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## Using CAMHS in Leicester and Leicestershire

Gathering the patient experience of accessing and using the Children and Adolescents Mental Health Services in Leicester and Leicestershire Page left BLANK

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### Introduction

Healthwatch Leicester and Healthwatch Leicestershire (Healthwatch) are the local independent voice of the public in the delivery of Health and Social Care in Leicester and Leicestershire. We collect feedback from members of the public about their experiences of using health and social care services. One of the ways that feedback is collected is through carrying out Special Projects. The findings are shared with service commissioners and service providers to influence service improvements.

The subject of a Special Project is chosen by Healthwatch the experiences shared by the public and conversations with the local authorities. Once a Special Project has been agreed, Healthwatch focus on the project between 3-12 months, gathering information and opinions of the public. The findings are shared with service commissioners and service providers to influence service improvements.

This project was undertaken to understand the experiences of people using the Children's and Adolescent Mental Health Services (CAMHS) in Leicester and Leicestershire.

Dyslexic friendly and large print versions of the report are available upon request.

### Background

Healthwatch have received feedback from parents over a number of years about delays in accessing treatment for Children and Adult Mental Health Services (CAMHS). Since then, work has been carried out by Leicestershire Partnership Trust (LPT) to address the delays within CAMHS. Recent feedback received by Healthwatch suggests this may have moved delays from waiting to be assessed, to waiting for treatment. Further investigation is therefore needed to see if this is the case.

This project will seek to evaluate peoples experience of the referral process and their treatment/plan of care and identify what changes may be needed to continue to improve people's experience. CAMHS was a national focus for Healthwatch England in 2017-18 and is an area of concern highlighted in several Healthwatch areas across the Midlands.

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### What We Did & Why

A survey was created to find out how people feel about different aspects of the CAHMS service. This included: -

- The referral processes
- Treatment/Plan of Care
- Venue/Transport
- Overall experience

The survey was made available on-line for people to complete. Healthwatch members of staff also attended clinics at Westcotes and Valentines Road and ask people attending the clinics to complete the survey whilst waiting for appointments.

We had hoped to complete more surveys and talk to people in waiting rooms, but due to COVID 19 we had to cease all face to face activities, so the report is based on the survey alone.

Demographic information was captured as part of this survey and can be found in Appendix A.

### Key findings

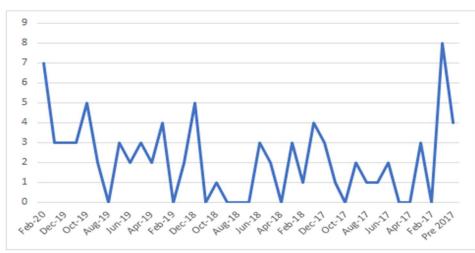
### Survey Results

90 surveys were completed. These included surveys completed on-line and face-to-face at CAHMS clinics.

### PART 1

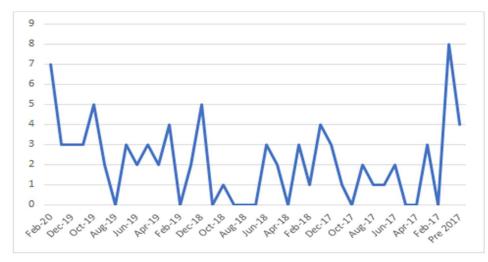
### **Questions About the Referral Process**

Healthwatch ask when people were first referred and then when they had their first appointment. The information provided is shown in the 2 graphs below.

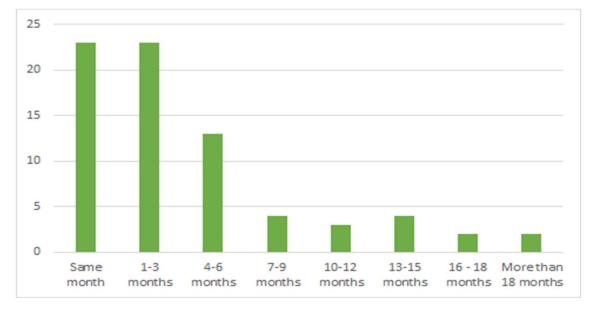


### Q1 When were you first referred to CAMHS?

### Q2 When did you have your first appointment/assessment after you were referred to CAMHS?

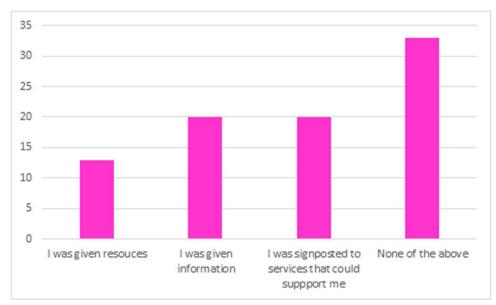


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Using this information, we were able to work out how long people wait between being referred and their first appointment.

Some people didn't answer when their first appointment/assessment was after being referred but we are able to compare 74 responses. 23 people (31%) were seen within a month of their referral and another 23 (31%) people were seen between 1-3 months. 13 people (17.5%) were seen between 4-6 months. 7 (9.5%) people were seen between 6 -12 months. 6 (8%) people were seen between 12 and 18 months and 2 people (2.7%) waited more than 18 months.



Q3 When waiting for your appointment/treatment were you given any resources or information, or signposted to any services for support? Please tick all that apply.

53 (62%) out of 89 people advised they were given some information, resources or signposted while waiting for an appointment/treatment. 33 people (38%) advised they did not receive any information of this kind whilst waiting.

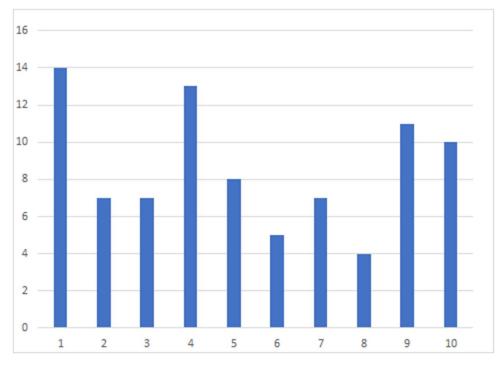
### Q4 Did you find the resources or information or signposting that you received useful?

67 people answered this question.

- 23 people said yes, very helpful (34.5%)
- 9 people said yes, not very helpful (13.5%)
- 35 said no (52%)

Q5 How do you feel about the length of wait from being referred to having your first appointment/assessment?

On a scale of 1-10 where 1 is a totally unacceptable amount of time to wait to 10 being very prompt.



49 people (57%) gave a score of between 1 and 5 with 14 people (16%) advising it was a totally unacceptable amount of time to have to wait before they had their first appointment/assessment.

37 people (43%) gave a score of between 6 and 10 with 10 people (11.5%) advising it was very prompt between being referred and their first appointment/assessment.

### Q6 During your initial assessment did the clinician seek your views and opinions?

80 people answered this question.

- 71 people said yes, they asked for my views (88.75%)
- 7 people said no they didn't ask me for my views (8.75%)
- 2 people said they tried to share their views but weren't listened to (2.5%)

Comments (sic)

- Cause my child behaved at the assessment she was dismissed as not being at risk
- Didn't feel comfortable with the clinician so became yes/no and just wanted to leave
- Tactless in parts, especially when dealing with autistic literalness
- Yes, however my wife was at the initial assessment

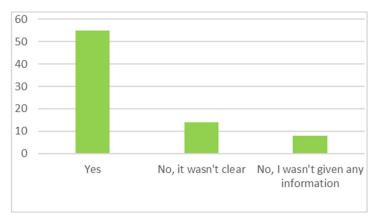
### Q7 After having your initial appointment did you feel you knew what was happening next?

80 people answered this question.

- 58 people said yes, they knew what was happening next (72.5%)
- 22 people said no they didn't ask me for my views (27.5%)

Of the 22 people who said they did not feel knew what was going to happen next, we ask them to tell us why. Below are some of the comments we received (sic).

- Didn't tell us
- I was 15 and confused
- Wasn't really explained
- I didn't know exactly what was going to happen
- $\circ$  The appointment felt rushed
- Wasn't told anything
- Everything was unclear and timeframes not given



### Q8 Was the information you were given after your first access appointment clear

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Out of 77 people who answered this question 55 (71.5%) said yes. 14 people (18%) said they received information, but it wasn't clear and 8 people (10.5%) did not receive any information.

### Q9 Did you feel involved in your care plan/plan of care with your clinician?

81 people answered this question.

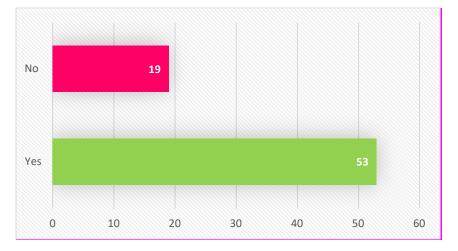
- 55 people said yes (68%)
- 13 people said no (16%)
- 13 people said they weren't sure (16%)

When asked why they didn't feel involved in their care plan/plan of care people left the following comments (sic).

- It was given to us rather than any discussion
- No one asked me about what I wanted
- As I wasn't consulted

### Q10 Did you agree with the proposed plan of care by the clinician?

72 people answered.



People who didn't agree with their care plan gave various reasons some are listed below

- Didn't understand fully
- Wasn't asked just informed
- Wait in between too long
- Didn't feel it was enough

No common theme emerged. The full list of reasons can be found in Appendix B.

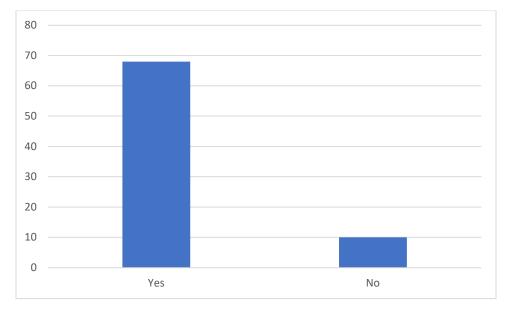
Q11 Do you have any additional comments or suggestions to make regarding your involvement with your care plan and the CAMHS professionals you have been involved with?

People left positive comments on their involvement in their care plan and with professionals as well as areas for improvement.

On the whole teams and individuals within the CAHMS service received good comments including clinicians being "great for my daughter" and "referred by eating disorder team, always rec'd huge amount of valuable support".

Improvements suggested by people using the service included more updates when waiting and interim appointments, home visits and faster times for a care plan to be sent out.

Full comments to this question can be found in Appendix C.

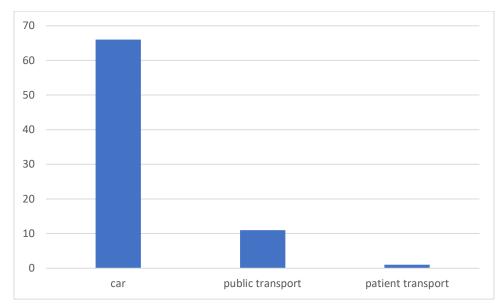


#### Q12 Was the venue that you attended for your first CAMHS appointment easy to get to?

68 people (87%) said it was easy to get their first appointment.

13 people (13%) said no it was not easy

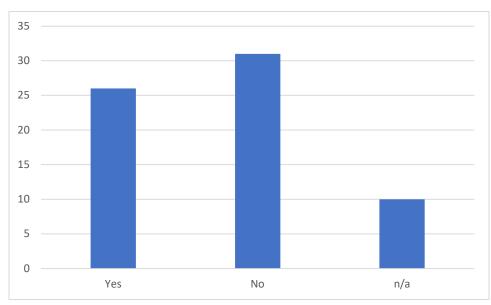
Reasons given for it not being easy were mainly because Leicester is too far away. Some people have to get a train or a more than one bus. Full comments are in Appendix D



#### Q13 How did you get to the initial appointment?

66 people (85%) got there by car. 11 people (14%) used public transport and 1 person used patient transport. Of the 66 people using a car 44 people (71%) said it was easy to park. 18 people (29%) answered no to this question.

Of the 18 people who said it was not easy to park, 2 of these said issues with parking had made them late for appointments. One person commented that there are not enough spaces.



### Q14 Could you use public transport if you needed to?

26 people (39%) said yes they could use public transport if needed. 31 people (46%) said No and 10 (15%) advised it was not applicable.

### Q15 If you used Patient Transport, were you picked up on time and returned within a reasonable time?

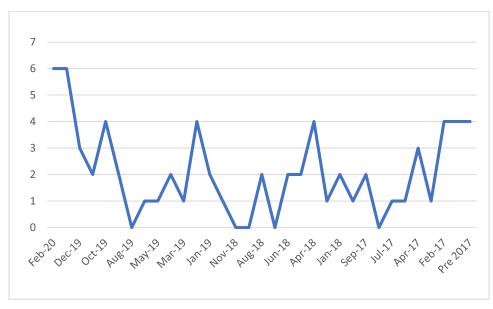
The one person who said they use Patient Transport in Q13 said yes, they were picked up on time and returned within a reasonable time.

5 other people also answered yes to this question. 10 people answered no.

### PART 2 - Questions About Treatment & Care

53 people advised they had started attending a clinic for support/treatment following their initial appointment

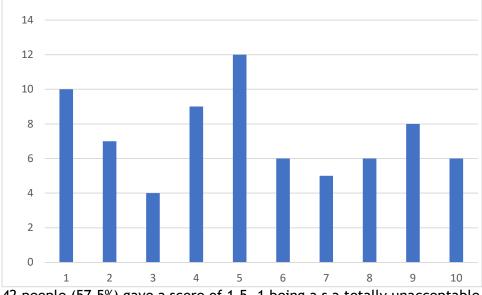
### Q16 When did your care/treatment start?



The graph above shows when people care/treatment started

Q17 How do you feel about the length of wait from first appointment/assessment to the plan of care/treatment starting.

On a scale of 1-10 where 1 is a totally unacceptable amount of time to wait to 10 being very prompt.



42 people (57.5%) gave a score of 1-5, 1 being a s a totally unacceptable amount of time to have to wait. 31 people (42.5%) gave a score of 6-10, 10 being a very prompt amount of time to be seen in.

Q18 Which part of the CAMHS services have	you been receiving treatment from?
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Service	Number	%
CAMHS City Outpatients	19	42.22
CAMHS County Outpatient	7	15.56
Young Peoples Team (YPT)	8	17.78
Eating Disorder Team (EDT)	0	0.00
Learning Disabilities Team (LDT)	1	2.22
Crisis	3	6.67
Group Work	0	0.00
Paediatric Psychology	7	15.56

Other services used by people answering the survey are listed below

- ADHD assessment team
- Family therapy
- Clinical psychologist and psychiatrist
- Physiotherapy

4 people said they use more than one service.

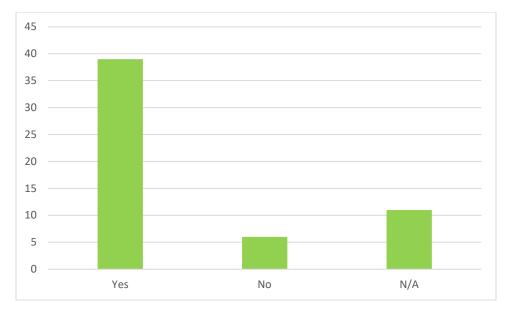
#### Q19 Does the care plan meet your needs?

60 people answered this question

- 12 people (20%) said no
- 40 people (67%) said yes
- 8 people (13%) said it was not applicable

Of the people who said the care plan does not meet their need the most common theme (4/12) was the wait in receiving their plan. One person who is happy with their plan said it had taken a year for the plan to be put together.

Full comments are listed in Appendix E.



#### Q20 Does the treatment you are receiving meet your needs?

45 people said this question was applicable to them. 39 people (87%) said that treatment meets their needs. 6 people (13%) said treatment does not meet their needs.

2 people who said the treatment does not meet their needs referred again to not having a care plan.

Other themes include: -

- Focus being on the parent and not the child
- Feeling they need more help but not "bad enough" to receive it
- Medication alone with no therapy

Full comments can be found in Appendix F

### Q21 Are you given any choice as to when your day and appointment time will be?

65 people answered this question.

- 32 people (49%) said No
- o 33 people (51%) said Yes

#### Q22 Are the days and appointment times suitable for you?

63 people answered this question.

- 32 people (51%) said no, it was not suitable
- 31 people (49%) said yes, it was suitable
- 0

#### Q23 Was the venue that you attended for your clinic appointment easy to get to?

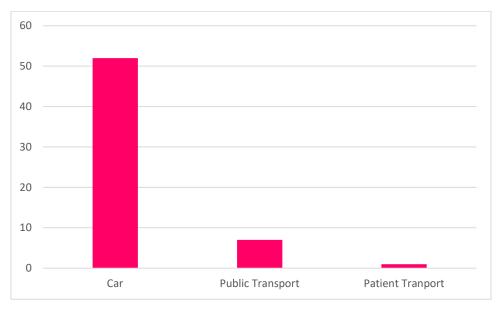
48 people (84%) said it was easy to get their clinic appointment.

9 people (16%) said no it was not easy

Reasons given for it not being easy were mainly because the clinic is too far away or public transport is not available. Full comments are in Appendix G.

### Q24 How did you get to your clinic appointment(s)?

52 people (87%) got there by car. 7 people (11.5%) used public transport and 1 person used patient transport.



For people using a car (52) 31 people (60%) said it was easy to park. 16 people (31%) said it was not easy to park.

Of the 16 people who said it was not easy to park, 1 person said issues with parking had made them late for appointments. 3 people commented that there is enough parking spaces.

#### Q25 Could you use public transport if you needed to?

25 people (50%) said yes, they could use public transport if needed. 22 people (44%) said No and 3 people (6%) advised it was not applicable.

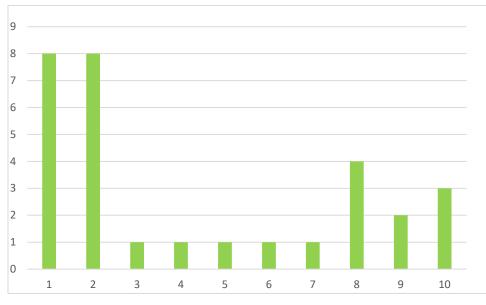
### Q26 If you used Patient Transport, were you picked up on time and returned within a reasonable time?

The one person who said they use Patient Transport in Q24 said yes, they were picked up on time and returned within a reasonable time.

1 other person also answered yes to this question. 5 people answered no.

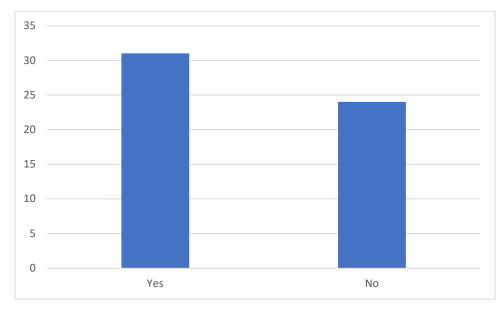
### Q27 How do you feel about the length of wait from first appointment/assessment to the plan of care/treatment starting?

On a scale of 1-10 where 1 is a totally unacceptable amount of time to wait to 10 being very prompt.



19 people (63%) gave a score of between 1 and 5 with 8 people (26.5%) advising it was a totally unacceptable amount of from their first appointment/assessment to the plan of care/assessment starting.

11 people (37%) gave a score of between 6 and 10 with 3 people (10%) advising it was very prompt from their first appointment/assessment to the plan of care/assessment starting.



Q28 Did the length of time waiting for treatment to start after you had your initial assessment have any impact on you?

50 people answered this question. 31 people (56%) said yes, it had an impact on them. 24 people (44%) said it didn't have an impact on them.

If the length of time waiting for treatment/plan of care impacted people, we asked people what this had been.

28 people left additional comments. The main themes were: -

- Worsened mental health (11 people 39%)
- Used private counselling whilst waiting (3 people 11%)
- Negative impacts to the wider family (2 people 7%)

1 person told us that whilst waiting they had made suicide attempts waiting for their treatment/plan of care to begin.

All comments have been included in Appendix H.

### Q29 Whilst waiting for your clinic appointments to start were you offered/signposted to any other type of support/care?

63 people answered this question.

- 21 people (33%) said yes
- 42 people (67%) said no

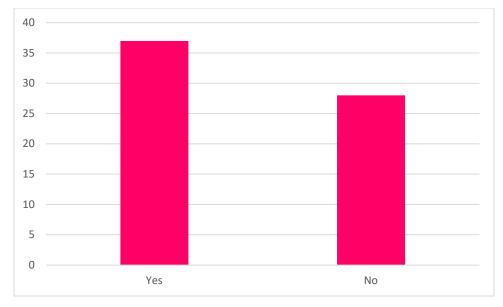
Q30 Would you know what to do if you had a concern or worry about your care within CAHMS?

64 people answered this question.

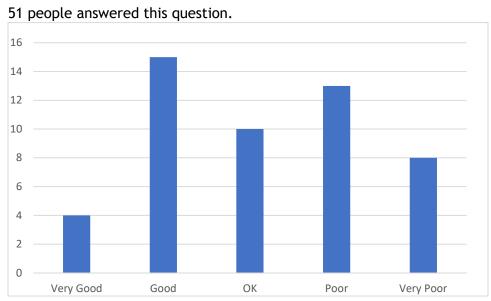
- $\circ$  34 people (53%) said yes
- $\circ$  30 people (47%) said no

### Q31 Would you know what to do if you wanted to make a complaint?

65 people answered this question.



37 people (57%) said yes they would. 28 (43%) people said no they wouldn't.



Q32 Overall, how satisfied are you with the service from CAMHS LPT?

19 people (38%) advised they thought overall the service was good or very good. 21 people (42%) advised they thought the service was poor or very poor. 10 people (20%) said it was OK.

### Conclusion

The survey illustrates that 62% of people are seen for their first appointment/assessment with 3 months of being referred. A small minority are still waiting a long time. This does appear to be historic, with the most people waiting 6 months or longer, having been referred before 2018.

Signposting and being given other places of support during the time people are waiting for their first assessment needs to be improved. 52% of people said they had not received any at all and 13.5% of people said they found the resources unhelpful. There is a lack communication between services and patients and carers, including information on wait times for assessment and treatment

Most people still feel it is too long to wait between being referred and their first appointment. 57% of people scored this wait time between 1 and 5 with 1 being a totally unacceptable time to wait. It is clear that the additional resources that have been put into place to bring the wait times down has been noticed by people using the service, however in spite of this investment, the majority of people feel that the wait time for assessment is too long. If additional high-quality signposting and support services were put in place, it could help to manage what patients and carers are going through, helping to make them feel supported.

The initial appointment was is a positive experience for a lot of people with 71% saying they felt listened to. We also received some positive comments relating to CAMHS staff and professionals. 72.5% of people also said they felt they knew what was going to happen next after the initial appointment.

This then seems overshadowed by the time treatment or a plan of care is started. 2 people who said the care plan didn't meet their needs specifically said this was due to the delay in the plan being started. All other issues with treatment or care plans were individual with no common themes.

The delay in treatment and care plans starting is having a detrimental effect on people using the service. 39% of people said they felt the delay added to existing mental health conditions. Increased depression and anxiety were particularly mentioned. One-person attempted suicide during this period. The impact to family was also mentioned by 2 people, one citing the wait causing a parent's mental health issue. Care plans need to be put in place in a timely fashion to ensure the patients and carers needs are supported from the very start.

Once begun, results show that treatment/plans of care do meet people's needs, confirmed by 87% of people. Care plans, overall, seem to be viewed positively. The majority (77%) of people with a care said it met their needs and 68% of people felt involved in the plan. This does mean that there is opportunity to further improve the personalisation of care plans to ensure that services better meet the needs of patients and their carers.

Most people said the venues for appointments and how easy they are to get to were positive with only 1 person saying issues with parking had made them late for an appointment. However, only 39

per cent of respondents felt able to use public transport is they needed to. The reasons behind this need to be explored further with patients and carers.

Information around what to do if anyone has a concern about their experience of CAMHS or what to do if someone wanted to raise a complaint looks like it could be improved. 67% of people said they would not know what to do if they had a concern and 43% said they would know how to raise a complaint. The process for complaining and ensuring that people know what support is available including through third parties, including mental health charities and POWHER, and the corporate complaints needs to be publicised more widely, including on the back of appointment letters or on posters in waiting areas.

Based on what people find acceptable, the survey does corroborate feedback Healthwatch received that delays have moved from referral/first appointment to first appointment/treatment or care plan beginning. More people (26.5%) found the wait between first appointment and starting treatment or a care plan totally unacceptable compared to 16% saying it was totally unacceptable between referral and first appointment. More people (63%) also gave the wait time a low score between 1 and 5 for time between first appointment to treatment/care plan compared to 57% giving a low score between 1 and 5 for the time between referral. There needs to be open, transparent, and regular communication about all the waiting times between service, patients and carer.

Overall people feel listened to once they have been engaged with CAHMS. They know what will happen next and feel the treatment or care plan meets their needs. If delays between being referred and a first appointment and treatment/care plan beginning could be improved and signposting for support during this would greatly enhance the service people receive from CAMHS. To help patients and carers have confidence in the service provided, it is important that the service makes them aware of the things that the service does well.

### Recommendations

These recommendations on the information and evidence gathered:

- Reduce waiting times between referral/ first appointment and treatment/care plan beginning concentrating on the time between first appointment and treatment/care plan beginning.
- Improve and ensure that there is regular communication between services, patients and carers to help set expectations by making patients and carers aware of waiting times for assessment and treatment and that after initial assessment, there is agreement between everyone about what happens next.
- Ensure that care plans are personalised to the specific needs of patients and their carers and ensure that they are put together in a timely fashion.
- Proactively publicise the ways in which patients and carers can make complaints or raise concerns about the service through internal and external processes.
- More useful signposting and making sure everyone is made aware of support services they can use whilst waiting should be considered and there is a need to ensure that it is a good quality and personalised offer. This would lessen the negative impact of long waiting times for people using the service.

- Champion and celebrate the things that CAHMS do well to help build patient and carer confidence and trust in the service.
- Unpick the reasons why patients and carers using CAHMS do not use public transport and provide support to enable patients and carers to use public transport.
- Further investigation could be carried out concentrating on CAHMS and Black and Ethnic Minority service users (BAME). 82% of people who completed the survey identified as white British. The investigation could focus on if this is representative of people using the CAMHS service and if there are any specific issues facing BAME communities when trying to access the service. (Due to lockdown, this is not something that we have been able to pursue further).
- Focus group and one to one interviews could also be considered as a way of building on the findings of this report.

### Next steps!

This report will be made publicly available through various channels including our website and social media to ensure that there is openness and transparency around the report findings and recommendations.

Once this report has been signed off the Board of Healthwatch Leicester and Healthwatch Leicestershire, then this report will be sent to the Executive Team and Board of the Leicestershire Partnership NHS Trust, service commissioners (including the Clinical Commissioning Group), the mental health and children young people delivery boards for Leicester and Leicestershire and other relevant partners who will be asked to give formal consideration of the report and how the recommendations could be implemented. The Board of Healthwatch will ask for a full response to the report from these bodies and will review the response in at a Healthwatch Board meeting. Through our Board lead for Mental Health and our Board lead for Children and Young People and the relevant Healthwatch staff support lead to keep under review the implementation of the review are truly listened to and to help ensure that this report leads to service improvements for patients and their carers. Where we have the contact information of those who took part in the survey and permission to make contact, we will update them on the outcomes of this review.

The report will be shared the commissioners of this report, with local authority lead members, the City and County Health and Wellbeing Boards and relevant Overview and Scrutiny Committees, the Youth Advisory Board of LPT and other relevant boards and committees, who may want to look into specific areas in further detail. We will be ready to help them in whatever we can.

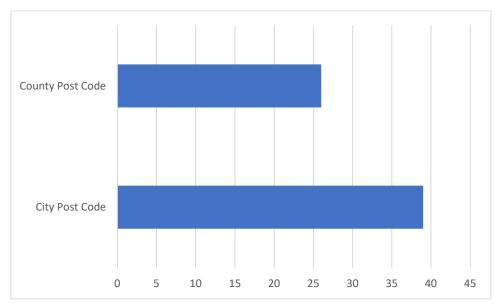
### Thank You!

Healthwatch Leicester and Healthwatch Leicestershire would like to thank all the participants who helped with this project. Without you this project would not have been possible.

### Appendixes

### Appendix A - Demographic Information

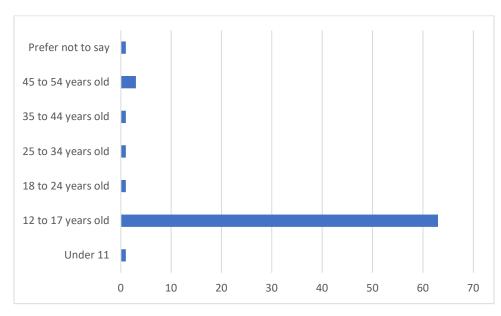
All demographic information that was completed is captured below. Some participants chose not to complete this section.



### 1. What is the first part of your postcode?

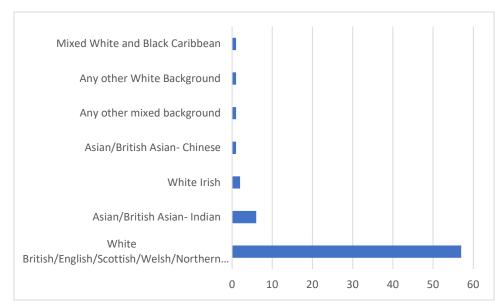
Based on postcodes, 60% of respondents were from Leicester City and 40% from Leicester County.

2. What age group are you in?



64 people who completed the survey and age group information were under the age of 17. As we wanted to capture the experiences of young people this show that we targeted the correct age group.

The survey didn't ask if it was being completed by a parent or carer. It could be that the older age groups are parents, but we can't be certain.



#### 3. What ethnic background do you identify as?

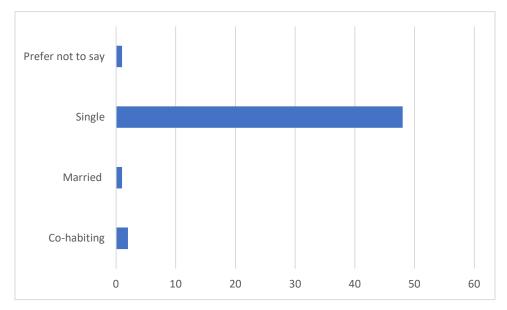
82% of people who completed the survey identified as white British. More needs to be done to look into the experience of Black and Minority Ethnic (BAME) within CAHMS. Investigations should also look into this majority and see if it is representative of people using the CAMHS and if so why more BAME are not being referred to the service.

Sikh Prefer not to say Any other religion or belief Hindu Hindu Muslim Christian Christian 0 5 10 15 20 25 30

### 4. What is your religion or belief?

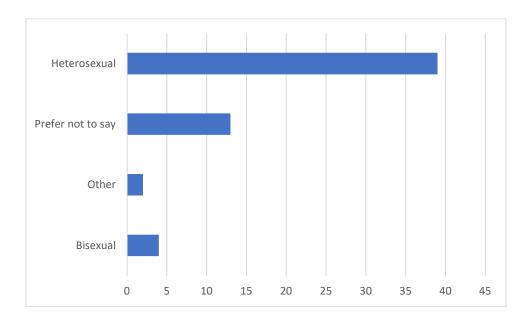
#### 5. What is your marital status?

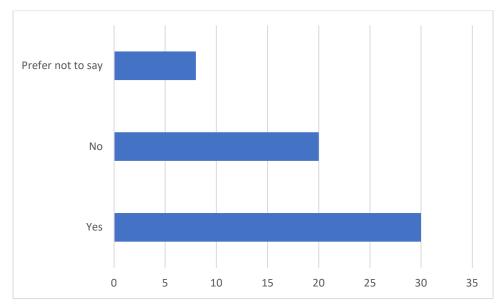
As this survey concentrated on young people and adolescents, we can't draw any conclusions from this information but it is included for your information.



#### 6. What is your sexual orientation?







7. Do you consider yourself to have a disability or long-term condition?

- o 20 people (35%) said no
- 30 people (52%) said yes
- 8 people (14%) preferred not to say

### Appendix B - all comments for question 10

If you did not feel involved in your care plan, please tell us why.

- o It was given to us rather than any discussion
- No one asked me about what I wanted
- As nothing was done on first appointment
- I didn't get one
- Not aware of care plan
- Because I wasn't myself, I didn't get the night care
- Can't remember a plan of action even though I remember seeing the care plan
- Care plan only issued after overdose
- Talked about it
- $\circ$  Still unsure what is happening seems to be little progress. We have been waiting for months to med
- Wasn't very good they didn't tell me anything
- As I wasn't consulted

### Appendix C- all comments for question 11

Do you have any additional comments or suggestions to make regarding your involvement with your care plan and the CAMHS professionals you have been involved with?

- $\circ~$  I don't mind that the care plan was given to us as CAMHS are professionals and knew what was needed
- $\circ~$  Plans more narrative of meeting and very basic plan. No real support more parent/carer to do
- Hanna is great for my daughter it's a very long process for help
- More updates when waiting & interim appointments felt like I was just left waiting -would be useful
- Very supportive to my son and his needs Dr Smith is very understanding
- I don't feel XXXX was has been well assessed. He had been discharged which should not have happened
- Asked for my view but didn't listen and wasn't time. Follow up tried to tell them I was feeling low
- I was seen very quickly which is good
- $\circ$  Lack of organisation, lost letters has made this all drag out too long
- Everything is good
- Very long waiting times for psychiatrist
- Having 3 children need going CAMHS it still a learning curve but staff are really helpful
- The first crisis nurse didn't seem to listen seemed to have already decided b4 the meeting
- Can the child choose the male/female. Maybe a home visit. Desperate people in need of help
- Process for ADHD should have started sooner
- They were very keen to pigeonhole my son. Had to fight to get complex needs considered
- MHP need to listen more, does not read my child's notes when is holding up the process
- When my son was first seen by CAMHS they spend 5 mins with him and said nothing about the diagnosis
- Need to see Dr more often and therapy /counselling
- Please try and ensure continuity of care, so don't have to explain detailed stuff every appt
- Seems very woolly. Unsure what progress is being made. Fully understand the need for patient
- Quicker response time for care plan to be sent out
- $\circ$  The wait was too long but once accessed the service was very good
- Very nice understanding man
- There should be more 24/7 online chats as Kooth and ChildLine are good but can't help all the time
- Greater face to face contact needed. All except 1st assessment done over the phone
- When you need the services urgently, like we did, there is a long waiting period but no help or support
- $\circ$  After being transferred to another physic things were much better
- Try getting the opinions of the child
- I made official complaint against child's lead worker in Nov 19 and I am still waiting
- $\circ~$  It would have been nice to have the next steps written down-due to wait between appointments was
- Referred by eating disorder team, always rec'd huge amount of valuable support

### Appendix D- all comments for question 12

#### All comments on why people find it difficult to get to their first appointment

- But only because I got a lift
- We had to get train and then taxi
- Leicester is either a 60-mile round trip or 36-mile round trip depending on route and traffic
- It was not near my house
- $\circ$  Taxi or 2 bus trips to and from
- Taxi or 2 bus trips her and back (4 bus trips)
- o I did get lost at Valentine Centre no signposts
- Need to get taxi and 2 buses
- Volume transport tricky
- Other side of city
- Just a long way
- We live in Loughborough
- But a long way to travel to
- o I don't drive, I'm disabled and struggle to walk

### Appendix E - all comments for question 19

#### If your care plan does not meet your needs please tell us why?

- Since diagnosis no real plan/intervention
- $\circ$  Need more intervention
- $\circ$  No support / extra diagnosis
- See previous comments
- $\circ~$  Other problems remain, only med is for ADHD not enough, other problems glaced over
- o Still waiting
- $\circ$  We are still waiting for a proper care plan
- It does now after 1 year and 3 assessments
- $\circ~$  He is on the waiting list for other treatments but the treatment at the moment is helping partially
- Can't get to speak to crisis without GP/MHP referral
- Sometimes
- $\circ$  Seems to be a little progress no meds prescribed for months
- No recent plan received
- $\circ$   $\,$  No as no one sticks to it
- $\circ$   $\,$  We have now been referred to a new worker and psychiatrist
- 00 Unsure as first appointment today

### Appendix F- all comments for question 20

### If the treatment does not meet your needs, please tell us why?

- Since diagnosis no real plan/intervention
- No pd help
- $\circ$   $\;$  We are still waiting for a proper care plan  $\;$
- Difficult to say at this time
- Now it does
- Need more help but apparently my is not 'bad' enough despite taking an overdose
- Only medication at the moment no therapy
- Focus on me and not on child
- Unsure as first appointment today

### Appendix G - all comments for question 23

### If it wasn't easy to get to your clinic appointment, please tell us why

- o Easy
- Westcotes good as walk in but Beaumont leys not had to use taxi
- Its 30-minute drive from my house
- o I don't drive can't get from Oakham
- 45min to 1hour as travel from other side of Leicestershire
- o No busses
- 40 minutes away by car

### Appendix H- all comments for question 28

### Did the length of time waiting for treatment to start after you had your initial assessment have any impact on you? If yes please explain how.

- Caused extra strain on family
- Don't / didn't know what to do as not diagnosed
- Waited years for paediatrician and diagnosis and now still unsure off diagnosis
- Yes, my daughter struggled and felt let down
- Huge because its mental health
- Once assessed the sooner you can start getting better
- o Better now only because I fought for his care
- Anxiety kicked in
- I was doing A-levels
- My child hasn't received the care she has needs

- $\circ$  Possibly but other services (social care) were delayed also
- $\circ$   $\;$  As daughter was not settled the uncertainty of what's next  $\;$
- o Increased mental health problems
- Private counselling was used
- Made my condition worse
- o Got worse
- o Son has anxiety disorder the anxiety got worse
- Yes, I had to pay for private counselling
- Anxiety got worse
- $\circ$  A long time
- Many days lost at school father depressed as a result
- Had to get private counselling
- No support, no assistance: anxiety, depression and abandoned
- Suicide attempts while waiting for support
- Quick referral
- $\circ$  No knowledge or information on how to deal with things
- Made my child's mental health worse
- More anxious

#### **End of Appendixes**

# **Contact us** <sup>50</sup>

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