



Rejected Referrals Child and Adolescent Mental Health Services (CAMHS)

A qualitative and quantitative audit



Scottish Government
Riaghaltas na h-Alba
gov.scot

Background

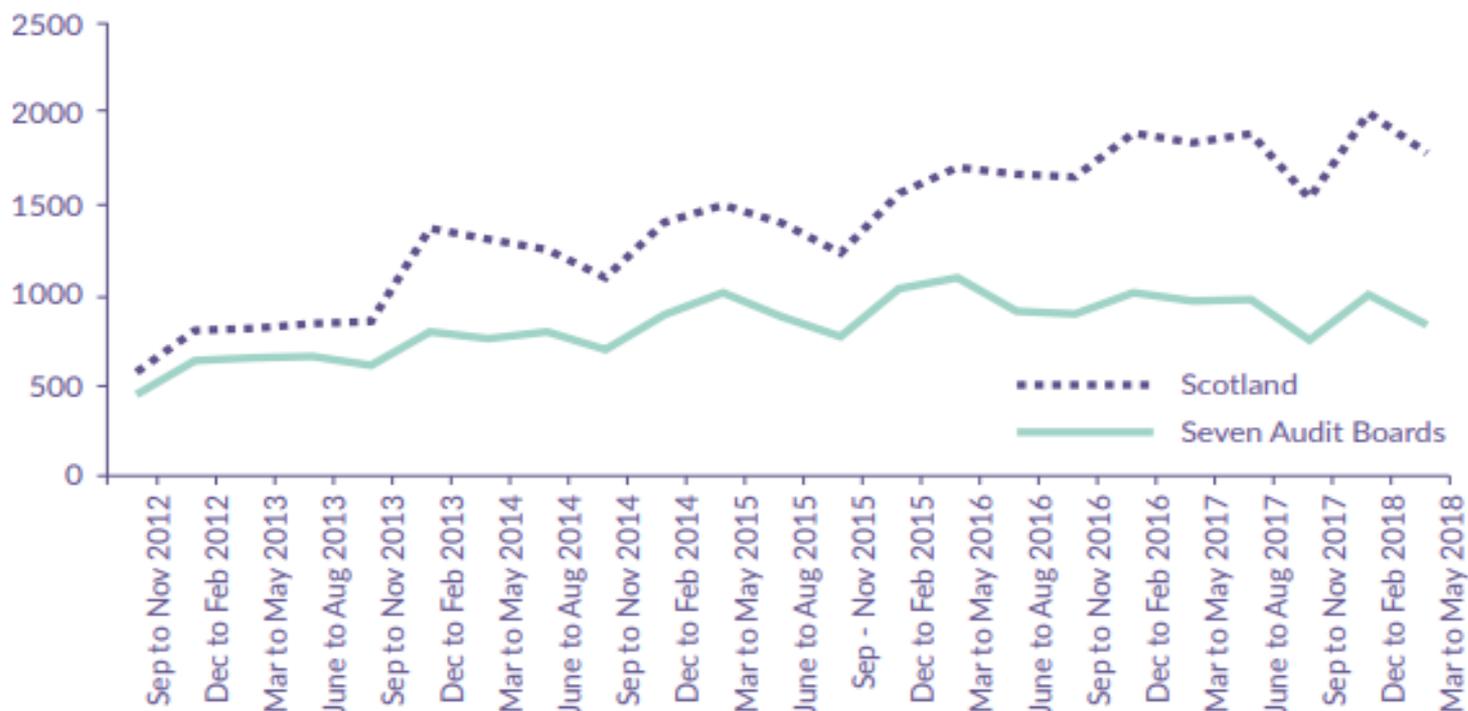
The NHS provides mental health services for children and young people through CAMHS.

CAMHS is structured in a **tiered framework**:

- Tier 1 (universal services): GPs, schools and social services
- Tiers 2, 3 and 4: Specialist CAMHS services

Background

- Referrals to CAMHS have been **rising** since 2012



Number of CAMHS rejected referrals by quarter

Source: ISD CAMHS Waiting Times

- Rejected referrals have remained **stable at 1 in 5**

Background

Research commissioned in fulfillment of the first half of Action 18 of the Mental Health Strategy 2017-27:

“Commission an **audit of CAMHS rejected referrals, and act upon its findings.”**

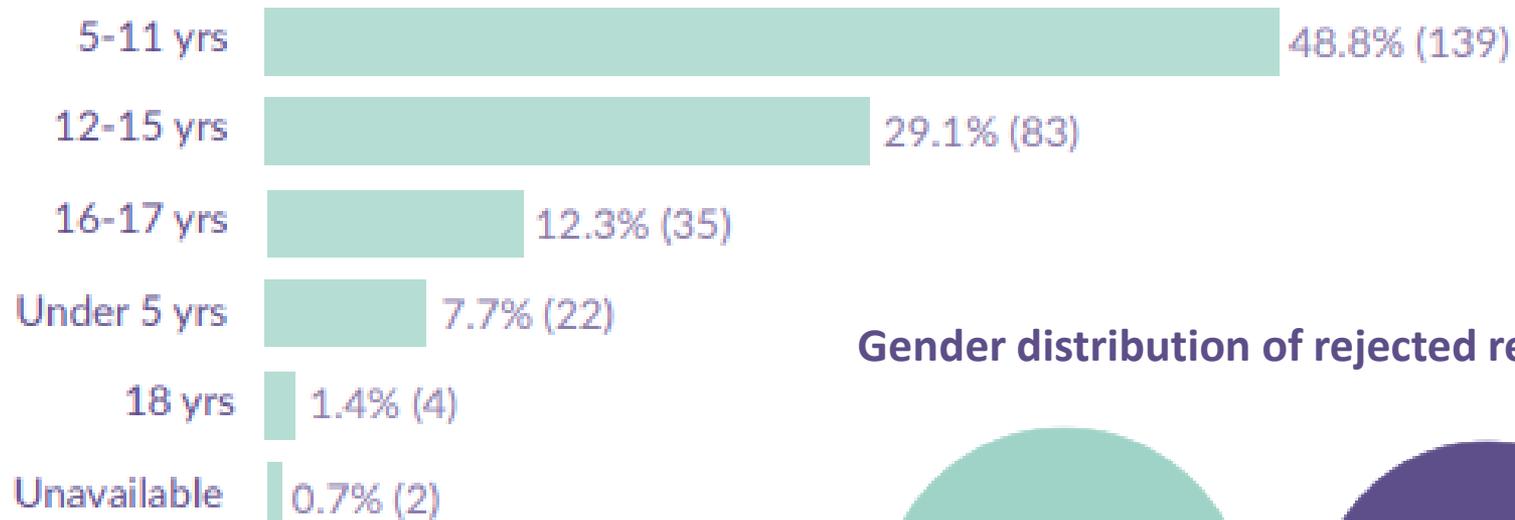
SAMH	ISD Scotland
SAMH carried out the qualitative research; speaking to 363 children, young people and their families.	ISD Scotland undertook the quantitative research; analysing data collected by seven Health Boards over February 2017.

Methodology – Quantitative

Data Sources	Data Collection	Analysis
<ul style="list-style-type: none">• All 14 NHS Health Boards were invited to participate• Seven did: NHS Ayrshire & Arran, NHS Borders, NHS Dumfries & Galloway, NHS Fife, NHS Forth Valley, NHS Greater Glasgow & Clyde, NHS Highland	<ul style="list-style-type: none">• Audit Boards were asked to collect data on any Tier 2, 3 or 4 CAMHS referral for a child or young person under the age of 18 received during 1 to 28 February 2018 where the referral was rejected.• Each Audit Board was provided with a specific list of data items to be collected for the audit and these consisted of data items that NHS Boards routinely collect about each patient.	<ul style="list-style-type: none">• The Audit Boards then provided this data to ISD, where the referral to CAMHS had been rejected.• The data was then analysed.

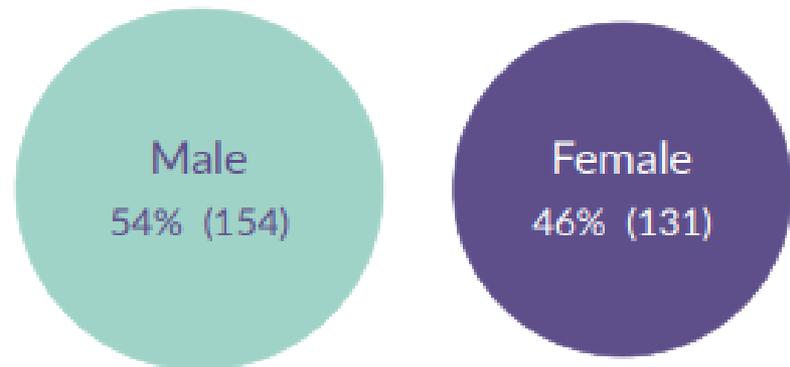
Methodology – Quantitative

Age of children and young people who received a rejected referral



Source: ISD CAMHS Rejected Referrals Audit

Gender distribution of rejected referrals



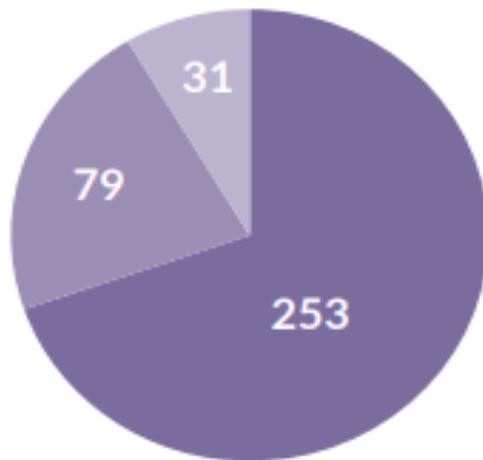
Source: ISD CAMHS Rejected Referrals Audit

Methodology – Qualitative

Screening survey	Contact made with all eligible participants	Group sessions	Telephone depth interviews	Semi-structured online survey
<ul style="list-style-type: none"> • Short online survey designed to create awareness and check eligibility for participation • Distributed to SAMH supporter database, a range of stakeholders and partners, and promoted via social media channels • Captured details of potential participants for follow-up research • 540 parents / family members / young people responded - 304 were eligible and willing to take part • 106 teachers and GPs also registered interest 	<ul style="list-style-type: none"> • Invited to participate in group discussion sessions in central locations • Telephone interviews offered to those living in outlying geographical locations 	<ul style="list-style-type: none"> • Group sessions held in Edinburgh and Glasgow • Topic guide designed to cover key aspects of referral journey • Attendance issues prompted rethink on methodology • Stirling groups went ahead in April • A total of 31 participated in group sessions across 4 dates in Edinburgh, Glasgow & Stirling 	<ul style="list-style-type: none"> • Telephone depth interviews offered more widely to those registered in screening survey • Greatest uptake amongst parents / carers • Consistent topic guide used to allow for consistent analysis • A total of 79 participated in a telephone depth interview 	<ul style="list-style-type: none"> • Semi-structured questionnaire designed to widen participation • Online survey promoted via partners and social media • Specifically targeted young people to increase numbers represented within overall sample • A total of 253 completed responses were received

Methodology – Qualitative

Profile of responses to qualitative research by method used



363 Cases

Method of Response

- Survey
- Depth interview
- Group discussion

	Survey	Depth interview	Group discussion	Total
Young person	87	5	3	95
Parent /carer	166	73	28	267
Sibling	0	1	0	1

Source: SAMH

Findings: being referred

Experiences prior to seeking CAMHS help

CAMHS is rarely the first port of call. In most cases, before a referral to CAMHS is considered there has been an escalation of issues to a **debilitating degree**.

“He was highly, highly stressed at school...the school weren't really aware, and that resulted in him refusing to go to school.”

“She was self-harming, scratching herself and drawing blood with fingernails. She's got scars all over her body from doing this. She was displaying OCD behaviours, light switches on, off, on, off all the time.”

“I was struggling with anxiety, I was having panic attacks every single day and self-harming, and then that's when I got referred to CAMHS the first time.”

Findings: being referred

Children, young people and their families' expectations pre-referral

- Main expectation at referral stage is that the child or young person **will get help from CAMHS**.

“I was hoping I could see a counsellor just to sort of talk through what I was worried about.”

“I didn't actually know that much about CAMHS, I hadn't ever heard of it before, so I really went in with no expectation.... I was just hoping that they'd help me.”

“We thought people were going to intervene, people were going to actually help us.”

Findings: being referred

Referral criteria

Reviewing the criteria documents showed that there is some consistency in the written criteria amongst the Audit Boards however; some do provide more detail than others.

Common referral acceptance criteria included:

- Age
- Consent
- Severity of Condition
- Geographical Criteria
- Referral Pathways
- CAMHS Waiting Times Definition

Findings: being referred

Reasons for referral from the quantitative element of the audit



Findings: being referred

Reason for referral, collected during qualitative element of the audit

Reasons for referral	
Anxiety	146
Low mood/ depression	87
Self-harm	67
Suicidal ideation	54
Other	52
Behaviour problems	47
Anger issues	41
ASD assessment	31
ASD / Autism / Aspergers	25
Eating disorder / eating problems	17
Sleep problems	15
ADHD	15
N/A	11

Note: it was possible to mention more than one reason

Source: SAMH CAMHS Rejected Referral Audit

Findings: being referred

Information given at point of referral

The information given at referral varied widely

- 29% of respondents to the online survey were given an idea of timescales at the point of referral.
- Some gave resources for use by parent and or young person whilst waiting for assessment
- Some expressed a lack of confidence that the referral will be accepted

“We were told that our referral would probably be rejected due to our daughters young age.”

- Some were given **no information at all**

Findings: being referred

Key Findings

- Substantial variation was found between the **reasons for referral** noted by NHS Boards and the reasons given by children, young people and their families.
- The qualitative element found parents and young people **lack understanding** of the referral process.
- When a referral is submitted, the **widespread expectation is help** and not being the referral being rejected.
- Many receive a rejection letter **quickly and feel angry, aggrieved, cheated and let down** due to a feeling that no proper assessment process has been undertaken.
- The **lack of alternatives** to CAMHS for children and young people was frequently mentioned

Findings: being referred

Participants' suggestions for Improvement

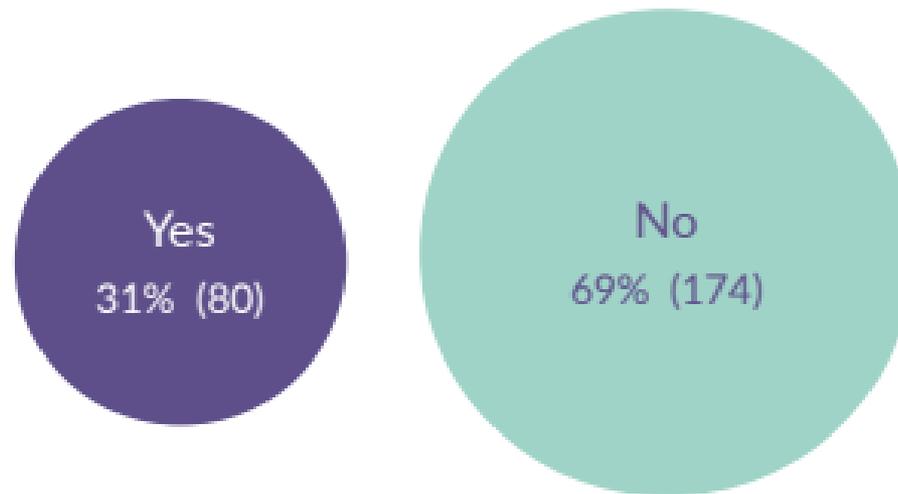
Parents and young people told us they wanted:

- More **clarity** on the requirements for being accepted to CAMHS
- More **information** to be submitted prior to the referral
- More thought about the **transition** process between CAMHS and adult services
- A potential “**fast track**” referral process for children and young people who are looked after, adopted or at risk
- Suggestions of **how to help** and **signposting** to websites, third sector organisations and other resources at the point of referral

Findings: being assessed

Most rejections are made on the basis of the written referral with **less than a third** having an assessment meeting.

Invited to assessment meeting with CAMHS



Source: SAMH

Findings: being assessed

There is **inconsistency** in terms of waiting times for an assessment, who attends and what information is given about what will happen next.

- Some waited months whilst others were assessed quickly

“First time it was two weeks, I think. Second time, rejected. Third time, rejected. Fourth time, it was a week but that was an emergency referral because I tried to commit suicide in school so that was an immediate referral.”

- Long waits had a negative effect

“You kind of just forget that it’s done because you don’t hear from them for so long, at first you’re like it’s a bit better because you know you’ve done something to try and get help but because it takes so long, that initial period is a bit more relief knowing that you’ve done something that’s going to maybe get you help, it kind of just goes away and you just go back to feeling as rubbish before, you kind of just feel forgotten.”

Findings: being assessed

We found an **inconsistent approach** regarding whether both the young person and the parent were at the assessment, or they were seen separately.

“We were in the same room which made it very difficult to speak openly in front of my daughter and so I requested a time to meet them separately but it was declined.”

“My son was observed in a different room while I had the opportunity to speak to the clinical psychologist.”

Findings: being assessed

Parents and young people told us they didn't feel **listened to** during the assessment.

"I just felt that they didn't want to listen to what I had to say."

For young people in particular the assessment process can be very **difficult** and quite **traumatic**.

"I told them all about my life and what's gone wrong in it, I didn't get to explain everything and it was a really difficult experience, having to retell everything wrong about my life."

I had self-harmed the night before the visit, as well as had been trying to kill myself at this point but could not bring myself to it. I told this to the person, as well as the fact I had a day in my head to try again. At the end of the session, they told me they could not help me for the **THIRD** time."

Findings: being assessed

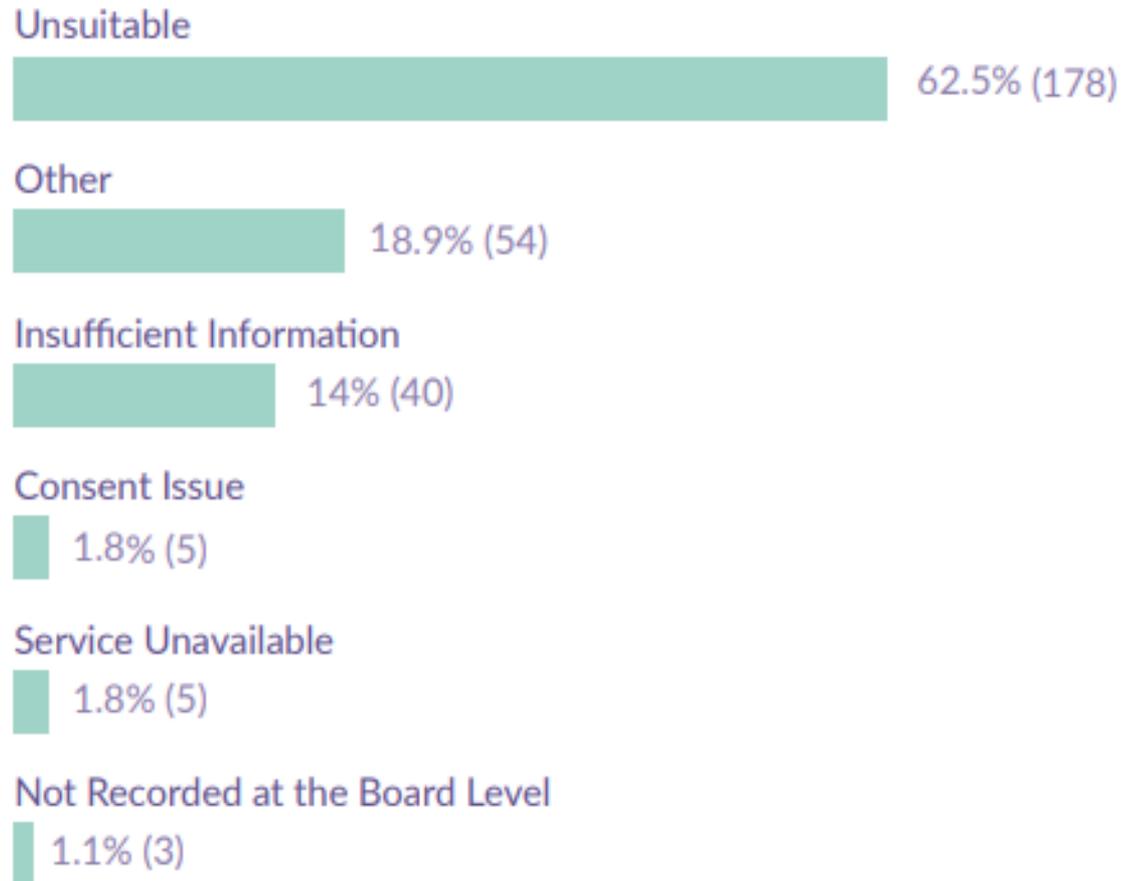
Key Findings

- Most rejections are made on the basis of the written referral and in more than **two-thirds of cases**, no assessment meeting was held.
- Assessments are **inconsistent** in terms of the time taken between referral and assessment, who attends the assessment and what information is given about what will happen next.
- Young people find the assessment **difficult** and many leave feeling that they have **not been properly listened to**.

Findings: being rejected

Reasons for rejecting the referral

Audit Boards rejected **three in five** referrals as they were deemed unsuitable.

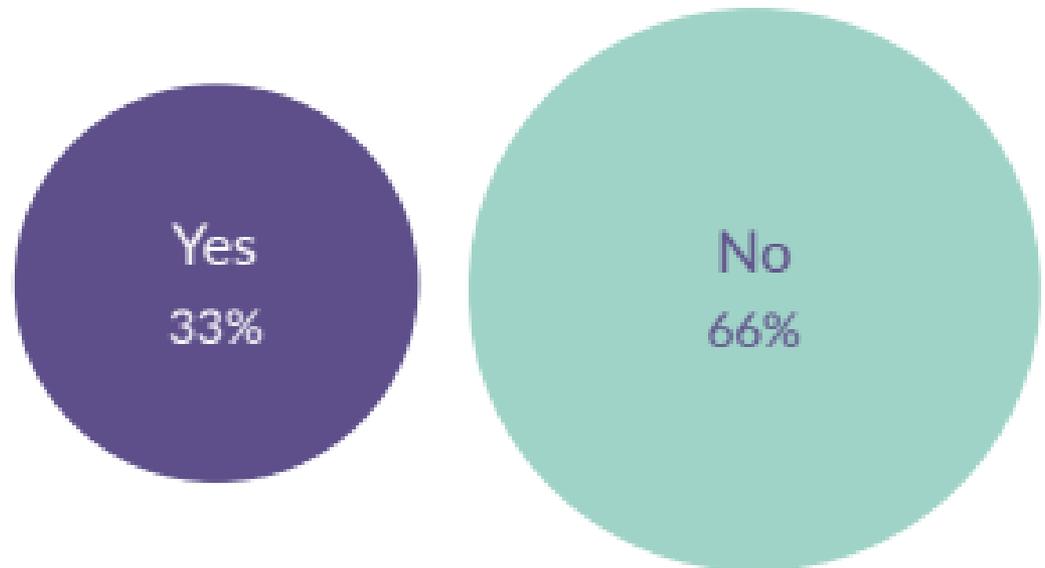


Source: ISD CAMHS Rejected Referrals Audit

Findings: being rejected

There was widespread belief that the reasons given for rejection are either inadequate or unjustified with people often **not understanding** why the referral was rejected.

Understanding of the reasons given for rejection



Source: SAMH CAMHS Rejected Referrals Audit

Findings: being rejected

The most common reason cited by young people for their referral being rejected is that their case was **not serious enough**.

“They said that he doesn’t have an eating disorder, he hasn’t committed suicide or tried to commit suicide.”

“I remember a bit from the letter that says that my daughter didn’t have a mental health problem.”

Some had their referral rejected on the basis that they did not have a mental health problem

Findings: being rejected

Failure to meet the referral criteria was another reason given for rejecting referrals

“They literally said, ‘She doesn’t meet the criteria’”

Some referrals were rejected for being ‘inappropriate’ this was mentioned in cases where children or young people had been sexually abused or assaulted.

“I got a letter through the door basically saying it was an inappropriate referral and that I was to be referred to Sleep Scotland.”

“CAMHS say, ‘No, it’s not an appropriate referral for us so go and see social work’, and then social work are getting inundated with things and, to be honest, it’s not their area of expertise either.”

Findings: being rejected

Some people were given **no explanation** for why the referral had been rejected:

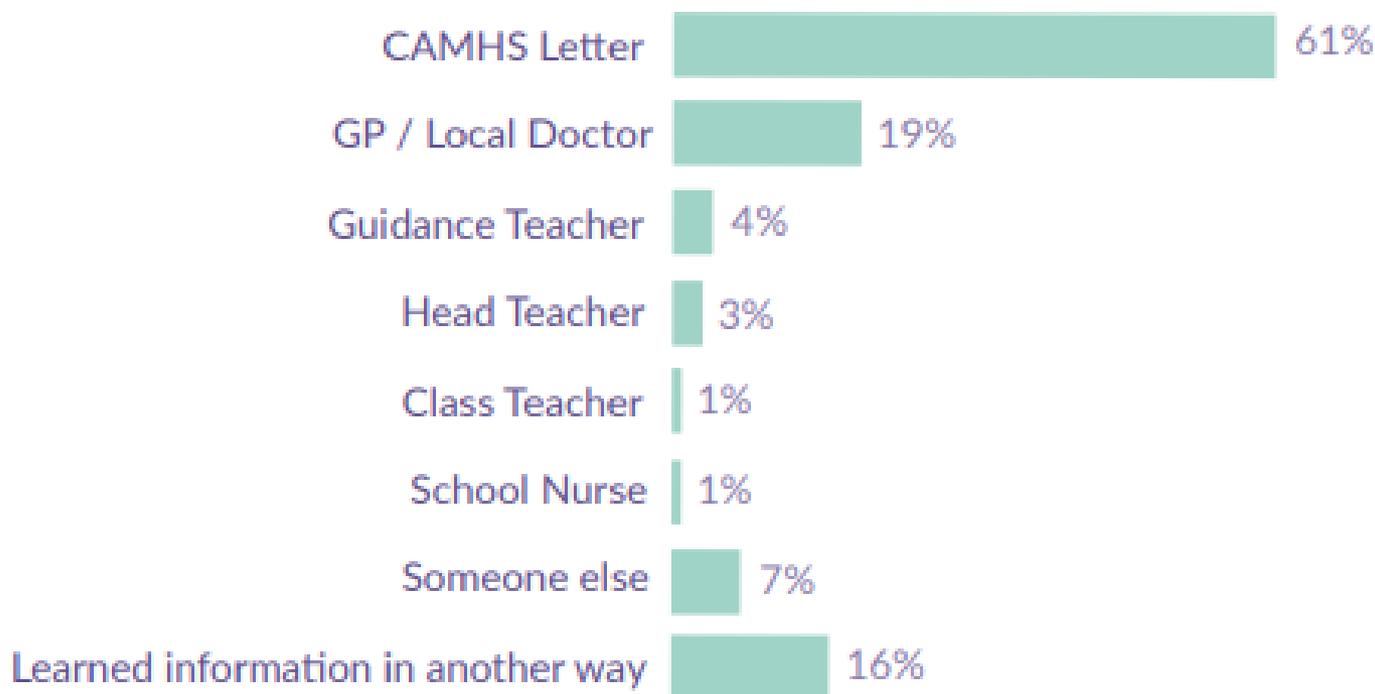
“It didn’t have any information about why they were rejecting it, it didn’t have any advice, it didn’t have a contact number, nothing, it just said “We’re rejecting the referral, go back and speak to your GP.”

Others did not hear back at all.

“It wasn’t technically rejected, we just didn’t hear anything back.”

Findings: being rejected

Who communicated the rejected referral from CAMHS, collected from participants of the online survey



Source: SAMH CAMHS Rejected Referral Audit

Findings: being rejected

How are rejected referrals are communicated?

Some were told at the end of their assessment:

“He [my child] spoke with her for about 15 minutes, then I was called in to the room and told he wasn’t severe enough and no further appointments would be offered.”

Others had to wait, before receiving a letter from CAMHS or contacting them themselves:

“I got a letter through the door, as I say very quickly, and the letter basically said along the lines of we’ve had a referral from your GP, we’ve discussed it and we won’t see him.”

“I phoned CAMHS and they said, ‘Oh, oh no, she never met the criteria, did the GP not tell you?’”

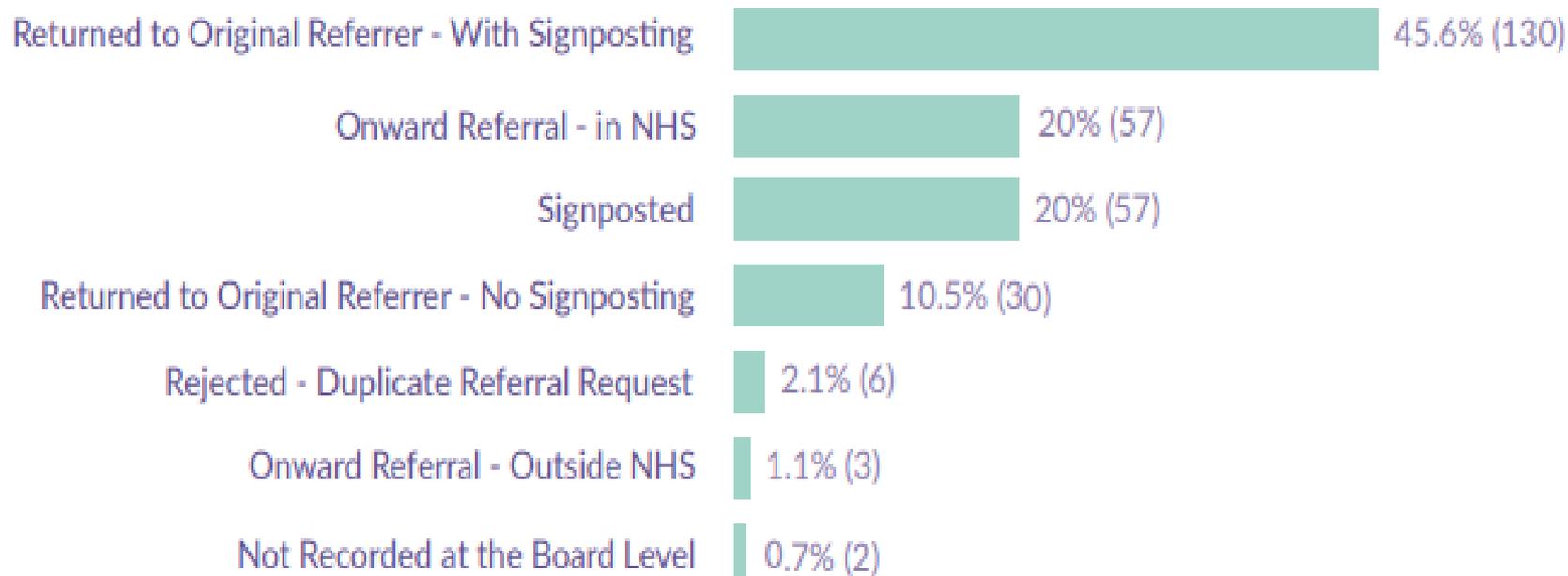
Findings: being rejected

We heard instances, where the referrer had been notified but failed to pass this information to the young person or family: leaving them falsely believing they were still in the system, waiting to be seen.

“Well when I got rejected I was waiting... I waited all summer for an appointment because I already knew that they sent your appointment in the post so I was waiting all the time, all the time and then it got about one month, because I’m not very patient, so I phoned up the GP and was like, ‘I’ve still not heard anything back’, and it was then the GP said, ‘CAMHS rejected your referral’, and then I was heartbroken, so heartbroken because I was like I’m never going to get help.”

Findings: being rejected

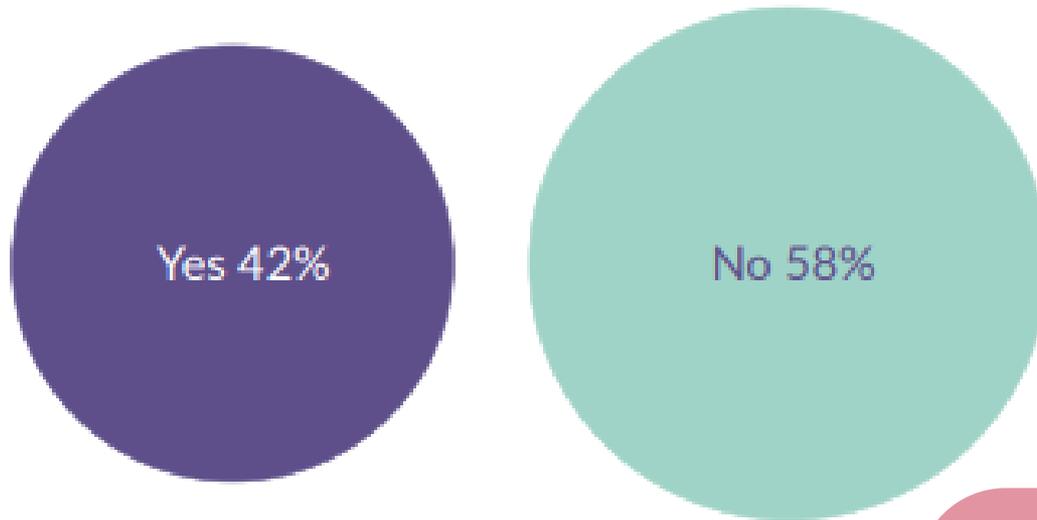
Actions taken by CAMHS following the rejection of a referral



Source: ISD CAMHS Rejected Referrals Audit

Findings: being rejected

Were people signposted to another service or resource?



Source: SAMH CAMHS Rejected Referral Audit

“She [CAMHS nurse] gave me the website Moodjuice...and basically for any other thing like helplines she said I would have to go back to my doctor and speak to them, because she didn’t know.”

“The only thing they suggested, and to put it really bluntly and to look back, it was a load of bollocks, it was just links to websites... I did visit the websites, and they were like generic, top 10 tips to deal with anxiety.”

Findings: being rejected

What people did next



Source: SAMH CAMHS Rejected Referral Audit

Findings: being rejected

What impact do rejected referrals have on children, young people and their families?

- Issues often **escalate and worsen**
- **Financial impact** of finding alternative, private, help
- Impact and strain placed on **family relationships**
- Feelings of being **let down**, with nowhere to turn
- Feeling **alone** and in despair
- Feelings of **guilt or failure** among parents

“When I kept on getting rejected I was just in a really, really bad place and I feel like say if I got the help that I needed then when I got rejected, I probably wouldn't have had as many suicide attempts or had to go up to accident and emergency so many times.”

Findings: being rejected

Falling between the gaps

A further issue we heard relates to **transitioning between child and adult services** – in a few cases the waiting time from referral to being seen meant that a young person became ineligible during the process.

“She was in fifth year at school when the process started of referral to CAMHS...It got to the point where it was three and a half months short of her 18th birthday and that’s a really significant timeframe because actually what happened was they wouldn’t accept a referral because it was too close to the 12 week window in which they refer young people. They basically refuse to take a young person if they’re within 12 weeks of their 18th birthday.”

Findings: being rejected

Key Findings

- Widespread belief that the reasons given for rejection are either **inadequate or unjustified**
- **1 in 10** sought private help following a rejected referral
- More than **half of young people** whose referrals were rejected took no further action
- **20%** of people were re-referred to CAMHS
- Current signposting was **unhelpful** to participants

Referrers' Views

Clearer guidelines on the referral and assessment process

Adequate provision of community and early intervention services,

GP's suggestions for improvement

Mandatory and relevant signposting

More multidisciplinary referrals

Referrers' Views

Teachers' suggestions for improvement

Improvements to other tiers of support

A standardised referral form with space for the views of the young person, parent and other agencies involved

Better interagency working and communication

Key Findings

- **1 in 5** children and young people's referrals to CAMHS were rejected during the period of the audit
- The decision to reject a referral happens **quickly**. Usually on the basis of **paper referrals**, without a face to face assessment.
- Audit Boards reported **66%** of referrals include signposting, compared to **42%** of people who felt they were signposted in the qualitative research

Key Findings

- Children, young people and their families report that signposting is **generic, unhelpful** and often points to resources they have already explored.
- Some young people whose referral has been rejected report a belief that they will not be seen by CAMHS unless they are **suicidal or at immediate risk of harm**.
- There is a strong indication of a gap in services for children and young people who do not meet the **criteria** for the most specialist help

Recommendations

Recommendations section 1: further research

We recommended the Scottish Government carried out work to **explore the CAMHS system as a whole**

Recommendations

Recommendations section 2: meeting the needs of children, young people and their families

- SG should consider whether the tiered model of CAMHS is fit for purpose
- Service availability for behavioural and emotional problems
- Funding at an appropriate level
- Development of a multi-agency assessment system
- Face-to-face assessments for all referrals
- Personal and meaningful signposting

Recommendations

Recommendations section 3: making immediate changes to CAMHS

- Have staff available to discuss referrals with referrers
- Review assessment procedures, considering capacity and consent
- Explanation of the role and process of assessments
- Notification of rejected referral to both referrer and young person
- Direct re-referrals where appropriate to other services
- Publish information on crisis support
- Everyone up to age 18 is able to access CAMHS services - regardless of their educational status

Recommendations

Recommendations section 4: data collection

We made recommendations to **improve data collection** on rejected referrals by ISD Scotland: with the Scottish Government and NHS Boards agreeing ongoing data needs

What happened next?

**Scottish Government accepted
all recommendations**

"Achieving positive outcomes for children and young people has been at the heart of this study and speaking to more than 360 children, young people and their families about their experiences has been a real privilege."

SAMH Chief Executive Billy Watson

Questions?

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