is given to how their health and wellbeing needs are met. Families of those with health needs in the criminal justice system face the dual impact of losing a loved one to imprisonment as well as the anxiety associated with a loved one's poor health.

The impact of supporting a patient in custody

Families described the far-reaching impact of supporting a patient in custody including: a loss of trust in services and systems, the loss of agency or role (as a carer, partner or parent), the impact on time and resources and the impact on their own health and wellbeing – both physically and mentally.

Support accessed by families

Almost a quarter of families had not received any support during their loved one's journey through the criminal justice system. Where support was received, it tended to be

accessed during their loved ones' custodial sentence, rather than at the start of the journey and was provided, in the main, by prison-based family support providers. Six of the 33 family members disclosed that they had accessed medical or therapeutic support for their mental health as a result of their loved ones' imprisonment.

Support required by families

Families felt that their needs were rarely acknowledged or understood and recommended that additional services be made available to families that provided: support throughout the criminal justice journey; proactive provision of accurate information about prison life and how to support a loved one in custody; information and guidance about how to support their loved ones' health and wellbeing needs; family-friendly, inclusive, non-judgemental, informed and empathetic support.

Call to action

9

Raise awareness about the health inequalities of families and carers of people in the criminal justice system in order to reduce the burden on community health and justice services and ensure services are appropriate and effective.

Call to action

10

Ensure targeted, informed and 'family-friendly' support is available and accessible for families and significant others at every stage of the criminal justice system.

Background and context

Healthcare provision in the criminal justice system

While the criminal justice system may deprive individuals of their liberty, their right to healthcare remains. Since 2013, NHS England has been responsible for commissioning health services in prisons, police custody and court Liaison and Diversion services in England. 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 acceptability⁸. Core20PLUS5 is a national NHS England and NHS Improvement public health approach to reducing health inequalities. Within the approach people in contact with the criminal justice system are identified as a group who experience health inequalities that should be proactively addressed.

NHS England's strategy for justice system health services aims to provide continuity of care throughout an individual's journey in the criminal justice system, to 'avoid unplanned treatment interruptions and ensure provision of ongoing care'⁹. This is particularly pertinent given that the majority of people sentenced to custody (74%) are sentenced to less than 12 months. Families will often be involved in patient healthcare both before and after their entry into the justice system and are therefore well placed to play a key role in supporting continuity of care.

For individuals with mental health, learning disability, substance misuse or other vulnerabilities the NHS England Liaison and Diversion service aims to improve health outcomes for those in contact with the justice system by ensuring effective early assessments are made and, where appropriate, referrals to appropriate treatment and support. The programme aims to ensure that 'criminal justice practitioners are notified of specific health requirements and vulnerabilities of an individual which can be taken into account when decisions about charging and sentencing are made'.

Despite the programme roll out due to be complete across England and Wales by 2021, a recent national evaluation of Liaison and Diversion services found that there continues to be an under-utilisation of diversionary or treatment orders¹⁰. In 2019 an HMI Probation report found that three quarters of people given short prison sentences did not have any report on their needs prior to sentencing, despite guidelines stating that this should happen¹¹. Similarly, in 2020 a joint inspection report by HMI Prisons and the Care Quality Commission into criminal justice for individuals with mental health needs found that 'information provided in courts... does not give enough attention to each individual's diverse needs and relies too much on self reporting'¹².

According to the Royal College of Psychiatrists, around 10% of the prison population (circa 8000 people a year), should be diverted into Mental Health Treatment by the courts, but instead, are placed in custody where their conditions worsen¹³.

For those individuals who are not diverted away from custody, evidence suggests that significant improvement is needed to effectively meet their health needs in prison. In 2018 the House of Commons Health and Social Care Committee stated that the 'Government is failing in its duty of care towards people detained in England's prisons'¹⁴ and the most recent Prison Strategy White Paper acknowledged that 'there is more to do to enable prisoners to access timely healthcare treatment'¹⁵. The continued decrease in prison investment, overcrowding, staff shortages, poor environments, lack of staff training and security-led regimes have all been identified as contributing to poor prisoner health outcomes.

The health of people in the criminal justice system

People in contact with the criminal justice system tend to be in poorer mental and physical health than the general population, with a greater need for health and care services¹⁶. For many of these individuals their families have played the role of care-giver, advocate and confidant before, during and after their time in custody.

- + Evidence has suggested that people in custody have a physical health status that is 10 years older than non-imprisoned individuals¹⁷ and a life expectancy 20 years younger than those in the general population.
- + In the 12 months to December 2021 the highest ever annual number of deaths in custody was recorded – 371, more than one death a day¹⁸. Of these deaths, 250 were classed as 'natural causes' (an increase of 13% from the previous 12 months). The Independent Advisory Committee into Deaths in Custody suggest that 'many of these deaths are preventable'¹⁹.
- + The male and female prison population is ageing and the number of prisoners aged over 60 has more than tripled in the last 20 years²⁰. The deaths of prisoners over-50 account for more than half of the deaths in custody and 90% of this age group have at least one moderate or severe health condition²¹.

Between 1 July 2020 and 31 March 2021, 52% of prisoners reported having mental health problems²². This is significantly higher than the general population where it is estimated that one in four people experience mental health problems in a given year²³.
- + In 2016, the Prisons and Probation Ombudsman found that 70% of people who died from self-inflicted means whilst in prison had already been identified as having mental health needs²⁴. During the first half of 2020 15,615 prisoners were put on ACCT due to being at risk of self-harm or suicide.
- + In the 12 months to December 2021 there were 86 self-inflicted deaths in custody, a 28% increase from the previous 12 months²⁵.
- + It is estimated that one in three people in custody are suffering from a serious drug addiction²⁶ and 38% of people surveyed in prison believed that their drinking was a big problem²⁷.
- + Around half of those entering prison have some form of neurodivergent condition, compared to an estimated 15-20% of individuals in the outside community²⁸. The Prison Reform Trust has reported that prisoners with learning disabilities or difficulties were almost three times as likely as other prisoners to have clinically significant anxiety or depression²⁹.
- + There is an over-presentation of racially minoritised individuals in our criminal justice system. 27% of the prison population are from a minority ethnic group and are more likely to report negatively about their experience of the criminal justice system, with fewer feeling safe in prison or feeling like they have positive relationships with staff³⁰.
- + Women in prison are more likely than men to have experienced trauma and abuse and present with complex physical and mental health needs. 71% of women in prison report a mental health problem compared with nearly half of men (47%) and nearly half of women report needing help with a drug problem on arrival in prison compared to three in 10 men³¹. Between June 2020 and June 2021 there were 3,808 incidents of self-harm per 1,000 female prisoners compared to 546 per 1,000 prisoners in the male estate³².
- + The COVID-19 pandemic resulted in significant changes to the prison regime with many prisoners being confined to their cells for 23 hours a day and face to face visits with family and friends being suspended. Inspections and consultations with prisoners have raised concerns about the long-term impact of these restrictions on prisoner health and wellbeing, including their access to healthcare and rehabilitation activities.^{33 34 35 36 37}

The role of families and significant others

Positive family and significant other relationships have long been identified as an essential element to effective rehabilitation and resettlement and their potentially valuable role in informing and promoting the healthcare of prisoners is widely recognised. NHS England's Director for Experience, Participation and Equalities stated that 'carers play a key role in helping people to get better' and thus contribute to more effective care and recovery for patients, and the delivery of more efficient use of resources, easing pressures on health services³⁸.

a) Promoting positive mental wellbeing

While the breakdown of family relationships or maintenance of abusive relationships can be detrimental to prisoner wellbeing, positive family relationships can play a key role in supporting wellbeing. The Mental Health Foundation states that 'loneliness and isolation remain the key predictors for poor psychological and physical health'³⁹ and yet prisoners, particularly during the restricted regimes introduced during the pandemic, often lose this social component of health.

Regular contact through telephone calls, emails and social visits can provide individuals with motivation, the opportunity to maintain relationships with loved ones (and therefore reduce feelings of isolation), the opportunity to share feelings and an essential connection to the outside world. In *Revolving Doors*' review (2020) into suicide in prison, contact with family proved to be a key issue for both men and women in custody⁴⁰.

b) Safeguarding prisoners

There have been repeated calls to ensure effective Gateway Communication systems are in place within prisons to maintain levels of continuity of care and enable families to share concerns about their loved ones' health and wellbeing (Harris Review 2015, Farmer Review 2017, IAP Keeping Safe Report 2017). The Strengthening Prisoners Family Ties Policy Framework introduced at the start of 2019, states that 'Governors will establish a process that enables family members and/or other

people with concerns about a prisoner's safety to contact an identified member of staff without delay' and that the process must include prompt feedback to the person who raised the concern. Despite this mandatory requirement, Pact, INQUEST and the Prison Reform Trust published a report in October 2019 that found that more than a third of prisons had no functioning safer custody hotline for families to share concerns.⁴¹

c) Informing assessment, care planning processes and continuity of care

Family involvement in the health and wellbeing of their loved ones however, should go beyond simply sharing concerns at the point of crisis, to ensuring opportunities are provided for proactive, valuable insight into processes such as assessments and care planning (where it is appropriate to do so).

The Harris Review of young adults in custody (2015) highlighted the need to develop prison cultures that 'acknowledge the important place of families and/or significant adults in the support of vulnerable young adults' and recommended that prisons engage families in assessment processes.

In 2017 the National Institute for Clinical Excellence produced guidance for the mental health of adults in the criminal justice system which states that 'all practitioners should ensure mental health assessment is a collaborative process that makes the most of the contribution of everyone involved, including the person, those providing care or legal advice and family members and carers.'⁴² 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'⁴³.

For particularly vulnerable patients with complex health needs, family involvement

can be even more important. The NHS guidance on meeting the healthcare needs of neurodiverse prisoners states that 'contacting family members, carers and community support staff (with consent) to gain useful insights and background information' is helpful in informing a person's care or treatment'⁴⁴. In addition, Adfam's report on families affected by the co-occurring mental ill health and substance misuse of a loved one found that '... having families involved wasn't just better for the person with dual diagnosis, but also better and more beneficial for services as it enabled them to carry out support more effectively'⁴⁵.

The Assessment, Care in Custody and Teamwork (ACCT) is the case management approach used in prisons to support prisoners who are at risk of self-harm and suicide. Lord Farmer stated that 'families (and significant others) should be properly informed about the opening of an ACCT document and able to request the opening of an ACCT document'. The most recent ACCT User Guidance (HMPPS, 2021) states that: 'it is important to invest the time to ask an individual who is being supported using ACCT whether they would like a family member, friend or other source of support to be involved in their care to boost the support available to them' and suggests that 'liaising with your third sector family support provider' can support both prisoners and families in the process.

Methodology

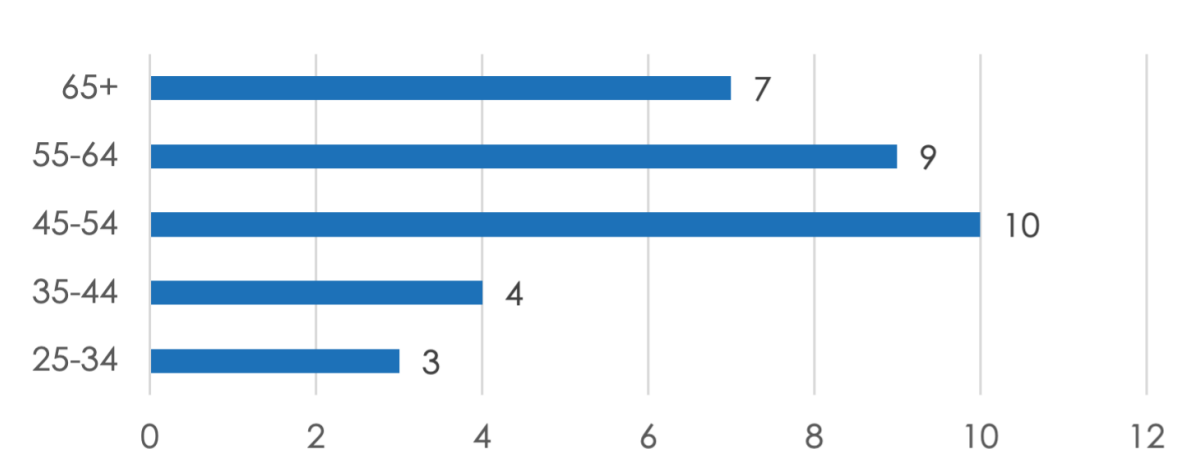
- **33** individuals were consulted as part of this research. 32 individuals were consulted via semi-structured interviews over the telephone or video call, and one via an online survey. Families interviewed also had access to an email address to share further views or experiences following their interview.
- Participants were identified via:
 - + voluntary sector organisations providing targeted support to families of prisoners
 - + community based organisations providing support (such as housing, drug and alcohol support, healthcare) to individuals in contact with the criminal justice system
 - + specialist services working with women involved in the criminal justice system
 - + specialist services working with racially minoritised communities
 - + individuals with lived experience of the criminal justice system.
- Organisations were provided with promotional material to share with families, including participant information sheets and posters. Once individuals had given consent to be contacted by Pact, they were then either telephoned or emailed with additional information about how they could take part prior to arranging an interview.
- All participants:
 - + had a close friend or family member currently in prison (or released in the last 24 months) who had ongoing health and/or wellbeing needs
 - + were in regular contact (or attempted to be in regular contact) with that close friend or family member while they were in custody
 - + five of the participants attended a follow up focus group to review the emerging findings and discuss potential solutions
 - + all participants received an e-voucher for their participation

Who we spoke to

a) Relationship to patient

- 45% (15) of the participants were the parent of the patient.
- 42% (14) of the participants were the partner of the patient.
- One participant was the child of the patient and one was the sibling.
- Four participants had been prisoners themselves and spoke both of their own experiences and that of friends or family.

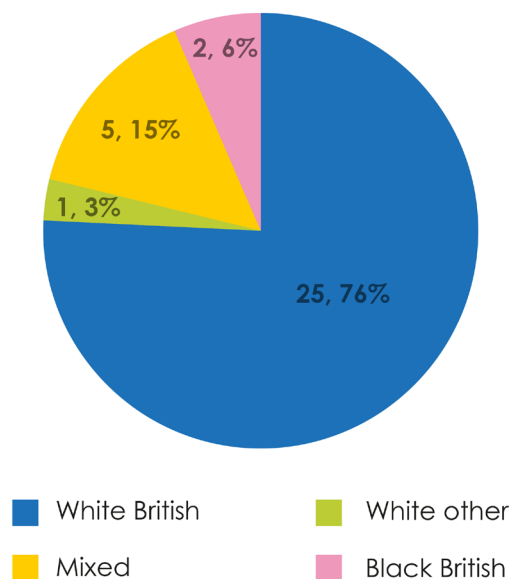
b) Age of participants



c) Location of participants



d) Participant ethnicity



Patient characteristics

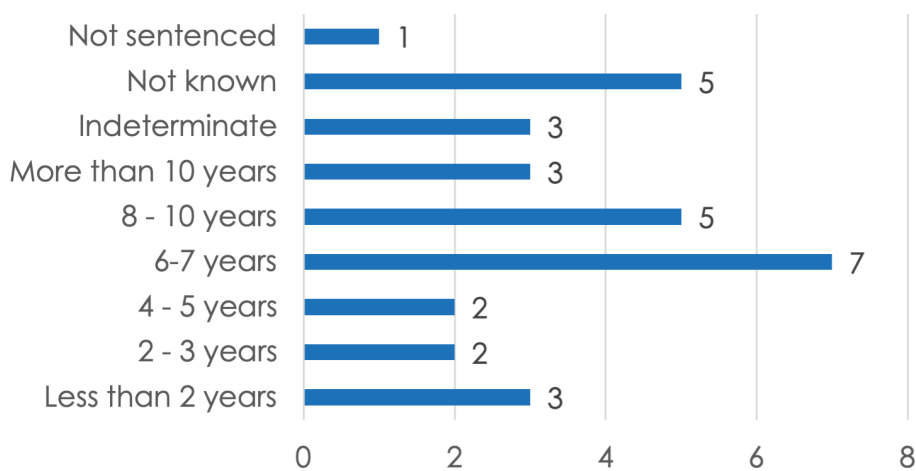
For the purposes of this report we refer to the individual in custody as the 'patient', as their experiences are considered in terms of their health and wellbeing needs.

a) Patients' gender

In the majority of cases the patient referred to by the participant was male (27 patients). 6 of the patients were female (18%).

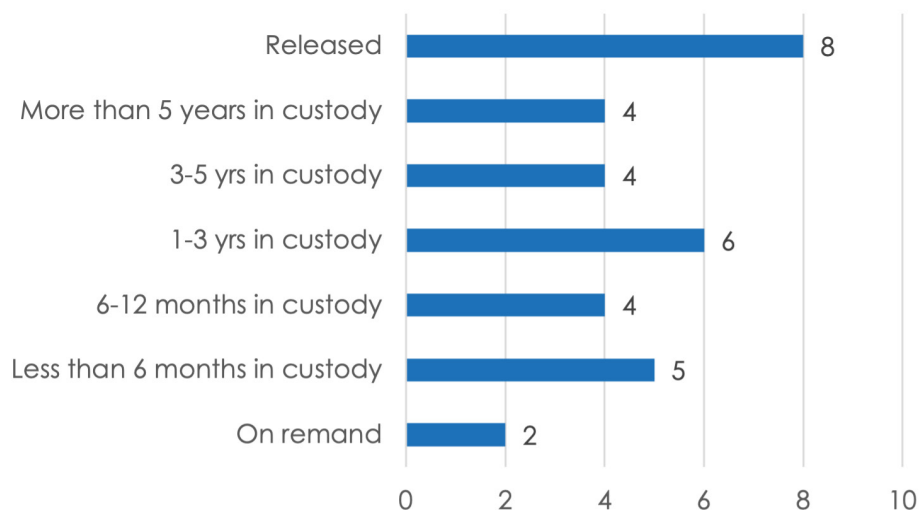
b) Length of patients' sentences

Where the length of sentence was not known, family members were either unsure of the length or chose not to share this information.



c) Patients' stages in criminal justice journey

Almost a quarter of the patients had been released from custody and therefore families were able to reflect on their entire journey through the criminal justice system.



d) Patients' prior experiences of custody

The majority of patients (64%) had not been involved in the criminal justice system prior to their current sentence. Half of the female patients however, had had prior experience of the criminal justice system.

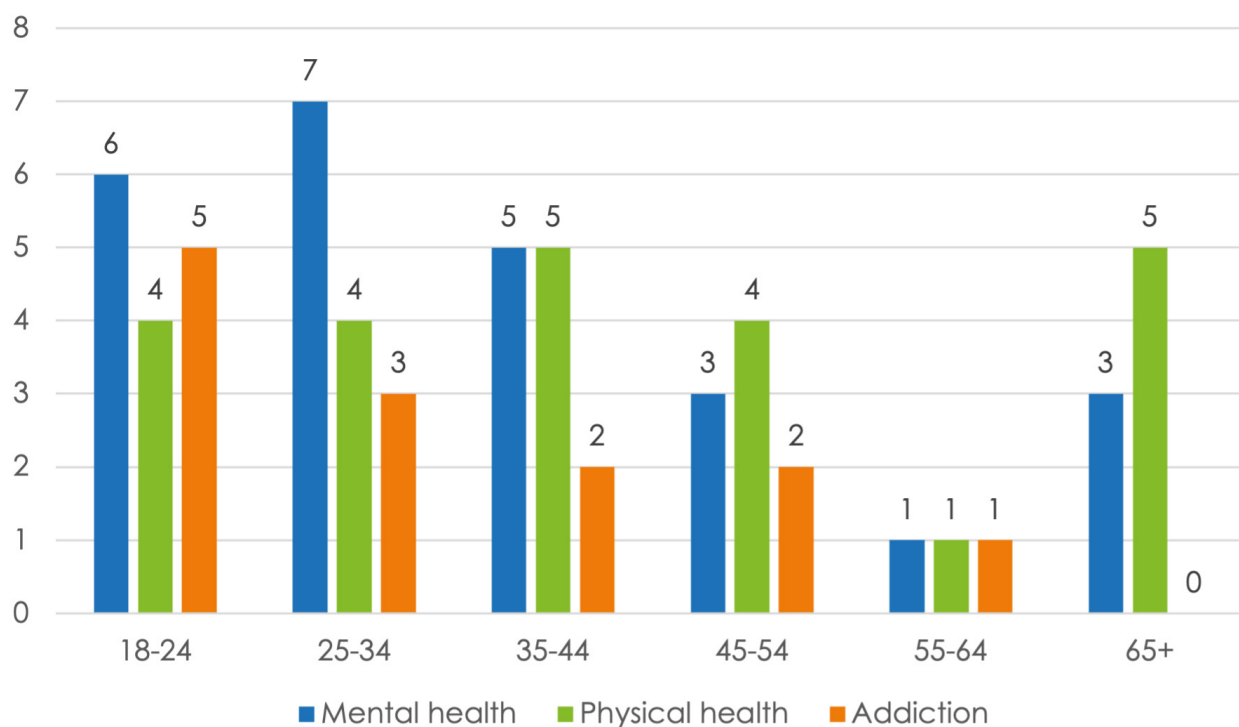
e) Patients' healthcare needs

The majority of patients were described by their family member as having both physical and mental health needs prior to coming into custody. For many patients they had gone on to develop additional health needs while serving prison sentences.

The table below details the health needs of patients (as defined/described by their family member) during their time in custody:

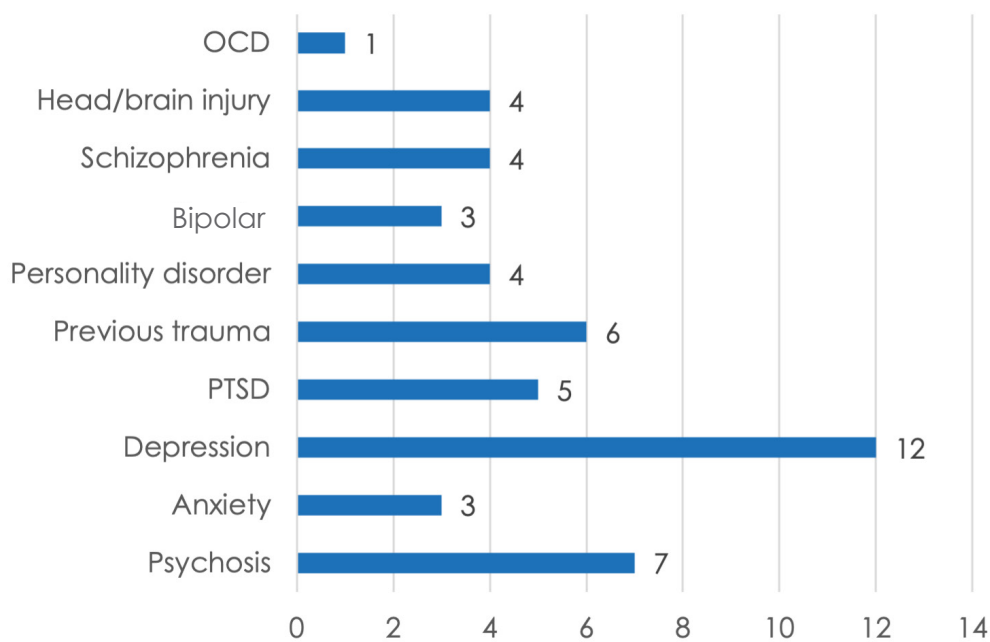
Mental health needs	25
Physical health needs	23 (of which 18 also had a mental health need)
Alcohol or substance misuse/addiction	13 (of which all also had mental health needs)

As the chart below demonstrates, the younger patients were more likely to be described as having both mental health needs and issues regarding alcohol and substance misuse or addiction.



18% (6) of the patients had been diagnosed with autism prior to entering custody.

ADHD	7 (21%)
Autism	6 (18%)
Dyslexia	2 (6%)
Severe learning difficulties	1 (3%)

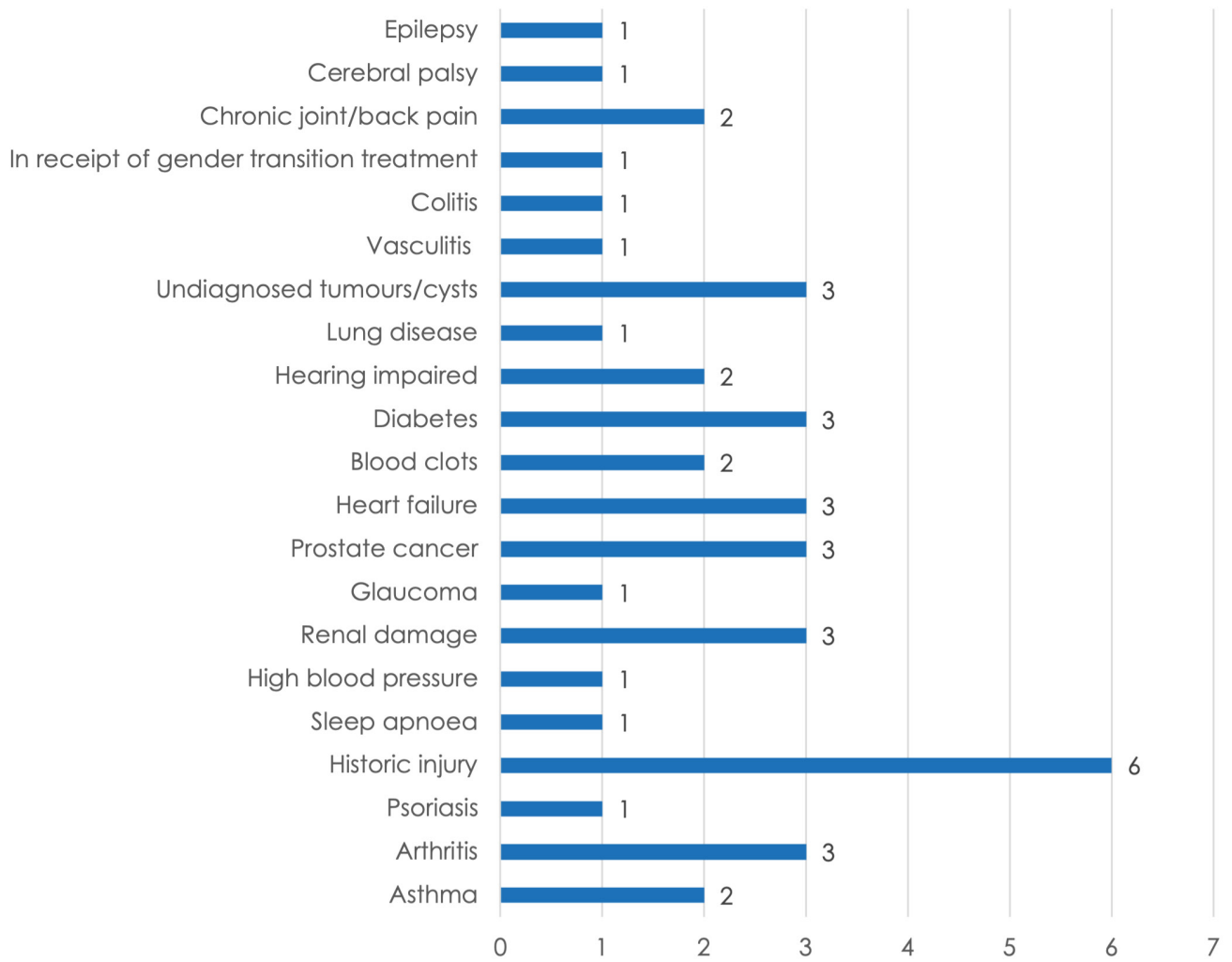


Almost half of the patients with mental health needs were described as struggling with depression. A quarter of patients' described as being depressed by their family member, had developed these symptoms since coming into contact with the criminal justice system.

A quarter of those patients with mental health needs had experienced significant trauma prior to coming into contact with the criminal justice system ranging from abuse, to bereavement and witnessing traumatic incidents.

In nine of the cases families described the patient as having a mental health crisis or psychotic episode immediately prior to their entry into the criminal justice system.

Families described their loved ones as suffering from a range of physical health conditions, the majority of which patients had had prior to entering the criminal justice system.



1 Families' experiences of the impact of the criminal justice system on the health and wellbeing of patients

Families and significant others are often the first to notice a deterioration or improvement in their loved ones' health and wellbeing: they know the subtle signs that suggests the patient is struggling, they are often the people who their loved ones' confide in and they understand what 'well' for that individual might look like. They can therefore provide valuable insight into the impact of the criminal justice system on patient health and wellbeing, and yet report that their voices are rarely listened to.

1.1 Care not custody

Many of the families consulted, while acknowledging their loved one had committed a criminal offence, felt that the **criminal justice system would only ever have a detrimental impact on the patient's health** as care not custody was required.

Many of the families consulted felt that their loved ones' involvement in the criminal justice system was a result of the **persistent, systemic failure of services** to meet their needs – whether those services be education, social care, health or criminal justice. This was particularly true of patients who were either neurodiverse or had chronic mental health conditions:

'Prison is not the place for her, this is the build-up of years of abuse and being let down.'

'At school they ignored our concerns... but I was the parent, I detected something, I sought support, got an assessment and got solicitors involved.'

'When he came out [of prison] they sent a support worker to the house, and do you know what he said 'I could have done with you before... all I needed was someone to talk to'... but he was never given anyone to talk to.'

Almost a third of the families described their loved one as having an acute mental health crisis immediately prior to their contact with the criminal justice system – the majority of which had resulted in medical intervention directly before they had committed the offence. Both families and patients had asked for help, but many had been met with **over-stretched services that were unable to meet their needs**.

'He woke me up in the morning and said he was going to go out and kill someone and he asked me to take him to hospital. He was assessed under the Mental Health Act, they all agreed that he needed a bed, but there were no beds available and it could only be on a voluntary basis... so he ran away.'

'After hurting himself we had asked the hospital not to release him as when we spoke to him on the phone he was delusional and paranoid, but they released him back to us despite our concerns and we just had to take him home...'

'The police just didn't know what to do with him and the mental health teams are just so overstretched that they don't know where to start with individuals like my son.'

Families shared their frustrations at what they felt was the **criminalisation of mental health and the lack of consideration given to alternative diversionary treatment**:

In one case, despite a community treatment order being recommended by the court, it was unable to be applied due to the patient being a foreign national:

'When I tried to engage with Liaison and Diversion they said that he already had a multi-agency team around him so it was not needed... His probation officer didn't even know what Liaison and Diversion was!'

'People like my son, who is extremely vulnerable, should have gone straight into hospital and not into prison... nothing was taken into account.'

'He was sentenced to a community treatment order but as he is a foreign national, his visa was due to expire during his sentence so his probation officer said that he couldn't meet the conditions of his sentence. So he was sent back to court where they said there was no other option than to give him a custodial sentence... as his sentence was less than two years he cannot access a treatment programme, so despite being recognised as requiring treatment he has received none.'

1.2 Custody as an opportunity to meet health and wellbeing needs

When the criminal justice system works well, positive health outcomes can be achieved for patients in custody. For some families, contact with the criminal justice system had, to some extent, had a positive impact on their loved ones' health and wellbeing. This had been achieved due to:

- + The patient being able to access consistent, ongoing support

'The lady in the mental health department persuaded me to get the medication and I kept seeing her two or three times a week throughout my sentence... the treatment I got in prison was better because it was a small community... they were more on it.'

- + Mental health diagnosis and treatment that had not been forthcoming in the community

'The Psychologist is helping and helping him to go back to his childhood - she is helping a lot.'

'The one thing I will say is that there is a mental health support lady and she is amazing and he has a real trust in her.'

- + Removal of 'risks' associated with previous lifestyle

'He's stopped smoking since he went in - completely. He's looking better in himself... less stressed and tense. If I'm honest it has probably given him a few more years on his life - his physical health has definitely improved.'

'Right now it's been the best thing that has happened to him because he is able to be in a room on his own all day and get his food delivered to him and he is able to keep himself safe. But that's not down to the prison it is because he has made a choice to self-isolate... Before I was worried all the time that he was going to overdose or that someone was going to kill him.'

+ Quicker access to healthcare

'To be fair the medical team seem to act quickly - probably quicker than they do in the community at the moment. He's had both his vaccines since he's been inside... and he probably got his flu jab before he would have got it on the outside.'

+ Access to peer support

'Other women could see when I was not right and they would call for support for me.'

'He's made some of the best friends he has ever had while in prison... I have been humbled by the love and loyalty we have seen.'

'His cell mate was an angel... he was only 27, but he looked after him... he helped change his catheter, changed his sheets... he was an angel.'

1.3 Barriers to health needs being met in custody

There is therefore potential for positive health outcomes to be achieved, however families consulted highlighted that when systems fail to meet patients' needs and provide opportunities for family engagement, poorer outcomes prevail, and unfortunately the majority of families had witnessed a significant decline in their loved ones' health – both mentally and physically.

'He has always been so happy go lucky in the whole 18 years I have known him, until now. Since he's been in custody he has tried a few times to end his own life.'

'There has been a significant decline in his health - there is no sense of wellness about my son.'

This decline was attributed to numerous and inter-related systemic factors that served to both exacerbate existing health conditions as well as create additional health needs. The extent of the impact varied depending on the patients' own health and wellbeing and the prisons in which they were residing, but factors included:

- + the prison environment
- + joint working
- + delays in healthcare provision
- + lack of health promotion
- + the prison regime
- + the use of ACCT
- + staff skills, knowledge and approach
- + patient voice

The prison environment

Families repeatedly described how the prison environment had had a negative impact on their loved ones' health and wellbeing: exacerbating existing conditions, creating new symptoms and rendering already vulnerable prisoners, more vulnerable.

Cells were described as overcrowded, unhygienic and uncomfortable – affecting both physical health and emotional wellbeing:

'It's just too overcrowded... the facilities are not designed for two people to be sharing one room – I was more concerned about being locked inside the cell and the impact on my mental health than the dangers of being outside the cell with people you don't know.'

'In one of the cells there was no running water for three days as it was over the weekend so no-one could fix it - there were fruit flies coming out of the sink and the toilet didn't flush and was backed up. The mattress was thin foam and the springs in the bed cut through it so I had to put a layer of cardboard over the springs.'

'She doesn't get a lot of sleep because of protests and banging on the walls and her cell has been freezing - so cold she often can't get out of bed.'

COVID exacerbated the impact of the prison environment on patient health – with restrictive regimes often preventing patients from leaving their cells for more than an hour a day – limiting exercise, socialising and access to daylight:

'He's been in prison since May this year and he looks like he's put on 2.5 stone... I'm worried about his diabetes.'

'Days would go past when you couldn't even get a shower and with my mental health I needed to feel clean, to feel in control - it had a big impact. On the specialist wing we had showers in our cells - it made a big difference things like that.'

Poor food was repeatedly highlighted as impacting on health and wellbeing – in terms of quality, quantity and nutritional value:

'Bad food equals bad mental health - food can be a real connection with home - good food equals happy, well-behaved prisoners.'

In addition to the physical environment, families referred to the social environment and the trauma experienced by patients as a result of witnessing violence, disruption and ill-health on a regular basis:

'He has been traumatised by his time in prison... he went in a handsome young man and now he looks like he's been at war.'

'He's experienced someone else slashing up and he has watched two prison officers being beaten up.'

While peer support had been a valuable contributor to the health and wellbeing of many of the patients, families described how the health needs of their loved one often made them more vulnerable to abuse and manipulation within the prison community:

'If you're vulnerable and people exploit you it's a lonely place to be - he's getting bullied, he's taking spice... he's lost. He's caught in a system that is doing him no good... underneath it he's a soft, caring young man... but he's too scared to be who he really is.'

'He's very vulnerable because of his health. His psoriasis makes him stand out. He works in the kitchen and some of the men have said they won't eat the food he's serving because of it.'

'When he tried to take his own life he was then marked... he was no longer top of the tree... His paranoia after that was very, very high and once a predator senses that - then yes, you are more unsafe, more vulnerable.'

Joint working

Information about patient health and wellbeing is recorded on two separate systems within a prison – NHS health records are stored on SystemOne and prison case notes on p-NOMIS. Research and reviews have repeatedly highlighted this as a barrier to joined up working and families consulted also raised this as a concern. They highlighted the lack of joined up working between systems as well as across services and staff, as having a negative impact on patient health.

'There is no joint working between the safer custody team, the healthcare team, the mental health team, the substance misuse team and they all place the blame on one another... everybody's pointing fingers.'

'Safer Custody told me that it was the GP's fault for not sending the prescription!'

They had witnessed a range of ways in which it had impacted on their loved ones' care and treatment, including:

+ Delays in treatment or medication

'My doctor and his psychiatrist wrote and said that he was on anti-psychotic medication and that he needed to be taking it...but they still said that the prison GP would need to prescribe it before he could have it.'

'He's just had to go for a check-up at hospital, but it has taken four or five months to get the ball rolling with all his medication and hospital things... it's all been down to the communication between the healthcare provider, the different NHS trusts for the different hospitals he has to go to.'

+ Pressure on patients to undergo repeat assessments

Families reported that lack of joint working and communication had resulted in patients having to be repeatedly assessed by different teams and services. Where patients struggled to trust new staff or build relationships this served to heighten anxiety and frustration. In addition, families were anxious patients could be re-traumatised by repeatedly having to discuss traumatic experiences that may have contributed to their ill-health.

+ Errors in care/treatment

Families suggested that lack of integrated systems led to potential errors being made in the care of patients, including cessation of medication that had previously been prescribed in the community and incorrect treatment:

'There has been that amount of different people and different prisons that there is a lack of clarity and a lack of people with the specialist knowledge that is needed. For six years his case notes had been mixed up with another offender who was a sexual offender and so he was put on courses and was speaking about stuff that really upset the family.'

+ A lack of continuity in care

Families shared examples of where continuity in care had been disrupted when patients moved from one establishment to another or were released from custody. In one case, when a patient tried to re-register at the GP after being released from custody, there was no record of them having been away and no records from any other health provider.

'I was shifted to another prison half-way through what was a short sentence so it was hard for them to track how I was doing.'

+ Lack of information for patients

Families reported lack of communication between healthcare, hospitals and prison staff often resulted in patients not being kept informed about test results, referrals or procedures:

'He was taken into ICU and developed blood clots. When he went back to prison he didn't get any discharge notes from the hospital and he has had no follow up - so he has no idea how he is. He saw a GP recently and the GP said they had no record of him having COVID or blood clots - my son knows nothing, so I know nothing.'

+ Patients' lack of trust in services

Families described how, in some cases, patients' experiences of disjointed services had led to a reluctance to engage with further treatment:

'He was supposed to have hospital appointments leading up to his operation and the prison took him on the wrong day and then to the wrong department. He just became more and more anxious and stressed... he just didn't trust that the prison were going to take him to the right appointments, give him the right medication or the right information at the right times.'

'She is reluctant to get further tests or treatment because she doesn't trust that she will receive the treatment she requires as there have been so many failures in her being able to get to and from hospital appointments - taxi's not turning up or being arranged.'

Families attributed the lack of joint working to:

- + ineffective communication between staff
- + the use of separate patient record systems
- + lack of staff knowledge and awareness
- + short sentences and/or regular transfers.

'They hadn't realised that social care packages were supposed to follow you into prison. So, despite my son having a social worker, a package already in place, a forensic case worker and all these other professionals involved in his care planning... they still had to send a social worker in to assess what care he needed and write up another care package.'

'Do they do handovers at the start of shifts on Wings? Do they identify which prisoners might be in crisis? My husband had just come out of hospital after having an operation - did they know that and if they did then surely they should have answered the buzzer!'

Delays in healthcare provision

Just under half of the families consulted said that they had witnessed a deterioration in their loved ones' health as a result of delays in the provision of medication, assessments,

equipment or medical treatment. Families had repeatedly attempted to contact the prison or community-based healthcare providers to resolve the issue on behalf of the patient:

'She is not being given her medication for her ADHD that she was on in the community and I have tried to tell healthcare that she needs them.'

Delays in medication were often said to have occurred at points of transition – either when a patient first arrived in custody, after they were transferred to a new establishment, when prescriptions were changed or when they returned to custody following hospital treatment.

'The hospitals are not electronically linked to the prisons – their systems are not joined up. So you can go to hospital from prison and be prescribed medication, but you can't have that medication until the prison has then processed the paperwork on their end – which can take time, especially if over the weekend.'

'Last week they agreed to let him have his meds in his possession but they accidentally cancelled his prescription at the same time... he waited three days for his medication. It was an absolutely horrendous problem... he's just had nothing.'

'When he was transferred to another prison the medication didn't follow him.'

'I was psychotic when I first went into prison and I had to wait weeks for my meds and I was a complete mess.'

In many cases families witnessed a significant deterioration in patients' mental health and behaviour as a result of delayed medication:

'It took them eight days to give him his mental health medication. When they did finally give him medication because his mental health had deteriorated so much by then he had developed severe paranoia.'

'His was on anti-psychotic medication when he went into custody but was not prescribed them... he misused any substance he could get his hands on as a form of self-medication.'

'Because it took a few weeks for her to get her medication she became very unwell... smashed up her cell and cut herself.'

Families had also witnessed the impact of delays in the provision of aids to support patients' health and wellbeing:

'He complained to the prison that his hearing aid was too amplified so the prison sent it off to be adjusted - so he went without them for three weeks. The prison complained about his behaviour - but he couldn't hear anything, he couldn't follow instructions!'

'In December he was not given a wheelchair when he got back into prison - so he was stuck in his cell and couldn't get out. He had been asking for a wheelchair for five months as he struggled to get to appointments and things.'

In addition, families described the impact of delays in treatment, interventions and appointments on patient wellbeing - heightening anxiety, potentially delaying diagnosis and exacerbating existing health conditions:

'I feel strongly that... if he had got physiotherapy when he had asked for it they would have picked up the Parkinsons earlier...'

'Last week he was supposed to have a telephone appointment with urology but that never happened. He was very upset about that and it's made him very down.'

'He was promised counselling 11 months ago but has still not received any.'

Lack of health promotion

Families also suggested that, had the patient been in the community they would have had additional access to support and resources to promote their health and wellbeing – which were often restricted or lacking within the prison environment.

'What he would normally use as therapy for his mental health has been taken away - music, medication, his Mum. They have withheld emails and letters because they say they are short of staff and then he gets a whole bundle in one go.'

'He's a brilliant artist but there seems to be a shortage of paper... I'm sending emails so he can use the paper to draw.'

'He didn't need to be rehabilitated but now he is being institutionalised and will definitely need rehabilitation as a result of being in prison. I just don't see why they keep them so disconnected from the outside world.'

The lack of mental stimulation available to patients was also identified as affecting mental health and emotional wellbeing:

'He found it difficult having the TV on constantly and no mental stimulation has affected his thinking and memory.'

COVID had exacerbated this lack of stimulation as prisoners had less time outside of their cells, restricted access to education, group work and social visits.

The prison regime

Families reported that the emphasis on security in the prison regime was often to the detriment of patient health and wellbeing.

Families shared their frustrations at the lack of information shared with patients, or families,

prior to hospital admissions. While they understood that this was to ensure high levels of security, this approach heightened anxiety in some patients and limited the support that families could offer:

'Because of his autism he doesn't like things sprung on him, he needs to have time to prepare and know in advance - so it is difficult for him not knowing when his appointments are going to be and just being told in the morning before he goes.'

Families also shared patients' experiences of being chained to prison officers in hospital environments – even when they were too

unwell to move. Families reported patients being physically injured through this practice, but also distressed by the stigma it created:

'He was supposed to have a follow up hospital appointment... now he probably wouldn't go if it was offered to him - he's too scared to go into hospital and be chained to an officer - he'd rather just put up with the headaches.'

The emphasis on security and safeguarding also impacted on patients' ability to access non-prescription medication, such as pain relief, in a timely manner:

'Basic access to medicines is a barrier - even in a school a child can ask for a paracetamol and be given one and the school nurse fills out a form, but an adult prisoner who is in pain cannot - it doesn't make sense!'

The time restricted nature of the prison regime was also identified by families as impacting on wellbeing, as medicines were distributed to meet regime/staffing requirements, as opposed to patient needs:

'At the moment they are giving him is medication at 4pm rather than in the evening ... so he is drowsy all evening.'

The use of ACCT

Despite the ACCT process being in place to safeguard those patients at risk of suicide or self-harm, families reported that patients had told them that isolation and lack of support had exacerbated their mental health and made them reluctant to disclose that they were unwell:

'He's frightened of telling them how bad he is feeling now as he doesn't want to be put on an ACCT... that solitary confinement makes you worse. When he comes off an ACCT he's worse... he says that they don't check on you enough and there is enough time for you to hurt yourself if you want to.'

'He is scared to speak about his mental health or admit when he is feeling suicidal - he is scared of being put on an ACCT. He thinks his privileges will all be taken away and he will be back to 'square one'.

None of the 33 families consulted had received information about ACCTs from the prison service or healthcare teams and therefore their understanding of the experience was entirely based on what patients, or other families, had shared with them.

Staff skills, knowledge and approach

Families reported that although some key staff played critical roles in effectively supporting patient wellbeing in custody, some staff practice had been detrimental to their loved ones' health. They identified the following ways in which practice had negatively impacted:

+ Mistreatment

Six of the 33 families consulted reported that their loved one had been mistreated by prison staff – resulting in injury and/or emotional trauma.

'He tried to take his own life last year following abuse he had experienced by prison guards.'

+ Understanding of mental health and trauma

Families were keen to emphasise that given the prevalence of mental health and trauma in custody, **staff should have a greater understanding of mental health** and how to respond appropriately and with compassion:

'There needs to be better training for new officers. For those that are dealing with traumatised people staff need to know how to not re-traumatise them and make it worse and they need to not label everyone with the same brush.'

A family member with previous experience of being in custody, described the **positive impact that trained, mental health aware staff can have** on the wellbeing of patients:

'Once I got on the Wing everything changes - I got therapy, I got the correct medication - they just took more interest in you and your mental health on that Wing - they heard me, they saw me. They would put their hand on me and say 'I understand...' and give me the time I needed and they listened to what I needed. I felt like a person again - that's how it should be everywhere in a prison.'

Families reported that a lack of understanding about mental health and how to respond appropriately, had had an impact on their loved ones' health and wellbeing, leading to:

- **Behaviour being misinterpreted** as non-compliant or destructive, rather than a communication of need:

'I think they just saw behaviour as 'bad' as opposed to a cry for help - they just saw us as prisoners who had done bad things - we were already condemned.'

'He hasn't left his cell for 10 months - to keep himself safe. He read out the recent report to me that OMU had written on him and it stated that he was still involved in drugs and gangs and was not compliant... but they have not recognised the change in him and the fact he is not using anymore - they just see it as non-compliant - rather than a positive step to keep himself safe and stop using.'

- Mental health **needs being dismissed**

'Staff in the prison have just become blasé because they hear it all the time and people do cry wolf... so nobody is taken seriously.'

- Effective **responses to mental health needs not put in place**

'When he was sentenced the Judge said that he should be given a single cell as stress can trigger his physical health conditions and due to his autism it was agreed that a single cell would help him avoid getting stressed... this has not been provided... despite repeated requests by [son] and the family he has been told he does not meet the criteria for a single cell.'

'He has not been given the quiet showers that are requested in his care plan and he has not been helped with his canteen sheet.'

+ **Discrimination**

Families reported that staff discrimination had resulted in the health and wellbeing needs of their loved one being overlooked. Families were concerned that individuals were seen as prisoners first and foremost, rather than patients in need of care:

'When you go and see a medic in prison they already have you down as bad, wrong or lying... they are seen as scum.'

'It's down to the staff and how much they really care... it all comes back to the staff on the frontline - their nature, their empathy and whether they care about the future of these guys and how much does that next layer of management care?'

In some cases, families felt that this attitude had led to patients being treated with a lack of dignity or respect:

'The whole time he was in hospital he was not given any of his things from his cell, he had no toothbrush, PJs, anything from his cell the whole time - he left hospital without any shoes and had to stand in the pouring rain in slipper socks.'

Families of patients with protected characteristics also shared experiences of patients' needs not being met or understood due to discriminatory practice or lack of knowledge/understanding:

'I think they don't understand a proper transgender person and they don't understand how important her regime is to her.'

Another family member stated that her son's behaviour had been mis-represented as 'gang-like' because he was a young Black man, rather than understood in the context of his mental health and developmental needs.

+ Consistent, trusting relationships

Families emphasised the value of consistent, trusted relationships between patients and staff and the role this played in supporting health and wellbeing. Where there were frequent staff changes or staff did not take the time to develop relationships, patients were less likely to reach out for support or feel safe in their environment:

'One of the problems is that he is sent all round the country on short sentences... he's in all these different places, so there's no continuity, no time for him to build relationships with staff.'

Patient voice

Both families and those who had had experience of being in custody reported that patients' lack of agency or voice in prison had a negative impact on their sense of wellbeing. Just as families felt frustrated with the lack of information and ability to have their voice heard, patients also reported feeling disempowered.

'There is a lack of routine and information shared with the men - it is really like they are in a black box - they don't know when they are going to be let out of their cell, if they are in isolation they don't know how long that will last, not told when their release dates change...'

'He doesn't know when he's going to hospital and he doesn't know what tests he's having when he's there... he has blood tests and they just arrive at the door and don't say why. He has had scans at the hospital but he has no idea why.'

Families reported patients resorting to violence, disruptive behaviour and in some cases self-harm, to have their voice heard:

'When they tried to move him from the vulnerable wing to the other wing he tried to hurt himself - he scalded his arm and cut his wrists with a blade.'

'His aggression is what gets him what he needs. He knew his health was deteriorating and he was saying 'I need help', 'I need help' but they did nothing.'

'At every parole hearing he would try and bring it up and he wasn't listened to and it really affected him, it made him more angry. Self-harm became a way to get the prison system to respond to him - he uses it as a way to grab their attention.'

'I was trying to tell them what I needed and they were just saying that I couldn't have that and they needed to check with people... I was completely psychotic and I wasn't being listened to which made it worse.'

Given the numerous challenges to health and wellbeing needs being met in custody, families were keen to emphasise that despite patients having the right to equitable care, it was far from comparable to what was available in the community:

'If he had been in the community the whole things would have been dealt with like the other times he had had infections, but in prison the PSA tests were delayed, his results were delayed, his medication was delayed.'

'Before going into custody he received light therapy three times a week for his psoriasis. This has got significantly worse since he has been in prison and no longer receives this therapy.'

'If he had stayed in the community he would have had talking therapy... with the best will in the world they can't do that in prison - there are too many people and not enough staff.'

'The social care package that he has now in prison is not comparable. He self neglects, he's scared to shower, he doesn't know how to complete a VO - social care should be helping him to do all these things.'

Call to action

1

Where patients present complex and/or significant mental health needs, alternative diversionary treatment should be more readily considered (in line with Public Protection requirements). This should be informed by all agencies currently working with the patient, as well as their family/ significant others (where appropriate).

2 Recognising the role of families in supporting the health and wellbeing of patients

Families rarely felt that their role (as carers, as advocates, as sources of information or vital support) was recognised or understood by the criminal justice system. Where it was recognised, families were grateful for the opportunity to remain engaged in the patients' care:

'The Duty Governor was brilliant. [My son] was in the hospital wing at that point and she agreed that I could ring every other day to speak to them and hear about how he was doing... because he would not come off the Wing they locked everyone else behind their doors and we were allowed to... meet him there in a room downstairs - they recognised he needed to see us and that we needed to see him too.'

Families and significant others bring with them not just crucial relationships with patients and often the services supporting them, but also the history, experience and knowledge of caring for their loved ones. The majority of patients referred to in this report had mental or physical health needs prior to coming into custody and all the families consulted had played an active role in supporting their wellbeing.

The desire to continue playing this role does not disappear once a loved one enters the criminal justice system. In many cases, it only served to increase a families' determination to ensure their loved ones' health and wellbeing needs were being met. Although families described significant challenges to playing this role, they also identified the many ways in which they supported the health and wellbeing of patients in custody.

2.1 Families' role prior to contact with the criminal justice system

Families' roles varied depending on the needs of their loved one and the nature of their relationship. Many of the patients had lived with their family member prior to custody and therefore the mutual support provided through sharing a home and an intimate relationship was fundamental to their wellbeing:

'We were together the whole time... we shopped together, we ran together, during lockdown we were together 100% of the time... we enjoyed it immensely.'

'I am typical of what you would expect a wife to be... I know him, I know his state of health.'

'I would always look after him and he's always looked after me... we have done that for the 43 years we have been married.'

As well as providing pro-social relationships that promoted wellbeing through love, continuity of care, trust and understanding, families had provided critical practical support for their loved ones' health and wellbeing prior to their contact with the justice system. This included:

- + informing and supporting attendance at care planning meetings
- + supervision and care while the patient was in a critical condition

- + arranging and/or supporting attendance at healthcare appointments
- + advocating for the patient when needed
- + supervising medication and/or treatment
- + practical support in accessing services – completing forms, applying for benefits, finding housing.

For many families – they had been identified as the 'primary carer' for their loved one prior to custody:

'During the pandemic his community care support package broke down - he lost his support workers so I became his primary carer.'

As is common amongst patients in the criminal justice system, many of the families were caring for loved ones who had multiple or complex health needs. Families described playing a particularly vital role in the health and wellbeing of their loved one where:

- + The patient was a young adult

Parents of neurodiverse patients described playing a key role in navigating not just healthcare services, but social care, education and criminal justice, throughout their child's life:

'Everything was done through me. I took him to every single appointment... because of lockdown he hadn't gained that independence that he would have otherwise or left home. I was still at the stage of liaising with his college tutors about his mental health.'

- + The patient was neurodivergent

Where the patient was a young adult, parents described still playing a crucial role in supporting their child prior to their contact with the criminal justice system:

'I have had to fight and fight and fight for everything all his life - in education, in healthcare - I've attended all his appointments, I've even been on courses to learn more about autism and ADHD so I knew what I was talking about with all the professionals. I've attended every one of his care planning meetings.'

The developmental needs of neurodivergent patients meant that they often relied heavily on support from family, significant others and carers.

'Although he was 19 and had a job and was independent in that way, he was still like a school child and had a developmental age of a 14 or 15 year old. I always made sure he had his appointments and went to his appointments with him, stayed with him, was there all the time when he was in hospital.'

'I would be in constant contact with him... I was the bridge between him and the services...I would advocate for him, liaise with services, go with him to appointments.'

'My son can't get from A to B without being chaperoned and he was only 18 when he went into prison. I was panicked when he got locked up because I didn't know how he would cope... I had done everything for him, filling in forms, all of that.'

+ The patient had chronic mental or physical health needs

For some of the family members, their loved ones' ongoing mental or physical health needs meant that they had developed critical roles in supporting their health and wellbeing, particularly during crisis periods.

'His family do everything for him - they take him to meetings, they house him - it's a role for them and without that role they feel a bit lost. It's like they are all in the same car on the same journey together...'

'Over time I gradually did more and more caring for her - the dressing and the showering.'

'I am pretty much his primary carer and his sister works in mental health care - so she helps as well especially through crisis times.'

2.1 Families' role within the criminal justice system

Despite playing vital roles supporting their loved ones' health and wellbeing in the community, families reported struggling to maintain this role once their loved one entered the criminal justice system.

'Those high walls are not just a physical manifestation... as a metaphor it is a barrier that is screaming 'you have no voice'!

'It's almost like a sect has taken hold of your child that you can't break into... they just don't recognise that he is part of a family.'

Families' determination and commitment meant that despite the challenges they faced, they were able to identify many ways in which they sustained their role in supporting their loved one in custody.

'I dread to think where he would be if I wasn't here... it would be disastrous.'

Providing regular contact with the outside world

Families described maintaining regular contact via visits, letters, emails, video calls and telephone as essential in supporting the health and wellbeing of their loved ones. Individuals who had served custodial sentences themselves also emphasised the value of regular contact:

'All the emails and letters and phone calls and visits... all that support is 100% why he copes.'

'When I miss a phone call it destroys me... because I know how critical that 10 minutes of contact with me is for the next 24 hours.'

'The best visit was the Purple Visit - he was actually able to be my brother because no-one else was in the room.'

'I wrote to him and his cell mate every single day with a quiz by email - it took me several hours a day to create - it had biology, chemistry... all sorts, and then I sent them the answers three days later.'

Providing emotional support

For patients, particularly those with mental health needs, families provided essential emotional support with someone they could trust and confide in:

'I listen to him offload everything and try and be understanding and stay positive for him.'

'I've been a listening ear... for him that is really valuable – he can break down and sob on the phone to me and that helps him.'

'He rings me constantly because he needs reassurance that I am still here for him... I am not just his Mum, I'm his counsellor, his advocate...'

Providing resources, tools and information to support and inform health and wellbeing

Families were often concerned that their loved one, particularly during the restricted COVID-19 regime, had limited access to resources they required for their health and wellbeing. As a result, families or significant others provided a range of information and resources:

'I make things to help his mental health, like his advent calendar with pictures of the family inside. I send photographs, like of our Christmas decorations at home...so he has a little bit of home in his cell. His partner has made him a special mental health book.'

'I send him books in and packs about recovery from substance misuse and Buddhism resources.'

'I have looked up his symptoms for him and made recommendations for him to pass on to healthcare.'

'When he came out of hospital his catheter was just hanging loose... his niece who is a nurse sent some of the straps through to healthcare in the prison.'

For patients who struggled to understand the prison regime, families provided vital explanations and information to reduce their anxiety and confusion:

'He is always ringing us and asking us to explain it to him and why it might have happened... a man from safer custody had been to see him and he needed us to support him and explain it all to him.'

Raising safeguarding concerns

The majority of participants had attempted to contact a prison to raise a concern about their loved ones' health or safety.

Families used a number of routes to attempt to share their concerns with the prison including the general switchboard, Safer Custody hotline, Chaplaincy, the prison Governor and healthcare teams. Families who were aware of the family service provider often relied on them to share concerns on their behalf, particularly when they felt the prison was not responding:

'Now I don't try to contact the prison I would go through Pact now - without Pact I am not sure what I would do.'

In extreme cases, where families were worried that their loved one's' life was at risk and the prison was not responding, they contacted external agencies including the police and their local MP:

'When he tried to kill himself, he rang his fiancé... we rang the police because we didn't know what else to do.'

Advocating for and sharing case history

Although the majority of families said they were prevented from being able to advocate for or inform their loved ones' care in custody, they described working hard to ensure that prison staff were informed of their loved ones' health needs, often acting as a conduit between healthcare in the community and the criminal justice system:

'I have put in written requests for his health records to be sent to the prison.'

'When he first arrived in prison they did not allow him his catheters that we had packed for him and when he was given one by healthcare it was the wrong size so I got the catheter prescription to the prison straight from the manufacturers.'

'I got the GP to phone the prison and the police station to say that he needed the medication.'

'At one point he had a cancer scare and nothing was happening so I wrote to one of the Governors, still nothing happened. I wrote a second letter and he eventually got an appointment.'

Challenging practice

While some families were reluctant to complain or challenge practice on behalf of their loved one for fear of repercussions, others took on this role in an attempt to improve their loved ones' healthcare, this included: requesting access to health records, preparing appeals and raising complaints with healthcare providers, the prison service and MPs.

Attempting to access alternative medical support

Frustrated at the lack of support for their loved one, some families attempted to access alternative medical support for their loved one while in custody:

'After every visit I would write down all his presenting behaviours and then send it to the forensic psychologist in the community.'

'I have tried to bring in his own therapist on a legal visit, but we have been told it is not allowed.'

Providing support for other prisoners

Families also spoke about supporting other prisoners who their loved ones had befriended: undertaking research into health symptoms on their behalf, updating family members if they had been unwell and sharing information, via their loved one, about support services.

'At Christmas he caught COVID and I just didn't hear from him, I was so worried. I got a call out of the blue from the wife of another prisoner whose husband was friends with my husband and wanted to let me know he had COVID, was in isolation and couldn't contact me... she'd found my details off the internet.'

2.3 Barriers to families providing support

When asked to identify the key challenge in supporting a loved one's health and wellbeing in custody the majority of families identified 'lack of communication'.

The majority of respondents stated that communication between themselves and the prison had been 'very poor' and while the following additional barriers were identified, 'lack of communication' underpinned them all.

Fear of repercussions

Families described a lack of trust in the prison service and the staff working within it. Many held the belief (as a result of patients' sharing experiences with them) that, by making a complaint or sharing a concern they were placing the patient at greater risk:

'I have a real fear of trying to help my son... the prison officers have made it much worse for him when I have.'

'You are afraid to make a complaint because you don't want him to get reprimanded... that was the hardest part.'

'There is no confidentiality within the system... that knowledge gives the officer you speak to leverage.'

Limitations on maintaining contact

Despite both families and those who have been in custody stating that maintaining contact was crucial for both family and patient wellbeing, many families had experienced challenges with visits, phone calls and secure video calls.

COVID-19 had had a significant impact on maintaining contact – with the cessation of face to face visits and restricted regimes that prevented those without in-cell telephones being able to make regular phone calls.

'I've only had six face to face visits since January because of COVID and the café is still closed and it is the things like being able to have a cup of tea together that make it feel more normal and we can't do that.'

Although secure video calls had provided an essential face to face contact for some families, others had found the calls limiting in their ability to provide a consistent and reliable service:

'We have tried to have secure video calls but either they are cancelled or they bring her through late and we hardly have any time.'

'The secure video calls seemed to operate separately to the prison and they often clashed with social visits.'

While other families, whose calls were conducted in busy rooms, found conversations difficult:

'Secure video calls take place with two other prisoners in the room so we can hear what one another is saying and there are technical difficulties and feedback. He can't tell me how he is feeling because the others can hear what he is saying.'

Where prisoners had no access to in-cell phones, families found it difficult to know when or if they would receive a phone call and calls were often limited:

'Recently they have been locked up for 48 hours over the weekends and he can't come out to make that critical phone call for 10 minutes to get him through to the next day.'

The cost of ensuring their loved one had sufficient money on their PIN to make regular phone calls was also challenging for some families:

'He's enhanced so he's allowed more money on his PIN – so I am topping it up all the time... it's not easy because I don't have his state pension anymore.'

Social visits were also challenging for some families due to distance, their own health needs, cost and the emotional impact of prison visiting:

'Visiting was one of the scariest things I have ever done... to be frisked and to be locked in a room and the sniffer dogs.'

In addition, families reported difficulties booking their visits:

'I struggle to get through on the booking line... I rang 82 times to make a visit!'

Lack of recognition or response from prison

Families described feeling disillusioned, frustrated and angry with Gateway Communication systems that provided them with little reassurance that their concerns had been heard or responded to. For some families this resulted in them choosing not to share information with establishments.

'We are not ringing that line anymore... it forces you into a corner where you just feel defeated... nobody's listening and nobody's getting back to you. At least if they rang back I would know he was still alive.'

'I've rung safer custody twice and I've never heard back from them. On one of the occasions I know my husband received a visit after I had rung but the other time nothing happened, I don't know if they ever listened to the message - you get no feedback. Now I don't try to contact the prison I would go through [Family Provider] now - without [Family Provider] I am not sure what I would do.'

'Two or three weeks ago my partner was suicidal, and I was really worried, terrified and I left a message on the answer machine and asked them to call me back. They didn't ring me back and no checks were made on my partner... my other half could have killed himself and I just wouldn't know.'

Patients' ill-health

For some families, the patients' health made it difficult for them to maintain contact or provide support. During periods of mental health crisis or increased substance misuse, patients had chosen not to engage in social visits – leaving families anxious and in the dark and patients with no family support. In addition, neurodivergent patients, or those with severe learning difficulties struggled to understand how to access resources such as secure video calls:

'He wouldn't know how to book a secure video call and now that he won't leave his cell he won't have a video call or social visit - I haven't seen him for 18 months!'

'When he first went in, I didn't hear from him... he was too ill to speak to me.'

'He just wasn't functioning when he first arrived. He couldn't even do things like put his friends names on his PIN or visiting orders - he just couldn't even write things down - it was a massive barrier.'

Families also shared how their loved ones' mental and/or physical health had impacted on their ability to communicate effectively:

'We couldn't have a proper conversation in the visit hall because it was just too loud and his hearing aid amplifies everything, it was just too overwhelming for him, in the end we had to cut short the visit because it was upsetting him too much.'

'He used to write once a week and I am heart broken that he can no longer write. The phones are on the corridors and he has to stand up to use them and some evenings he is just too tired to stand so we only speak briefly. I am just so worried that soon we won't be able to communicate at all.'

Data protection and patient confidentiality

Families reported that 'data protection and patient confidentiality' was often used not just as a reason to prevent information being shared but also as a reason to prevent families from being able to speak to healthcare providers:

'Healthcare would never speak to you... they would just say 'can't tell you it's data protection.'

'I think they are using patient confidentiality to protect the agency rather than to protect the patient.'

'How come they can write about people in the paper and claim they are allowed to do that because that person has lost their liberty but then can't speak to their family when they are in prison because of data protection?!'

Judgement and discrimination

Families described being stigmatised and discriminated against, not just by people in their communities, but also by the professionals working with their loved ones in the criminal justice system:

'I've heard them say 'like mother like daughter' in the background.'

'They need to walk in my shoes for a day... I never thought this would happen to me, I just had no idea what it would be like... they have no empathy for people.'

'The hardest part of the whole process was being made to feel like a criminal ourselves... they couldn't get us off the phone quickly enough.'

Some families reported feeling 'labelled' by the prison and healthcare staff as 'interfering' or 'overbearing' as a result of attempting to support their loved ones' health and wellbeing:

'They see me as a safeguarding concern – in his notes they talk about how to manage me.'

'I was really scared for him... I just wanted to be heard. I have just been viewed as an over-anxious, over the top Mum... but I know his needs better than anyone - who better is there to ask?'

Lack of information for families about how to inform health and wellbeing of a patient in custody

Families felt that their ability to support their loved one was often hindered by the lack of information available to them:

'We were flapping around like headless chickens, not knowing what to do or who to speak to.'

'I don't understand prison... there is nothing that comes to us and they don't communicate anything with the prisoner to be able to tell us.'

Inconsistency in practice and service provision

Families reported frustration at the lack of clarity about how they were able to support and maintain contact with their loved one. As patients moved from one establishment to another, rules and guidance associated with visits and property changed and families were often not informed. In addition, families found that there were inconsistencies depending on individual staff members' knowledge and experience within an establishment.

'I double checked if I was able to send in photos of her daughter and her school report and was told it was ok and then they got sent back... but then there have been times when things have slipped through.'

'I tried to get some clippers for him... that was last August and he still doesn't have them. They told me it was ok to get them as they were directly from Amazon, but now they are saying that he can have them when he is released...'

'At [prison] I had a direct link with the Family Engagement Worker – she was there liaising with me and I felt she understood... but when he moved all that stopped.'

'They need to be more coordinated, one says one thing another says something else.'

**Call to action
2**

Families' knowledge and experience must be recognised, valued and acted upon in the pursuit of better health outcomes (in line with NHS England's Strategy for Health Services in the Justice System). The NHS national Patient and Public Voice (PPV) framework should be extended to include the families/carers of patients in prison to provide the mechanism for them to have a voice in the development and delivery of justice healthcare services.

**Call to action
3**

The new HMPPS National Regime Model should be developed in line with Lord Farmer's recommendation that family and significant other involvement be integral to all aspects of prison delivery. Barriers to that engagement, particularly regarding the health and wellbeing of patients, should be addressed at local and national levels.

3 Creating opportunities for families to support the health and wellbeing of patients

'We are told we are the golden thread - then they should let us be involved, they should let me know what is going on and they should let me communicate with them. If I am the person who is going to have to look after him when he is released then they need to be involving me now.'

While policy and guidance regarding family involvement in healthcare provision and criminal justice routinely highlights the value of relationships, families' experiences demonstrate that once a patient moves into the criminal justice system their ability to be heard and play a role in supporting the health and wellbeing of their loved one is often severely restricted.

Patients therefore lose access to 'relationships' as a tool in promoting good health at a point at which they are often at their most vulnerable. Equally, families in the community who may have previously played a key role in their care are locked out at a time when they too are often at their most anxious.

'Sharing of information and collecting of information - it is all neglected. They need to be asking more questions about their mental health - they have never asked us questions like you have - like the questions you are asking me - what has happened, how he is feeling...'

Families identified a number of ways in which practice could be developed in order to ensure the potential of family relationships is realised.

3.1 Proactive family engagement throughout the criminal justice journey

Only three of the 33 family members shared experiences of being proactively contacted by prison or healthcare staff to inform the care of their loved one in custody. The examples demonstrated the value of engaging families: via telephone and face to face meetings families were able to share vital histories, information that the prison had been previously unaware of and inform staff when their loved one may have been more vulnerable:

'We received three phone calls in the first week and one was 40 minutes long - when they asked us for a full history - they told us that they didn't know he had been discharged from hospital the day before even though we had told the prison.'

'Communication started off very good with the Governor and Head of Safety... they responded well and invited me into meetings.'

'They would even tell me things like how much he had eaten that day - it really helped, and I could ring in with things like when it was the anniversary of his baby dying so that they knew that he might be struggling.'

Unfortunately, in all three cases, families said that this practice was neither sustained nor consistent through their loved ones' time in custody.

Families emphasised the need for criminal justice and healthcare staff to proactively engage families – rather than rely on families to contact them when they had concerns or wanted to share information. Families identified key points at which health and criminal justice practitioners should be 'thinking family':

Pre-custody

For families, where their loved one was taken into police custody, they highlighted the importance of police listening and proactively engaging with families to help ensure:

- + the patient had access to prescribed medication
- + the health needs of the patient were understood
- + the patient's communication needs were understood and responded to appropriately (particularly where the patient was neurodivergent or had severe mental health needs)
- + the other professionals involved in working with the patient were informed (if required)
- + the patient had access to support from family/significant others/appropriate advocate.

'From the moment he was arrested nobody has asked for any background information about him from us... the only thing they asked us for was his hearing aid... we wanted to get his bypass machine and his medication to him but they wouldn't take anything.'

'I rang the police custody suite and said he had mental health issues and a learning disability and that he needed an advocate.'

In addition, families emphasised the importance of being listened to during the sentencing process to ensure that their loved ones' health and wellbeing needs were met and understood:

'I wrote a letter to the judge... it was a true picture of my husband, what sort of man he is and what had happened to our daughter and the impact that it had had on him... The judge said it was an incredibly powerful letter and said I'm sorry you lost your daughter... it was definitely taken into consideration.'

'Nobody at the court asked us about the fact he had tried to section himself – they just didn't listen.'

'The barrister actually said to him 'you don't need your Mum to come in with you - you are a grown up boy'... In court I asked if they needed a copy of his educational psych assessment or his mental health records - but they didn't use either.'

Families also highlighted the need for families to be given information about the judicial process to ensure they were able to support and prepare their loved one for a potential custodial sentence:

'We were told he would most likely get a non-custodial sentence so he didn't even take a bag to court – he had no clothes, no reading glasses... it was all quite traumatic.'

Early days in custody

Families highlighted the importance of prisons 'thinking family' as soon as an individual arrives in custody to ensure that health and wellbeing needs are understood and key supportive relationships are identified.

'They don't listen to families – they make assessments based on what a very ill patient is saying or on people who meet them for 20 minutes - rather than listening to families or the healthcare professionals who worked with them in the community.'

'Anyone who goes into prison should have an assessment around family contact and their vulnerability... particularly if they are vulnerable, the prison can then contact the family and maybe set up some sort of meeting with them - that meeting should include health.'

Where patients were neurodivergent or had severe mental health needs, families reported that they were often unable to share crucial information about health needs in early assessments, or due to stigma, were reluctant to disclose mental health needs. Families therefore play a crucial role in informing early-day assessments:

'He was not well enough to say that he needed medication, he didn't even know where he was, he wasn't in a fit state to ask for anything.'

'I honestly don't know what he told them when he went in... He has a lot of bravado - he's always been ashamed of struggling with his mental health so he may not have told them. His substance misuse was probably seen as the presenting issue - he was just put into the 'addict' box and they did not give him the time to find out more.'

Prison transfers

Families identified prison transfers as a time when both patients and family members felt anxious – particularly when a patient is unwell, has complex needs and/or relies on medication:

'The move from one prison to another is traumatic for all of us - not just him - they lose property, their medication is not forthcoming, they have to get to know different people.'

Where family's provide vital support for patients, it is therefore essential that they are promptly informed of transfers (if patients are unable to) and their details are shared with the new establishment. Families can then play a key role in supporting the patient through the transition and are aware of who to contact with any concerns or information.

Families also suggested that prisons could undertake family impact assessments when considering the transfer of individuals with ongoing health needs – to ensure that the move does not impact on a families' ability to provide ongoing support:

'It said in his medical records that his family were an important support to him and he had two young children, but then they moved him to a prison a six hour drive away because that was the only place he could get treatment for his PTSD - we had to stay overnight to be able to visit him - I had to live on my overdraft.'

Changes in health needs

Families had rarely been informed when their loved one became unwell, their health deteriorated, or they received a new diagnosis – instead they relied on the patient informing them.

'There is no communication... I have never received anything from the prison. When my son tried to kill himself he rang me and he told me that he had tried to commit suicide. He was highly distressed...'

Families emphasised the importance of prisons proactively reaching out to families (where consent was in place and where families were identified as a key source of support) to ensure that they were able to provide timely and informed support to their loved ones:

'When my husband became unwell with Parkinson's then it is at that point that they should have said to him who else is supporting you, who else shall we get involved?... I should have been involved because I am clearly my husband's support.'

One third of the families consulted reported that their loved one had been on an ACCT during their custodial sentence. Only one of the 11 families had been informed by the prison that their loved one had been put on an ACCT (families had either been informed by the patient or by the family engagement worker) and only one had been invited to contribute to the ACCT assessment process:

'He was put on an ACCT because he didn't want to take his medication - I wasn't told anything about it.'

'He has been on an ACCT but they have never told me about it (I only know from having seen his medical records).'

'I have only ever been told by my son that he is on an ACCT - I've never received any information about it - I had no idea what it was - I have had to do all the research myself.'

While families were keen to be offered the opportunity to engage in the ACCT process, they also emphasised the importance of prison and healthcare staff engaging with them effectively prior to the patient reaching crisis point to avoid an ACCT having to be opened:

'When he was very bad health wise I phoned safer custody and left five or six messages and at no point did anyone get back to me. I know him very well and I could see what was going on and they just couldn't see it... he ended up going on an ACCT. If they had listened to me the outcome would have been very different.'

'I would definitely like to be involved when he was on an ACCT - it would help me to understand the processes that they are going through.'

Release and resettlement

Families also described the potential impact that release from custody could have on their loved ones' mental health:

'Their mental health can't cope with so much when they are released - all the colours, noises, money, the internet... it's just impossible to express what they have to deal with and as the family we are the only ones who are there to help them cope with all of that - as a family we have to deal with that.'

Families emphasised the importance of being provided with information and support to enable them to care for their loved one effectively and promote continuity of care. Where patients had been released from custody, families described receiving little support or guidance:

'He moved in with us from prison and seemed okay at first but over the coming days he was up and down. We were not given anything... absolutely nothing, no discharge notes, nothing.'

'I have had no paperwork - nothing like that since he has come home.'

'I have contacted every single one of the probation workers that my brother has ever had to say I am a family member who cares, contact me if you need anything and generally they just say they just deal with the prisoner.'

Where patients had been in custody multiple times, families emphasised the importance of effective support for patients and their families in preventing a revolving door back into the criminal justice system:

'When he has been discharged from prison he's never been discharged with a package that demonstrates he is vulnerable... he just ends up back in prison.'

3.2 Development of staff knowledge, skills and awareness

In order for staff within health and criminal justice to be able to realise the potential of families in supporting the health and wellbeing of patients, families recommended that they receive additional training:

'More in-house training within the prison to deal with both prisoners' needs and wellbeing and also their loved ones who visit and care about their family members in prison. Prison staff do a very difficult job, they need more regular in-house training.'

Families suggested training should include:

- + the importance of engaging with families and the potential role of families in supporting prisoner health and wellbeing
- + the impact of the criminal justice system on families' health and wellbeing
- + the policy and guidelines concerned with engaging families
- + communication skills that enable staff to engage with families in an empathetic, compassionate and non-discriminatory manner.

It was suggested that families should be involved in both the recruitment and training of prison staff to enable them to understand the needs of families:

'Prison staff need to meet with family members - to understand them... family members should be on the interviewing board for prison staff.'

3.3 Improved Gateway Communication

Families are often aware that their loved one's health or wellbeing is deteriorating before prison or healthcare staff – they may have witnessed changes in their demeanour on a social visit, a patient may have disclosed concerning information on a phone call or contact may have abruptly stopped. Effective Gateway Communication systems are therefore vital to enable families to share information with relevant teams to safeguard the patients in their care. The vast majority of families consulted had experienced difficulties sharing concerns via safer custody teams: they struggled to find the correct number, answer machine services provided no reassurance that their call had been received or staff were reluctant to put them through to the relevant team. Families emphasised the importance of safer custody hotlines providing:

- + a staffed service (rather than an answer machine)
- + return calls to families to reassure families that their concern had been actioned and update families on any outcomes
- + accountability – to ensure that sites demonstrate they log and action concerns.

'The safer custody hotline should be manned, there should be a log of the actions taken and people should be held accountable.'

'If I ring safer custody please ring the family back and let us know that they are not hanging in their cell.'

'If I ring safer custody please ring the family back and let us know that they are not hanging in their cell.'

Families emphasised the importance of Gateway Communication enabling them to not only share information when their loved one was at the point of crisis, but also to share information that may help prisons to provide pre-emptive support to the patient:

'I did speak to [Family Provider Organisation] when it was my daughter's birthday coming up and I thought he would struggle. The lady arranged for the Chaplain to go and sit with him...'

3.4 A single point of contact for families and patients

All the families consulted identified effective communication and the opportunity to build relationships with key staff as imperative to enabling and supporting family engagement in the health and wellbeing of patients.

Families suggested that a single point of contact for families would not only improve outcomes for patients (by enabling families to support and inform care), but may also reduce pressure on safer custody teams:

'It would help to have family wellbeing workers - it would probably help safer custody so they don't get so overwhelmed.'

'It would save a lot of trouble and self-harm.'

Families recommended that the **role should provide:**

- + an **advocate** for patients and their families
- + a service that has the ability to be heard and to **challenge the system** and processes on behalf of family/patient when needed
- + **emotional and practical support** for families

'It would help to have family wellbeing workers - it would probably help safer custody so they don't get so overwhelmed.'

- + a **conduit** between families, the patient, healthcare and prison staff.

'The [Family Engagement Worker] has been a bit like that... it has allowed both me and my husband to have the same point of contact - so that we are both communicating with the same person and that is so valuable - for the prisoner, their family and the worker to be all working together.'

- + an **accessible service** that is available by telephone and email and at the weekends (when there is often less healthcare provision in place)

'They would need to have their own line inside the prison so that the prisoners could phone them directly - it would be fine if they could just do it over the phone as there wouldn't be the resources for them to be seeing everyone all the time.'

'...support on the weekends is absolutely imperative.'

- + an **independent service** that is embedded within the prison

'They need to actually have access to healthcare and to know things and be able to do things like give you the number to the Chaplain when you need it and they should be able to contact us directly.'

- + a service that **proactively provides families with updates** and informs them of a patients' progress

'You need to be kept up to date with what is happening - what courses he has completed, copies of the certificates they have got - when it is a long sentence it would be good to get something like a review report each year - what they have done, achieved, how they are doing.'

Families stated that the role should be staffed by individuals with the **appropriate skills, knowledge and approach** to engage families and achieve positive outcomes for patients, including:

- + the **confidence** to challenge systems

'Someone who is not intimidated by prison staff and someone who will listen. Someone who is not afraid to challenge the regime.'

- + the ability to **work effectively with both patients and families**

- + **up to date knowledge and understanding** of the systems, processes and service in place

'Having a single point of contact is needed - but they need to have relevant, informed information that is up to date, accurate and specific.'

- + an approach which is inclusive, empathetic, **compassionate and non-judgemental**

'The important thing is the type of person - they need to be real, friendly, open, they need to care and be like a real person.'

- + **good communicator**

- + **trauma informed**

'They need to have knowledge of trauma - recognising when someone is dissociated - training should be the priority.'

One family member highlighted concerns about the establishment of a single role to support family engagement in patient wellbeing – citing the significant workload and risk of institutionalisation of someone based inside a prison:

'If they are based inside the prison there is the risk of them falling into the same way of thinking as prison staff... seeing prisoners as bad men... I'd also worry that there would be an overwhelming volume of work and so it would end up being diluted or less accessible.'

In order to address the significant demand on such a role, it was suggested that prisoners on each wing could be training and appointed to support the role:

'I think having a prisoner on each wing and using existing prisoners would help balance the weight of need.'

**Call to action
4**

Refocus national and local policies, processes and procedures to integrate family at key points in a patient's journey through the criminal justice health system: pre-custody, early days in custody, prison transfers, when health needs change and at release/resettlement.

**Call to action
5**

Encourage staff to 'Think Family' when patients are on ACCTs by:

- + developing staff knowledge and skills about how and why to engage families effectively and
- + establishing effective monitoring (whether family was involved, how they were involved and if not, reasons why) that enables estate-wide scrutiny of family engagement and holds establishments to account.

**Call to action
6**

Ensure that staff recruitment, supervision, management and training across prison and healthcare systems, promotes an inclusive and non-discriminatory 'Think Family' approach.

**Call to action
7**

HMI Prisons and Operational and System Assurance Group (OSaG) should hold prisons to account for the delivery of effective safer custody hotlines that consistently record, action and respond to concerns from family members/significant others (in line with the HMPPS Strengthening Prisoner's Family Ties Policy Framework).

**Call to action
8**

Establish a 'single point of contact' for families within justice healthcare services to inform and empower family/significant other engagement in patient health and wellbeing.

4 Supporting families to support patients

'Family support is critical for prisoners, but where is the support for us – the families – so that we are able to support them? We need to know the information so that we can then help them.'

In order that families can continue to support the health and wellbeing of their loved ones they need to remain resilient. It is therefore crucial that consideration is given to how their health and wellbeing needs are met.

4.1 Impact of supporting a loved one in the criminal justice system

Families of those with health needs in the criminal justice system face the dual impact of losing a loved one to imprisonment as well as the anxiety associated with a loved one's poor health. Previous research has repeatedly demonstrated the potential impact of imprisonment on all aspects of life, including family wellbeing, stigma and isolation, financial security, relationships and housing, and this was echoed by participants:

'There isn't a word for how it has affected me, it has affected every part of my life. I've lost family, close friends, my daughter, I am going to lose my home.'

'I haven't been back to work since it happened. It's just been completely devastating.'

'It's a huge burden not telling people and I am worried about whether I need to tell them... I am just so paranoid I could lose my job.'

'I am having to learn prison life... it is completely annihilating our whole family.'

'Financially it has had a big impact... the car we had was on finance and that's gone now and we won't get a mortgage.'

In addition, families described the additional impact of supporting a loved one in the criminal justice system on their health and wellbeing:

Impact on families' health and wellbeing

Families spoke about having to 'stay strong' for their loved one in order to be able to support them both during their sentence and upon release. The strain of navigating a system which they felt was often against them, whilst attempting to advocate for and support their loved ones, had a significant impact on the health and wellbeing of every family we spoke to.

'It's despair, hopelessness and forever having to drag up another level of energy.'

'I cry a lot... it just overwhelms me.'

'The mental stress and it is down to lack of communication and lack of trust in them wanting to do the best for my son.'

'I can't sleep, I struggle, some nights I only get an hour. I pretend to him I am fine but my alcohol intake has definitely gone up dramatically.'

Individuals also described the impact that ongoing stress had had on their physical health and the resulting anxiety that they may not be strong enough to support their loved one:

'I have tummy troubles now. I am exhausted all the time. All my energy goes into visits, keeping my work going and buoying my husband. I feel as though I am drowning. I am really scared that I am not going to be well enough to nurse him when he is released.'

'I had a big heart attack last year when he was on bail... I can't afford to be ill as I made a promise to stand by him.'

'It has affected my mental health which in turn has affected by diabetes.'

Where the patient was a parent or 'significant other' in a child's life, families spoke about the significant impact that their imprisonment had on children's health and wellbeing:

'It has killed my kids... people knew what I had done and they had to live with knowing that.'

'My son struggles, my grandchildren struggle...'

Individuals also described the impact of losing the emotional and practical support that their loved ones had provided for them in the community and the impact that this had had on their own wellbeing:

'I wasn't able to talk to him the day of my Grandmother's funeral or when our cat died, I was looking at ways to kill myself because my other half could not support me.'

'When he was home we'd have rides out and little walks, but I'm not doing that now because I haven't got him.'

'She used to phone me three times a day and I used to love cooking dinner for her, it was nice having her here for me.'

Impact on trust

Families described a sense of disillusionment and a loss of trust in services as a result of their ongoing battles to be heard and their experience of systems (whether criminal justice, health, social care or education) continuing to fail their loved ones:

'It has made be very wary about things... it's broken my trust, not in people but in the services. This experience will never leave me, it has changed me forever.'

'I have no confidence in the mental health team as they have let him down so much and have just left him with me to look after...'

'It impacts on how you trust people, I've learnt now that organisations and systems, instead of doing the right things they do the wrong things to cover up.'

Loss of agency/role

Many of the families described a sense of being disempowered. They felt that their role – whether partner, parent or carer, had been taken away from them or minimised as a result of feeling unable to support their loved one's health and wellbeing:

'I felt my motherhood has been diminished and the sense of failure has been overwhelming in being a mother, a supporter, anyone with influence.'

'You want the best for your son, you want them to have a happy and fulfilling life... this has rendered me powerless as a father.'

'I just feel like my voice hasn't been heard... I just wanted to look after him, I am his Mum.'

'I've always been there for her - but I don't think I am doing my role now as her Mum because it is just so difficult.'

Impact on time and resources

For many families the amount of time and resource spent trying to ensure their loved one was safe and their health and wellbeing needs were being met had had a significant impact on their lives:

'I haven't been back to work since it all happened... the feeling that I have to do everything because I can't trust he is getting what he needs... just the horror of not being there if he calls and I can't answer... I don't know how I could go to work.'

'My days are filled with paper work, secure video calls, court days, visits, sorting finances, it's a full time job.'

'I found myself saying that I couldn't go out in case he rang and his calls were so erratic and I would feel so guilty if I missed a call...so I have ended up doing things like going to the supermarket at 10pm.'

'I haven't got a life – I live for my son. I've moved to be close to him – I just live 10 minutes from him now, knowing I am so close has definitely helped.'

4.2

Support accessed by families/significant others

Almost a quarter of the families consulted had not received any support during their loved one's journey through the criminal justice system.

'I do need more support - he was here and then he's gone. Nobody tells you what to do... I just had to Google everything. There is just not enough help out there for families.'

'I have just felt as though nobody has really bothered about me... I was the last piece of the jigsaw that they thought about.'

Three of those individuals did not feel like they needed additional support (two had had previous experience of the criminal justice system):

'I'm in recovery anyway so I have that support network that I can draw on...'

'I'm a tough one, I don't need it - I just get on with it.'

'I didn't feel I wanted that - I didn't want to talk to anyone about it. I just used Google.'

Three individuals spoke about their reluctance to ask for support due to the stigma attached to imprisonment:

'If I had asked for help they would have just said 'well he is a criminal' - the whole family is condemned.'

'The social worker is not going to help me while he is still in the picture. If I was a single Mum I would be getting loads of support. There is a huge judgement because he is in prison - they are the last people I would turn to - I try not to talk to them about him.'

Where support was accessed, it tended to be accessed during their loved one's custodial sentence, rather than at the start of the journey:

'I wish I had known what support was there while he was being sentenced – I had to do that all on my own... I don't know how I got through it looking back.'

18 of the 33 individuals had received some support from a voluntary sector provider – 17 were providers based in the prison and one organisation was community based. Support ranged from ad hoc support in visit centres and on the telephone, to online forums and one to one case work.

'I have been shocked by the online forum really - it has been so helpful... when you come into all of this in your 70s like I have - it is a complete shock.'

'The [Family Engagement Worker] was a good support - she was great. It is the approach - she did not come with judgement or preconceived notions.'

'The [Family engagement worker] has been like a Guardian Angel - what she does and how she does it - that is the type of person that you need.'

Six individuals said that they had accessed support for their mental health as a result of their loved one's involvement in the justice system. Two individuals disclosed that they had contacted the Samaritans.

'I have had three years of therapy because of how angry I was because of what has happened to him.'

'I got counselling through work, I am just exhausted with it all.'

'I had to phone the GP and they gave me anti-depressants and now I suffer really badly with anxiety... this has left me really traumatised.'

Peer support was identified as particularly valuable by individuals and for some, their experience of the criminal justice system had provided the opportunity to form firm friendships:

'It has brought some of the best people I have ever met into our lives. The compassion and kindness that you find sitting in those visit centres.'

4.3 Support required by families/ significant others

Despite the significant impact of caring for a loved one involved in the criminal justice system, families felt that their needs were rarely acknowledged or understood.

'They need to invest more in families because they release these individuals to us!'

'More support for families - we need a Prisoners' Families Commissioner - one focal point - we need someone who recognises prisoners' families.'

Families identified a number of ways in which support should be improved/developed to enable them to provide the best possible support to their loved ones:

Support throughout the criminal justice journey

Families are often a consistent presence throughout their loved ones' journeys through the justice system and each stage of the journey brings with it new questions and anxieties. The majority of families had only received targeted support once their loved one was in custody, and they felt that support should be available from the point of sentencing through to the resettlement process:

'When you go into court the victims have support from the victim liaison people - but we get nothing.'

'I think as soon as they are taken away there should be someone in court to come and talk to us... Just someone to say something like 'I know you won't be able to take anything in at the moment, but tomorrow I will visit you and I will tell you what all the procedures are'.'

'Families need support on release... if you are worried about them and think they are struggling you are not going to go to probation and tell them that you are worried because they will just get them recalled... We need someone who we can go to, like when they are in prison, to say we are worried, they are struggling and they need some extra support.'

Families emphasised that these services should be promoted effectively to ensure that families were made aware of them at the earliest possible opportunity:

'I just think organisations should be promoted a lot more.'

'It was a complete fluke that I heard about [family engagement worker] - one of the other women on the Facebook group sent me her email - it shouldn't have to be a fluke that you come across them!'

Proactive provision of information for families

Families spoke about the time and energy that it took to undertake their own research about prison life and how to effectively support and remain engaged with their loved one. They recommended that prisons proactively provide families with information as soon as their loved ones come into custody.

'The prison should email information to the family about how to get in touch, basic understanding of what's available - how to send in money, setting up Email a Prisoner - just a small A5 flyer with the important information on.'

'One of the things I would have appreciated would be an information pack about what to expect... about phone calls or property... I just got no information at all... nothing on visits or property, I just had to find it all out on Google.'

'If someone is doing more than six months then there should be an induction for families - they should be given all the information they need right from the start.'

Information and guidance about how best to support their loved ones' health and wellbeing

Some families spoke about the anxiety associated with supporting their loved ones' developing health and wellbeing needs and suggested that additional support and information be made available to families, where required, to provide them with the necessary knowledge and skills:

'I don't have the skills to deal with the person that he has become... I need the tools to be able to deal with it.'

'It would be great if there was some sort of family liaison officer inside the prison - almost like a social worker. They would give the family some of the skills to deal with the situation and maybe open their eyes a bit to how they can best support their family member.'

'Families definitely need to know about things like benefits, power of attorney, counselling services and how they can get support to help them integrate back into society.'

Family-friendly support services

Families emphasised the need for support (whether targeted or provided through existing services) to be 'family-friendly' and offer non-judgemental, informed and empathetic support:

'People need to understand what we are going through, only then can people help.'

Some families also spoke about the benefits of receiving support from an independent organisation, separate from the criminal justice system:

'The whole family need support from someone independent to the prison but who is there to support the prisoner and their family.'

**Call to action
9**

Raise awareness about the health inequalities of families and carers of people in the criminal justice system in order to reduce the burden on community health and justice services and ensure services are appropriate and effective.

**Call to action
10**

Ensure targeted, informed and 'family-friendly' support is available and accessible for families and significant others at every stage of the criminal justice system.

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