## **Health and Social Care Committee inquiry into Community Mental Health Services** February 2025

#### **About Picker**

Picker is an independent health and social care charity based in Oxford, with expertise in understanding, measuring, and improving people's experiences of care.

We pioneered the patient experience approach, now widely adopted around the world, and advocate for the delivery of the highest quality person centred care for all, always. We work with policy makers, providers, professionals, and patients and the public alike to influence, inspire, and empower person centred care.

We are commissioned by the Care Quality Commission (CQC) and NHS England (NHSE) to design, deliver, and analyse the NHS patient survey programme, the cancer patient experience surveys, and the NHS staff survey. England's national community mental health survey is part of the NHS patient survey programme.

Please note, our submission only responds to the questions we are best placed to answer.

#### **Key points**

- The most recent community mental health survey results show that improvement is needed across the board, with service users reporting generally poor experiences of care.
- Service users would like to see improvement in the support they receive while waiting to access care, their involvement in their care, crisis care support and access, and the support they receive related to other areas of their life.
- We currently have limited information on people's experiences of waiting for access
  to community mental health services, as respondents are asked about their
  experience of waiting after they have accessed care.
- There is also a gap in our understanding of the experience of patients under the age of 16 accessing Child and Adolescent Mental Health Services (CAMHS).
- Three in five older CAMHS users (61%) said they had to wait too long to access services and 60% said their mental health got worse while they were waiting.
- Platforming good practice provides an opportunity to scale what works locally and allows providers to learn from each other and find solutions to common challenges.
- In our view, there is a role for the Department of Health and Social Care (DHSC) and NHSE in ensuring there is capacity within the system to afford staff the time needed to innovate. As part of this, they need the tools to understand and interpret the rich and robust data already available.

 We would like to see government commit to improved support for people waiting for care across NHS services, delivery of funding that matches current and predicted demand pressures, and commitment to staff numbers that deliver the required capacity to meet these demand pressures.

## What does high-quality care look like for adults with severe mental illness and their families/carers?

- 1. The Picker Principles of Person Centred Care, developed with patients, their families and healthcare staff, set out a framework for understanding what matters most to people receiving care, and what high quality person centred care looks like<sup>1</sup>. These eight principles are applicable across healthcare specialities and settings, including care for adults with severe mental illness (SMI) and community mental health services more broadly.
- 2. Since 2003, CQC have commissioned Picker to design, deliver and analyse the community mental health survey. However, due to methodological and survey design changes across this period, not all results allow for cross-comparison. The most recent results published in April 2024, using data from 2023, show that patients would like to see improvement in the support they receive while waiting to access care, their involvement in their care, crisis care support and access, and the support they receive related to other areas of their life<sup>2</sup>.
- 3. In January 2025, the government announced its Elective Reform Plan focused on elective recovery and the care provided by acute providers<sup>3</sup>. While it was welcome to see patient centric elements as part of this plan, including boards appointing 'Patient Experience Champions' by April 2025, these elements should also be applied outside of acute elective pathways and providers. It is essential that the implementation of this plan involves and engages with patients, service users, their families, and carers.
- 4. The NHS Long Term Plan, published in 2019, was ambitious in its aspirations for transforming community mental health services and delivering an integrated care model for people with SMI. It was centred on integration across physical and mental health, primary and secondary care, and health and social care. While these were all worthy objectives, with plans for co-design embedded, results from the survey show that there remains considerable work to be done to improve service users' experiences of community mental health services.

<sup>&</sup>lt;sup>1</sup> Picker. *The Picker Principles of Person Centred Care*. <a href="https://picker.org/who-we-are/the-picker-principles-of-person-centred-care/">https://picker.org/who-we-are/the-picker-principles-of-person-centred-care/</a>

<sup>&</sup>lt;sup>2</sup> Care Quality Commission (18<sup>th</sup> April 2024). *Community mental health survey 2023*. https://www.cqc.org.uk/publications/surveys/community-mental-health-survey

<sup>&</sup>lt;sup>3</sup> NHS England (6<sup>th</sup> January 2025). *Reforming elective care for patients*. https://www.england.nhs.uk/publication/reforming-elective-care-for-patients/

- 5. We note that this question is narrowly focused on adults with SMI and would like to draw the Committee's attention to the broader services provided by community mental health teams, which is reflected in the survey's participant cohort<sup>4</sup>.
- 6. The most recent survey results, published in April 2024, cover people who interacted with services between 1<sup>st</sup> April and 31<sup>st</sup> May 2023. The next iteration of the survey will be published in spring 2025. We would be happy to provide the Committee with further insights post-publication.

## How could the service user journey be improved both within community mental health services and in accessing support provided by other services/agencies?

- 7. The most recent survey results shows that improvement is needed across the board, with service users reporting generally poor experiences of community mental healthcare.
- 8. Survey analysis identifies the following areas for improvement: overall quality of care, crisis care, support while waiting to access care, and planning and involvement in care. These areas for improvement are also identified by people using CAMHS, however, it should be noted that the survey for CAMHS patients only currently includes those over the age of 16. The experience of people accessing Older People's Mental Health Services (OPMHS) is, however, better.
- 9. Currently, we have limited information on people's experiences of waiting to access community mental health services, as respondents are asked about their experience of waiting after they have accessed care. We are of the view that better data could be collated on the experience of waiting, across all services, if people were asked about their experience while they are on the waiting list, or at the end of their wait ahead of their first appointment or interaction with healthcare professionals. This would give greater insight into the impact of waiting without the potential impact of recall, and/or halo effect biases<sup>5</sup>: it would also allow us to understand the impact of long waits on people who break contact with services prior to being assessed or treated.

<sup>&</sup>lt;sup>4</sup> Since 2021/22, NHSE have implemented a phased transition from a 'care cluster' to a 'mental health currency' model (known as Mental Health and Neurodevelopmental Resource Groups (MHNRGs)). As a result, 'care cluster' recording was phased out of our survey analysis by 2023. The new model was due to be fully implemented by April 2024, however, external implementation delays mean we were unable to replace the former 'care cluster' variables in the 2024 results.

<sup>&</sup>lt;sup>5</sup> Community mental health survey respondents are only asked about their waiting time if they have been in contact with NHS mental health services for two years or less, and if they are still receiving care. The survey question is subjective, to measure how they felt about the length of time they were waiting. NHS trusts have data on exact waiting times.

#### How could this be measured/monitored locally and nationally?

- 10. Picker delivers the NHS patient experience programme, commissioned by CQC, and the cancer patient experience surveys, commissioned by NHSE, across a range of specialties. These surveys provide robust, national, benchmarkable data that allows providers to compare themselves with peers. In turn, this provides an opportunity for the sharing of good practice. These surveys have been commissioned for a number of years, affording a longitudinal view, where methodology allows.
- 11. At present, there is a gap in our understanding of the experience of children and young people under the age of 16 accessing CAMHS. We would recommend the introduction of a family measure to address this, particularly in the context of the rapidly growing demand for CAMHS<sup>6</sup> and the detrimental impact of waiting times on children and young people in particular<sup>7</sup>.
- 12. In our view, there is also a role for patients, their families, and carers, in pathway design. It is essential that co-production and co-design are integral parts of processes to adapt and transform services and that community mental health services offer holistic support.
- 13. There is also a role for local and national clinical audit to aid the understanding of people's outcomes, to identify outliers, and to support quality improvement, for example the National Clinical Audit for Psychosis, run by the Royal College of Psychiatrists and commissioned by the Healthcare Quality Improvement Partnership<sup>8</sup>. While audit providers and commissioners already consult with service users and experts by experience as part of audit design, audits should build on existing best practice and expand the use of patient reported outcome and experience measures (PROMs and PREMs) to amplify the voice of patients and service users.
- 14. As outlined in our General Election manifesto<sup>9</sup> and in our recent submission to the ten-year plan consultation<sup>10</sup>, there is a need for all NHS staff to be trained in patient

<sup>&</sup>lt;sup>6</sup> Children's Commissioner (15<sup>th</sup> March 2024). *Press notice: Over a quarter of a million children still waiting for mental health support, Children's Commissioner warns.* 

https://www.childrenscommissioner.gov.uk/blog/over-a-quarter-of-a-million-children-still-waiting-for-mental-health-support/

<sup>&</sup>lt;sup>7</sup> Rethink Mental Illness (6<sup>th</sup> November 2024). *The hidden toll of CAMHS waiting lists on young people's mental health*. https://rethink.org/news-and-stories/news-and-views/2024/the-hidden-toll-of-camhs-waiting-lists-on-young-people-s-mental-health/

<sup>&</sup>lt;sup>8</sup> Royal College of Psychiatrists. *National Clinical Audit of Psychosis (NCAP)*. https://www.rcpsych.ac.uk/improving-care/ccqi/national-clinical-audits/national-clinical-audit-of-psychosis

<sup>&</sup>lt;sup>9</sup> Picker (2<sup>nd</sup> July 2024). *Picker's NHS manifesto: Our vision for a person centred health service*. https://picker.org/research\_insights/pickers-nhs-manifesto-our-vision-for-a-person-centred-health-service/

<sup>&</sup>lt;sup>10</sup> Picker (3<sup>rd</sup> December 2024). *Change NHS – what does Picker want to see in the upcoming ten-year plan?* https://picker.org/research\_insights/pickers-response-to-the-change-nhs-consultation/

experience and the delivery of person centred care. This support could in future be coordinated by a dedicated national centre of excellence for patient experience, which would provide access to reliable expertise not present in all NHS providers. Barriers to staff accessing training should be addressed as part of this, including financial barriers and access to protected training time. Training and learning are iterative, so it is essential that training on person centred care is not reduced to a tick-box exercise or one-time event.

- 15. The Personalised Care Institute, hosted by the Royal College of General Practitioners, was funded by NHSE to deliver a programme of personalised care training to patient-facing NHS staff<sup>11</sup>. Central funding for this programme ended in March 2024, but the PCI remains active and continues to deliver training to NHS staff. With appropriate resource, these existing and accredited resources could reach more NHS staff.
- 16. It is our view that NHS staff must also be trained to understand the wealth of experience data already available to them<sup>12</sup>. This training would also create a learning and development opportunity for staff, aiding retention, and recruitment, while also improving patient experience.

# What is the current state of access for adults with severe mental illness to community mental health services?

- 17. The 2023 survey found service users are concerned about access to care, particularly crisis care <sup>13</sup>. While 78% of respondents said they would know where to go in a crisis, 22% said they would not. Data from this survey between 2020 and 2022 shows between 26-28% of respondents did not know how to contact someone in the event of a crisis, suggesting some improvement in recent years. When asked about waiting times when contacting crisis care teams in the 2023 survey, 21% of respondents they felt they had waited too long. In 2022, 19% of respondents said they had waited too long to get through to a crisis team <sup>14</sup>.
- 18. In 2023, a majority of service users reported they were not asked if they needed support to access care (59%), and of those who did require support, and received it, 31% said the support offered did not meet their needs.
- 19. In CAMHS, 2 in 5 people (38%) responding to the 2023 survey did not know who to contact in a crisis, and only 26% of respondents who accessed crisis care said they 'definitely' received the care they needed. A majority of respondents (65%) said they

<sup>&</sup>lt;sup>11</sup> Personalised Care Institute. <a href="https://www.personalisedcareinstitute.org.uk/">https://www.personalisedcareinstitute.org.uk/</a>

<sup>&</sup>lt;sup>12</sup> Picker (3<sup>rd</sup> December 2024). *Op cit*.

<sup>&</sup>lt;sup>13</sup> Care Quality Commission (18<sup>th</sup> April 2024). *Op cit*.

<sup>&</sup>lt;sup>14</sup> Care Quality Commission (2023). Community mental health survey 2022. https://nhssurveys.org/surveys/survey/05-community-mental-health/year/2022/

had not been asked if they needed support to access care, and of those who indicated they did require support and received it, only 20% said the support offered 'completely' met their needs. Over 4 in 10 (41%) said the support offered did not meet their needs, while 39% reported it did 'to some extent'. Three in five CAMHS users (61%) said they had to wait too long to access services, and 60% said their mental health got worse while they were waiting.

20. Conversely, 71% of respondents reflecting on their experience of accessing OPMHS said they knew who to contact in a crisis, and 60% reported 'definitely' getting the support they needed if they made contact. When asked if they were offered support accessing care, 49% of respondents said they were not. Of those who did require assistance and received it, 18% said the support did not meet their needs.

How can community mental health services work with social care, the third sector and local government to better address service users' health and wider social needs that are wider determinants of mental health outcomes?

- 21. The community mental health survey includes questions for patients about their experience of wraparound support<sup>15</sup>, including support for their physical health, accessing social activities, findings and/or keeping work, accessing government benefits and financial advice, managing the increased cost of living, or involving family and/or friends in their care.
- 22. The most recent data shows that 40% of respondents reported that, while they would have liked support with their physical health needs, they had not received support for these. Data from the 2020 to 2022 surveys shows that the number of people not receiving support for their physical health needs, when they would have liked to receive this, has increased year-on-year from 36% in 2020 to 40% in 2022<sup>16</sup>. The 2023 results show poorer experiences are more likely for those who accessed support via telephone, for disabled people, and for people who use adult mental health services. CAMHS users were, however, more likely to have been offered support with their physical needs.
- 23. When asked about support related to social activities, 44% of respondents said they had not received help or advice on accessing these. Most respondents (70%) reported they had not received support on finding or keeping work, while 67% said they were not supported with advice on accessing support related to government benefits or financial advice. Furthermore, 78% said they did not receive support or advice on managing the cost of living.

<sup>&</sup>lt;sup>15</sup> Care Quality Commission (18th April 2024). *Op cit*.

<sup>&</sup>lt;sup>16</sup> Care Quality Commission (2023). Op cit.

- 24. Data from surveys conducted between 2014 and 2022 show that the number of respondents not receiving financial advice or support on accessing government benefits increased from 44% in 2014 to 51% in 2022. Similarly, the proportion of respondents stating they did not, but would have liked to, receive support on finding and maintaining work increased from 43% in 2020 to 50% in 2022<sup>17</sup>.
- 25. In 2023, disabled respondents were less likely to report they had 'definitely' been offered support in finding a social group, finding and/or keeping work, or on involving family and friends in their care. Males, those accessing services face-to-face, and patients with dementia were more likely to report being offered support related to accessing financial advice and government benefits.
- 26. In the context of Integrated Care Systems being on a statutory footing since July 2022, there is a role for stronger and more effective cross-NHS and system partner working relationships, to support patients access the support they need that does not fall under the remit of the NHS or that crosses NHS internal boundaries. We would also note that for those accessing mental health services there remains a risk of 'diagnostic overshadowing' when they access other health and care services.

### What blockers or enablers should policy interventions prioritise addressing to improve the integration of person-centred community mental health care?

- 27. CQC's 'State of Health and Care' report (2024) notes high demand for community mental health services, which is resulting in long waits and service gaps 18. This is particularly concerning as service users with SMI have significant needs and require consistency in the care they receive, as well as comprehensive wraparound support.
- 28. This report also highlights concerns about access barriers to CAMHS. As across the rest of the system, long waiting lists create inequities – those who can afford private healthcare are able to avoid a longer wait, unlike those who cannot afford to access these services. People facing economic disadvantage may also be at particular risk of further deterioration in their mental health.
- 29. COC also note the impact of waiting lists on the demand for crisis services. This is similar to what is seen across the wider system with pressures on urgent and emergency care due to the length of waiting lists elsewhere in the system. We know that waiting times create additional uncertainty for patients and service users and can cause a worsening of their physical and mental health<sup>19</sup>.

<sup>&</sup>lt;sup>17</sup> Op cit.

<sup>&</sup>lt;sup>18</sup> Care Quality Commission (25<sup>th</sup> October 2024). The state of health care and adult social care in England 2023/24. https://www.cqc.org.uk/publications/major-report/state-care/2023-2024

<sup>&</sup>lt;sup>19</sup> Picker (12<sup>th</sup> September 2024). Waiting for improvement: person centred care and the future of the NHS. https://picker.org/research\_insights/waiting-for-improvement-person-centred-care-the-future-of-thenhs/

- 30. In our view, the following blockers and enablers should be prioritised:
  - Improved support while waiting for care, including clarity on what the expected wait will be, what support is on offer while waiting, and who to turn to if the patient needs support while they are waiting.
  - The introduction of data collection on people's experiences while waiting for care.
  - · Ensuring funding matches demand pressures.
  - Ensuring that staff numbers deliver the required capacity to meet demand pressures, while supporting a positive staff experience that includes a consideration of staff wellbeing and career development opportunities.

## What are the examples of good or innovative practice in community mental health services?

- 31. Positive outliers, performing better than expected, from the 2023 survey were: Southern Health NHS Foundation Trust (now part of Hampshire and Isle of Wight Healthcare NHS Foundation Trust), Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust, and NAVIGO Health and Social Care CIC.
- 32. Picker runs an annual award ceremony, the Picker Experience Network Awards (PENA) (formerly the Patient Experience Network National Awards), focused on celebrating the delivery of innovative person centred care<sup>20</sup>.
- 33. In 2024, Cheshire and Wirral Partnership NHS Foundation Trust was a finalist for its inclusion of Healthy Lifestyle Coaches (HLCs) within its intensive community mental health rehabilitation service. HLCs were introduced as part of the multi-disciplinary team due to the impact of physical ill health on the life expectancy of those with complex and severe mental health needs. Since their introduction, the team have seen improvements in patient's physical health markers, as well as positive changes in their activity levels, diet and the use of alcohol and cigarettes. They have also seen HLCs are successful in maintaining engagement with individuals who have previously struggled to engage with the service<sup>21</sup>.
- 34. Northumbria Healthcare NHS Foundation Trust was runner up in the 'measuring, reporting and acting' category, in 2024, for its 'giving voice to patients and staff in an out of view service a relational approach' initiative. The initiative set out to bridge the gap between staff and patient feedback, to make the data more meaningful. This was a joint initiative bringing together ward staff, patients, their families and carers,

<sup>&</sup>lt;sup>20</sup> Patient Experience Network (2024). https://patientexperiencenetwork.org/awards/penna-2024/

<sup>&</sup>lt;sup>21</sup> Patient Experience Network (2024). *PENNA 2024 - Book of best practice, (p.35).* https://patientexperiencenetwork.org/wp-content/uploads/2024/10/PENNA24-Book-of-Best-Practice-Final.pdf

and the Trust's Patient Experience Team. The project team were particularly conscious that OPMHS is a less visible service when designing this initiative<sup>22</sup>.

## What needs to happen to scale up the adoption of these practices across the country?

- 35. Platforming good practice provides an opportunity to scale what works locally and allows providers to learn from each other and find solutions to common challenges, while accounting for local autonomy and the need to adapt for diverse local populations and communities. One example of this platforming is PENA, which takes place annually.
- 36. Additionally, there is a role for NHSE and DHSC in facilitating the sharing of good practice, not just with regard to the tools for this, but also in ensuring there is capacity within the service for designing, delivering and evaluating innovation and reform.

<sup>&</sup>lt;sup>22</sup> Patient Experience Network (2024). *PENNA 2024 - Book of best practice, (p.77).*<a href="https://patientexperiencenetwork.org/wp-content/uploads/2024/10/PENNA24-Book-of-Best-Practice-Final.pdf">https://patientexperiencenetwork.org/wp-content/uploads/2024/10/PENNA24-Book-of-Best-Practice-Final.pdf</a>