Data evaluation project for Children and Young People and Families' voices on health care across Leicester, Leicestershire and Rutland: Report of Findings

The Centre for Public Innovation

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The Centre for Public Innovation is a Community Interest Company that provides research, training, support and advice in the fields of health, social care, criminal justice and community development.

Our mission is to improve the outcomes of services for their users, with a particular emphasis on the most disadvantaged.

Contents

Glossary

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CYP	Children and young people
EHCP	Education Health and Care Plan
LLR ICB	NHS Leicester, Leicestershire and Rutland Integrated Care Board Integrated Care Board
LGBTQ+	Lesbian, Gay, Bisexual, Transgender and Queer/Questioning
LLR	Leicester, Leicestershire and Rutland
PMLD	Profound and multiple learning disability
SEND	Special educational needs and disability
UASC	Unaccompanied asylum-seeking children

1. Executive Summary

Young people today navigate a world vastly different from that of older generations, influenced by distinct social, political, and technological factors. They occupy and operate in unique spaces, often rendering traditional engagement methods and timelines ineffective.

To understand how children and young people (CYP) experience their healthcare, it is crucial for Leicester Leicestershire and Rutland's (LLR) NHS to actively engage and incorporate CYP voices and participation. LLR faces numerous health inequalities, particularly among the Core20PLUS5[1] cohort of CYP, and there is a significant need to integrate prevention into every pathway.

The NHS Leicester, Leicestershire and Rutland Integrated Care Board (LLR ICB) publicly engaged young people, their parent/carers and healthcare professionals who work with them to answer the question:

"What do we need to do to improve the health outcomes of children and young people in Leicester, Leicestershire and Rutland?"

In total 3,002 people across the LLR area participated in the engagement. Participants comprise:

2,239 – children and young people

682 – parents and family carers of children and young people

81 – staff caring for children and young people

People participated through a number of methods shown below:

Children and young people

- 1,884 completed an online survey.
    - 1,775 completed the main version of the survey (Online: 872, Hardcopy: 903)

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[1] Core20PLUS5 is a national NHS England approach to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort and identifies '5' focus clinical areas requiring accelerated improvement.

  - 109 online easy read version of the survey
- 355 participated in focus groups and other activities

Parents and family carers

- 659 completed an online survey
  - 632 completed the main version of the survey (Online: 617, Hardcopy: 15)
  - 27 completed an online easy read version of the survey
- 23 participated in focus group and other activities

Health Professionals

- 81 completed an online survey

Key headline findings

Overall Assessment of Health Services

Children and young people (CYP) generally hold a positive view of healthcare services. A significant majority (73.6% n= 1,335) rated their last health service encounter as good or excellent, and 69.5% (n= 1,135) rated their overall healthcare experience positively. Parents and carers were slightly less positive, with 59.8% (n = 364) rating their child's last service encounter positively and 52.2% (n=287) giving an overall positive assessment. Despite some concerns, the overall sentiment towards healthcare services among young people is favourable.

Health Concerns of Children and Young People

Mental health emerged as the most pressing concern across all groups, with 60.8% (n=1,103) of CYP, 92.1% (n=605) of parents, and 90% (n=72) of professionals identifying it as a key issue. Sleep was identified as the second most important issue, with significant concern from both CYP and parents.

Knowledge of How to Access Healthcare Services

A majority of young people (78.8% n= 1,399) know how to access healthcare services, with 59.7% (n= 983) knowing how to access mental health services. Parents/carers also showed high awareness, with 88% (n=566) knowing how to access health services for their child. Most young people (59.9% n=1,118) would turn to parents/carers first when facing a health concern, highlighting the critical role parents play in healthcare access. However, nearly a quarter (22.3% n= 417) said they would search online first.

Health Services Used

The most commonly used health services were dentists (74% n=1,363) and GPs (72.9% n=1,344). A notable 25% (n= 461) of young people reported using A&E in the past year.

Waiting Times and Access

Long waiting times for both primary and secondary care were a major concern. Difficulty in getting GP appointments was frequently reported, with some young people giving up on trying to secure appointments. Secondary care wait times also varied significantly.

Being Listened To

Young people value being listened to and having their concerns taken seriously. While 68% (n= 1,231) felt listened to, 12.4% (n=225) did not. This discrepancy was also noted by parents/carers and professionals, indicating a need for better communication.

Caring and Compassionate Staff

Kindness and compassion from staff significantly impact young people's perception of healthcare. Approximately 74.3% (n= 1,344) felt they were treated with care and concern, though parents/carers reported a slightly lower rate (68.6% n= 418).

Next Steps and Advice

Many young people (39% n=653) only "sort of" knew the next steps in their treatment, with 17.3% (n= 280) not knowing at all. Communication about post-treatment steps and advice needs improvement.

Onward Referrals

Only 25.4% (n=457) of young people reported getting onward appointments quickly. The quality of referrals was also a concern, with only 35.8% (n= 479) stating that the referred service had details of their condition.

Support for Professionals

Less than half (38.9% n= 28) of professionals felt fully equipped to support young people, citing a lack of mental health resources, improved referrals, and better collaboration.

2. Background and context

2.1 About the scoping and engagement project

2.1.1 Context

NHS Leicester, Leicestershire and Rutland Integrated Care Board (hereafter LLR ICB) undertook a comprehensive engagement process with children and young people (hereafter CYP) to hear about their views on their health and on health care.

The engagement process was aimed at young people aged 11 to 25 years of age.

In parallel with the engagement with young people, engagement was also carried out with parents and family carers of CYP aged 11 to 25 years and with health professionals working with this age cohort. This would enable a 3-dimensional view of services to inform future commissioning and provision of care.

The Centre for Public Innovation (CPI) were commissioned as an independent evaluator to undertake analysis of the data gathered during the engagement process and produce this Report of Findings.

2.2 About the engagement approach

The Children and Young People and Families' voices engagement on health care across LLR was open between Monday 27 November 2023 to Sunday 3 March 2024.

In undertaking a public engagement, the LLR ICB is fulfilling a duty to involve the public. Specifically meeting the duty which statute has placed on the ICB, s.14Z2 of the NHS Act 2006 (as amended):

Public involvement and consultation by ICB:

> (1)This section applies in relation to any health services which are, or are to be, provided pursuant to arrangements made by a clinical commissioning group in the exercise of its functions ("commissioning arrangements")

2) The ICB must make arrangements to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways):

(a) in the planning of the commissioning arrangements by the group,

(b) in the development and consideration of proposals by the group for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and

(c) in decisions of the group affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.

The engagement also takes into account Article 12 of the United Nations convention on the rights of the child which says every young person has the right to express their views, feelings and wishes in all matters affecting them and to have those views considered and taken seriously. The participation of young people is also protected by law in section 19 of the Children and Families Act 2014 and the Care Act 2014.

In order to maximise the reach of the public engagement and to encourage as many people as possible to participate, a multi-channel approach was used.

A population study was carried out before the engagement to understand the age, ethnicity, religious and protective characteristics demographic of LLR CYP, aged 11-25 years old. This informed the communication and engagement strategy, as well as the VCSE Alliance members the ICB commissioned, to ensure proportional representation in the results.

The Children and Young People and Families' voices engagement on health care used a survey which could be answered by respondents online (using the QuestionPro survey tool, which collected the data from respondents) or offline by completing a printed survey. CYP also had the chance to take part in creative participatory activities and focus groups to share their views. This approach ensured that the NHS heard from those with protected characteristics, the vulnerable and young carers. The vast majority of respondents to the engagement answered the questions online.

A population study was carried out before the engagement to understand the age, ethnicity, religious and proactive characteristics demographic of LLR. This informed the communication and engagement strategies to ensure we had proportional representation in the results.

In addition, the public engagement used a variety of both online and offline tools and techniques to communicate with the CYP, their families and health care professionals across LLR. These included, but were not limited to, the following activities:

- The ICB commissioned a local arts and media youth charity, Pedestrian, to work with their young people to create a relatable engaging look and feel to the campaign which would resonate with their peers. Signed off by NHS Leicestershire Partnership Trusts' (LPT) Youth Advisory Board.

- The ICB partnered with 11 Voluntary Community and Social Enterprise Alliance (VCSE) members to reach into the heart of communities and particularly reach those with protected characteristics, CORE20Plus5, young carers and those communities who are seldom heard.

- Widespread utilisation of social media, including local NHS-owned platforms, VCSE's platforms, Spotted and community pages targeting users of Facebook, Instagram and X (formerly Twitter). Activity and reach across main social media platforms for organic promotion, is circa 80,5043.

- Utilised LPT's CYP text messaging database. Sent out to all contact numbers attached to YP (11-18 years old) patients of CAMHS (4,559) and Paediatrics (4,124) - Total = 8683

- Key partners also promoted the survey including Healthwatch Leicester and Leicestershire and Healthwatch Rutland, local authorities, parish councils and military champions.

- Paid-for social media and Digital Ad Exchange advertising reaching 21,1976, enabled us in the latter stages of our promotion to target areas where responses were lower and reach out to seldom heard communities.

- Email marketing throughout the engagement to 1,366 VCSE organisations, schools, colleges and universities and key business associated across LLR.

- Email marketing to councillors (county, district and parish) delivered information about the engagement, and asked for support in disseminating within their community.

- Written communications with ICB staff and staff working at University Hospitals of Leicester, Leicestershire Partnership Trust and upper and local tier authorities.

- The survey was also communicated to the LLR NHS Online Citizens' Panel (1,200 members), through ICB Five on Friday and the Youth Advisory Board.

- Posters and postcards provided to Leicester Royal Infirmary, Leicester General Hospital Glenfield Hospital, LPT's Mental Health bases, LLR's Family Hubs, and local community venues. Disseminated to GP practices through Primary Care Networks and Patient Participation Grous (PPGs)

- Hardcopy surveys provided to mobile phone free schools

2.3 Methodology

Survey

A survey was developed specifically for the purpose of the engagement exercise and co-designed with children and young people groups. The survey addressed a wide range of areas including:

- Health issues of concern to young people,
- Knowledge/awareness of health services,
- Health services used/accessed,
- Assessment of the quality of health services,
- Referrals to other services.

Separate questions explored physical and mental health (and for the latter, transitioning from young people's mental health services to adult services).

In addition to questions on health a range of questions explored the profile of respondents, which were optional to provide, including:

- Age,
- Gender and sex,
- Religion,
- Sexual orientation,
- Ethnicity.

Data was also captured on protected characteristics and additional areas of interest, again these were optional to provide, including:

- Pregnancy,
- Caring status (whether they care for another person),
- Whether they have an Education Health and Care Plan,
- Whether they have been in care.

Respondents were also able to provide information on any health conditions that they might have.

The parent/carer survey followed the format of the young people's survey, covering the same issues.

To note, the parents and carers participating in the engagement may not be parents and carers of the young people who also took part.

Participatory Activities

In addition to the survey, to gain qualitative data, LLR ICB commissioned a number of local third sector organisations from their Voluntary, Community and Social Enterprise Alliance (VCSE) to undertake consultation with the CYP with which they worked. The commissioned VCSE targeted with protected characteristics, CORE20Plus5, young carers and those communities who are seldom heard. In total 11 organisations participated in engagement work. Participating organisations were provided with training about data collection and provided with a data capture template. The topics covered in the participatory activities closely resembled those explored in the survey.

The participatory activities took place in schools, community centres, on youth outreach buses, in hospitals, youth clubs (including church youth clubs), Madrassas, a Gurdwara, further education colleges, special education settings, a Saturday school, and in both rural and city youth outreach settings.

The commissioned VCSE were able to utilise their expertise and local knowledge to engage with their CYP, in a way which makes sense to them. It was considered that this approach would deliver more insightful and candid insight, compared to what a traditional survey-based engagement would.

A number of different participatory methods were used by the VCSE. Creative artifacts, such as posters and arts were produced by CYP to allow them to look deeper into subject matter and to take time to produce a considered response. Artifacts were submitted along with facilitator feedback from which insight could be gathered.

Other methods included training up young people as peer researchers so they could go out into their communities and speak to their peers. First aid workshops used as an way to get the CYP thinking about healthcare, and safe spaces were created, such as coffee mornings for young parents with crèche's provided, football sessions and focus groups at youth clubs.

Participation workers reported that children and young people were pleased to be given this opportunity to contribute their experiences and views on the health services they used.

In some cases, the participation workers provided detailed notes on the focus groups they facilitated and in other groups children and young people had completed questionnaires themselves.

Strengths and weaknesses of working with VCSE

The participatory activities were carried out by commissioned VCSE organisations. It should be noted that there are strengths and weaknesses in working in this way to gather insight, especially from children and young people. The strengths are that the VCSE have local knowledge, access, established relationships and the skillset to engage with seldom heard groups. In this case, a large majority of CYP taking part in participatory work were from vulnerable and seldom heard communities so may have different experiences to healthcare than general population.

VCSE organisations are also agile and flexible in changing engagement methods if things are not working. In some cases, CYP did not want to engage in participatory group work and would prefer to complete a survey afterwards. Some conversations were held over What's App, or through online group chats, as this was the CYP preferred way of giving their voice.

It should also be noted that the VCSE received training in gathering insight, however, are not professional researchers. Gathering equality information proved to be difficult in some situations, for example, Traveller communities would not identify themselves as Travellers on forms due to historical discrimination, and SEND young people are not aware of details such as their postcode.

Finally, working with CYP can be complex, and that is why this project decided to work with VCSE who have the experience and skills to support CYP to share their voice.

2.3.1 Children and young people's survey

A survey was prepared targeted at CYP. The survey was developed with support from Leicestershire Partnership Trust's Youth Advisory Board (YAB). The survey was accessible online via hyperlink and was distributed by LLR ICB. A hard copy (paper) version of the survey was also distributed to health settings and public events. Hardcopy versions were distributed to a mobile free school at their request. In parallel to the main survey, an easy read version was also developed.

The survey was open from 27 November 2023 to 3 March 2024.

In total 2,239 CYP were involved in the consultation process:

- 1,884 completed the online survey
    - 1,775 completed the main version of the survey (Online: 872, Hardcopy: 903)
    - 109 completed an online easy read version of the survey
- 355 participated in focus groups and other activities

2.3.2 Children and young people's participatory activities

The data provided by the third sector organisations indicates that 355 children and young people were consulted. This number should however be treated with a degree of caution given that a number of third sector organisations did not collect equality monitoring data in a clear format and so there is a possibility that there is some degree of double counting, as well as a possibility that data was not collected for all young people participating.

The following is a list of VCSE organisations that engaged young people. Please see note above regarding engagement numbers.

VCSE or Group	Type of participant	Participatory Activity	Area of engagement	Numbers engaged
AAA Foundation	CYP At risk of offending High multiple deprivation Experiencing health inequalities	Interactive workshops - Arts and crafts, football Online focus groups Classroom based conversations	Beaumont Leys Castle Ward Evington Ward Fosse Ward Western Ward	67
Cedars Academy	CYP Co-educational secondary school and sixth form	Health and Wellbeing Council	Birstall	13
Coalville CAN	CYP Children in care SEND YP experiencing mental health issues YP with experience of the criminal justice system	Class based conversations in schools Focus groups at youth clubs Young people were supported to complete the main CYP survey	North West Leicestershire	3
Ellesmere SEND College	CYP SEND	Classroom based conversations using visual aids	LLR wide young people	26

HCYC	CYP Irish Traveller community Young Carers	One to one face to face conversations Focus groups at youth clubs	Harborough	55
Jamelia's Legacy	CYP South Asian Young people with poor mental health	Arts and crafts to explore experiences of healthcare Online focus groups	Spinney Hill Ward	27
Leicestershire Cares	CYP Care experienced young people Unaccompanied asylum seeking young people Involved in criminal justice system Facing housing/homelessness issues	Podcast and creative arts Peer researchers conducting focus groups	Belgrave Ward Castle Ward Evington Ward Humberstone and Hamilton Ward Rushey Mead Ward Thurncourt Ward Troon Ward Spinney Hill Ward Wycliffe Ward	22
LPT Youth Advisory Board	CYP	Online focus group	Online: LLR young people	6

	Experiences of CAMHS and general population			
Project Polska	CYP Eastern European Community Young people with vulnerabilities and experiencing negative mental health	Using CPR workshops to spark conversations One to one conversations	Melton Loughborough	47
St Philips Centre	CYP Young people from Muslim (mixed ethnicity), Sikh (Indian), Christian (Black African) or Hindu (Indian)	Poster making Focus groups	Charnwood Oadby and Wigston Rutland	82
UHL Youth Forum	CYP Lived experiences of hospitals and long-term conditions	Mind mapping Focus group	Braunstone Ward, however, young people come from across LLR	7
				Total: 355

2.3.3 Parents and carers survey

A survey of parents and carers of CYP aged 11 to 25 years was prepared and, as per the CYP survey, was made available online and was promoted by LLR ICB. Also, as per the CYP survey, a parallel easy read version of the survey was also prepared. The survey ran from 27 November 2023 to 3 March 2024.

In total 682 parents and carers were involved with the engagement:

- 659 completed an online survey
    - 632 completed the main version of the survey (Online: 617, Hardcopy: 15)
    - 27 completed an easy read version of the survey
- 23 participated in focus group and other activities

The following is a list of VCSE and groups who engaged parents and carers in focus group activities.

VCSE or Group	Type of participant	Participatory Activity	Area of engagement	Numbers engaged
Carers Centre	Parent and Carers of CYP with SEND	Online focus group	Online: Parents from Leicester City and Leicestershire	19
Second Battalion Royal Anglian Regiment	Parent/Carers Military families	Focus group	Rutland	4
				Total: 23

2.3.4 Professionals survey

The final aspect of the engagement process was aimed at health professionals working with CYP aged 11 to 25 years. The survey was made available online and was distributed by LLR ICB. The survey ran from 27 November 2023 to 3 March 2024.

In total 81 professionals responded to the online survey.

2.3.5 Research ethics

Data collection and anonymity

Care was taken to ensure the anonymity of all participants in the engagement exercise.

None of the three surveys (children and young people/parents and carers/health and care professionals) collected data that could be used to identify an individual person (such as name or date of birth). While postcode data was collected for the children and young people's survey and the parents and carers survey, this was requested for the first five characters only, to avoid revealing specific addresses.

The young people's participatory activities were undertaken by local voluntary organisations who collected the data on behalf of the ICB. The notes of their sessions and completed monitoring forms were then evaluated, contributing to this Report of Findings.

Survey methodology

Both online and postal surveys included closed ('tick-box') questions and open-ended questions for comments. Key questions from the online and postal surveys were, as far as possible, replicated in the participatory activities undertaken by the VCSE sector; however, broader questions and scenarios were included to gather richer data.

Apart from the initial data protection question, none of the questions in any of the surveys were compulsory. This resulted in some surveys being only partly completed. These were included in the final analysis, leading to variation in the number of responses per question, which are identified in this report as 'valid responses'.

Data analysis

In addition to analysing the closed questions, a thematic analysis of the open comments from the online and postal surveys was completed, coding responses into themes for quantification.

This document summarises the findings from the independent analysis.

3. The profile of respondents to the consultation process

This section sets out the profile of those who engaged in the engagement process. It should be noted that the base numbers are calculated on the responses given, where the response was left blank the valid total has been calculated for those who have provided a response as opposed to the overall total response rate[2].

3.1 Children and young people

To ensure that a broad-cross section of young people with a range of characteristics were engaged and participated in the engagement process, both the survey and the participatory activities gathered data about CYP across a wide range of variables. The data on the profile of CYP was regularly reviewed through the engagement period to ensure that there were no gaps in the data – that is, groups of young people who had not contributed to the process.

Data on the profile of CYP who participated is set out below.

3.1.1 Children and young people's survey respondent profile

In total 1,884 CYP responded to the survey. The total estimated population of those aged 11 to 24 years across LLR is some 263,066. This, therefore, gives a survey sample rate of 0.7% of CYP in the area.

Sex and gender

55.7% (n=883) of respondents to the survey indicated that they were female and 41.3% (n=654) male thereby meaning that girls and young women were slightly over-represented in the survey population. 0.8% (n=12) of respondents stated that they were intersex and 3.1% indicated an 'Other' sex.

94.2% (n=1,479) of respondents identify with the gender they were assigned at birth.

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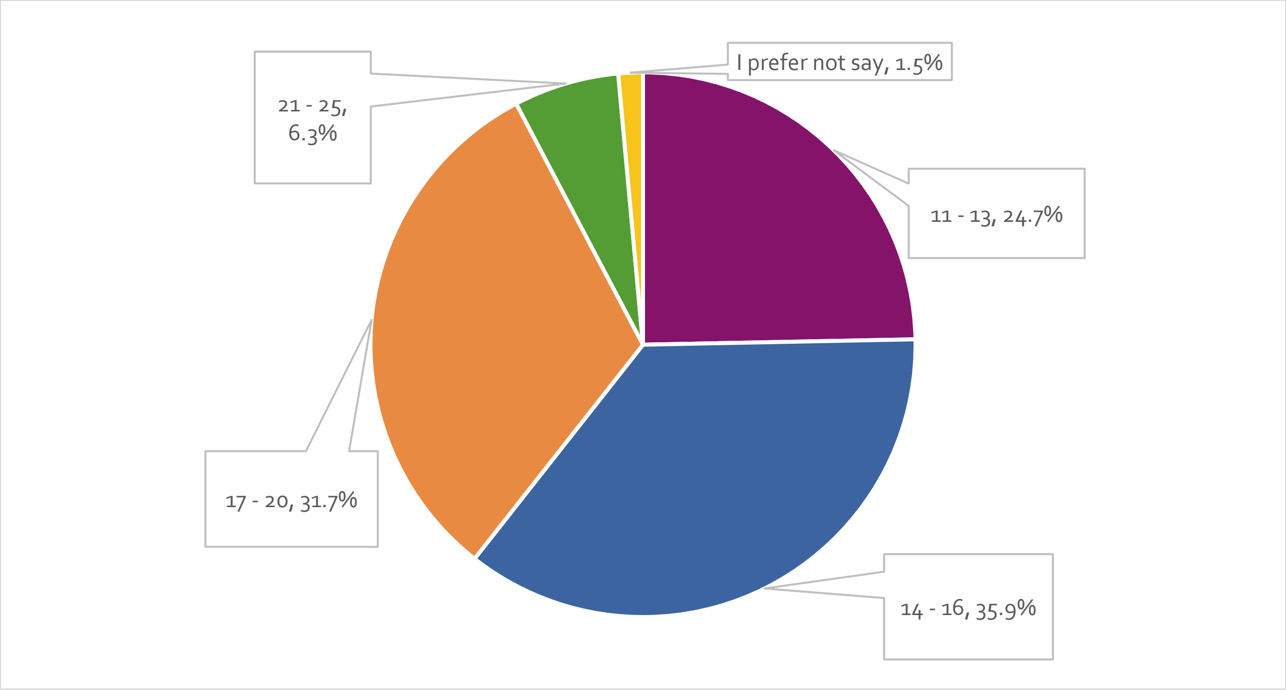
[2] The total response rate to the CYP survey was 1,884 however not all respondents completed the survey. Thus for some questions, the 'valid total' is the number of CYP who provided a response and therefore lower than the total response rate.

Age

Young people aged 14 to 16 years made up the single largest cohort of respondents (35.9%, n=569). A full breakdown of the age of the survey population is set out at Figure 1.

Figure 1: Age of survey respondents



(valid responses = 1,584)

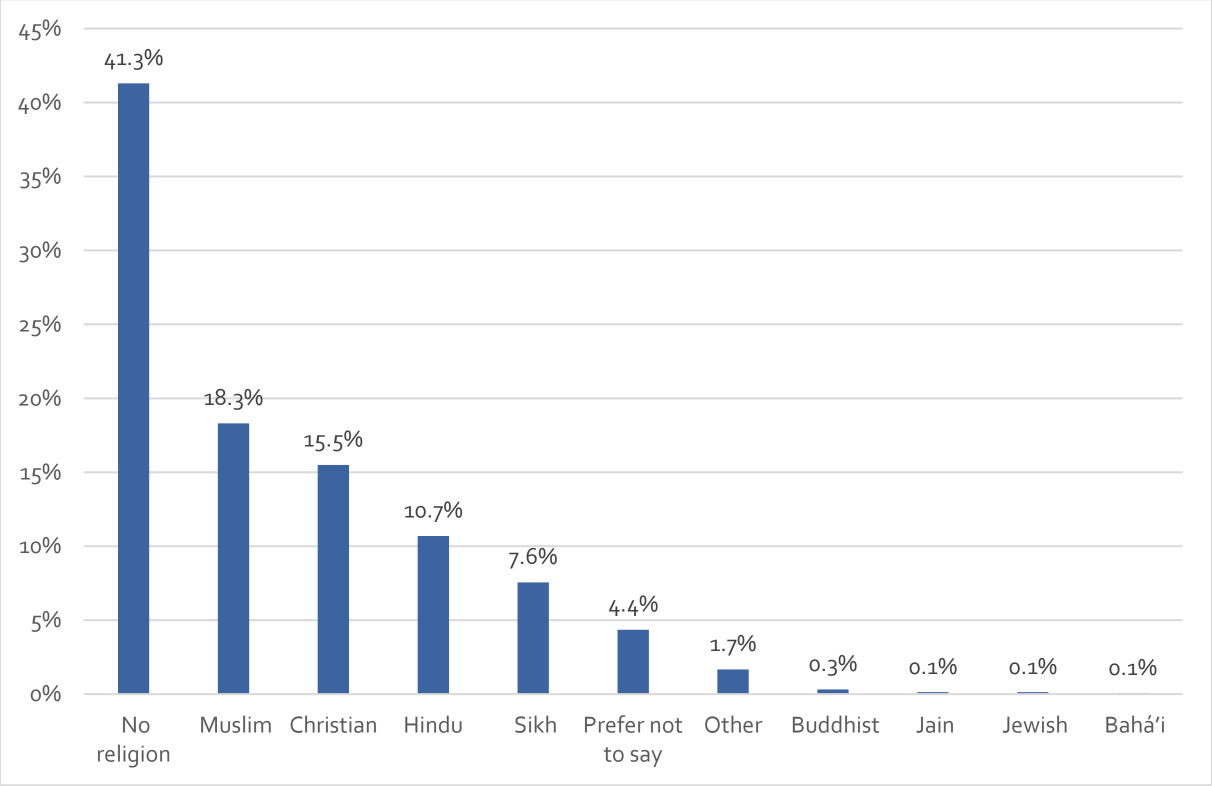
Age	Number
11 - 13	391
14 - 16	569
17 - 20	502
21 - 25	99
Prefer not to say	23

Given that there is as even split in the age categories in the population as a whole (that is in the wider 11 to 25 year old population we would expect about 25% of young people to fall into each cohort) in the survey those aged 21 to 25 years were under-represented making up 6.3% (n=99) of respondents. Conversely, those aged 14 to 16 years are over-represented.

Religion

The single most common response with regard to faith was those who indicated that they were of no faith (41.3% n=645). Muslims made up the largest cohort of those with a faith (18.3%, n=286) followed by Christians (15.5%, n=242). A full breakdown of results is set out at Figure 2.

Figure 2: Religion of survey respondents



(valid responses n=1,562)

Religion	Number
None	645
Muslim	286
Christian	242
Hindu	167
Sikh	118
Prefer not to say	68
Other	26
Buddhist	5
Jain	2
Jewish	2
Bahai	1

Ethnicity

The ethnicity of the survey population is set out at Table 2.

Table 1: Ethnicity of the survey population versus the population as a whole

	Percentage %	Number (n)
Asian	35.6%	548
Black	4.6%	76
Mixed	6.6%	102
White	48.6%	748
Other	2.7%	42
Prefer not to say	1.4%	22

(valid responses n=1,538)

Just under half (48.6%, n=748) of respondents indicated that they were White, while 35.6% (n=548) were Asian and 4.9% (n=76) Black.

The results, when compared to the population as a whole, indicate those of White heritage are under-represented in the survey population, those of Asian heritage over-represented and those of Black heritage represented in line with the population as a whole.

A full breakdown of all ethnic codes is set out at the Appendix.

Sexual orientation

77.3% (n=1,188) of respondents stated that they were heterosexual, 8.2% (n=126) stated that they were bisexual and 3.2% (n=49) stated that they were gay or lesbian. (A little under 10% (n=141) of respondents preferred not to respond to the question). [valid responses n=1,537)

Pregnant or had given birth

2.2% (n=34) of respondents stated that they were currently pregnant or had given birth in the last 26 weeks.

Provided care for someone

9.8% of respondents (n=185) stated that they provided care for someone younger than themselves (such as a brother or sister). 7.6% (n=143) stated that they provided care for someone older than themselves (such as a parent).

Looked after or currently in care

17.8% (n=275) of respondents indicated that they had ever been or were currently in care.

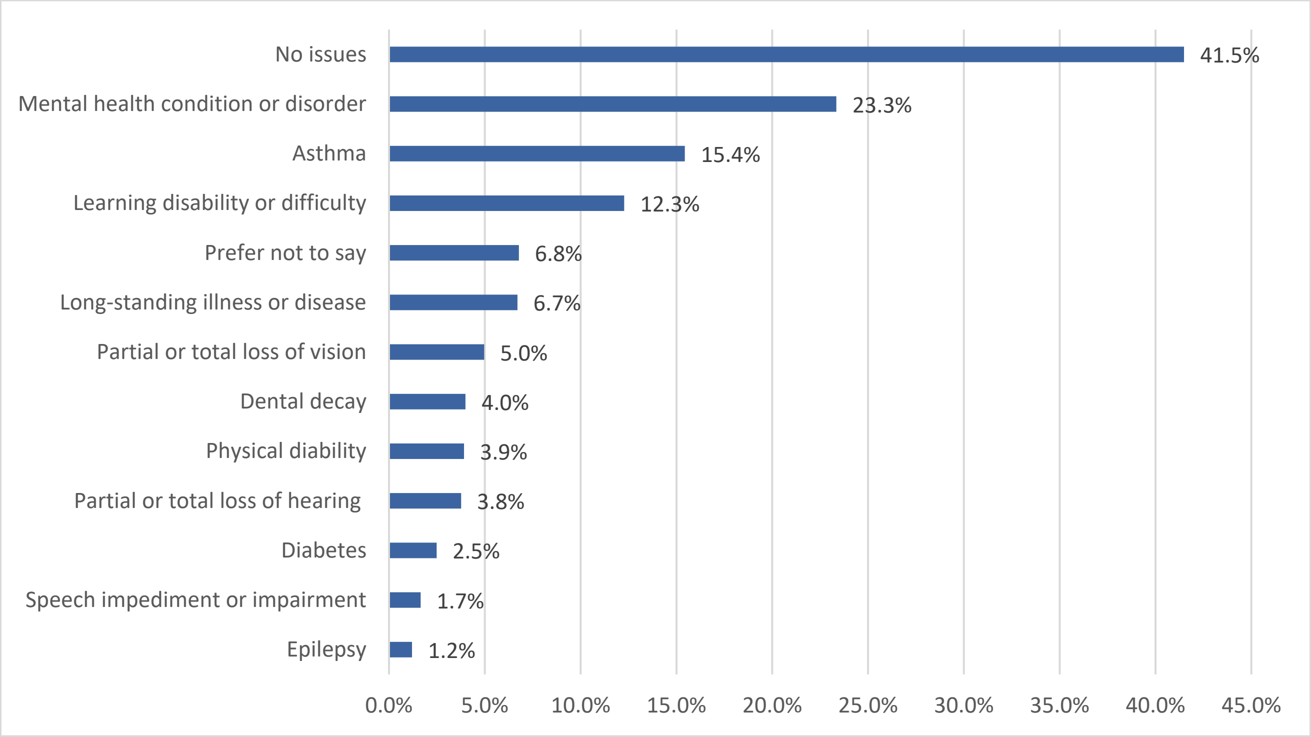
Education Health and Care Plan (EHCP)

12.5% (n=191) of respondents stated that they have an Education Health and Care Plan or receive support for a special educational need in education.

Health conditions

CYP were asked whether they had any health conditions. The results are set out at Figure 3.

Figure 3: Health conditions of respondents



(Valid total = 1,328)

Health condition	Number
No issues	551
Mental health	310
Asthma	205
Learning disability	163
Prefer not to say	90
Long standing illness	89

Health condition	Number
Vision	66
Dental decay	53
Physical disability	52
Diabetes	33
Speech impairment	22
Epilepsy	16

The most commonly cited health issue was mental health as identified by 23.3% (n=310) of respondents. This was followed by asthma, cited by 15.4% (n=205) of respondents. 41.5% (n=551) of respondents indicated that they had no issues.

3.1.2 Children and young people's participation activities profile

Young people aged 11 to 25 throughout LLR were consulted through youth participation events to give their views on their experiences of health services in LLR.

The quality of monitoring form completion was inconsistent, with some being completed (or not) by children themselves with others completed by participation workers. Some groups had made use of pie charts, or bar charts with broadly defined y-axes, which made absolute numbers difficult to calculate exactly. It was therefore hard to determine exactly how many children participated we have data from 355 children and young people were engaged between December 2023 and March 2024.

The children and young people were from diverse backgrounds and included children and young people:

- with SEND and/or a parent,
- from travelling communities,
- young carers
- with long term conditions and with serious health conditions requiring inpatient hospital care,
- young mothers under 25 years of age,
- from African Caribbean communities,
- from the Polish community,
- from South Asian backgrounds,
- Unaccompanied asylum seeking children (UASC).

There were apparently no children and young people in LGBTQ+ groups (that is, none of the data provided by the organisations who undertook the participatory work indicated engagement with CYP who identified as being LGBTQ+).

3.2 Parents and carers

As per the consultation with CYP, parents and carers were asked to provide details about themselves in order to help ensure that a wide cross-section of residents from a range of communities participated. The profile of parents and carers who responded to the survey is set out below.

2.2.1 Parents and carers survey respondent profile

Sex and gender

88% (n=461) of respondents to the survey indicated that they were female and 10% (n=50) male. (3%, n=14 - of respondents stated that they would prefer not to say.)

97% (n=510) of respondents identify with the gender they were assigned at birth. The remainder preferred not to say (n=16).

Age

Parents/carers aged 35 to 49 years made up the single largest cohort of respondents (51.9%, n=274) followed by those aged 50 to 64 years (35.8%, n=189). A full breakdown of the age of the survey population is set out at Table 4.

Table 2: Age of parents/carers

Age	Number	%
16 – 19	5	1.0
20 – 24	5	0.9
24 – 34	28	5.3
35 – 49	274	51.9
50 – 64	189	35.8
65 – 74	14	2.7
75 – 84	2	0.4
85+	1	0.2
I would rather not say	10	1.9
Total	528	100

Number of children

Almost exactly half (49.4%, n=253) of parents/carers reported that they had two children. See Table 5.

Table 3: Number of children

Children	Number	%
None	7	1.3
One	100	18.9
Two	253	47.9
Three	118	22.3
Four or more	50	9.5
Total	528	100

Age of children and young people

Parents/carers were asked about the age of their children. The results are set out at Table 6.

Table 4: Age of children

Age	Number	%
11 – 13	243	46.1
14 – 16	244	46.3
17 – 20	202	38.3
21 – 24	97	18.4
25+	80	15.2

(Valid total 527) Note that respondents could tick more than one option – i.e. one per child where they had several children thus the total percentage equals more than 100%.

Religion

The largest group of respondents to the survey (46.3%, n=243) indicated that they were of no faith. Christians made up the largest cohort of those with a faith (40%, n=210). A full breakdown of results is set out at Table 7.

Table 5: Religion of parents/carers

Age	Number	%
No religion	243	46.3
Baha'i	1	0.2
Buddhist	1	0.2

Age	Number	%
Christian	210	40.0
Hindu	17	3.2
Jain	1	0.2
Jewish	0	0.0
Muslim	9	1.7
Sikh	2	0.4
I prefer not to say	34	6.5
Other	7	1.3
Total	**525**	**100**

Ethnicity

The ethnicity of the parent/carer survey population is set out at Table 8.

Table 6: Ethnicity of parents/carers

Age	Number	%
Asian	30	5.7
Black	6	1.1
Mixed	12	2.3
White	451	85.9
Arab	0	0.0
Chinese	2	0.4
Polish	2	0.4
Somali	1	0.2
Any other	1	0.2
I would prefer not to say	20	3.8
Total	**525**	**100**

A large majority (85.9%, n=451) of respondents indicated that they were White, while 5.7% (n=30) were Asian and 1.1% (n=6) Black.

Education Health and Care Plan (EHCP)

38% of respondents (n=199) stated that their child/one of their children have an Education Health and Care Plan or receive support for a special educational need in education.

Serving in the Forces

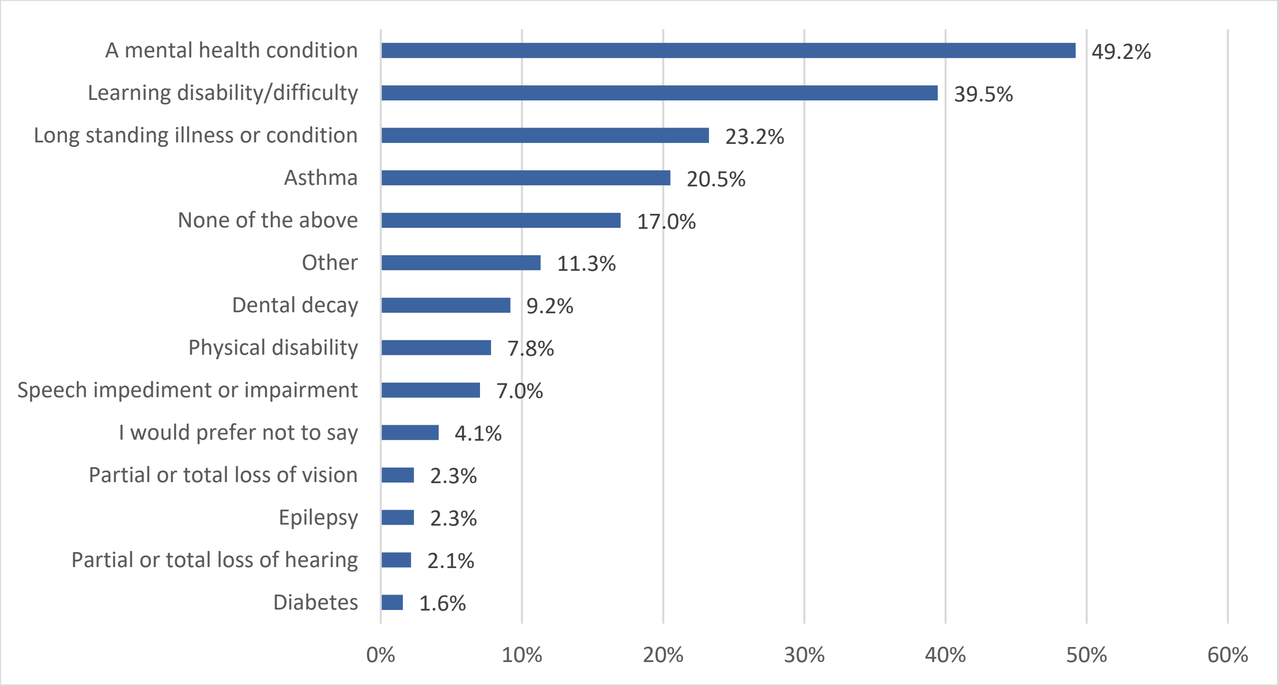
A very large majority of respondents (96.2%, n=503) stated that they had not served in the Armed Forces while 0.8% (n=4) stated that they had.

Health conditions

Respondents were asked whether any of their children had a health condition.

The most commonly cited condition was a mental health condition as noted by 49.2% (252) of respondents. This was followed by Learning Disability/Difficulty reported by 39.5% (n=202) of parents/carers. 17% (n=87) stated that their child/ren had no health conditions. The full results are set out at Figure 4.

Figure 4: Health conditions of children



Valid total 512 - Note respondents could give more than one response thus the totals equal more than 100%.

Condition	Number
Mental health condition	252
Learning disability	202
Long-standing condition	119

Condition	Number
Asthma	105
None of the above	87
Other	58
Dental decay	47
Physical disability	40
Speech impediment	36
Prefer not to say	21
Epilepsy	12
Loss of vision	12
Loss of hearing	11
Diabetes	8

3.3 Professional survey

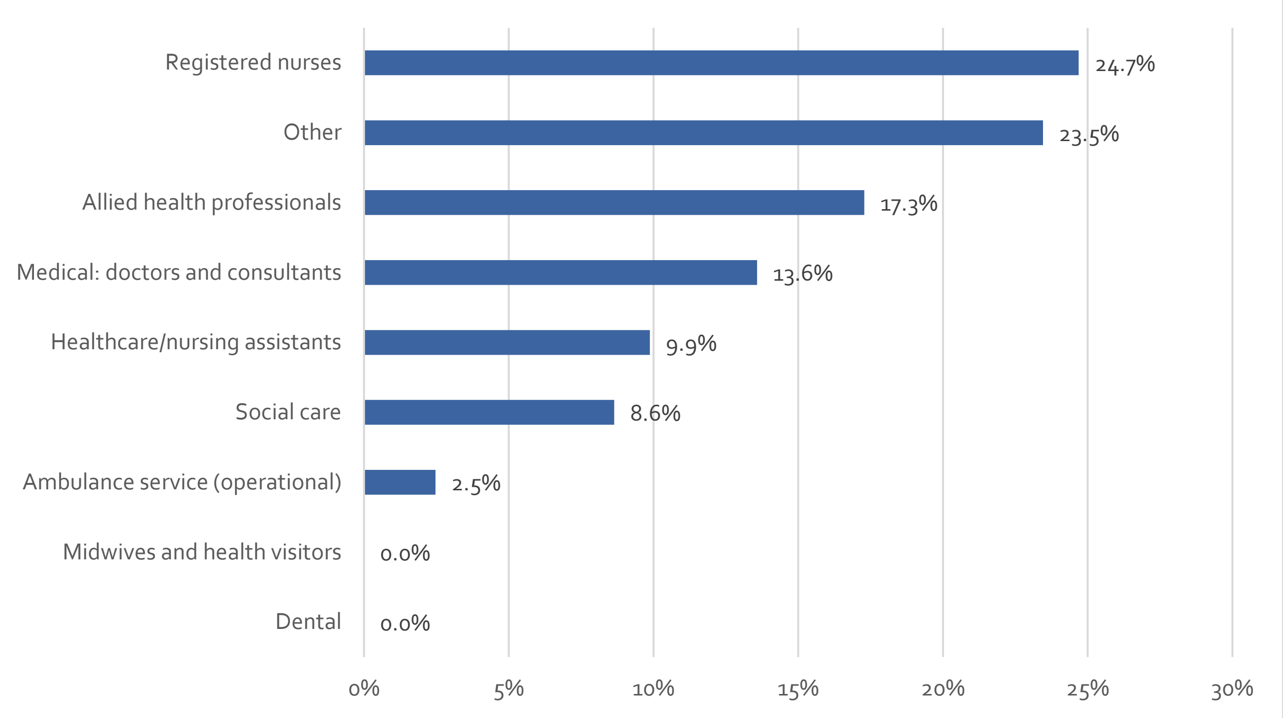
In total 81 professional responded to the survey.

Professionals were asked to give some detail about themselves.

3.3.1 Occupational group

Respondents were asked to indicate which occupational group they came from. The results are set out at Figure 5.

Figure 5: Occupation of professional respondents.



Valid total 81 - Note that people were able to tick more than one option.

Profession	Number
Allied health professional	14
Ambulance service	2
Dental	0
Healthcare/nursing assistants	8
Medical	11
Midwives and health visitors	0
Registered nurses	20
Social care	7
Other	19

The next most commonly cited profession was registered nurse (24.7%, n=20). The second most commonly cited response was "Other" professionals as given by just under a quarter of respondents (23.5%, n=19).

Of the 23.5% who cited an "Other" profession, the following roles were given[3]:

- Physiotherapist (n=3),
- Occupational therapist (n=2),
- Youth worker (n=2),
- Counsellor (n=2)
- Youth worker (n=2),
- NHS school nurse (n=1),
- Youth justice health lead (n=1),
- SEND group 11 – 16 (n=1),
- Manager (non-specified), (n=1),
- NHS Employment Support Specialist (n=1),
- Manager of a daycare service for adults with PMLD (n=1),
- Dietician (n=1),
- Pharmacist (n=1),
- Mental health practitioner (n=1),
- Speech and language therapist (n=1),
- Sixth Form College, Student welfare (n=1),
- Education Mental Health Practitioner (n=1),
- Clinical psychologist (n=1),
- Peer support worker (n=1),
- Eating disorder specialist (third sector), (n=1),
- "Holistic approach" (n=1)
- Commissioner (n=1),
- "Local government" (n=1),
- Peer support worker (n=1).

3.3 2 Where they provide health services from

Professionals were asked to indicate where they deliver health services from. The results are set out at Figure 6.

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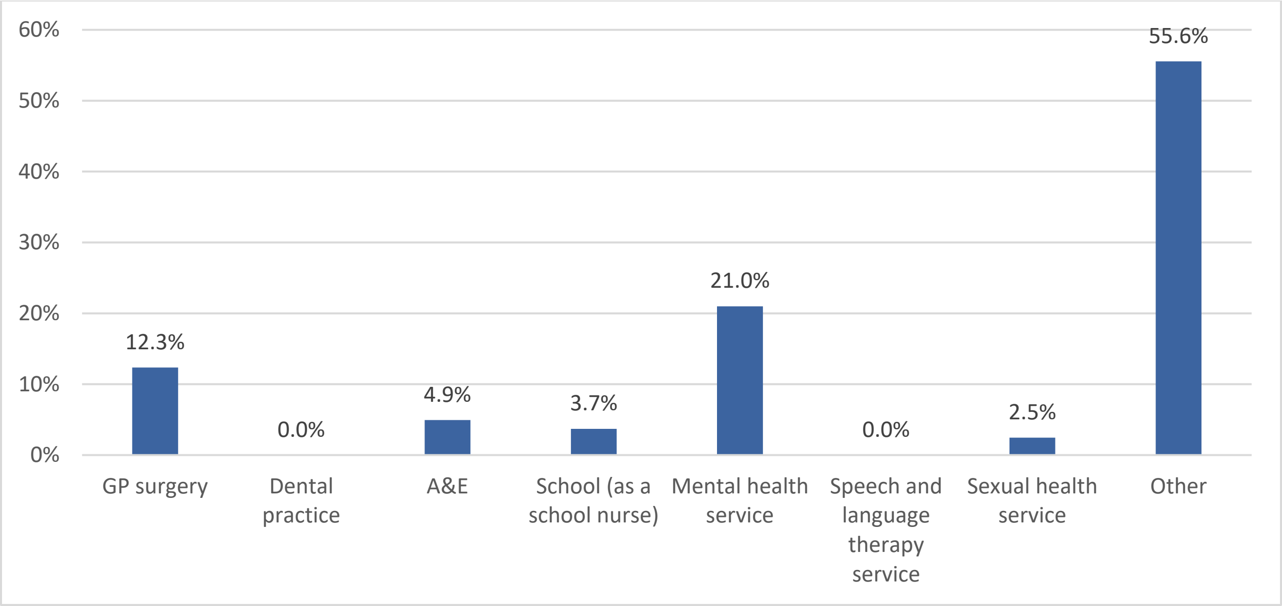
[3] It should be noted that Allied Health professionals were also able to provide an 'Other' response for their profession.

Figure 6: Where health professionals deliver services from



Valid total 81.

Location	Number
GP surgery	10
Dental practice	0
Emergency department	4
School	3
Mental health service	17
Speech and language	0
Sexual health	2
Other	45

55.6% (n=45) of professionals cited an "other" location. The following responses were given (note that some respondents gave more than one response):

- Hospital/hospital ward (n=18)
- In the community/community visits (n=12),
- Out-patient department (n=4),
- Further/Higher education setting (n=3),
- Charity (non-specified) (n=2)

- Children’s centre (n=2),
- Schools (n=2),
- Youth club (n=2),
- Youth Justice Service (n=2),
- Health centre (n=1),
- Domestic abuse service (n=1),
- Council (non-specified) (n=1),
- Community learning disability service (n=1)
- Children’s services (non-specified) (n=1),
- Day service (non-specified) (n=1),
- “Acute tertiary centre" (n=1),
- Nursing home (n=1),
- “Acute health setting” (n=1),
- Home Office (n=1).

The next most commonly cited health location given was a mental health service cited by over a fifth of respondents (21%).

4. Voices of children and young people

This section sets out the findings from the engagement with children and young people.

In total 2,239 children and young people responded to the engagement made up of 1,884 participating in the survey and 355 participating in activities coordinated by the voluntary, community and social enterprise sector. This section of the report looks at feedback from each questIon..

4.1 Survey results

In total 1,884 children and young people responded to the survey, broken down as follows:

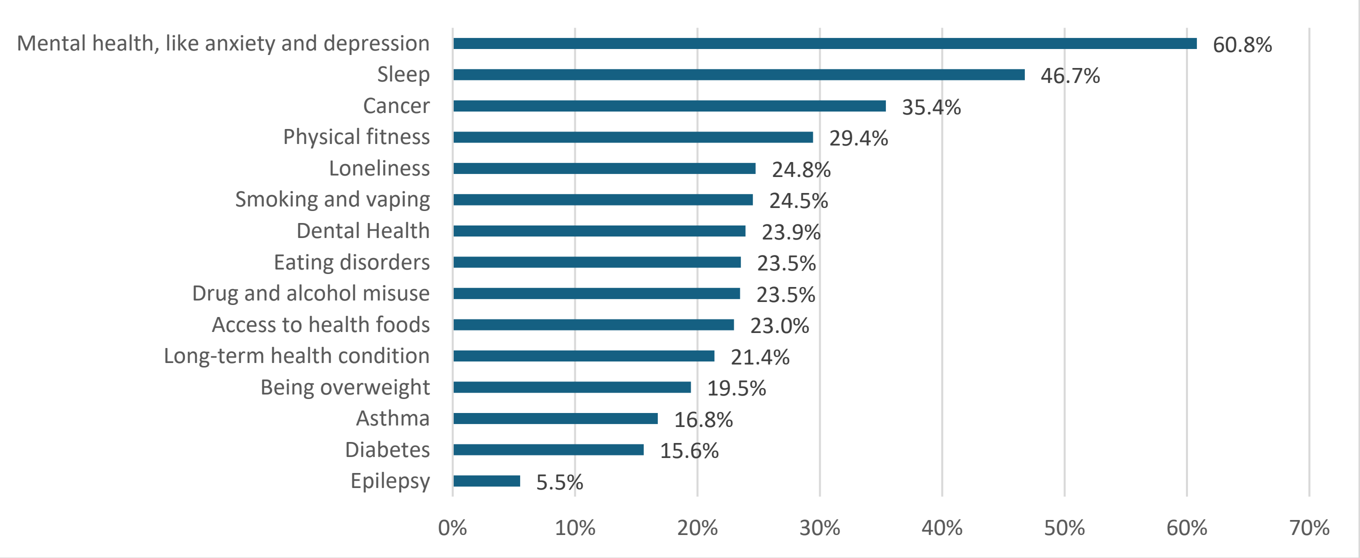
- Children and young people's survey: 1,775 respondents (Online: 872, Hardcopy: 903)
- Easy read survey: 109 respondents.

The findings from the survey are explored below.

4.1.1 Key health issues affecting children and young people

CYP were asked to indicate what health issues affect or matter most to them. The results are set out at Figure 7.

Figure 7: What health issues do you think affect or matter most to children and young people?



(Valid Total =1,814. The results equal more than 100% as respondents could select up to five options).

Conditions that matter	Number
Mental health	1,103
Sleep	848
Cancer	642
Physical fitness	534
Loneliness	449
Smoking	445
Dental health	434
Eating disorder	427
Drug and alcohol	426
Access to healthy food	417
Long-term health	388
Overweight	353
Asthma	304
Diabetes	283
Epilepsy	100

Over half of all respondents (60.8% n n=1,103) stated that mental health issues like anxiety and depression were critical health issues, followed by sleep (46.7%, n=848), worries over cancer (35.4%, n=642) and physical fitness (29.4%, n=534).

Respondents were able to give an "other" option. Of those giving an other health issue:

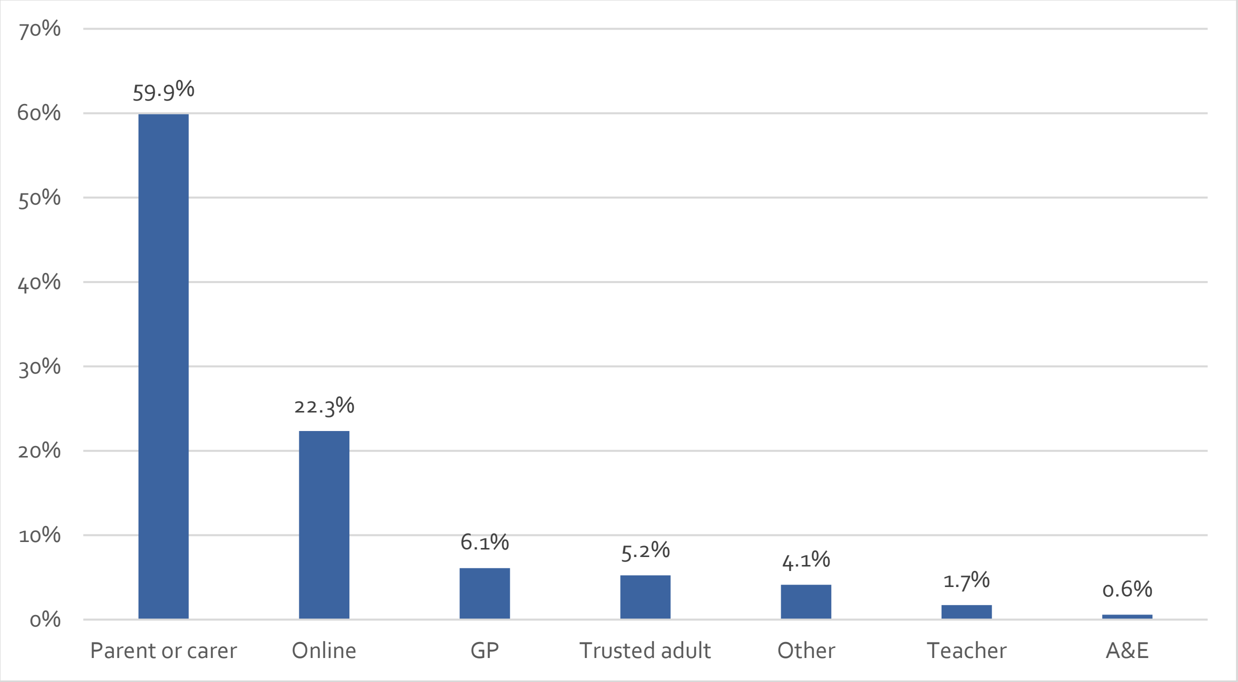
- 11 cited issues relating to neurodiversity (ASD, autism and non-specified),
- Six cited issues around female reproductive health with another three specifically referencing polycystic ovary syndrome,
- Four cited eczema,
- Three stated irritable bowel syndrome.

4.1.2 Accessing health services

Knowing about health services

CYP were asked, "If you were worried about your health, what would you do first?". The results are set out at Figure 8.

Figure 8: If you were worried about your health, what would you do first?



(Valid total = 1,867)

What would you do	Number
Parent/carer	1,118
Online	417
GP	114
Different adult	98
Other	77
Teacher	32
A&E	11

The majority of respondents (59.9%, n=1,118) who answered this question stated that they would speak to their parents or carers if they were concerned about their health. Nearly one-quarter (22.3%, n=417) stated that they would search online about a medical or health concern.

Engagement with a GP was only considered for 6.1% (n=114) of respondents.

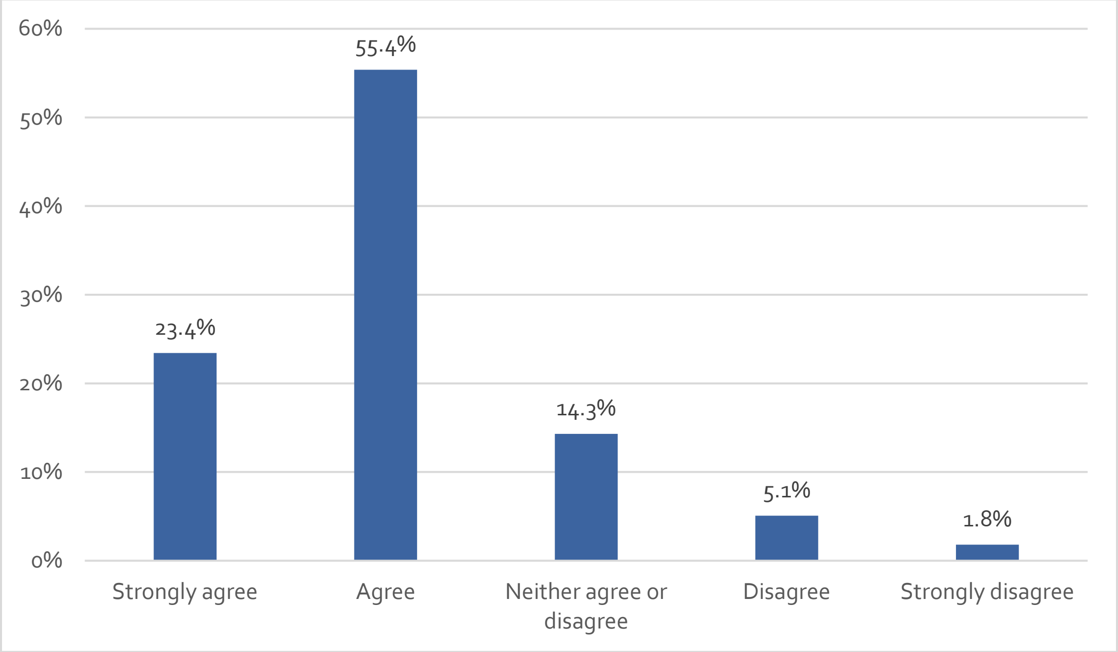
Of those who gave "other" as their response, of some concern, 17 would do "nothing" ("Nothing until I felt it was serious"). The most common response was to tell a friend (n=18).

Of some interest only one respondent indicated that they would use NHS 111 which may indicate that this service is not well known among young people.

Knowing what health services to use

Respondents were asked: To what extent do you agree with the statement: "I know what services to use if I become ill" (for example coughs, colds, serious injuries and long-term conditions). See results at Figure 9.

Figure 9: I know what services to use if I become ill



(valid total =1,775)

What services to use	Number
Strongly agree	416
Agree	983
Neither agree/disagree	254
Disagree	90
Strongly disagree	32

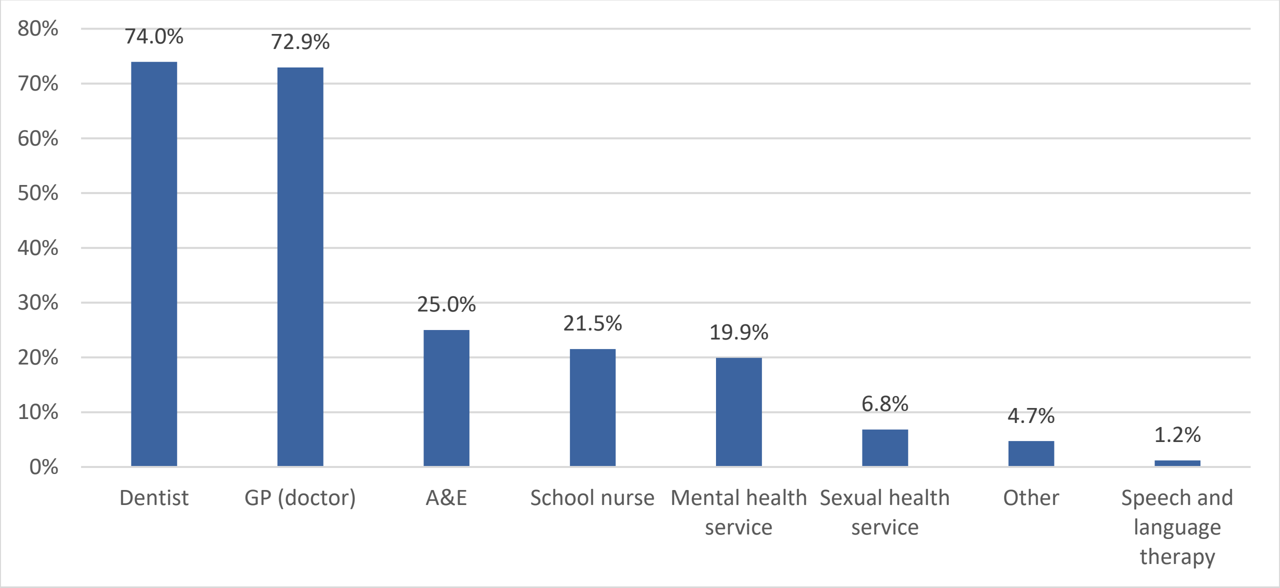
A large majority of CYP indicated that they knew what to do should they become unwell with 78.8% (n=1,399) stating that they agreed or strongly agreed with the statement. Only 6.9% (n=122) of CYP disagreed or strongly disagreed.

Health services used

When asked what health service they had used, two thirds (64.5%, n=1,216) of CYP indicated a physical health service, around one in six (14.9%, n=281) a mental health service while the remainder could not remember.

Young people indicated what health services they had used in the last 12 months. The results are set out Figure 10.

Figure 10: What health services have you used in the last 12 months



(Valid Total =1,843. The results equal more than 100% as respondents could select more than one option).

Health service	Number
Dentist	1,363
GP	1,344
A&E	461
School nurse	397
Mental health	367
Sexual health	126
Other	87
Speech and language	22

The majority of respondents stated use of the Dentist (74%, n=1,363) and GP (72.9%, n=1,344) in the past 12 months.

Reasonably high utilisation rates were noted for the emergency department (25%, n=461), school nurse (21.5%, n=397) and mental health services (19.9%, n=367).

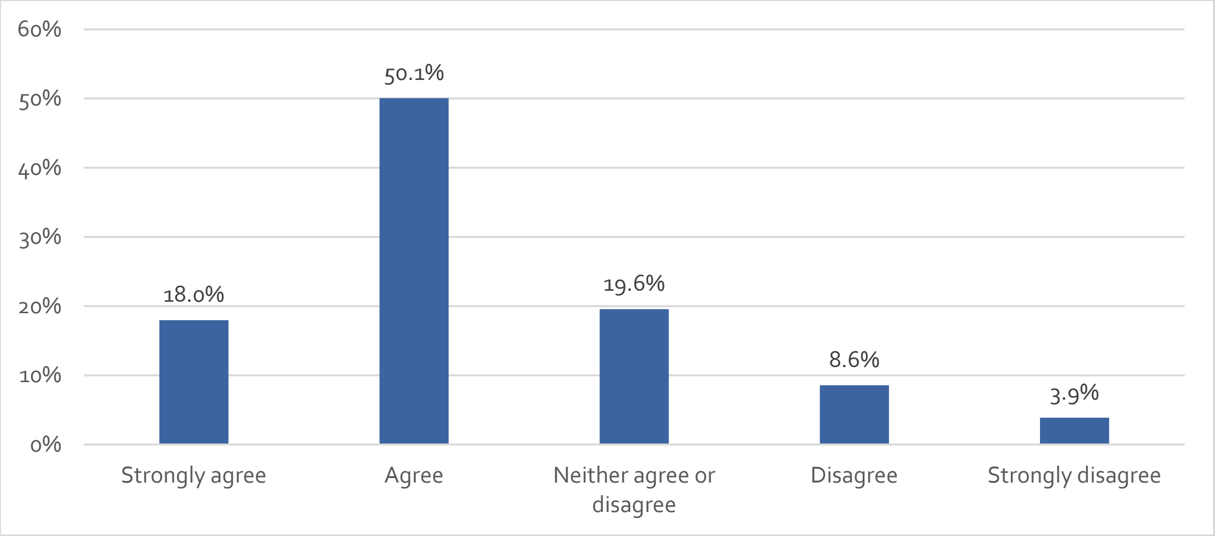
Those who gave an 'other' response were invited to specify what health services they had used.

The most commonly given other service was optician (n=25), followed by orthodontist (n=7), and physiotherapist (n=6) and NHS 111 (n=6). Of interest, only three respondents indicated that they had used a pharmacist.

4.1.3 Health professionals

CYP were asked, "Thinking about the last time you used a health service, to what extent do you agree with the statement: "I felt listened to by health staff"? The results are shown at Figure 11.

Figure 11: I felt listened to by health staff



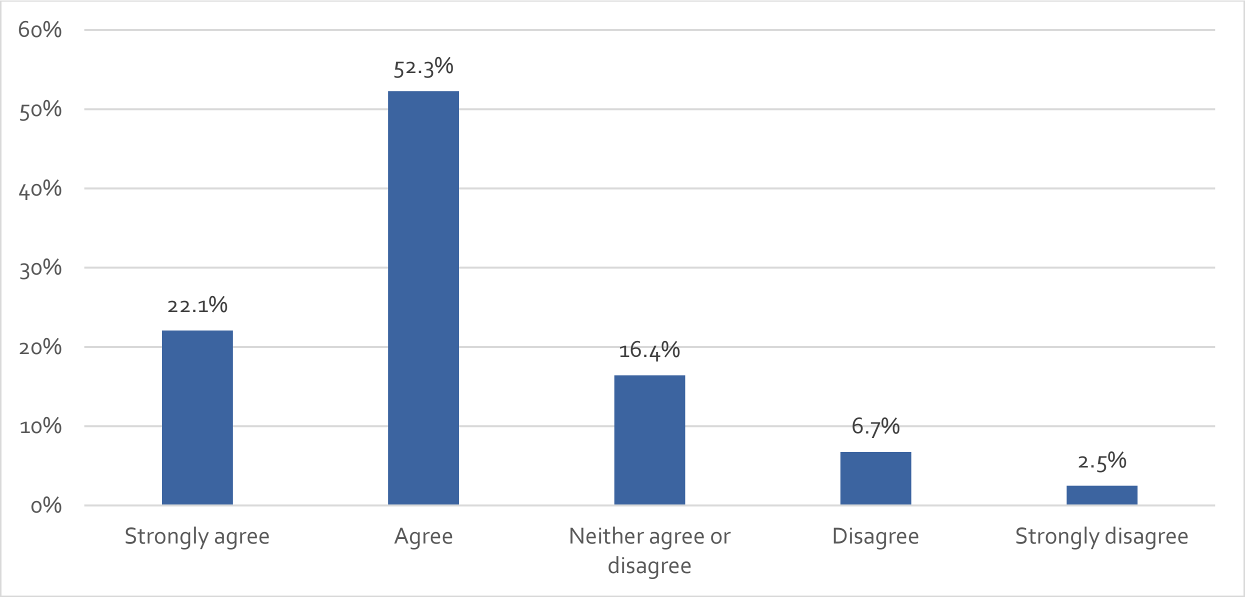
(Valid total = 1,810)

Listened to	Number
Strongly agree	325
Agree	906
Neither agree/disagree	354
Disagree	155
Strongly disagree	70

Over two-thirds (68.0%, n=1,231) of respondents said they felt listened to by health staff.

CYP were asked to respond to the statement: Thinking about the last time you used a health service, to what extent do you agree with the statement: “I was treated with care and concern”? See Figure 12.

Figure 12: I was treated with care and concern



(Valid total = 1,808)

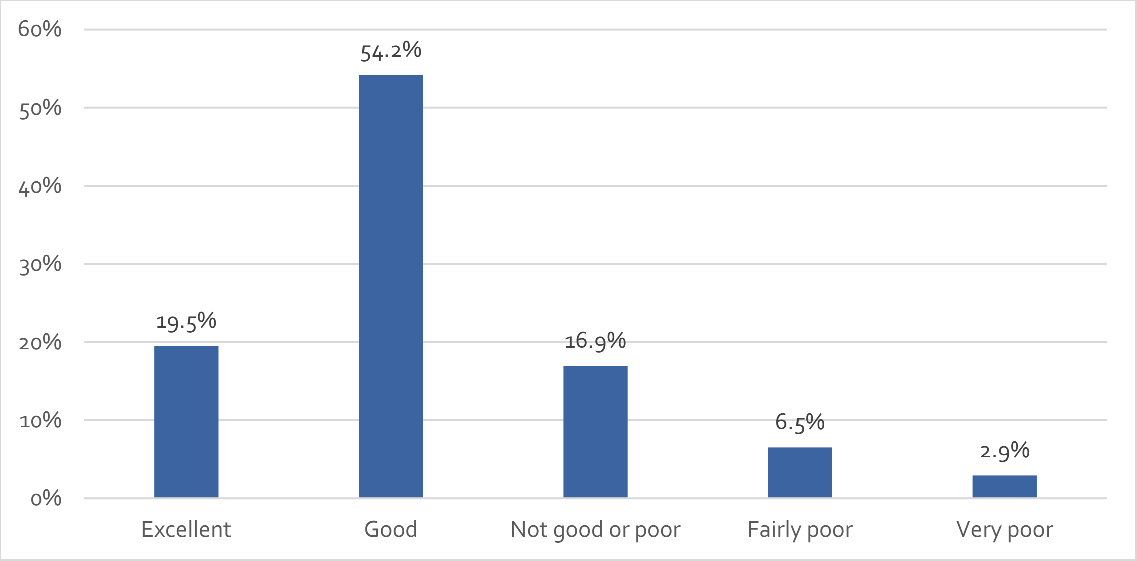
Treated with care	Number
Strongly agree	399
Agree	945
Neither agree/disagree	297
Disagree	122
Strongly disagree	45

Just under three-quarters (74.4%, n=1,344) of respondents agreed or strongly agreed with the statement that they had been treated with care and concern. Fewer than one in ten (9.2%, n=167) of respondents disagreed or strongly disagreed.

4.1.4 Assessment of health services

CYP were asked to rate the last health service that they had used. The findings are set out at Figure 13.

Figure 13: How would you rate the last health service you used?



(Valid total = 1,813)

Assessment	Number
Excellent	353
Good	982
Neither	307
Fairly poor	118
Very poor	53

Nearly three-quarters of respondents (73.7%, n=1,335) stated that the last health service they used was either excellent or good. Fewer than one in ten (9.4%, n=171) gave a negative rating.

Respondents to the survey were asked to give some further information about the rating that they had given. The results are set out in relation to the key themes that emerged.

Caring, compassionate staff

Somewhat strikingly, by far the most commonly given response were comments about caring, compassionate, understanding and supportive healthcare staff that young people had encountered (with 180 respondents giving this as the reason for their rating). A number of quotes illustrate the kind of response given about staff young people had encountered:

- “Because they were very caring and quick.”

- “The staff were nice and polite while doing their job.”
- “My hospital nurse and Dr listen to me and treated me with respect even though I am young.”
- “They took the time to explain things to me and were patient. They didn't do anything that could make me feel judged or uncomfortable.”
- “I was quite worried before my appointment, but I was treated with care and respect.”
- “They were attentive and talked me through everything, I went in not feeling confident but they reassured me and made me feel safe.”
- “Lovely people and genuinely were caring and considerate.”
- “I went to Cahms to have a routine check up before my autism diagnostic exam and the man that I spoke to was very kind and provided me with useful information.”
- “The doctor helped and prescribed medicine, they seemed very concerned and caring.”
- “I was treated very well, checked upon regularly and anything I needed help with I was helped well.”
- “They always have my best interest at heart and want me to be as well as possible.”

Waiting times/long-waits

The next most commonly given issue raised was with regard to waiting times and having to wait for appointments, with this raised by 120 respondents.

- “Ok but it took a really long time to get an appointment even though I was in a lot of pain.”
- “A&E is too long of a wait.”
- “Long waiting time and no clear instructions in specific departments in the hospital after departments changed location.”
- “Because I waited 6 hours to be seen after a car crash.”
- “The waiting time was 8 hours, and I had a broken bone.”

Commonly, while highlighting long waiting time, respondents indicated that the treatment that they received was of a good quality.

- “Waiting times and diagnosis are long and difficult but actual care, when received, is excellent.”
- “It was high quality service but it took 5 hours of waiting in hospital.”
- “The treatment and care given by the staff was great but it was quite a long process and was really exhausting.”

- "I gave this rating as I had to wait 9 hours in a and e but the appointments I go to are very nice in Kettering."
- "The nurses were lovely and it was very efficient and well done but it took a long time to get an appointment."

A somewhat countervailing picture was offered by 50 young people who stated that they had been seen quickly:

- "It was amazing as I was in and out within an hour."
- "I was attended to quickly and my concerns were taken seriously."
- "I had a checkup and it was quite fast and really good."

Being listened to

Young people very highly valued being listened to as this was the third most commonly given reason for the rating (given by 88 young people).

- "The doctor listened to me and talked me through my options well."
- "Was seen on the same day and GP gave advice and booked scans and blood test straight away. I felt listened to and all my concerns were acknowledged."
- "They listened to everything and quickly got everything sorted."
- "Since they listened to what me and my parents said and gave me instructions to how to solve my problems."
- "The staff were attentive and gave me options concerning my problem and were patient."
- "They sat and listened to everything I had to say and did not interrupt me."
- "They were attentive and talked me through everything, I went in not feeling confident but they reassured me and made me feel safe."

Not being listened to

Given the importance and emphasis placed on being listened to, it is not surprising that young people gave negative assessments of their care when they did not feel that their concerns were being listened to or that healthcare staff were taking the time to hear what they were trying to say. Not being listened to was raised by 75 young people.

- "I was dismissed quite early on with no explanation."
- "They didn't take my injury seriously and they said I was fine when I wasn't."

- “Wasn’t listened to by the staff when I was explaining that I was in pain and my cannula was all bruised they said it was normal and left me.”
- “When talking about what was wrong with me physically and mentally they brushed me off and didn’t listen to what I was telling them and blamed it on basically me being a woman and me overeating.”
- “I felt like what I told them was completely disregarded but for me to actually go to a doctor I have to be really ill and this was painful and didn’t seem to be clearing up on it’s own.”
- “Because they never listen to anything I say about my health.”
- “Went in for suspected UTI - have had several before and dip test showed increased leukocytes - when advised by nurse was told it was more likely irritation from fragranced bath products. I did not want to argue as I felt vulnerable for other reasons unrelated to the appointment, and had to wait 5 days for a course of antibiotics when urine sample came back and showed I DID have a UTI, after I had suffered over the weekend and had my trip with my partner ruined by my symptoms that I was unable to manage myself. I felt I had not been listened to and that a lot of physical pain and discomfort could have been avoided if the nurse had listened to me in the first instance of contact.”
- “I was prescribed an external antibiotics zineryt for 8 months instead of the maximum of 8 weeks. I brought this to my doctors attention multiple times and was either laughed at or not responded to.”

Not being listened to was often accompanied by a report that a healthcare worker had not really investigated the issue that the young person was seeking help for:

- “The doctor was reluctant to look at the new rash and diagnosed it with the words 'its probably just' before they had seen it, the other symptoms were coughing up blood for a two day period.”
- “I gave this rating because , last time I went to emergency a & e services they told me it was something not to worry about and then I went home with some tablets and my illness became worse and I had to go back.”
- I was seen by a nurse who tried to play down how ill I was feeling and said that the pains I had were heartburn when it was an infection.”

Uncaring attitude

55 young people reported an uncaring attitude displayed towards them by healthcare staff:

- “Sometimes you feel a bit dismissed by it and that they are just checking boxes.”

- “I felt there was a lack of care and concern , it was like I was another name on their list of patients, no after care was given to me and I ended up having to have my procedure re done.”
- “Mental health issues get ignored and doors slammed in your face no one cares.”
- “I struggle with Urinary Retention and Constipation that happened suddenly in Easter 2023. To be told in September 2023 by a Doctor that I would ‘just have to live with it’ after only 2 tests was disgusting and heartbreaking.”
- “I was told by a doctor to 'stop crying like a baby' before an injection for a broken toe.”

Effective treatment

It is an interesting finding that the actual effectiveness of the treatment provided was highlighted less than the issue above (cited by 51 CYP) – tending to indicate that being treated in a caring fashion and being listened to are, to some extent, more important to young people than clinical outcomes:

- “I gave this rating because they helped me with my ear ache that was excruciatingly painful.”
- “I am receiving treatment for depression and anxiety. All sessions I have had has left me feeling refreshed and hopeful for a solution to my problems.”
- “I went to the GP for acne and was prescribed cream and antibiotics last week. it's already working well and my acne is reducing. I am also a patient with a new adult NHS mental health service and I receive good personalised care from my therapist who I meet with weekly and am making real progress on mental health conditions.”
- “The doctor gave a clear diagnosis, medication and coping strategies.”

Didn’t help/no help given

A small number of respondents (n=55) stated that they received no treatment and/or were discharged without any support or assistance.

- “In some ways they listened, but overall, felt they didn't do much, just sort of pushed me away.”
- “Nothing was done with the concerns I had.”
- Staff member was nice - however I’d been refused many times before for not being ill enough (including about my self harm and suicidal ideation).
- “I have a heart condition and have had a couple operations but at my last checkup I didn’t feel as though I was listened to about my family history with heart conditions as I was asking to be tested for another heart defect that runs heavily in my family in both men and women but my

doctor decided to only test my younger brother and didn't want to test me despite my history which was upsetting and dismissive."

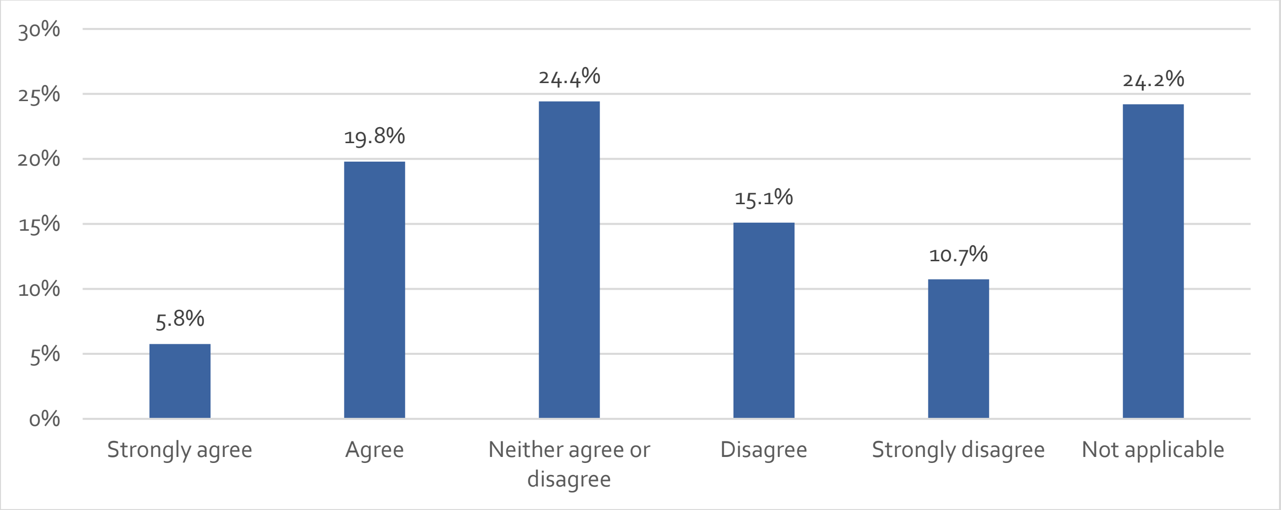
- "I have had tonsillitis multiple times in my teenage years, I went to the GP KNOWING I needed antibiotics and was told there was basically nothing wrong."

4.1.5 Transferring between health services

Speed of transfer

CYP were asked if they had been transferred from one health service to another to get a diagnosis or treatment, and whether this happened quickly. See Figure 14.

Figure 14: I got an appointment for a diagnosis and treatment quickly



(Valid total = 1,789)

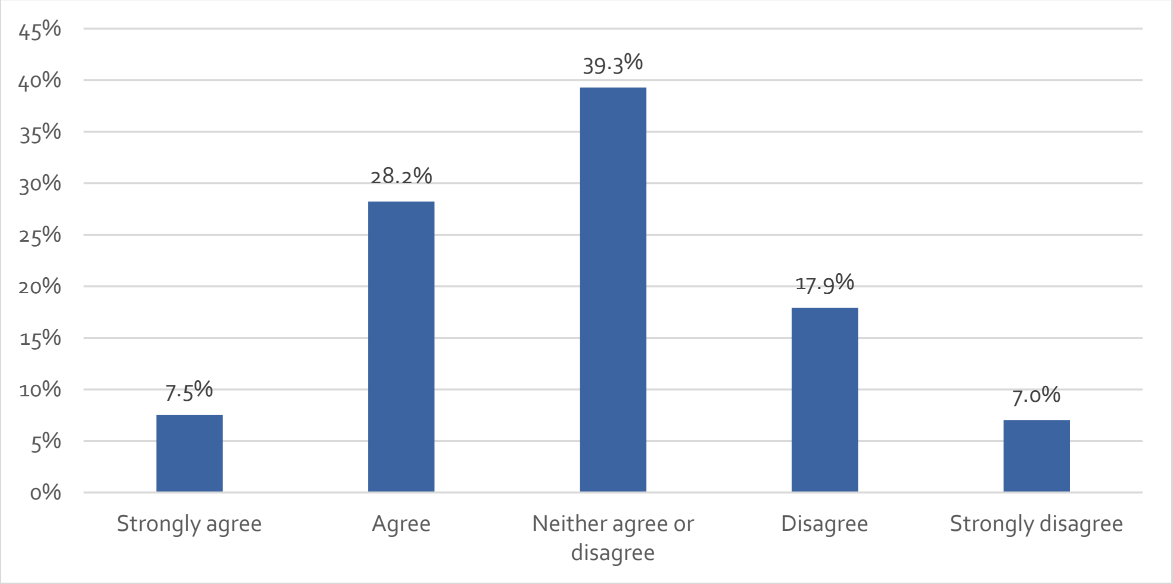
Appointment	Number
Strongly agree	103
Agree	354
Neither	437
Disagree	270
Strongly disagree	192
Not applicable	433

A quarter (25.6%, n=457) of respondents stated they agreed with the statement of accessing an appointment quickly, with a further quarter (24.4%, n=437) neither agreeing nor disagreeing. Around a quarter (24.2%, n=433) stated this question was not applicable to them.

Effectiveness of transfer

Respondents were asked 'if you transferred from one health service to another to get a diagnosis of your problem or to receive treatment to what extent do you agree with the statement: "The service I was transferred to had details of my condition and I didn't have to tell my story again"?

Figure 15: The service I was transferred to had details of my condition and I didn't have to tell my story again



(Valid total = 1,339)

Service transfer	Number
Strongly agree	101
Agree	378
Neither	526
Disagree	240
Strongly disagree	94

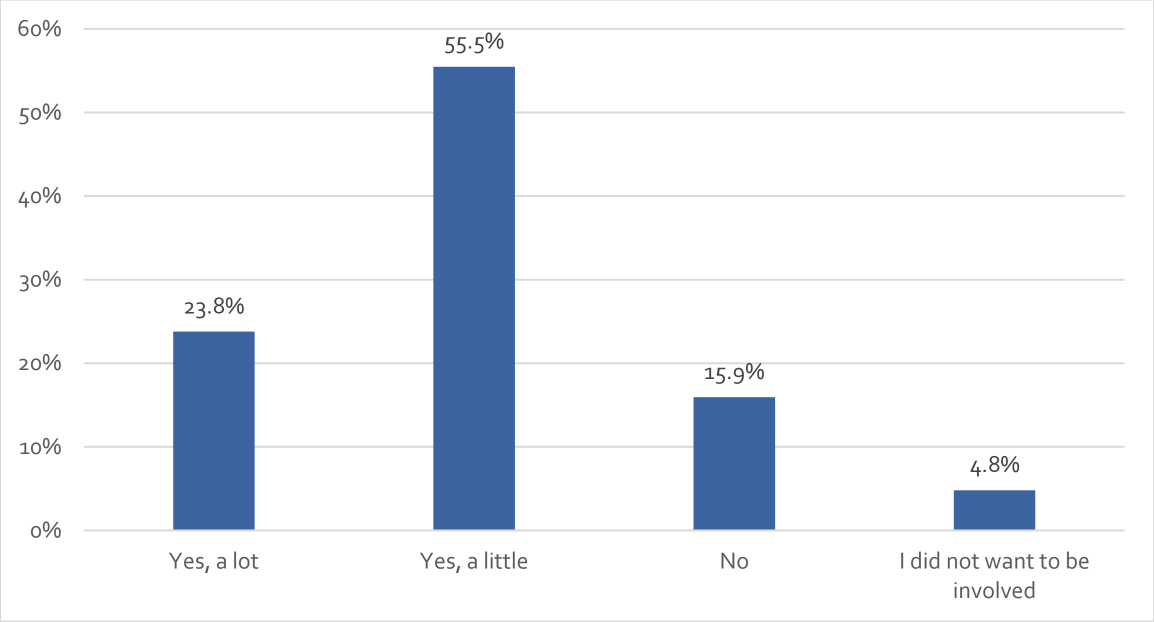
The largest grouping (39.3%, n=526) stated that they neither agreed nor disagreed with having to repeat their diagnosis, although around one-quarter (24.9%, n=479) disagreed (including strongly disagreed) with the statement.

4.1.6 Young people's engagement in health provision

Young people's involvement

Young people were asked whether they were involved in decisions about their care and treatment the last time they accessed a health service. The results are set out at Figure 16.

Figure 16: Were you involved in decisions about your care and treatment



(Valid total = 1,707)

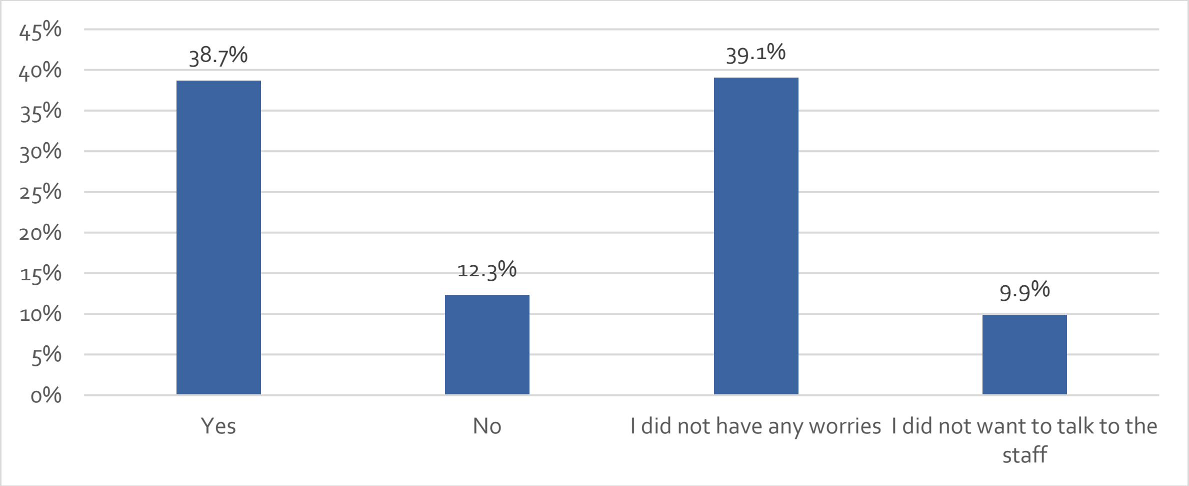
Decision making	Number
Yes a lot	406
Yes a little	947
No	272
I didn't want	82

A large majority (79.3%, n=1,353) of CYP stated that they had some involvement in their decisions about their treatment, with around one in six (15.9%, n=272) stating that they had no participation in their treatment.

Talking to health staff

Young people were asked, if they had any worries, whether a member of staff talked to them about them. See Figure 17.

Figure 17: If you had any worries, did a member of staff talk with you about them



(Valid total = 1,709)

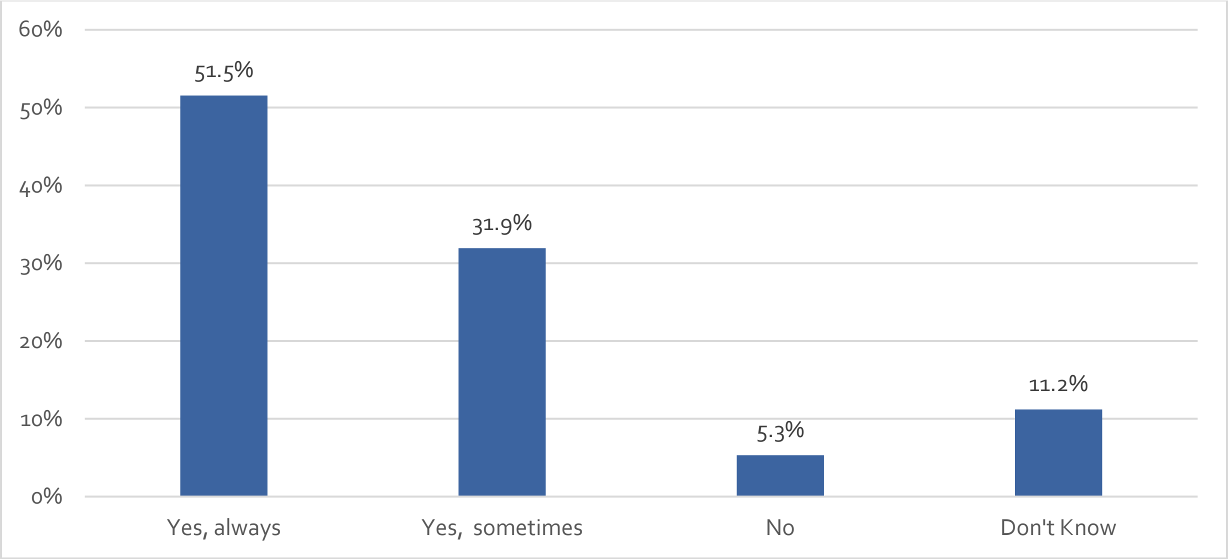
Worries	Number
Yes a lot	661
No	211
No worries	668
Did not want to talk	169

39.1% (n=668) of respondents had no worries or concerns, and 38.7% (n=661) did have concerns and spoke to a staff member about them. Only a minority of respondents (12.3%, n=169) had doubts or worries and did not speak to staff.

4.1.7 Privacy

Young people were asked whether they were given enough privacy when they received care or treatment. The results are set out at Figure 18.

Figure 18: Were you given enough privacy when you received care and treatment



(Valid total = 1,713)

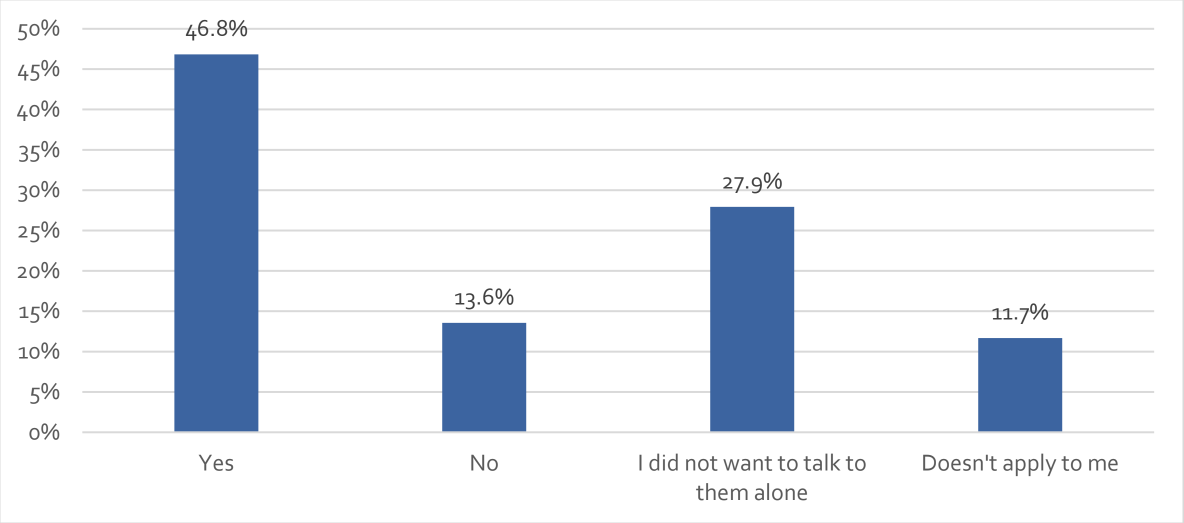
Privacy	Number
Yes always	883
Yes sometimes	547
No	91
Don't know	192

83.4% (n=1,430) of respondents stated that they received privacy during their care and treatment either always (51.5%, n=883) or sometimes (31.9%, n=547).

Engaging health services without parents/carers

Respondents were asked whether they were able to talk to health professionals without a parent or carer being there. See Figure 19.

Figure 19: If you wanted to, were you able to talk to a health professional without your parent or carer being there?



(Valid total = 1,704)

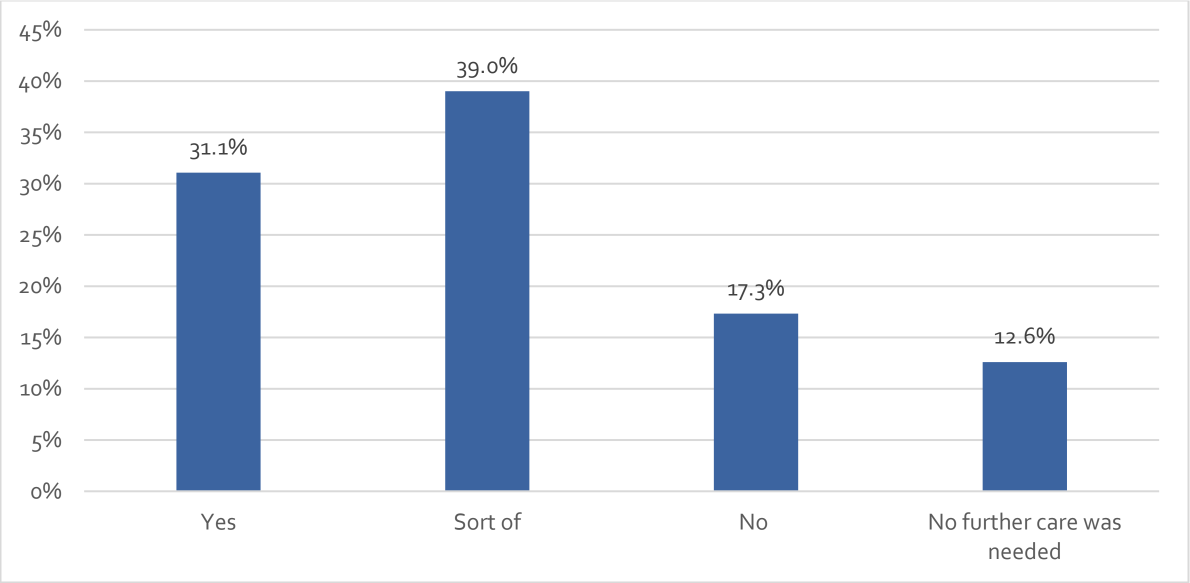
Without parents	Number
Yes	798
No	231
Did not want to talk	476
Does not apply	199

Just under half (46.8%, n=798) stated that they could talk to a health professional without a parent/carer in attendance. (Of interest 27.9% (n=476) of CYP did not want to talk to a health professional alone).

4.1.8 After treatment

CYP were asked 'when you left your treatment, did you know what was going to happen next with your care?

Figure 20: When you left your treatment, did you know what was going to happen next with your care



(Valid total =1,674)

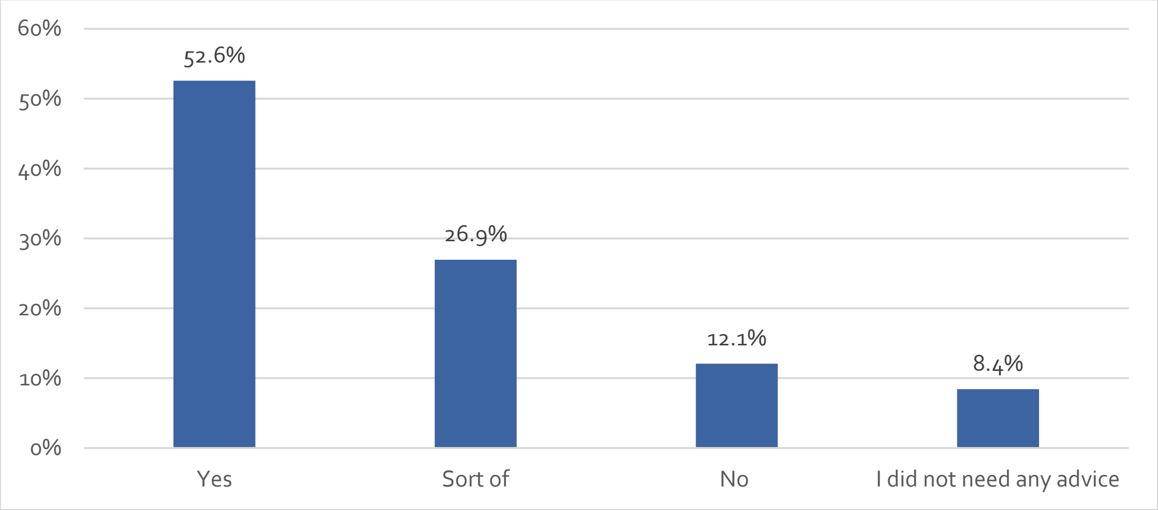
Happen next	Number
Yes	550
Sort of	653
No	290
No further care	211

Less than one-third (31.1%, n=550) of respondents stated that they were sure of the next steps in their care, with 39% (n=653) exhibiting a degree of uncertainty about their next steps. More than one in six CYP (17.3%, n=290) stated that they did not know what the next steps were going to be.

Advice from health staff

Young people were asked "Did a member of staff give you advice on how to look after yourself after you left your treatment?

Figure 21: Did a member of staff give you advice on how to look after yourself after you left your treatment



(Valid total =1,674)

Advice	Number
Yes	880
Sort of	451
No	202
No further care	141

Over half (52.6%, n=880) of respondents stated that they had received advice on looking after themselves post-treatment, with over one-quarter exhibiting a more ambiguous response (26.9%, n=451)). Around one in eight (12.1%, n=202) had not received advice.

4.1.9 Discrimination

Young people were asked whether they had experienced any discrimination or barriers when using health services.

9.8% (n=163) of young people indicated they had experienced discrimination or a barrier, while 73.4% (n=1,222) said not. 16.8% (n=279) did not know. (The remainder did not answer the question).

Respondents who had experienced discrimination or barriers were asked to give further information.

Racism

The most commonly cited form of discrimination highlighted was racism as identified by 11 CYP. Comments provided that referenced racism included:

- "A lady didn't think my chicken pocks were severe as they didn't display how it should have if I was white."
- "The doctor was saying to test my blood that me and my mum should go to India. Me and my mum are Indian."
- "Called a racist word p*** (short for Pakistani)."
- "Simply just being treated more kindly due to my religion choice and being treated as if I didn't understand when I have lived in England my whole life."
- "Assumed I was Asian instead of asking ethnicity."

Sexism

Ten young people believed that they had experienced sexism in relation to accessing healthcare services. As one noted: "As a woman with sexual health issues, I felt ignored and there were a lot of barriers that my GP put into place to getting the help I need."

Others felt that their symptoms were discounted based on their sex, "As a woman with sexual health issues, I felt ignored and there were a lot of barriers that my GP put into place to getting the help I need". And as another observed: "Being a female and being seen by a male professional can sometimes feel difficult or like they expect us to be emotional or over exaggerate". One noted that, "Not receiving adequate treatment. Due to lack of understanding of women's autonomy to receive actual treatment for lifelong symptoms rather than masking it with the pill." Another noted, "When you're round and a girl, every issue you tell your gp will either be down to your period or growing pains, even if severe. And they'll probably push you to go on the pill without thoroughly going through it with you."

Not believed

Nine respondents indicated that they felt that they were either not listened to or that healthcare staff disbelieved them on the grounds of their age. As one noted: "The long-term health condition I have now was complicated that when I was younger, my problem was dismissed as being entirely, or largely mental due to me being a 'child'. There was a failure of the duty of care due to my age." Other comments included:

- “That fact that I'm young doctors don't think I know what I'm talking about when it come to my own health.”
- “A doctor said my anxiety wasn't something I should worry about because its normal for a teen to feel anxious.”

Transphobia and being misgendered

Five young people reported incidents of what they perceived to be transphobia or that they were misgendered. Comments included:

- “Yes, when undergoing my gender transition I felt judged and prejudged from heterosexual members of the healthcare industry. They frowned upon me for my sexuality decisions, this partly being due to my religion.”
- “I am trans and felt unsafe to get help from my gp and physio as there was no signposting for inclusivity.”
- “I was misgendered by someone who thought my long hair made me a girl and referred to me as such, which I found very upsetting. There was no need for them to refer to me as a boy or a girl.”

Neurodiversity

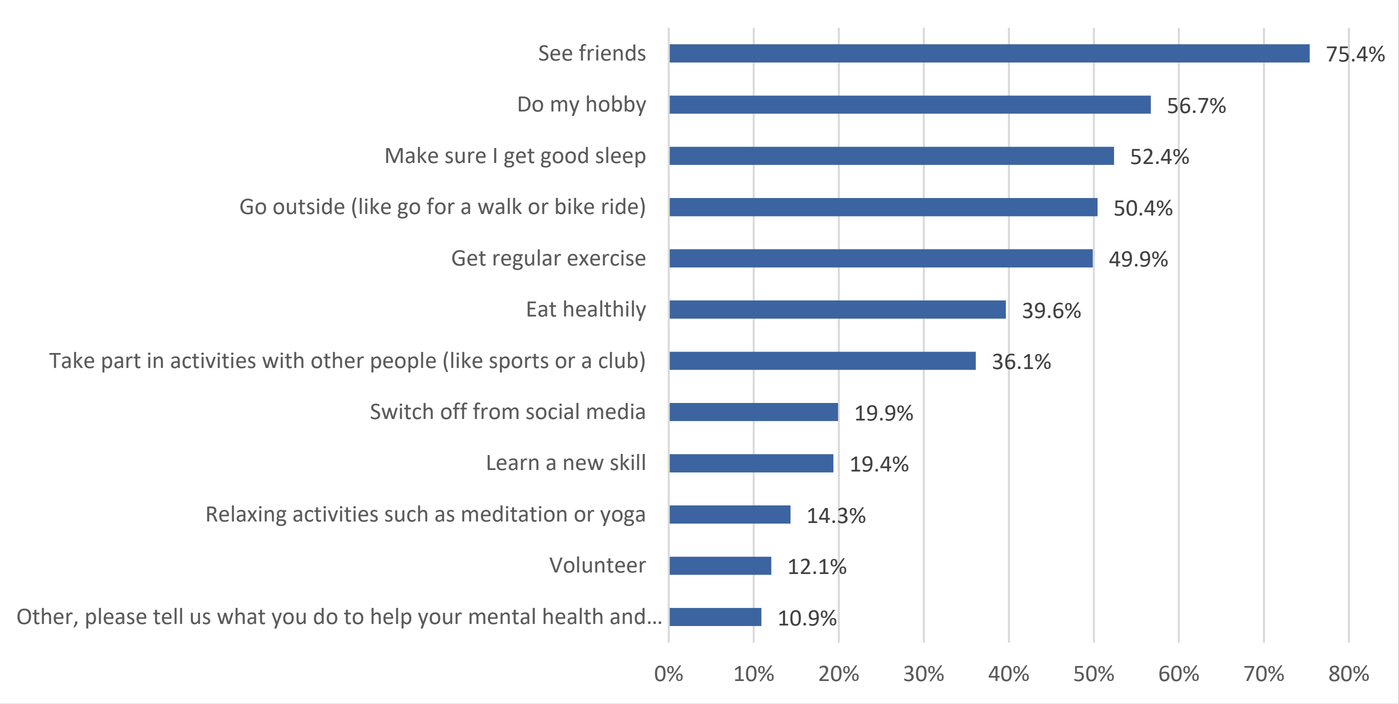
Young people with neurodiversity (n=5) felt that health services either didn’t understand their needs or failed to take their neurodiversity into account when treating them:

- “As a person with ASD I had multiple instances of my pain not being taken seriously as I ‘looked to calm to be in pain’ I find it hard to express emotions in general so of course I looked calm/expressionless. I do not see why the staff could not just take my words seriously. Fortunately that has not happened again in the last 1 year or so, which is great.”
- “Lack of autism awareness, belief that I was overreacting rather than actually being extremely distressed.”

4.1.10 Managing their health

Young people were asked what they do to help their mental health and wellbeing. The results are set out at Figure 22.

Figure 22: What do you do to help your mental health and wellbeing



(Valid total = 1,642) It should be noted that respondents could select more than one option so the totals equal more than 100%.

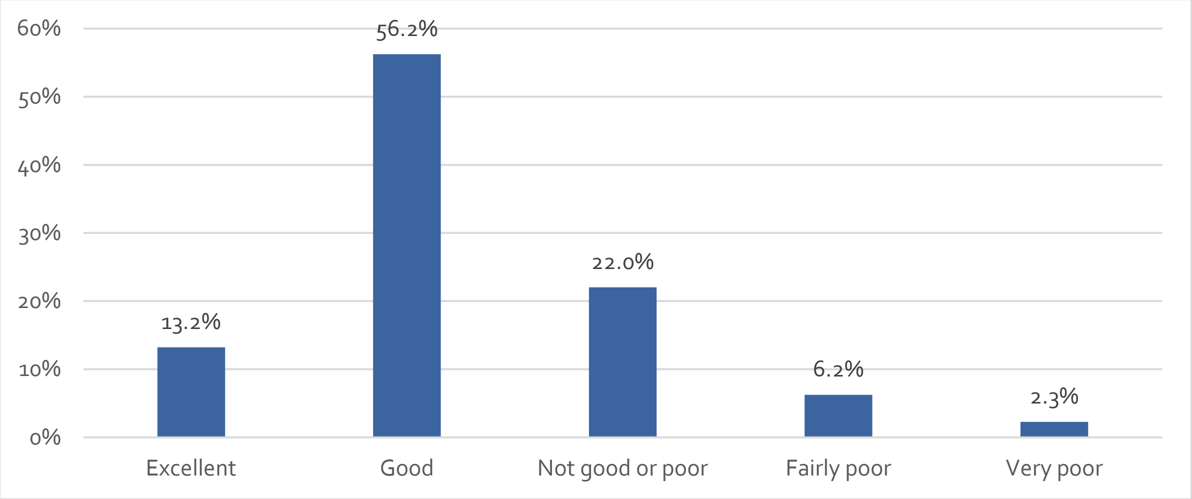
Mental health	Number
See friends	1,238
Do my hobby	931
Good sleep	860
Go outside	828
Exercise	819
Eat healthily	651
Activities	593
Switch off social media	327
Learn a new skill	318
Meditation/yoga	235
Volunteering	198
Other	179

Over three quarters of respondents, 75.4% (n=1,238) stated that they see friends to help with their mental well-being. Other activities included doing a hobby (56.7%, n=931) getting good quality sleep (52.4%, n=860), going outdoors (50.4%, n=828) and getting regular exercise (49.9%, n=819).

4.1.11 Overall assessment of healthcare

Young people were invited to give their overall assessment of healthcare. See Figure 23.

Figure 23: Overall, how would you describe your experience of your healthcare?



(Valid total =1,634)

Overall assessment	Number
Excellent	216
Good	919
Neither	360
Fairly poor	102
Very poor	37

Over half (56.2%, n=919) of respondents stated that their overall healthcare experience was good. More than two-thirds (69.5%, n=1,135) reported that their experience was positive (excellent or good).

Respondents were asked to say why they gave the rating they did for their overall assessment of healthcare experience. Around 8% (n=93) of respondents stated that they had no issues and that was the reason for their response, and a further 5% (n=58) said they did not know or had no idea.

Respondents were invited to provide further information about why they had given the rating that they had about their experience of healthcare (as set out at Figure 23). The information that they provided is analysed below.

Good or positive experiences

28% (n=240) of the comments about their rating of healthcare indicated that the respondent had had a positive experience. Positive comments included:

- "I have been treated really well, a few slip ups but still good."
- "It's good. They do what they need to do."
- "The service I got was just all round great."
- "I have had many doctors, nurses etc. over the years, and for the most part I have been treated very well and they have been very supportive during difficult times. Many got to know me on a personal basis and it make me feel supported. I appreciate everything the NHS have done for me."

Respondents also stated that they felt listened to, supported, and understood by caring and helpful staff. Comments included:

- "People dealt with my situation with good care and I felt listened to."
- "Very caring and easy to talk to. Listen to me when I raise concerns."
- "Professionals I've spoken to have always been helpful and welcoming."
- "There when I need it. Treated with compassion. Feel listened to."
- "I know that there is support around me and I feel happy."

Others stated that they had given a positive rating because they had always had good experiences of the health service.

- "I appreciate and am grateful for the free healthcare provided for people in full time education such as myself, and have not had any negative experiences or unjust treatment by any staff that I can remember."

Waiting times

Whilst the majority of comments stated that the service they had received was good (see above) over one in ten comments made (12%, n=106) cited waiting lists as an issue when assessing their overall experience of healthcare:

- “Apart from long waiting times for appointments quality of care is good.”
- “Long waiting time and last minute appointment cancellations.”
- “Long waits and sometimes staff do not make an effort to understand.”
- “Waiting times for appointments and diagnosis is poor. It has affected my life negatively and I am losing trust that the nhs is the best place to manage my health and care.”
- “The help received is good but it has long waiting times or long periods between sessions and appointments.”
- “I’ve been on waiting lists and waiting lists for so many years my condition has taken over my entire life. it’s so scary.”
- “The healthcare is good however waiting lists are very long”

Mental health care

Other respondents identified issues around mental health care and accessing CAHMS as a reason for their rating. Comments included:

- “Mental health is not prioritised and often ignored especially as someone who is physically fit.”
- “Physically it has been very good but trying to receive help for my mental health has been slow and pretty much unhelpful as it always leads to dead ends.”
- “Within CAMHS I have felt dismissed a lot and only taken seriously when I was in crisis or in hospital after an attempt on my life.”

Furthermore, respondents stated that whilst the physical health and medical care they had experience was good, accessing appropriate and good mental health care was a challenge:

- “Medical care has always been good, easy to access and care given appropriately mental health care was appalling. No support given whatsoever.”
- “I had a negative experience with CAHMS, wasn’t taken seriously nor listened to. However, as for physical health it has typically gone well.”
- “In the physical care aspect such as my asthma and immunizations staff are lovely and quick to help or respond to any concerns. In the mental health area I feel that it is a real struggle to receive much support without it being an emergency situation.”

Access to appointments

Another issue raised by respondents when giving a negative rating was how hard it is to access appointments, particularly with their GP:

- "When I do get an appointment and speak to someone it is great, but it is almost impossible to get an appointment online and I work when the reception is working so calling to book an appointment is difficult. It got to the point at which I just give up and either see a doctor when I visit my parents in my home country or just go private".
- "It's incredibly hard to get a GP appointment. Once I got one it often ended on a phone call or on a very short, vague face to face visit. I don't feel like my concerns were ever taken seriously. What seems to be a chronic condition lasting 5 years keeps being disregarded. Every time I go to the GP I'm advised to take painkillers as if I'm not doing that already. I would like to get better advice and actual diagnosis. Also the last time I spoke to a GP about my mental health, I was shown a religious quote (I'm not religious myself) saying that I should accept the things I cannot change. I made a formal complaint and never heard back about the outcome of that. It's overall really disappointing and it makes me question calling my GP for help in the first place."
- "It's hard to access care from GP and I'm always made to feel like my calls are unnecessary or that I'm wasting their time."
- "Very hard to get an appointment - staff seem to be under pressure so don't give you full priority when speaking you (reception staff can be rude)."

Additional observations

Having given an overall rating for health services (as explored above), respondents to the survey were asked to provide any last comments about their health, health services or the NHS.

Of those who provided additional comment, the most commonly referenced issue was in relation to mental health which was raised by 25 CYP. The focus of their comments was for greater attention to be paid to this issue:

- "Better services are required in Leicester for treating mental illnesses such as eating disorders, OCD etc."
- "Don't brush signs of mental health issues under the carpet and stop underdiagnosing."
- "I don't suffer with mental health issues but I have friends that do and they find it particularly hard to seek help, know where to go and when they do the waiting lists are 18 months - 2 years

long. Unless you are immediately about to harm yourself or others, there is no immediate support."

- "I feel like the mental health uni of the NHS is very poor and there is no one who listens or cares, I'm trying to get a diagnosis and I have to jump through so many hoops to access the right care.
- Mental health is not taken as seriously as it should, especially regarding diagnosis of disorders.
- Mental health services are shocking. I was kicked out of an and e whilst trying to hurt myself and kill myself whilst experiencing psychosis. I attended A & E four times and hadn't slept for a week before I was admitted to a CAMHs unit in Nottingham. Worst experience at the Leicester Royal Infirmary and by the Crisis teams EVER. disgusting and traumatising.

A number of young people specifically referenced the need for greater levels of investment:

- In general I feel that the mental health side is severely lacking in funding, resources, and dedicated and experienced staff. I feel that staff should be trained in more specific areas rather than having a basic knowledge of all areas and a lack of ability to prescribe .
- Mental health services need more funding and people who actually understand mental health running them. Need doctors to believe patients more and not just decide they are wrong or dismiss their concerns.
- Please give more funding to mental health services, they are severely understaffed and the waitlist is ridiculously long to get treatment.

In addition to the general comments on mental health, seven young people referenced issues in relation to CAMHS. Comments included:

- "With camhs I've only been to one appointments in the past year and a half, I know the wait is long but if there is anything to reduce waiting lists that would be amazing, it almost seems you need to become really ill to be treated, it shouldn't be this way."
- "Being on a long waiting list for camhs and not being given work to do at home due to my anxiety and feelings around school-this is unfair and impacts on my learning."
- "CAMHS needs better funding / improvements."
- "Fix your approach to CAMHS, for everyone there is not sufficiently cared for."

Consistent with findings elsewhere in the survey, following mental health, the next most commonly cited issue was waiting times (referenced by 22 respondents):

- "I had to wait a long time 2 to 3 years. It affected my life a lot."
- "Waiting lists are too long, needs sorting."
- "Waiting times are ridiculous, especially for surgeries after covid."

Seven young people reported that there needs to be a greater focus on neurodiversity:

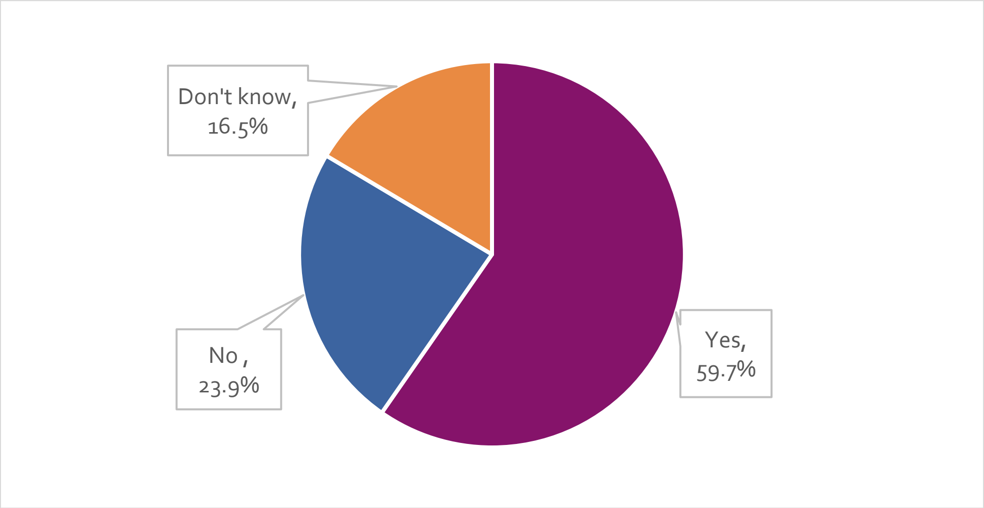
- "ASD diagnosis - Took ages, and was a battle. I have blanked out most of the process, so I do not have any idea exactly what happened."
- "Make sure that more people get tested for things like autism and adhd as it can cause a lot of problems, I have been waiting for my diagnosis of autism since I was 5 and I am now 14 and nothing has been done."
- "I couldn't get a referral for an ADHD assessment and my family had to pay privately as CAHMS didn't help at all."
- "I've been waiting ages for my ADHD assessment appointment."

4.1.12 Mental health

Seeking help for mental health

Respondents to the survey were asked, if they wanted help with their mental health, would they know who to contact and how to contact them. The responses are set out below.

Figure 24: If you wanted help with your mental health, would you know who to contact



(Valid total =1,632)

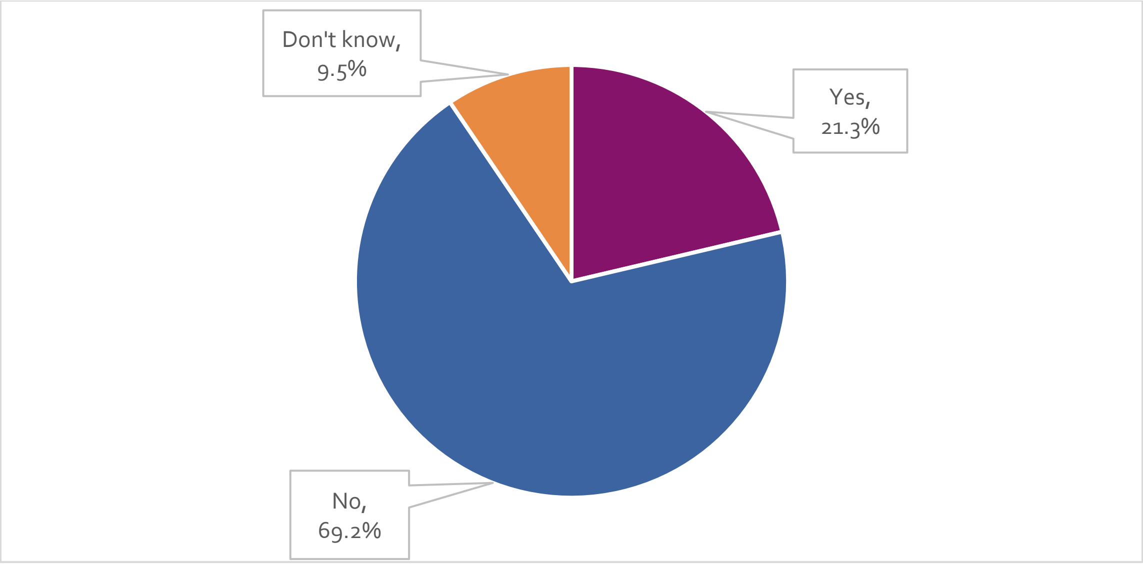
Who to contact	Number
Yes	983
No	393
Don’t know	271

Most respondents (59.7%, n=983) stated that they would know who to contact and how to contact them. Just under one quarter (23.9%, n=393) of respondents did not.

4.1.13 Use of mental health provision

Respondents to the survey were asked whether they had used a mental health service.

Figure 25: Have you used a mental health service



(Valid total =1,656)

Used	Number
Yes	353
No	1,146
Don’t know	157

Around one-fifth of CYP (21.3%, n=353) stated that they had used a mental health service at some time in the past.

Supporting mental health

CYP who accessed mental health services were asked what other support they would like.

176 young people provided information on support.

Of some interest, the most common response was "Don't know" (given by 22 young people) thereby clearly indicating that young people do not necessarily know what additional support would help.

Of those who gave an indication of what support they would like, the most given was support in schools, identified by 11 young people:

- "People to talk to in schools for EVERYONE, not just the most and in-need cases."
- "Meaningful advice in school and courses for parents."
- "More talks in schools, better skilled staff, more training for adults."
- "I think it would help within schools and universities for each academic department to have its own pastoral or mental health support, specific to that area. There could also be more awareness of anxiety and depression and other mental health conditions and basic teaching about how schools and universities can support students better that have these types of mental illnesses."

Related to support in schools, some young people also felt that teachers should receive training:

- "Giving teachers more SEND training so they have the ability to pick up on SEND more easily and earlier on. Thus providing more health and support as they grow rather than having to "fix" problems down the line."
- "More understanding/ knowledge within teaching staff."

Eight young people indicated that therapy should be more widely available and free at the point of access (some noting that they had had received therapy privately"): "Therapy one to one paid for by the NHS." As another noted, "I was referred to Cahms and adult mental health and neither of them could see me within 12 months so I have had therapy and counselling privately multiple times due to the NHS lack of help."

Young people also requested free access to counselling:

- "Making counselling more accessible and affordable as I find it really useful but depending on my finances I sometimes can't afford it and it really makes a difference."
- "Counselling without years long waiting lists."

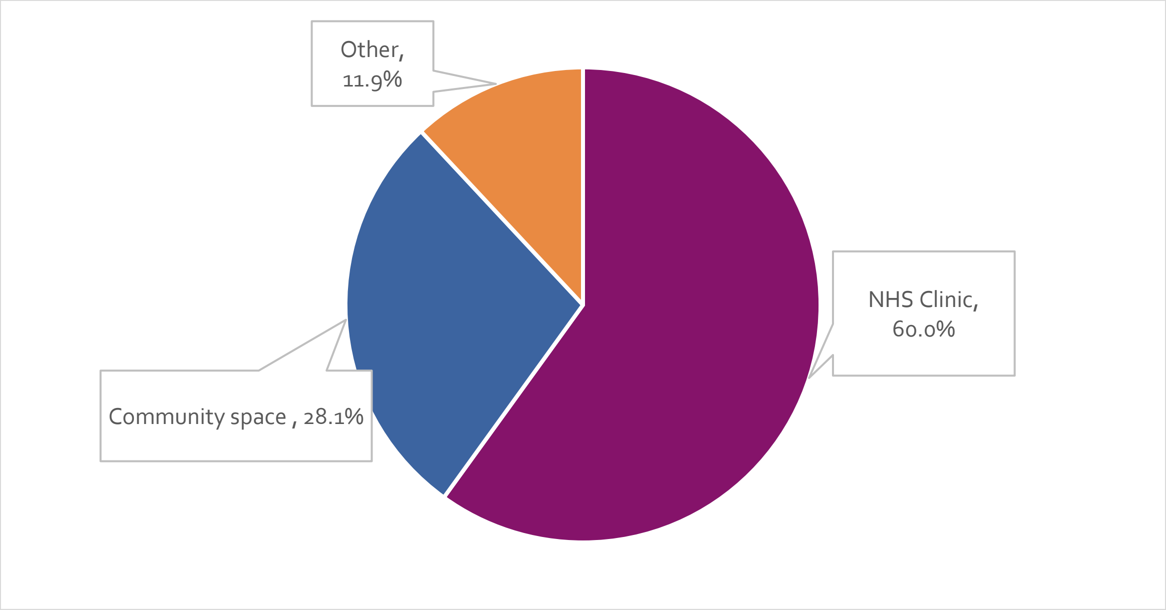
Of some interest, young people did not ask for additional support online, with only three respondents indicating that they wanted more web-based resources. One respondent stated that mental health services are: “virtually non-existent....always referred to checking out a website......not always the best advice when you feel bad.”

Also of some interest, four young people wanted increased/better access to medication.

Where they wish to access mental health services

Young people who had used a mental health service (therefore a subset of the entire survey population) were asked if they had an appointment with a mental health service, where they would like it to take place.

Figure 26: If you were to have an appointment with a mental health service, where would you like it to take place?



(valid total = 477)

Where	Number
NHS Clinic	286
Community space	134
Other	57

60% (n=286) of respondents (who had used a mental health service) stated that their preference was for a mental health appointment within an NHS Clinic, with over one-quarter (28.1%, n=134) preferring a community space (e.g. a café or youth centre).

Young people who cited "other" were given the opportunity to indicate where they would like the appointment to take place:

- 10 young people indicated at home,
- Seven stated at school,
- Four that it should happen in a "private" location (non-specified),
- Three stated that it should be online/virtually.

Transitioning to adult mental health provision

18.7% (n=83) of young people with experience of CYP mental health services had transitioned from children's to adult mental health services.

Of those who had transitioned to adult mental health provision:

- 31.7% (n=63) indicated that they had understood about the transition process,
- 34.3% (n=68) had been provided with information about adult mental health services or services available in the community,
- 33.9% (n=65) said that information about adult services was easy to understand.

Young people were asked to suggest what a good mental health transition service would look like.

A key issue raised by a number of young people related to how the transition process was (or was not) communicated to them. Various aspects regarding improved communication were raised. As such all comments on this theme have been set out below:

- "Being given more knowledge on services."
- "Good communications between both services. All information transferred before transmission. Ensuring that the patient has immediate support after the transition. Making sure patient is aware of what is going to happen. Listen to their concerns and don't make decisions for them."
- "Giving warning before had that this would occur and through the process explaining how things work/ what difference there are without having a time where there is no contact with the patient."

- “Was a bit confused and didn’t completely understand. Would of liked a bit more detail on the differences.”
- “Someone who would explain in full detail but for a kid to understand.”
- “Mental health professionals informing me, rather than teachers.”
- “Digestible information with not too much information.”

A commonly cited theme was the idea of a “smooth” transition. Young people offered a diverse range of ideas about what would constitute a more seamless handover. Given the range of issues explored, the comments on this theme are set out verbatim below:

- “One appointment with paediatric and adult services and me, then a quick transition to adult services. You should not be discharged from paediatric services until the adult service is in place. They need to listen to the patient on what adult service is going to work for them rather than making assumptions.”
- “To not be discharged as soon as you go into adults!”
- “Having a clear profile of my information to pass on so that I don't have to tell my whole story again.”
- “Being introduced by your CAMHS worker to the other workers and having a meeting together with yourself and your CAMHS worker involved with the adults team.”
- “As a young person is turning 18 (in the 6 months prior) they should be introduced to their new workers and informed of who/where they need to go for different conditions.”
- “Slow and steady! I felt like I was just discharged from CAMHS within a click of the fingers with no other help.”
- “More appointments between the two services for a proper handover.”
- “Appointments flow smoother rather than being dropped after CAMHS.”
- “One that involves the same staff that know me, not having to repeat everything all the time.”
- “One where the NHS don't kick you off the waiting list? Or a GP who doesn't take you off of your sleeping tablets. Reminders of the fact you are changing over to Adults Mental Health. Letting you know when you move up on the waiting list.”

Three young people emphasised having a supportive environment in adult services:

- “Welcoming place.”
- “A calm area with helpful staff who can explain things in a simple manner.”
- “They listen and make you feel comfortable.”

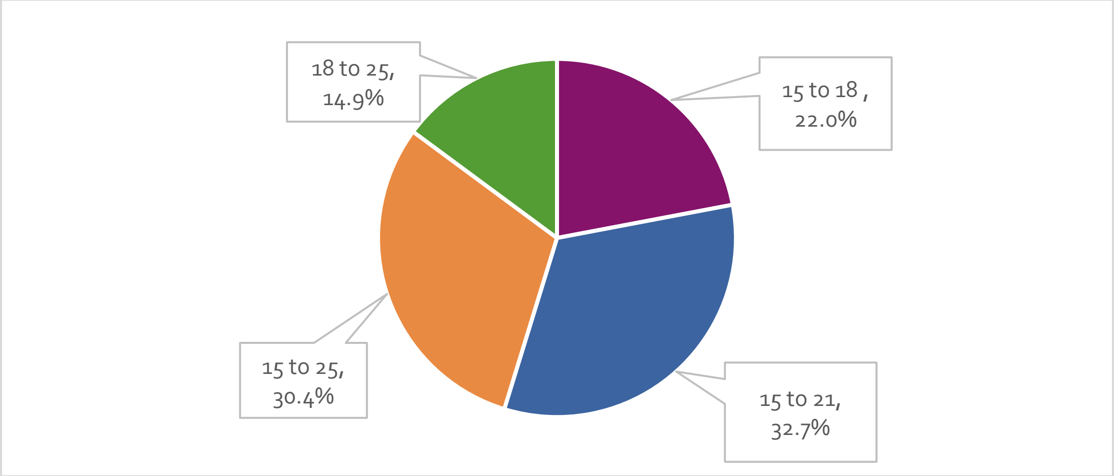
One young person explored how their gender identity was supported during the transition to adult services: "Be more accepting of my unsure identity as I felt a bit judged when using the services and explaining how I don't want to be my gender anymore. This made me feel hurt and rejected by society and I wish more transgender individuals like myself were present in the mental health service community. When undergoing my hormone treatment and surgical genital removal, I wished I had more support as I felt isolated from my classmates who laughed when I began to grow breasts."

Finally, there was an interesting observation from a young person who had elected not to transition into adult mental health service but felt that more information could have been given to inform this decision:

- "It's hard to say, I was discharged from cahms and decided not to pursue adult services at the time as I had gotten out of crisis point and mental health was improving. Now I am in treatment for trauma related to past crisis point. It would have been good to know what transitioning to adult services would look like. For example would I have counselling or someone to check in with every now and again at a local gp surgery. I feel I didn't want to go down the route of adult services at the time, but perhaps if I knew more about what it would entail I may have chosen to do that."

Young people were asked the age range that mental health transition should cover. The responses are set out below.

Figure 27: What age range should the mental health transition service cover?



(valid total = 168)

Age	Number
15 – 18	37
15 – 21	55
15 - 25	51
18 - 25	25

There was a wide range of responses to this question, with the most favoured response including a 15-21 age range (32.7%, n=55) followed by 15-25 years (30.4%, n=51). Caution is advised in the interpretation of this finding as there was a high level of non-response (i.e. from the large majority of CYP who had not accessed mental health provision.

4.2. Participatory activities

As noted in the Methodology section, 355 young people were engaged via participatory activities. All young people consulted were asked to explore both physical and mental health concerns. A range of other themes were also identified in the data from the participatory activities. These themes are explored below.

4.2.1 Health concerns

By far the main health concern that young people expressed was about their mental health with nearly two-thirds of responses being about this topic.

The conditions they commonly experienced were depression, anxiety, autism, stress, and ADHD.

The factors underlying these issues included pressures at school, while others discussed the pressure about appearance that came from social media and cyberbullying. Family breakdown was a factor for some. Others, like a group of young men, had experienced significant trauma. Young people reported that there are delays in getting support, diagnosis, and treatment for mental health difficulties and these were expressed in all focus groups and in answer to several of the topic questions.

Behavioural difficulties appear to be a grey area for treatment in specialist mental health services with one facilitator commenting that "*Without a formal diagnosis, schools may be unable to enrol these* *children in supported programs designed to address their specific needs. This lack of timely intervention not only impacts the child's learning experience but also increases the likelihood of temporary discharges, suspensions, or expulsions from school, further exacerbating their mental health struggles*".

4.2.2 Mental health self-help

Because CYP reported that they could not get timely support or treatment for their mental health difficulties a range of self-help strategies were reported. Most of them talked about their problems with someone they could trust such as a friend or family member and many used exercise to improve their emotional wellbeing. Some turned to music, journaling, religion, prayer and meditation, although as one observed "*Who wants to meditate if you have poor mental health? Why would you want to be alone with your thoughts*?"

Of some concern, several young people said they would rather just keep things to themselves. This particularly applied to the asylum seekers who felt that they might not be understood by services when they tried to explain what had happened to them. A young person from the Polish community in Leicester felt it would be "*better to just bottle things up-keep quiet*", and a young mother said her response to her mental health difficulties was to "*cry*". A few other young mothers used positive self-talk to "*tell myself I am OK*". Only one young person from all those consulted mentioned taking an antidepressant medication.

One group of young people were reluctant to go to their parents for mental health support as they felt they would not understand the pressures they felt "*The world has changed since their day*".

Although some identified social media as a source of emotional distress, several turned to TikTok to cheer themselves up. Only one group thought that limiting access to social media would be a way to support their mental health.

While young people clearly wanted to talk about their problems and to socialise to lift their mood, they did not always feel that therapy or counselling was the answer. Some said that they "*don't like to talk much about their feelings*". As one noted: "*I think it would be great if there was something where people can open up… it's not even about paying for it, it's more like therapy, but not "therapy" because people don't like the word "therapy" it's more like having social groups where you make friends and can talk about how you feel*." A group of young men were cautious about therapy because "*I had that before and then I had an appointment with the doctor for mental health. They say they're going to help you in different ways… but if you focus with them in some way, you're going to be crazy more than that [group laughs in* *agreement] because they're going to remind you of the thing you want to forget, they're going to remind you… I want to forget*."

Adding to this, one young person said: "*That's why going to a therapist is something that most of these guys would not really go to… it's easier to bury down the pain than to just open it out*." .Their trauma was such, and the experiences they had had, were so distressing that they could not face thinking about them in a therapeutic context.

A couple of focus groups revealed situations where young people felt despair, for example one who said "*I don't do anything; I just stay in bed all day*" and another who believed that "*they turned me away because I haven't killed myself yet. They could have tried to at least help me".* (It is understood that these young people have since received therapeutic support from the service conducting the focus group.)

4.2.3 Physical health concerns

Apart from the mental health concerns discussed above, key health concerns for CYP were vaping, diet and weight, and long-term health conditions such as asthma.

4.2.4 Sources of health support

Children and young people mostly went to their parents or another trusted adult in the family or a friend for health advice when they felt unwell. Several had asked a teacher or had accessed a school nurse. A young woman commented that "*The school nurse pays attention to your needs and picks out the thing that needs the most work*".

Most were familiar with going to the GP, using 111, or, for mental health problems, accessing CAMHS, a therapist or counsellor. Many young people reported going online or using social media to get health advice and information.

Some had used A&E departments or had called an ambulance but reported having been surprised at the lengthy waiting times.

Others had appropriately made use of pharmacists and walk-in centres where available.

Many young people in this participatory engagement reported using exercise to improve their physical, and often, their mental health.

4.2.5 Appointments and waiting lists

It was a universal complaint that getting a GP appointment when needed was extremely difficult and time consuming. The most common experience was being told to call at 8.00am, waiting in a long queue but then not getting an appointment at all. As noted by a young person: "*It's not easy, you have to call two or three times.... They say from 8 to 8:30, but when you call them they don't pick up*." "*You have to be on the phone bang on 8 o'clock to get an appointment*.

As noted by a facilitator: "*Most of the young people would say it's generally good service but could be better if they didn't have to wait 6 months for hospital appointments and GP surgeries often have no appointments left after 9am waiting 30 mins on the phone in a queue they say no more appointments left.*"

Appointments, when offered, could be in school or work hours and the advice given by a GP was not always understood or appreciated. Some young people reported that they felt "fobbed off" when told to take paracetamol without an explanation or prescribed medications that they didn't really understand.

Some thought that the NHS was understaffed and that doctors were probably underpaid, although a couple felt that doctors should not go on strike. A group also mentioned extreme difficulties in getting access to a dentist. As one young person stated: "*For someone to be able to get into a dentist is hard... it's usually referral to referral to referral*". This is despite the fact these young people are looked after by the local authority so are required to have a dental check up every six months.

Travelling out of the LLR ICB area was an option for some with one centre reporting that:

"*It is practically impossible to be seen by a specialist if you need. Many will travel to Poland [their country of origin] to see the specialist they need. This is quite common".* A carer had this experience: "*Fortunately, we were told that we could get seen sooner in Nottingham. So, we opted for that. But we are able to travel there. Some people cannot*".

4.2.6 Being listened to

Listening to patients and parents

Some young people had good experiences of being listened to, especially in cases where they had gone to A&E for injuries. A 13-year old said " *I hurt my ankle after football and my mum took me to the doctor's; they sent me for a x-ray and I thought he was fine he listened to me and checked my ankle properly*".

A 10-year old said "*I went hospital with my mum because I fell on my head tripping over something at home but it was bleeding so we went and they took care of me nicely*."

However, a very large number of children and young people felt they had not been listened to or respected in their encounters with health care professionals. Young mothers felt they were seen as "*hysterical*", "*overdramatic*", or not as capable of caring for their babies as older parents. They felt their concerns were dismissed, even in cases where it turned out that their baby was seriously ill – for example one infant who eventually went on to being fed by tube because of feeding difficulties that had been dismissed. It was reported that it felt as though health staff were often in a rush: "*They listen to what they want to listen to so they can get the appointment done quicker."*

How practitioners listened and explained could depend on the specialism or the condition being treated with specialists thought to be better than GPs.

"*It really depends on the service; GPs are not great. I go to my physiotherapist, and he is great, really approachable and communicates well with me if I have questions*". As another young person observed: "*GP's don't listen or communicate very well. Specialist CYP doctors do. It can't be hard*?"

Another reported that: "*Specialist paediatricians are very good at communicating with children with SEND. My GP is not good. I understand that people have different experiences, but speaking to children must be a skill that all doctors/nurses have*".

Parents of children with special needs expressed particularly poor experiences. For example: "*I have so many complaints lodged. I don't want to, but if I don't, nothing will get done. My kid could not do this, and shouldn't be expected either*. *The hours I have put into fighting to get my child the correct medical care are taking their toll. I have had to give up jobs to lobby to get the right care. Complaining costs money and my wellbeing*".

Communication between services

Problems were identified with services not communicating with each other. A young person with a long-term condition said "*When you don't fit into the system, communication between hospitals doesn't work. I got discharged from Great Ormond Street Hospital, and came under UHL's carer. At GOS I was having physio and I was getting better. When I arrived in Leicester, the In-patient Physio said they couldn't work with me and I had to go to the Out-patient Physio. The Out-patient Physio said I didn't meet their requirements. I ended up having to do my own research and find a charity organisation who could help me with my physio. All the time I was getting worse and worse*."

4.2.7 Equality of treatment

Many young people believed that health services treated everybody equally. This view predominated among groups of young people from mainly white focus groups (such as those conducted in some schools). One young person assumed that the NHS treated everyone equally: "*I'd think so since they campaign for race and gender equality. This is good, training staff and making sure healthcare professionals are recognising people as individuals*".

A facilitator of one group emphasised that equal treatment depended on particular variables: "*For those that did feel seen, they were happy with the care they received, yet this did depend on the healthcare professional's ethnic background or their level of cultural competence and it was different across the organisation.*"

Language, accessibility and cultural competence were all highlighted as important parts of ensuring equal treatment.

Language and interpreting

One group felt that language access was "ok" because, "*GP surgeries are ok around Highfields because they can speak their language and that helps*".

One group had other strategies: One person said he used his phone: "*For me, with any translation I use my phone. It can be a long wait for translation services, but you can just write what you want on your phone and it translates into English.*"

Others disagreed and said they would ask for translation to be provided by health services: "*First time when we came here, I'm not speaking English, so I need it. Never had any problem getting access to translation services, always been a good experience*".

Experiences of discrimination

Particular groups reported experience of discrimination, based on age, ability and race. These are explored below.

Age and gender

It was a common experience in the group of 26 mothers aged under 25 that they felt that they were looked down on, for example a 20-year old woman who said "*I feel as though people get mistreated, people such as young mums, get treated unfairly and as though we are incapable of doing what a 30-year old mum can do*" (Young Mother) and "*When I was in hospital with baby they looked down on me*"

Race and ethnicity

Young people reported experiences of racism: "*Ethnic minorities are treated with much less care because doctors assume that black people can handle pain and underestimate our symptoms*". Young people from the same group were clear that practitioners do not understand what certain conditions, such as jaundice, look like on dark skins.

One young person explained that "*There can be stereotypes and racism anywhere; just because they make you feel better doesn't mean their views on you might be good*"

4.2.8 Long-term health conditions and disability

Children with long-term health conditions were affected by appointments that took place during school hours which impacted their learning and privacy. Those who had been able to access CAMHS expressed similar difficulties with appointment times. Recently CAMHS appointments have gone online which was not satisfactory:

"*CAMHs online meetings don't really work. When dealing with mental health it is better to be face to face. I only get notified 10 mins before my online CAMHs appointment when I am at school. It is hard to find a private place in school, and Wi-Fi or my mobile data is dodgy at school*" We note that it is not clear how this will work if schools prohibit mobile phones.

Children and young people with disabilities had fundamental problems with access: "*Wheelchair access. The Adolescent area in Children's ED can't fit a wheelchair in, so you must sit with the little kids*

Both children with long-term health conditions, and carers were fed up with having to repeatedly explain their condition to professionals. "*If you have long-term conditions, building relationships with your health team is important. You need trust. But lots of professionals leave or move around. You end up having to explain everything to the new staff member*". Better record keeping and retention of key staff members would help with this, but this reflection is another comment about the importance of good listening and communication between teams and services.

4.2.9 SEND and profound and multiple learning disability

Families with children and young adults with SEND had serious difficulties in accessing services and receiving equal treatment. A group of eight mothers of children with complex needs expressed difficulties getting appropriate care for their children who were usually unable to advocate for themselves:

"*I have lost trust with the NHS. As parents of children with special needs, we have to tell our story over and over again. You have to fight for every inch of healthcare. You get drained of energy, you are angry, frustrated. Nothing changes. This then filters into our home life. It doesn't just end at the end of the telephone or at the end of the appointment*".

One mother and her son with special needs had a frightening experience of treatment that was not adjusted to the family's needs. "*My son needed a CT scan. I have a two-year old as well. I couldn't get childcare, so I had to bring the two-year-old with me. My 11-year-old son had to have a CT scan on his own. I was not allowed to go with him because I had the two-year-old with me. There was no play specialist or provision to put my two-year-old in for a few minutes. My son came out and he was very shaken by the experience. So was I*".

Another mother said "*My 22-year-old child has Down Syndrome and she can't understand everything. Especially complex medical things. If the doctor cannot explain the issue to me in a way that I can understand, how can I explain it to my child?"*

Students at a Special School wanted more accessible eye tests: some of the young people said they had been for an eye test but didn't really know their alphabet very well. As a result, they were worried they have the wrong prescription for their glasses. However, the young people also said that they like to have their appointments with the opticians on their own (without a parent), because they feel that they can handle it and there won't be any difficult questions.

4.2.10 Information and communication

The participants were well informed about sources of healthcare but wanted to understand more about the NHS and have things explained in a way that they understood. It was reported that one group said: "*Young people like the personal touch. They like verbal and face to face information given to them. It makes them feel human*. *Follow up info to refer to, young people said they like leaflets, and especially when the GP talks them through the information*".

A group of Polish young people wanted:

- Pop up sessions and roadshows,
- Dedicated apps for young people,
- Online peer to peer opportunity,

- Working with social groups and clubs to engage young people on topics like vaping/mental health.

Many young people wanted something that was integrated with school such as assemblies or in the curriculum. A higher profile for NHS health information on social media, especially YouTube and TikTok would be something they would all appreciate.

4.2.11 How could NHS services in Leicester, Leicestershire and Rutland be improved for children and young people?

The children and young people consulted had plenty of ideas for improving NHS services in LLR. The responses gathered from the activities are set out below.

More resources

They had views on the infrastructure around NHS services. Many thought that it would be a good idea to build more hospitals. They thought that the NHS needs more staff especially at GP practices. According to these participants the way to recruit more GPs would be to pay them more. Others wanted the staff that are already employed to do things differently.

Easier access

Having a better system for making appointments was commonly requested – especially answering the phone more quickly. Others wanted the attitude of staff towards young people to change "*Employ people who are passionate and care about young people. There are people who clearly don't like young people or are a bit afraid of working with them. Could we provide healthcare staff with Young People awareness training*"?

Dedicated services

Children and young people would like dedicated primary care services for their age group. Surgery times at GPs just for children and young people were one suggestion and one group suggested that there could be a separate 111 line just for young people. Many people in this consultation had used 111 and found it helpful when they couldn't get a GP appointment.

Improving health

Young people were aware of the importance of health promotion and disease prevention. Nearly all the young people were aware of the importance of exercise to improve both physical and mental health and many suggested that free gym entry or exercise programmes would be a benefit to both the NHS and the young people themselves. More advice on getting into shape would be welcome such as using social media and apps such as YouTube to encourage fun fitness activities for children.

Young people wanted more restrictions on vaping which they recognised is both addictive and very accessible.

Several groups reported that they would like regular health check-ups and blood tests as they sometimes fear they may have a serious condition which doctors are missing, or even dismissing.

Working with schools and youth workers

One group suggested that Youth Clubs are a great way to improve mental health and to better engage young people.

"*For mental health, work more with youth clubs and support these: "Youth clubs – they clearly work. People love going to youth clubs as a way for them to, like… Youth clubs have lots of facilities like pool tables, TVs, PS4s, that's a good way for people to enhance their mental health because it's a good place for them to relax, no stress or nothing."* Another young person felt that youth workers would be useful staff members in the NHS working alongside healthcare practitioners "*Employ more staff who have good senses of humour and are good at working with young people. These could be youth workers as well*".

Integrating more with schools would help them understand both the services that are available and how to look after their own health. There were several suggestions that there could be guest speakers from the NHS at assemblies. While acknowledging the confidentiality issues, healthcare teams need to communicate better with schools. A child with a long-term health condition said that it had taken "*ages*" for a SENCO at school to realise she was in hospital and send some work for her.

4.2.12 Being Chief Executive for the day

Young people were asked what they would do if they had the opportunity to be the CEO of the NHS for the day.

Young people wanted health chiefs to listen to them, both as individuals and in consultations.

A young mother wished that:

- Everyone is listened to,
- Everyone is treated fairly,

- More appointments available,
- More groups available, and
- Help everyone no matter the age

A group of young people made the following suggestions:

- Make ads that help children feel more comfortable with healthcare.
- Put time into teaching medical workers to take young people seriously and to make school initiatives that encourage children to not hide medical/mental illness.
- Regular engagement opportunities for young people; visibility in schools
- Improve the wait time and hire more people with the correct pay.

A group of mothers who cared for young people with complex learning disabilities wanted the Chief Executive to know that:

- MH services need investment, for all ages.
- CAMHs admissions process must be fixed. Waiting lists need to be reduced and communication to young people and parents about what is going on needs to be better.
- Waiting lists need to disappear!
- "*I'd swap my bonus and invest it in understanding neurodiversity in young people – it probably wouldn't go far!"*
- *"I want people in power to really understand our situation*."
- "*I would recognise the lost hours of children's education. They miss out on so much education to fit in their healthcare*."

CYP people wanted to feel that they had been treated fairly, seen promptly and that someone had listened to and understood their concerns. They needed treatment options and plans to be clearly communicated to them and to feel that nothing serious had been missed.

4.3 Key Findings

The key findings from the 1,884 young people who completed the survey were:

4.3.1 CYP Survey

- The most commonly cited health issue of concern to CYP was mental health, as noted by 60.8% (n=1,103) of survey respondents. Of some interest, the next most commonly cited issue was sleep as identified by 46.7% (848) of CYP. Also, of some interest cancer was identified by over a third (35.4%, n=642) of young people. Perhaps related to the concern around mental health, almost a quarter (24.8%, n=449) of respondents stated that they were concerned about loneliness. (All data Figure 7). (Note how this finding correlates with the most commonly given response given by young people regarding what they do to help their mental health, with three quarters (75.4%, n=1,238) indicating that they see friends. (See Figure 22). The concern around mental health was picked up in the free text aspect of the survey where young people, when asked what else they would like to share, were most likely to raise mental health as a key issue to be addressed. (See Section 4.1.11).
- When asked what they would do if they had a health concern, the majority of young people (59.9%, n=1,118) indicated that they would talk to a parent/carer. 22.3% (n=417) would evidently seek to "self-serve" the information they need by going online. Of considerable interest, only 6.1% (n=114) would contact their GP. (See results at Figure 8). Allowing for the fact that the majority (60.7%, n=960) of the survey population are minors and might therefore rely on their parents/carers to make decisions about contacting primary healthcare, it is also the case that over a third (38%, n=601) of those consulted were aged 17 years or older. It is somewhat surprising therefore that, given this profile, more young people did not indicate that they were prepared to contact their GP of their own accord.
- Slightly countervailing the picture set out immediately above, a large majority (78.8%, n=1,399) of young people reported being confident about knowing what services to use should they become ill. A very small minority (6.9%, n=122) were uncertain what to do should they become ill. (Data at Figure 9).
- Despite few young people reporting that they would contact a GP, the majority (72.9%, n=1,344) of CYP indicated that they had seen their GP in the last year. This may tend to imply (as suggested above) that parents/carers are the primary means by which young people access primary care. A similar proportion (74%, n=1,363) of young people reported having seen a dentist. Of some interest, a quarter (25%, n=461) had attended A&E. This is possibly indicative

of a lack of access to primary health services but this is necessarily conjectural. The data however indicates much higher levels of use of emergency medicine than might otherwise have been expected. (Data at Figure 10).

- There is a generally positive endorsement of health professionals with over two thirds (68%, n=1,231) of CYP stating that they feel listened to by health staff. (Figure 11). Equally CYP felt that they were treated with care and concern, with 74.4% (n=1,344) supporting this statement. (Figure 12). Note also that CYP were positive about the health service that they had most recently had contact with, around three quarters (73.7%, n=1,335) of CYP rating their most recent contact as excellent or good. (Figure 13). Young people's overall assessment of healthcare as also positive with over two thirds (69.4%, n=1,135) reporting their experience as good or excellent. (Figure 23).
- The accompanying qualitative data to the rating on the last health service used provides considerable insight. The most commonly given reason for giving a positive assessment of health services was that staff were caring and compassionate. Young people also emphasised the need to be listened to. Strikingly, these two themes were mentioned more often than a positive clinical outcome. Note also that uncaring staff and not being listened to were key reasons that young people gave for a negative assessment of health services. (See Section 4.1.4).
- For those young people who had been transferred from one health to another only a quarter (25.6%, n=457) of young people indicating that they got an appointment quickly. (See Figure 14). Almost exactly as many (25.8%, n=462) indicated that they had not got an appointment quickly. Note also that a quarter (24.9%, n=334) of young people who received an onward referral indicated that the service did not have details of their condition (also that the most common response was neither agree nor disagree). (See Figure 15). The results therefore tend to indicate some issues where CYP are transferred or referred between health services.
- A positive endorsement was given by young people in relation to feeling involved in decisions about their care and treatment, with the majority (79.3%, 1,353) feeling engaged (albeit that the majority - 55.5% (n=947) - felt they were engaged "a little"). A small minority, 15.9% (n=272), of young people did not feel involved in decision-making which gives some cause for concern. (Data at Figure 16).
- More strikingly, while evidently involved in decisions about their care, less than a third (31.1%, n=550) of CYP left treatment knowing what would happen next. Around one in six (17.3%, n=290) stated that they did not know what would happen next. (See Figure 20). Note also that only

around half (52.6%, n=880) of young people were given advice on how to look after themselves after treatment. (Figure 21).

- Discrimination was said to have been experienced by 9.8% (n=163) of young people. When asked to explain what they had experienced young people offered examples of racism, sexism and transphobia (albeit low numbers of young people reporting each). A small number of young people felt that health staff did not understand the needs of neurodiverse patients. (See Section 4.1.9).
- With regards to mental health, while the majority (59.7%, n=983) of young people indicated that they knew where to seek help, around quarter of respondents(23.9%, n=393) did not. (Figure 24).
- Consistent with the findings whereby mental health was the biggest health concern among CYP, just over a fifth (21.3%, n=353) of survey respondents had accessed a menta health service. (Figure 25).

4.3.2 CYP Participatory activities

The key findings from the 355 youth participation groups were:

- The prevalence of mental health conditions and concerns, together with difficulties in getting support and treatment with those concerns.
- Difficulty in getting appointments with primary care services and lengthy waiting lists for hospital treatment.
- Not feeling listened to or respected by healthcare professionals.
- Inequalities within healthcare provision for some groups of children and young people and their families.
- Most young people went to parents, friends, or family for help with healthcare, but they were also aware of, or had used, GPs, pharmacists, 111, 999, social media and A&E services.
- Information would reach them best on YouTube and TikTok, but they liked verbal information too.
- They had a variety of suggestions for how services could be improved for young people and children.

Above all, young people wish to be listened to and taken seriously and helped promptly when they ask for help.

5 Voices of parents and carers

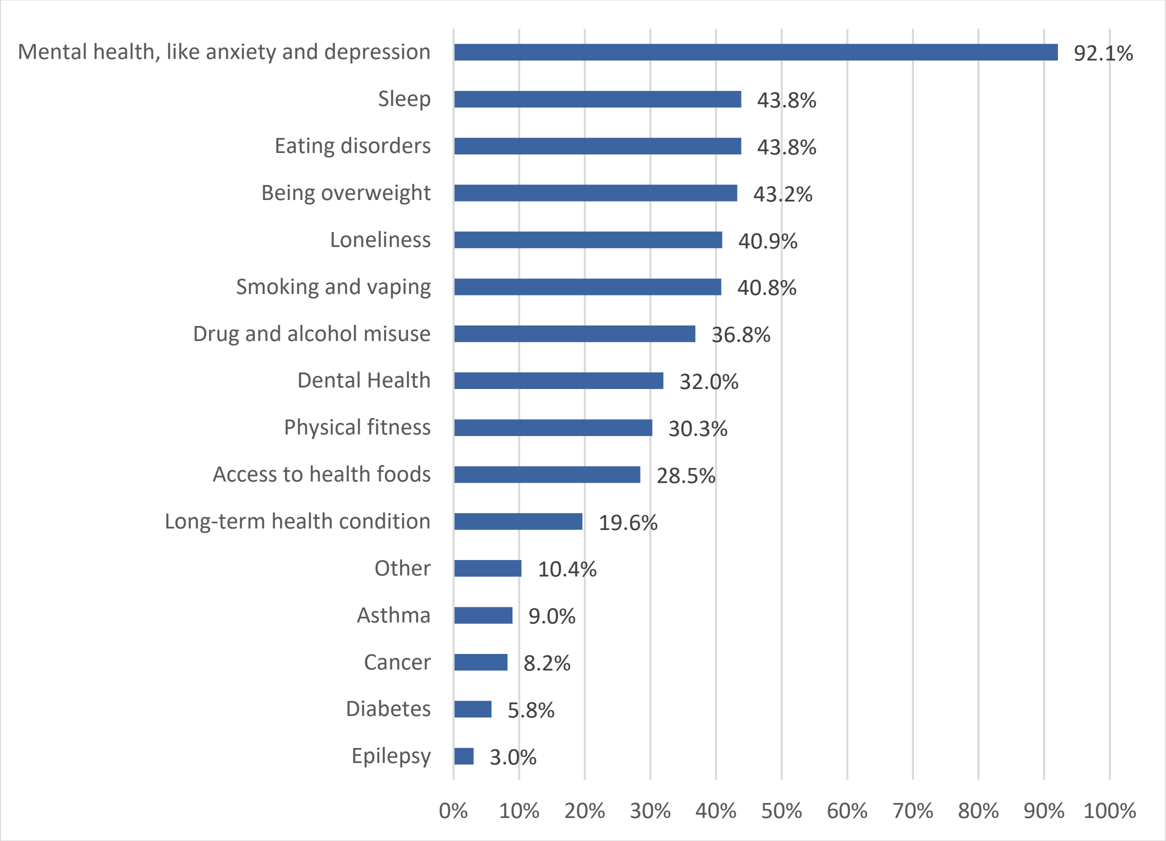
This section sets out the findings from the consultation with parents and carers. In total there were 659 respondents to the parent/carer survey.

5.1 Findings

5.1.1 Key health issues affecting children and young people

Parents/carers were asked what health issues they thought matter most to CYP. The findings are set out at Figure 28.

Figure 28: What health issues do you think affect or matter most to children and young people?



(Valid total = 657. Note that parents/carers could cite up to five health issues).

Condition	Number
Mental health, like anxiety and depression	605
Eating disorders	288
Sleep	288
Being overweight	284
Loneliness	269
Smoking and vaping	268
Drug and alcohol misuse	242
Dental Health	210
Physical fitness	199
Access to health foods	187
Long-term health condition	129
Other	68
Asthma	59
Cancer	54
Diabetes	38
Epilepsy	20

As is evidenced at Figure 28, the key health concern was mental health which was expressed by 9 out of 10 of the respondents (92.1%, n=605). Over 40% of respondents cited, Sleep (43.8%, n=288), Eating Disorders (43.8%, n=288), Being Overweight (43.2%, n=284), Loneliness (40.9%, n=269) and Smoking and Vaping (40.8%, n=268).

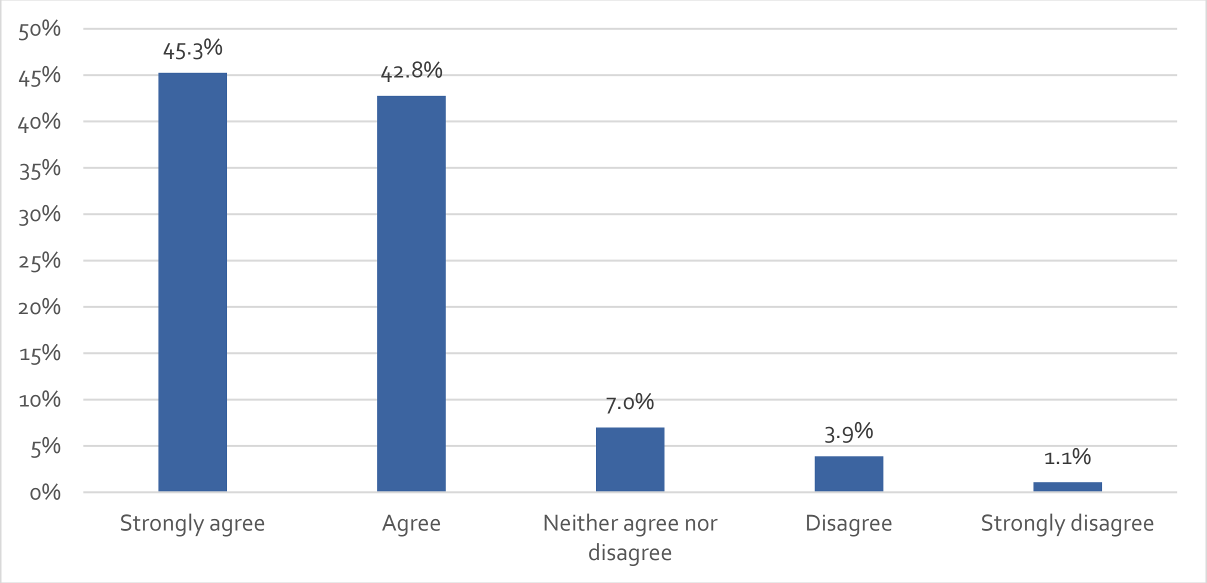
The views of parents/carers are consistent with the views of CYP who also indicated that mental health was their top concern (see Figure 7).

5.1.2 Accessing health services

Physical health care services

Parents/carers were asked to respond to the statement, "If my child became ill (for example coughs, colds, serious injuries and long-term conditions) I would know what services to use"? The results are set out below.

Figure 29: Parents/carers knowledge of what health services to use



(Valid total = 643)

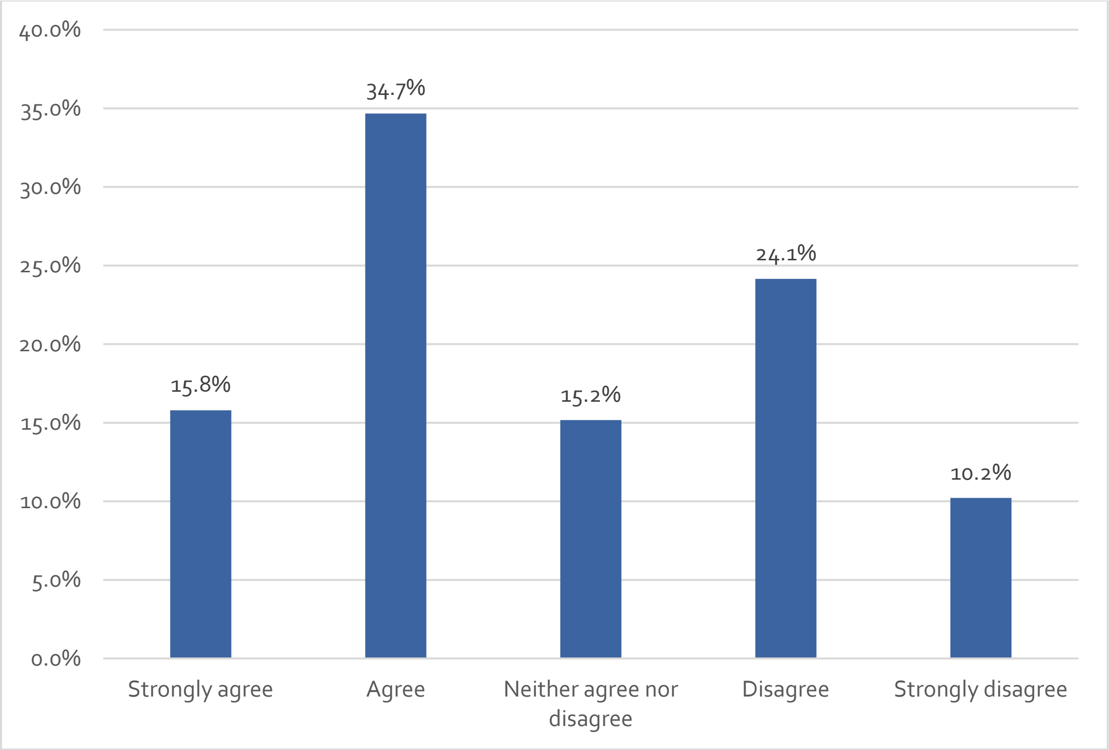
Assessment	Number
Strongly agree	291
Agree	275
Neither agree nor disagree	45
Disagree	25
Strongly disagree	7

88.1% (n=566) of parents/carers agreed or strongly agreed that they would know what health services to use should their child become ill. 5% (n=32) indicated that they disagreed or strongly disagreed.

Mental health services

Parallel with the question on physical health, respondents were asked to respond to the statement, “I know what health services to use if my child needs help with their mental health and wellbeing (for example feeling down, feeling anxious)"? The results are set out at Figure 30.

Figure 30: Parents/carers knowledge of mental health services to use



(Valid total = 644)

Assessment	Number
Strongly agree	102
Agree	223
Neither agree nor disagree	97
Disagree	156
Strongly disagree	66

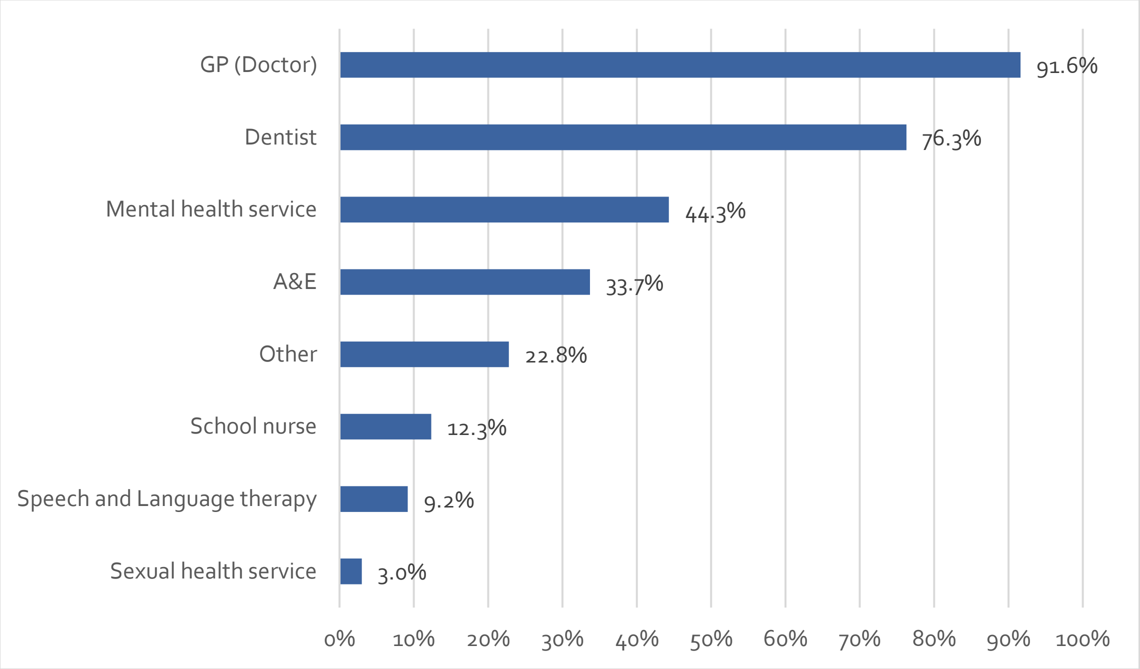
The results for mental health services differed significantly to those regarding accessing physical health services (see above). Almost exactly half (50.5%, n=325) of parents agreed or strongly agreed (down from 88.1% (n=566) for physical health) whilst 34.4% (n=222) disagreed or strongly disagreed (up from 5%). The results evidently highlight a much lower level of knowledge and confidence regarding access to mental health services for their children.

Health services used

Parents/carers were asked, the last time they had used a health service what type of service it was. Just over half (54.3%, n=327) stated that it was for a physical health service and 42.5% (n=256) a mental health service.

Parents/carers were asked what health services they had used for their child/ren in the past 12 months. The findings are set out at Figure 31.

Figure 31: What health services you have used for your child(ren) in the last twelve months



Note that parents/carers could cite multiple options, thus the valid total is 632.

Service used	Number
GP	579
Dentist	482
Mental health service	280
Emergency department	213
Other	144
School nurse	78
Speech and language	58
Sexual health	19

As per the results of the engagement with CYP, the most commonly cited health service was GPs, which made up 91.6% (n=579) of health services used in the last 12 months by parents. This compares to 74% (n=1,344) of CYP (see Figure 10).

Of the 8% who had used an "other" health service, details are provided at Table 9.

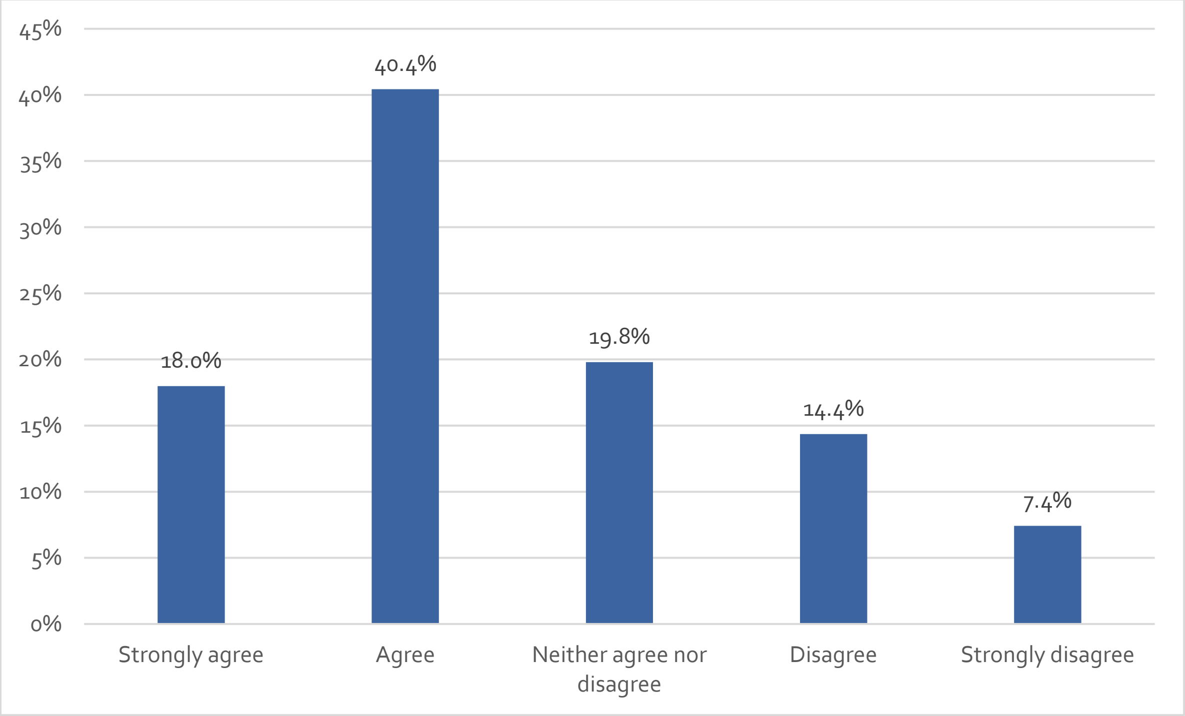
Table 9: "Other" health services used

Health Service	Comments
Mental health/CAMHS	29 families had accessed mental health, psychiatry or counselling services through the NHS. Two were still waiting for a service and two had accessed CAMHS alongside services for autism and ADHD.
Paediatrician	28 families had access services mostly described as paediatricians/hospital care/. Some were using paediatric services alongside specialist services for other conditions e.g. orthopaedics or urology.
Walk in/pharmacy/111	Eight had used one of these services with most of them using the pharmacy.
School services	School counselling had been available to two respondents
Neurodiversity	18 had sought a consultation of ADHD, through CAMHS or the ADHD nurse. Two these had accessed private healthcare for ADHD
Ophthalmic	Four had been to the opticians optometrist or ophthalmic specialist.
Other specialist	39 families had consulted a specialist for a wide range of conditions including diabetes, asthma allergies, ENT, orthopaedics, physiotherapy, dermatology, renal care; coeliac disease etc.
Urgent care	Two families had attended urgent care. One for an x-ray
Private health	Ten families had consulted private mental health practitioners. Three specifically mentioned ADHD or autism. One had been to an osteopath Others had been to private mental health therapists and psychiatrists.
Occupational therapist	Eight had seen an occupational therapist.
Vaccine	Two had had recent vaccines.

5.1.3 Health professionals

In relation to the last time their child had used a health service parents/carers were asked to respond to the statement, "My child felt listened to by health staff". The results are set out overleaf.

Figure 32: My child felt listened to by health staff



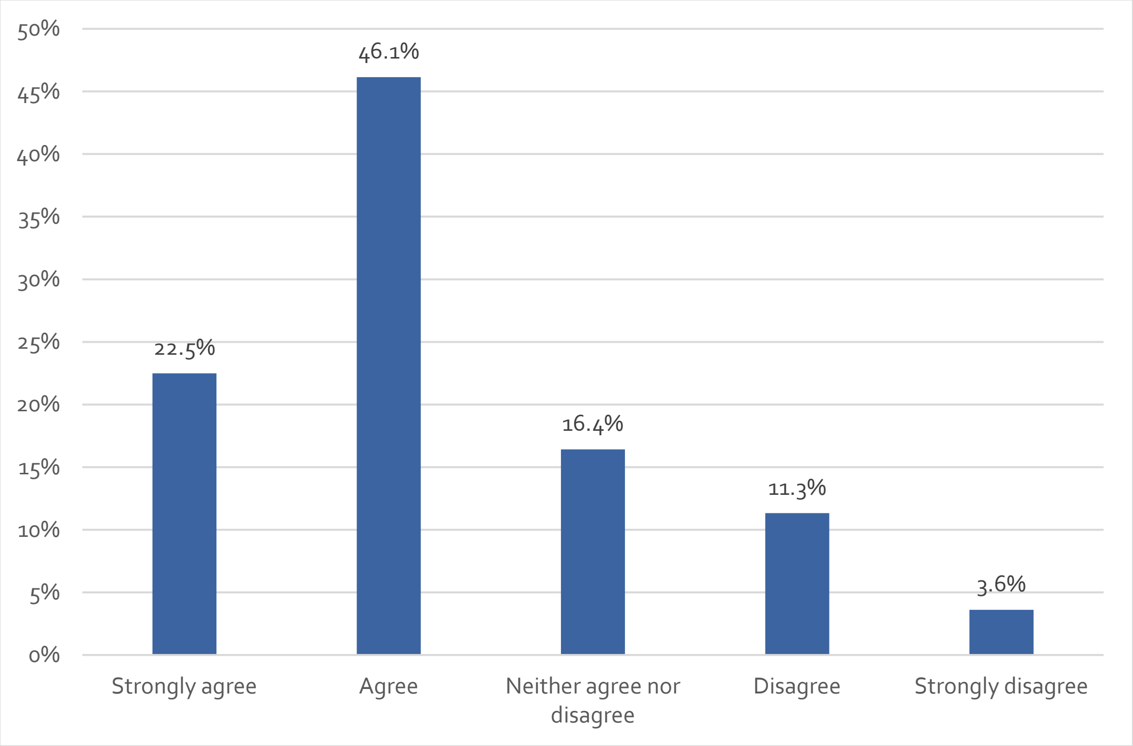
(Valid total = 606)

Assessment	Number
Strongly agree	109
Agree	245
Neither agree nor disagree	120
Disagree	87
Strongly disagree	45

58.4% (n=354) of parents/carers agreed or strongly agreed with the statement while over a fifth (21.8%, n=132) disagreed or strongly disagreed.

Parents/carers were asked to respond to the statement, "My child was treated with care and concern". The results are set out overleaf.

Figure 33: My child was treated with care and concern



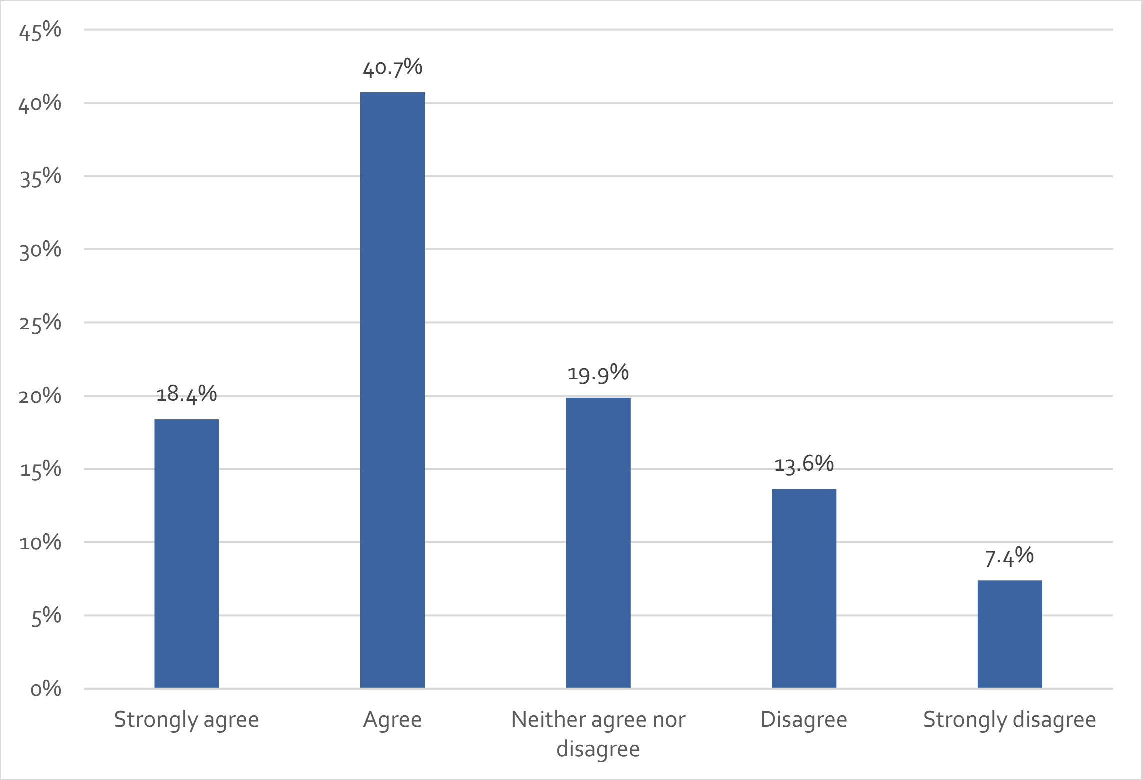
(Valid total = 609)

Assessment	Number
Strongly agree	137
Agree	281
Neither agree nor disagree	100
Disagree	69
Strongly disagree	22

A little over two thirds (68.6%, n=418) of parents/carers agreed or strongly agreed with the statement whilst 14.9% (n=91) disagreed or strongly disagreed.

Respondents were asked to what extent they agreed with the statement, "I feel that I was listened to". See Figure 34.

Figure 34: I feel that I was listened to



(Valid total = 609)

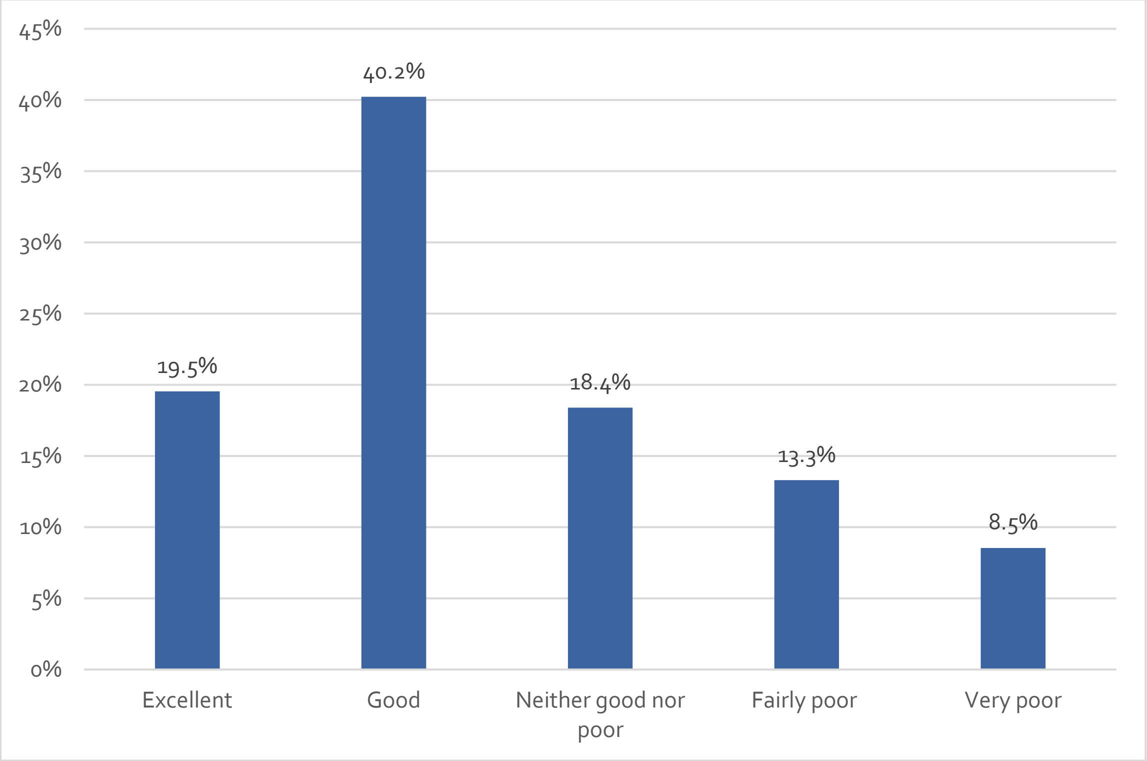
Assessment	Number
Strongly agree	112
Agree	248
Neither agree nor disagree	121
Disagree	83
Strongly disagree	45

59.1% (n=360) of parents/carers agreed or strongly agreed with the statement whilst just over a fifth (21%, n=128) disagreed or strongly disagreed.

5.1.4 Assessment of health services

Parents/carers were invited to rate the last health service you used for their child. The findings are set out at Figure 35.

Figure 35: How would you rate the last health service you used for your child?



(Valid total = 609)

Assessment	Number
Excellent	119
Good	245
Neither good nor poor	112
Fairly poor	81
Very poor	52

59.8% (n=364) of parents/carers rated the last health service they had used as good or excellent. Just over one in five (21.8%, n=133) felt that the service had been fairly poor or very poor.

Parents/carers were asked to provide information about why they had given the rating. In total 400 parents/carers gave further information. The key issues explored are set out below.

Waiting times

The most commonly cited reason given for the rating related to waiting times or delayed access to care which was cited by 85 respondents. Comments on waiting times included:

- "My daughter has been on the waiting lists to review her ADHD medication and discuss the possibility of anxiety medication for over 18 months and we've yet to speak to someone that can do this because she is not yet at crisis point they do nothing."
- "Still awaiting assessments after four years of being on the wait list."
- "My son has been waiting to see a paediatrician now for over 2 years his mental health declined massively and no body wanted to know . I had to end up paying private to get the help I needed."
- "It takes years to get through wait lists and referral loops to actually get seen by the right support by which time the child is feeling hopeless, suicidal and hates the NHS."
- "Because the waiting lists for assessments (e.g. autism) are far too long. So far, that's all we've managed to achieve, but my son needs some help now. It shouldn't take two years, just to have an assessment."

It is of some interest that a number of responses highlighting long waits noted that, once they were in contact with health services, they found the service to be helpful or that staff were supportive:

- "Consultation, Treatment & outcome good for a jaw problem but waiting time was 2 years to be seen!"
- "Each individual staff member was brilliant - it's just the epic delays in being able to access support in the first place that's the biggest concern and lead to serious deterioration in my child's health."
- "CAMHS - ridiculously long waiting lists, lots of nice staff but no actual active help. I have been seeking help for my son since he was 9. He's now 14 and it's still horrendous."

Caring and compassionate staff

The next most commonly given response related to praise for caring and compassionate staff which was highlighted by 67 respondents:

- "The appointment wasn't rushed and the nurse took the time to explain everything to both my child and I. She made my child feel in control and made us feel comfortable."

- "The adhd nurse has taken time to get to know my child and their needs, as well as having a good understanding of their condition, medication and non- medication options. My child now trusts them and will converse, they would not do this so freely with an unfamiliar person."
- "The nurse didn't rush us, my daughter went in very anxious and wanting to let it out the term the nurse used was "like a can of pop shook up wanting to release" the nurse sat with her for over 40 mins and allowed her space and time to talk and say what was happening with school, how she felt mentally and her struggles with her ADHD, we got lots of numbers to call to get her support she needs and she is doing loads better."
- "The last NHS service we used as our local GP surgery. Our doctor understood my child's disabilities as she is no verbal and tried his best to communicate with her in a way she would be able to try and understand. I voiced my concerns to the go about her health and he understood my concerns and made a referral to the respiratory team at the hospital."
- "The consultant we saw was kind and friendly. He explained everything really well so we knew what was happening and why."
- "We were in a very relaxed environment and compassion was shown for my sons behavioural and health problems, the only concern is the waiting list times for the next stages."

Good quality care

58 parents/carers stated that their child had received good quality care:

- "ADHD Nurses are prompt with scripts, really receptive and responsive. I know I can talk to them honestly and with no judgement. I felt that they get us as a family and treats my son as he should be!"
- "Excellent service from clinicians including their listening to my 11 year old's experiences and views."
- "Above and beyond happy with the contact we had."
- "Our GP is amazing and treats my daughters as individuals and listens to their concerns."
- "We had to attend A&E and were given the best treatment throughout."

Child listened to

Closely correlated to views about the quality of the care provided was the fact that their child had been listened to, with 56 parents/carers giving this as the reason for their assessment:

- "Myself and my child were listened to, he felt that that he was heard and could be himself without masking."

- "Recent admission to hospital and the care was great Staff really listened to me and my child. They were very patient with my child's anxiety and autism and kept communication going throughout."
- My son is going through assessments for ADHD and for the first time he and I felt understood when we got to speak face to face with an assessor from the ADHD clinic and she knew exactly what we were saying and describing to her how my son felt, he felt finally listened to and he felt great when leaving the appointment because someone understood what he's going through."
- "Treated well and spoken to like an intelligent adult."
- "Trainee GP - listened to me and my child, enquired about the physical problem we brought to the appointment. When we asked another question about mental health we were listened to, they checked with senior Drs (as some knowledge gaps). Did not feel rushed."

Conversely, 32 parents/carers gave a negative rating on the basis that their child was *not* listened to:

- "Although it was my teenager they still spoke to me rather than really listen to my child."
- "Didn't listen to how she felt, didn't listen to my concerns or the family history of mental health, just told her to talk to the school nurse. You get hold of the school nurse, there isn't one in the school. She came out more anxious then calm, she still struggling now, but I'm helping her with my experience."
- "We were not listened to about anything that we talked about and treated as if we didn't know what we were talking about. We informed them of severe superficial self harm leaving multiple scars she was disinterested and we believe she should have at least tried to ask if she could see the scars so she would have had a better understanding of the extent of the self harm."
- "The last health professional my daughter saw was an orthopaedic surgeon having been referred by the orthopaedic team at the same hospital. She came away from the appointment crying asking why he wouldn't listen to her, why he scared her. I tried to discuss with him but he had the opinion that he knew everything and we knew nothing and wasn't prepared to listen to anything and that everyone we had seen before him was wrong. Came away feeling like it was a total waste of everyone's time. And more and more I am getting this impression from consultants...that they think they know everything and no one else knows anything and won't discuss anything. They shut you down. With this attitude it will be very difficult to get my daughter to see a consultant again because she doesn't think anyone will take her concerns seriously or answer her questions."

No support provided/help given

55 parents/carers reported that their child had left health services without having been given support or had been told that there was nothing that could be done for them:

- "My child has not been able to get help she needed for last 5 years. I feel her mental condition has to get dangerously bad to receive support she needs. There is no suitable help to prevent it getting worse in the first place, for example by providing long term therapy to overcome anxieties caused by childhood traumas."
- "I have been fighting for my child who has clear ADHD/ASD/ODD since 2017, the referral was rejected!!! We've had to start the process again, my child is so much worse now thanks to be failed. Waiting time too long so now I have to go thousands of pounds into debt and go private. Shocking."
- "Can't get enough help with mental health you just go round in circles but no one actually helps enough."
- "My child is not at all support with issues with gender dysphoria, depression or anxiety. Services are not aware of their needs and there are no services to help my child or me. I find this despite working within health myself so can't imagine what it's like for people less informed."

Mental health/CAMHS

As can be identified from the sample of quotes set out above a large number of responses (n=62) from parents/carers specifically mentioned their child's mental health needs and/or CAMHS within the comment. On the whole the comments that cited mental health highlighted issues around waiting times and access:

- "Mental health services need to be readily available for children the process is far to long. Dr refers, then approximately a year wait just to decide where to send the child next."
- "We had to pay privately to get our child the mental health support and medication he needed due to how long the what's were and poor support through the NHS mental health service CAMHS... If we hadn't gone private, we would still be waiting to get the mental health treatment he so badly needed."
- "The consultant listened well about my daughters mental health problems. It's not the consultant themselves which is the problem it's the huge waiting lists to access them!"
- "No realistic prospect of counselling within a year + of waiting. Paid for private psychotherapy."

Some parents/carers highlighted the fact that no mental health support was available for their child:

- "I took my daughter in to the GP - she was self harming, bereaved, being bullied and at a very low state. The Dr said as you haven't attempted to take your own life it's not a priority and referred us to CAMS and I never heard from them. It was very distressing and I felt very alone."
- "Concerns not addressed as they were not classed as severe enough. Its a shame that children have to be classed as suicidal to receive any meaningful help."

Neurodiversity

Mention of neurodiversity and specific conditions such as autism and ADHD featured in 32 of the comments. As per mental health the comments were largely in relation to waiting times for their child to be seen:

- "There is not enough support for neuro diversity. You have to fight to get support and the waiting lists are faaaaar too long."
- "My daughter is on waiting lists for assessment of both ADHD/Autism and Gender Identity. On both she will likely not reach the top of the list until she qualifies to be out on an adult waiting list."
- "We have been using CAMHS for a neuro diversity assessment - whilst the staff are lovely and the interactions have been positive, the efficiency of the service is awful. It has taken 4 years to get from referral to medication for ADHD. 3 years to get a diagnosis and a further year to have a consultation for medication. The time frame is ridiculously long and has meant my child has gone right through the entirety of high school struggling when it needn't be necessary."
- "My daughter is still awaiting an appointment for potential ADHD assessment. She has finished school and is well into a university course and has still not received an assessment."

Also as with mental health parents/carers highlighted a lack of provision:

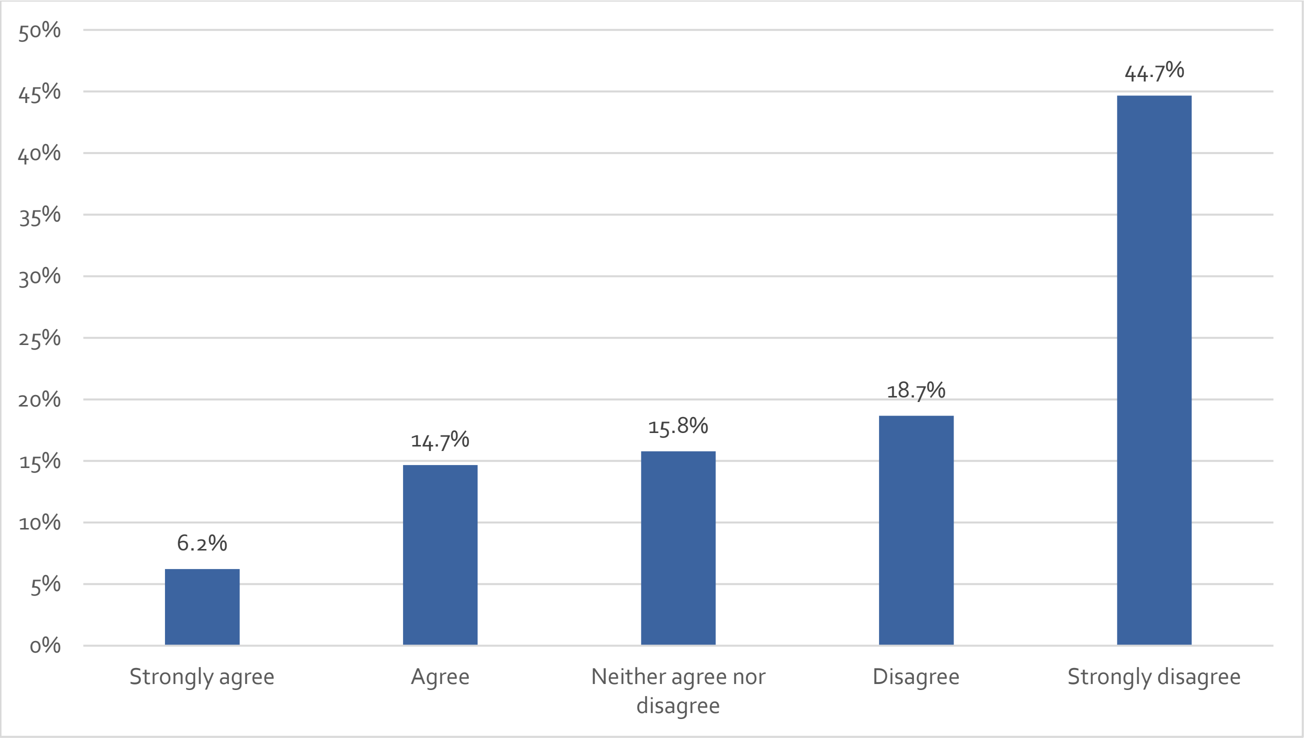
- "Waiting times for ADHD and autism assessments within Leicestershire are incredibly long so the support given to the child and parents in the meantime is insufficient. There doesn't seem to be anywhere that deals with children who might have ADHD or autism."

5.1.5 Transferring between health services

Speed of transfer

Parents/carers were asked, if their child had been transferred from one health service to another (to get diagnosis or treatment) whether this was done quickly.

Figure 36: My child got an appointment for a diagnosis and treatment quickly



(Valid total 450)

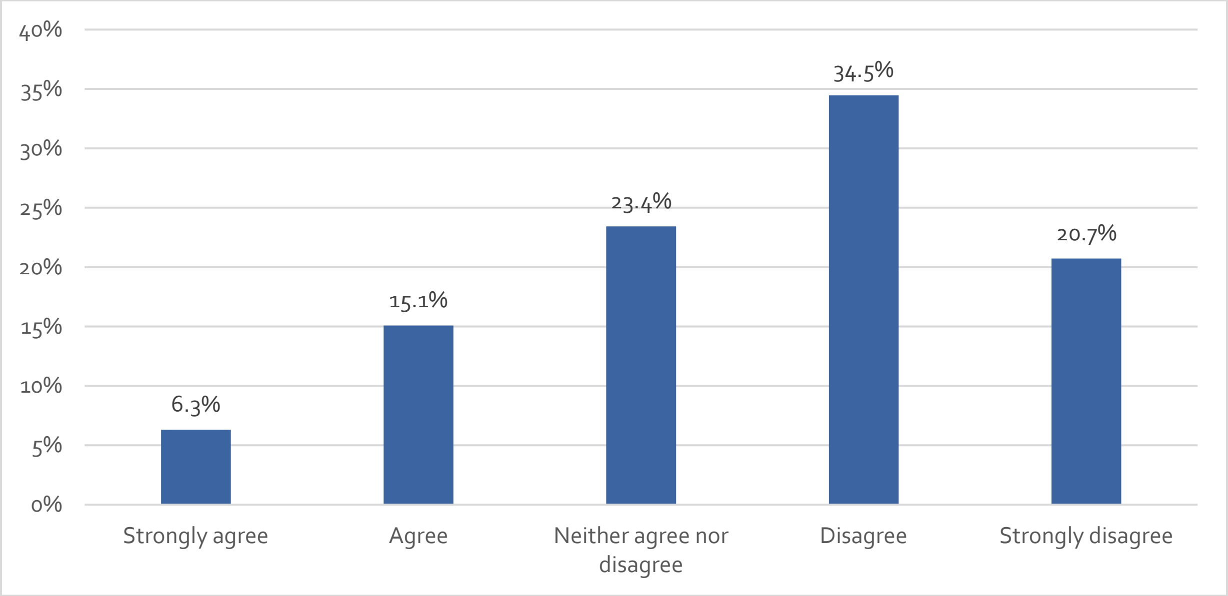
Assessment	Number
Strongly agree	28
Agree	66
Neither agree nor disagree	71
Disagree	84
Strongly disagree	201

The results at Figure 36 indicate that nearly two thirds of parents/carers did not believe that their child got an appointment quickly with 63.3% (n=285) either disagreeing or strongly disagreeing. Just over a fifth (20.9%, n=88) agreed or strongly agreed.

Effectiveness of transfer

For parents/carers who had a child who had been transferred, they were invited to respond to the statement, "The service my child was transferred to had details of their condition and they didn't have to tell their story again". The findings are set out below.

Figure 37: The service my child was transferred to had details of their condition and they didn't have to tell their story again



(Valid total 444)

Assessment	Number
Strongly agree	28
Agree	67
Neither agree nor disagree	104
Disagree	153
Strongly disagree	92

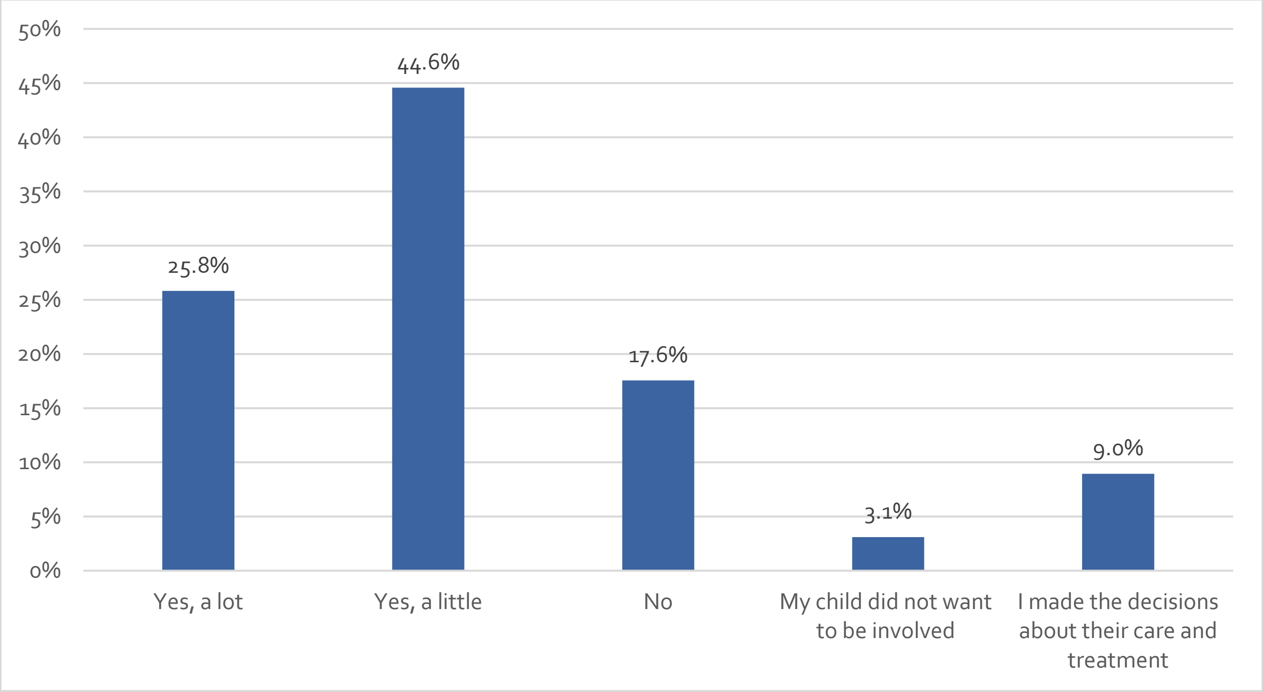
Consistent with the findings about the speed of transfer (see Figure 36), the majority of parents/carers (55.2%, n=245) disagreed or strongly disagreed with the statement. Around a fifth (21.4%, n=95) agreed or strongly agreed.

5.1.6 Young people's engagement in health provision

Young people's involvement

Parents/carers were asked the last time their child had accessed a health service, whether their child was involved in decisions about their care and treatment.

Figure 38: Was your child involved in decisions about their care and treatment?



(Valid total 581)

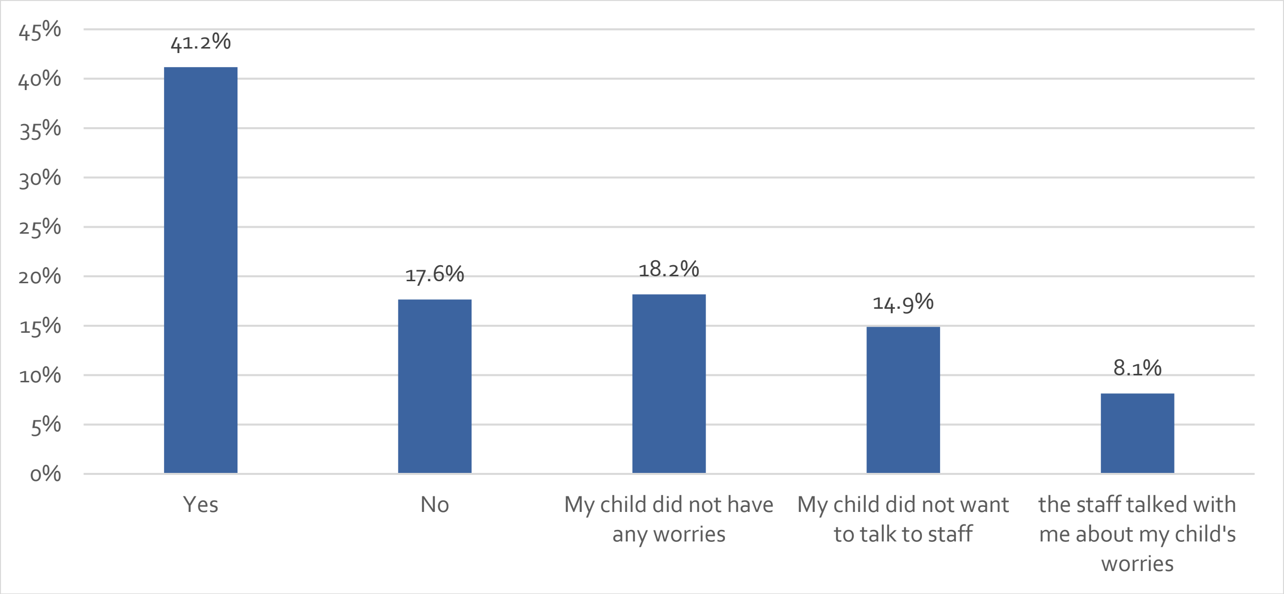
Assessment	Number
Yes, a lot	150
Yes, a little	229
No	102
Didn't want to be involved	18
I made decisions	52

The majority of parents/carers (70.4%, n=379) indicated that their child had been involved in decisions about their care. Just under one in ten (9%, n=70) parents/carers stated that they had made the decision on behalf of their child.

Talking to health staff

Parents/carers were asked, if their child had any worries, whether a member of staff talked to them about them.

Figure 39: If your child had any worries, did a member of staff talk with your child about them?



(Valid total 578)

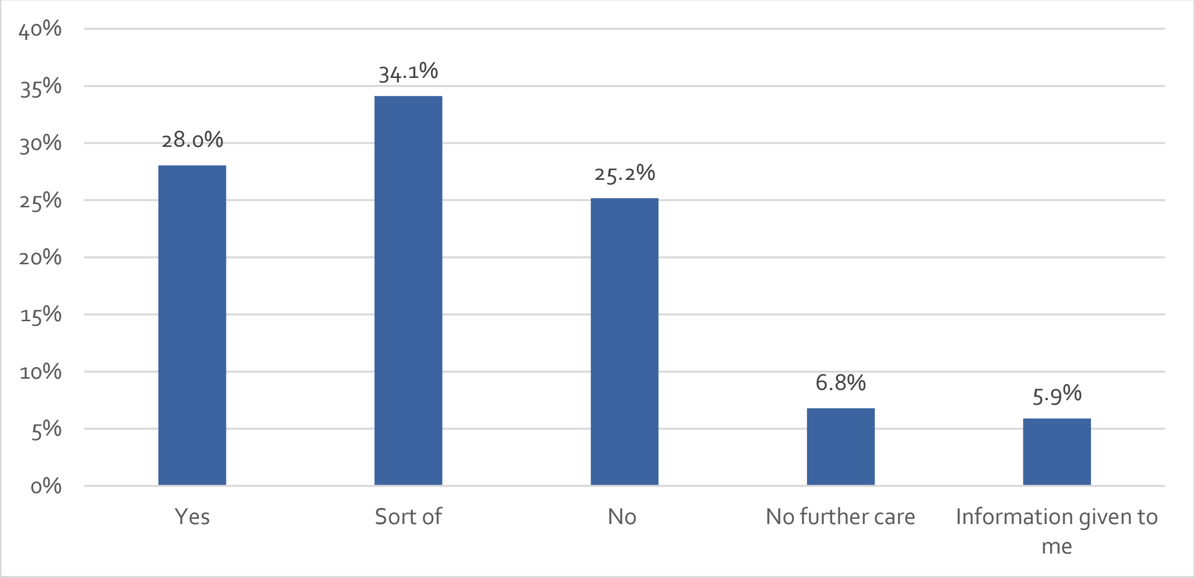
Assessment	Number
Yes	238
No	102
Child did not have worries	105
Did not want to talk	86
Staff talked to me	47

41.2% (n=238) of parents/carers stated that a member of staff had spoken to their child about their worries. 18.2% (n=105) indicated that their child did not have any worries and 17.6% (n=86) that staff did not talk to the child about their concerns.

5.1.7 After treatment

Respondents were asked, when their child left treatment, did they know what was going to happen next with their care.

Figure 40: Did your child know what was going to happen next with their care?



(Valid total = 560)

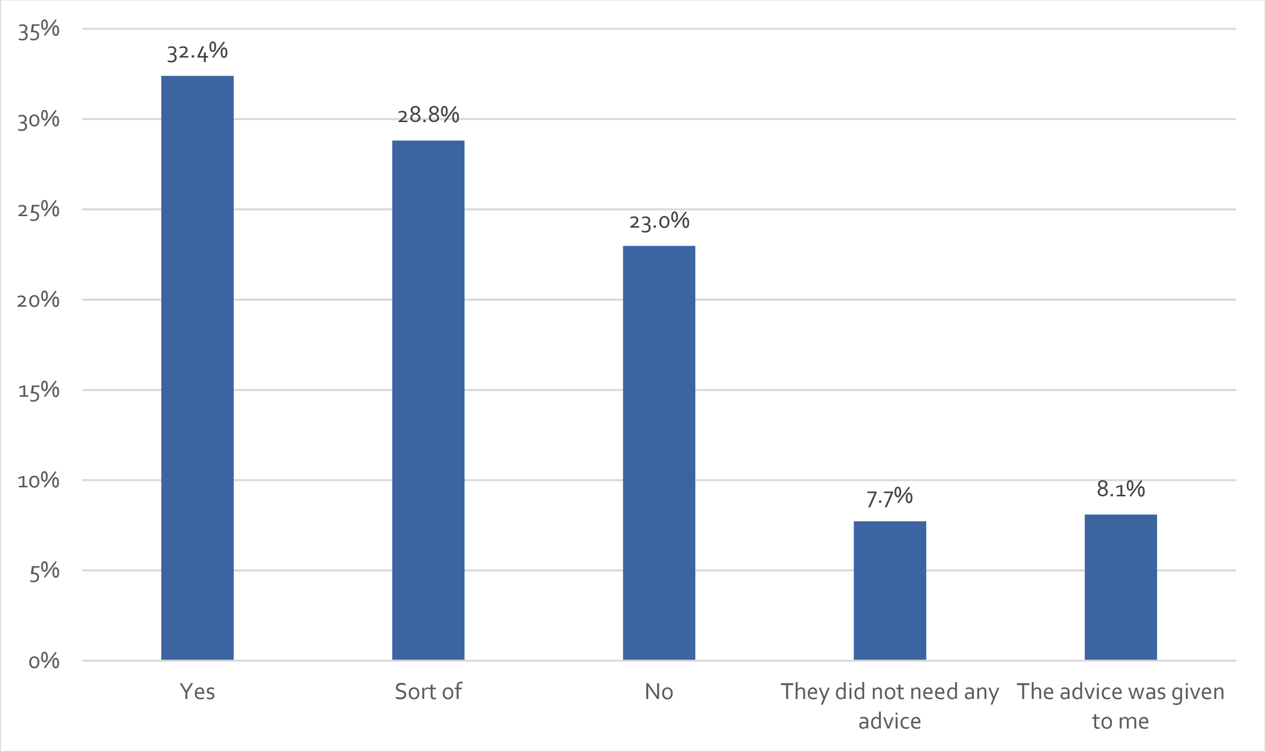
Assessment	Number
Yes	157
Sort of	191
No	141
No further care	38
Information given to me	33

Over a third (34.1%n n=191) of parents/carers indicated that their child "sort of" knew what was going to happen next with their care. Over a quarter (28%, n=157) stated that their child did know and a quarter (25.2%, n=141) that their child did not.

Advice from health staff

Parents/carers were asked, "Did a member of staff give your child advice on how to look after themselves after they left treatment"?

Figure 41: Did a member of staff give your child advice on how to look after themselves after they left treatment?



(Valid total = 558)

Assessment	Number
Yes	181
Sort of	162
No	130
Did not need advice	42
Advice given to me	43

Just under a third of parents/carers (32.4%, n=181) stated that their child had been given advice while 28.8% said that advice had "sort of" been given. Just under a quarter (23%, n=130) stated that no advice had been given.

5.1.8 Discrimination

Parents/carers were asked whether their child had experienced any discrimination or barriers when using a health service.

The majority of parents (65%, n=362) stated that their child had not experienced any discrimination while over a fifth (21.9%, n=122) said that they had. 13.1% (n=73) stated that they did not know.

Parents/carers were asked to give examples of the discrimination or the barriers that their child had experienced. A number of key themes emerged which are explored below.

Neurodiversity

The main area of discrimination reported was around neurodiversity and a lack of understanding or support, including parents/carers reporting that they and their child were not being listened to**.**

A repeated theme throughout the data was that parents/carers felt they were not listened to or understood by healthcare practitioners. In particular parents felt their child was not understood by either specialist (such as CAMHS) or general healthcare services if they were autistic meaning that some other conditions could be missed:

"Has faced barriers with communication and not being listen to, being discriminated against with physical issues assumed to be 'just autism' rather than investigated and professionals looking at reasons for overall health needs**.**"

Staff were said to talk over children with autism as if they could not understand. In relation to CAMHS, some parents mentioned that anxiety was dismissed as simply being part of autism and therefore not treated. As one parent said**:** "Mental health services are not set up for autistic kids".

A family was told that their son with ADHD should be booked in for a vasectomy as other family members had ADHD, the implication taken by the parent was that that he should not "produce any further offspring with ADHD**.**"

One child with severe mental health difficulties and selective mutism was told in A&E that, if the family could not cope with her "behaviour", arrangements could be made with Social Services for her to be taken into care.

In addition parents/carers reported not receiving timely treatment with one reporting a wait of seven years for their child to be seen.

Transphobia

Two respondents had experienced transphobia and one said: "My child is transgender and some health professionals refuse to use their chosen name and pronouns. My child is autistic and has complex mental health issues, numerous consultants immediately wrote off physical health issues as being caused by mental health without listening."

Age

Some parents felt their children had been dismissed or "fobbed off" because of their age. Young people were stereotyped and, again, not listened to so that they did not receive appropriate treatment.

Racism

Three parents reported racism with one noting: "Unconscious bias and microaggressions due to judgements being made based on faith, culture and ethnicity".

Disability

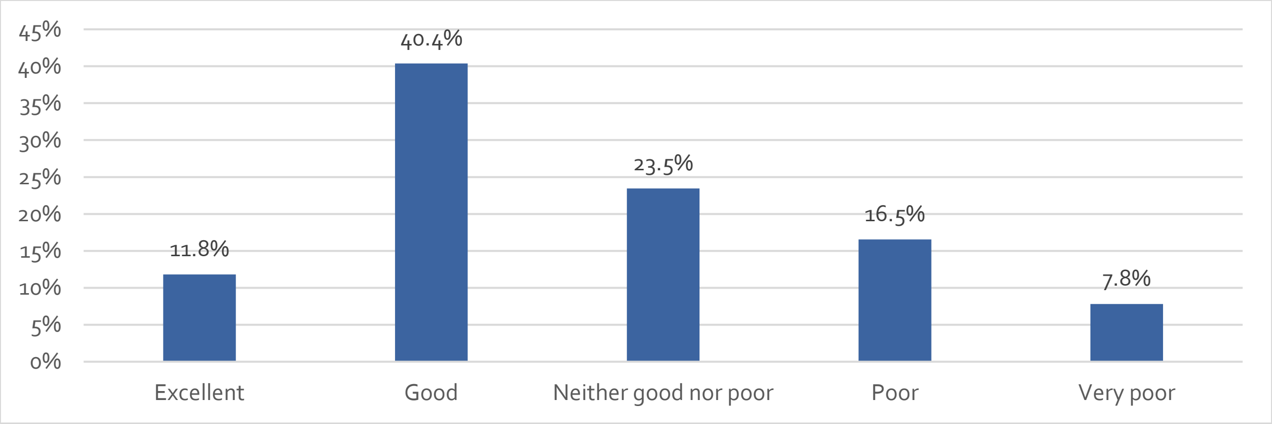
Five respondents experienced discrimination around disabilities other than neurodiversity. One child was visually impaired, one deaf and one in a wheelchair.

Some children and young people are non or pre-verbal and one parent suggested that all healthcare staff learn some basic Makaton. One young person who had a physical disability had been transferred to an adult stroke unit on transition to adult services which was not appropriate for her condition or social needs.

5.1.9 Overall assessment of healthcare

Parents/carers were asked to give their overall assessment of healthcare. The results are set out at Figure 42.

Figure 42: Overall assessment of quality of healthcare



(Valid total = 550)

Assessment	Number
Excellent	65
Good	222
Neither good not poor	129
Poor	91
Very poor	43

Over half (52.2%, n=287) of parents/carers gave a positive assessment of healthcare, rating it as good (40.4%, n=222) or excellent (11.8%, n=65). Just under a quarter (24.4%, n=134) of respondents gave a negative rating of either poor (16.5%, n=91) or very poor (7.8%, n=43).

This compares to the findings from the CYP survey where 69.5% (n=1,165) of CYP gave a positive assessment of healthcare and 8.5% (n=139) a negative assessment.

Respondents were asked to give further information about why they had given the rating. The responses are explored below under the key themes identified.

Mental health and neurodiversity services

The most prevalent reason for a negative sentiment about services related to mental health services such as CAMHS with a very large number of parents complaining of excessive waiting times for assessment, diagnosis, and treatment - often seemingly running into years - especially in cases where young people also had ADHD or autism.

- "There is not enough support for neuro diversity. You have to fight to get support and the waiting lists are faaaaar too long."
- "We have been using CAMHS for a neurodiversity assessment - whilst the staff are lovely and the interactions have been positive, the efficiency of the service is awful. It has taken 4 years to get from referral to medication for ADHD. 3 years to get a diagnosis and a further year to have a consultation for medication."

Parents noted that their children had to be in crisis to get seen, and even then there was likely to be a wait: "Still waiting for CAMHS and she is still really struggling".

Many had gone private with some going into debt and taking out loans to afford treatment. "We had to pay privately to get our child the mental health support and medication he needed due to how long the waits were and poor support through the NHS mental health service CAMHS. He is also on a waiting list for an ASD assessment to which we have been told for the past year he is at the top of that waiting list next to be seen, yet after almost 2 years of waiting we still have not been offered an appointment for this assessment. If we hadn't gone private, we would still be waiting to get the mental health treatment he so badly needed."

Some parents/carers reported that their children had left school, gone to university and had still not received an initial assessment.

Listening

It was a frequent complaint that families and children were not listened to, again, especially where they had mental health difficulties and/or a neurodiversity. "We were not listened to about anything that we talked about and treated as if we didn't know what we were talking about. We informed them of severe superficial self-harm leaving multiple scars she was disinterested and we believe she should have at least tried to ask if she could see the scars so she would have had a better understanding of the extent of the self-harm."

As another noted: "Neither my child nor I were listened to. It seemed that the staff did not really care and my child and I felt as though our concerns were being dismissed as silly."

Six parents specifically used the term "fobbed off" in their responses - in all but one instance this related to mental health care.

Parents/carers reported that it made an enormous difference to experiences when parents and children felt they were listened to and treated with respect and empathy. "Trainee GP - listened to me and my child, enquired about the physical problem we brought to the appointment. When we asked another question about mental health we were listened to, they checked with senior drs (as some knowledge gaps). Did not feel rushed."

Some health care professionals did well. "The last NHS service we used as our local GP surgery. Our doctor understood my child's disabilities as she is non-verbal and tried his best to communicate with her in a way she would be able to try and understand. I voiced my concerns to the go about her health and he understood my concerns and made a referral to the respiratory team at the hospital."

Explaining "all the options" made a difference to the acceptability of treatment, whereas for example one parent felt "fobbed off" when physiotherapy was prescribed for back pain perhaps without a proper explanation of this treatment.

GPs had a mixed reputation in this respect with some being described as very good, listening and offering clear explanations for courses of treatment, but others were thought to be harsh: "I took my daughter in to the GP - she was self-harming, bereaved, being bullied and at a very low state. The Dr said as you haven't attempted to take your own life it's not a priority and referred us to CAMHS and I've never heard from them. It was very distressing, and I felt very alone."

There were some positive comments about ADHD Nurses.

"ADHD Nurses are prompt with scripts, really receptive and responsive. I know I can talk to them honestly and with no judgement. I feel that they get us as a family and treat my son as he should be!"

Continuity of care was valued: "Adhd nurse. We see the same nurse every 3 to 6 months, so there is good communication".

Waiting times

There were many accounts of long waiting times for all types of service. The worst appear to be for neurodiversity assessments such as for ADHD, and for orthodontics - both of these were said to run into years.

- ADHD: "We have been using CAMHS for a neuro diversity assessment - whilst the staff are lovely and the interactions have been positive, the efficiency of the service is awful. It has taken 4 years to get from referral to medication for ADHD. 3 years to get a diagnosis and a further year to have a consultation for medication. The time frame is ridiculously long and has meant my child has gone right through the entirety of high school struggling when it needn't be necessary".
- Orthodontics: "We waited over 5 years from referral by the dentist to the specialist appointment at the hospital and a further 10 months for the essential op. They cancelled the last brace tightening appointment and re made it months later. The staff are great but the waiting lists are a real anxiety".

These waiting lists caused deterioration in health. "Each individual staff member was brilliant - it's just the epic delays in being able to access support in the first place that's the biggest concern and lead to serious deterioration in my child's health".

"My other child also received a referral and whilst the initial assessment has taken place and a full assessment has been determined to be necessary, he will turn 18 before the assessment can take place and so he has been referred to adult services instead. His mental health has suffered considerably and watching him struggle with depression and anxiety whilst sitting in a years-long waiting list has been incredibly hard".

5.1.10 Mental health

Parents/carers were asked whether their child had used a mental health service.

Just over half of respondents (51.6%, n=272) indicated that their child had used a mental health service, 44.6% (n=235) that they had not and the remainder did not know.

Where they wish to access mental health services

Parents/carers with a child who had accessed a mental health service were asked where they would like the appointment to have taken place.

The most commonly cited response was NHS clinic (55.3%, n=166), followed by community space (25.6%, n=77) then "other" (19%, n=57).

Among those who cited an "other" option, most respondents (n=22) wanted the mental health care to be at home as they felt their child would be more comfortable there.

Seven respondents thought the GP surgery would be a good option as it is local, familiar, neutral and private.

Four thought school was a good option as it is least disruptive to the child's learning.

Online was good for a child who neither felt able to go out nor meet people in their home. For another child online was good as they could access the treatment at school, so minimising disruption to learning.

While one person valued flexibility between face to face and online, another thought that consistency of location was very important and it should be "the same place each time".

Some parents/carers stressed that it is important that the location is local and on convenient public transport links. Comfortable spaces were said to be important - some locations are clinical and office like and this did not help children and young people. Above all the child needed to feel safe in the setting.

A couple did not mind where the appointment took place so long as they got one given the lengthy waiting times for treatment.

Assessing mental health services

Parents/carers of children who had accessed a mental health service were asked to rate the service. The findings are set out below.

Transitioning to adult mental health provision

Parents/carers of children who had accessed mental health services were asked whether their child had transitioned to adult mental health services. Over three quarters (77.2%, n=227) of respondents said that their child had not transitioned, while 12.2% (n=36) said that their child had. 10.5% (n=31) did not know.

Parents/carers of children who had transitioned into adult mental health services (n=63)[4] were asked follow-up questions:

- 23.8% (n=15) said that their child understood the transition process, while 34.9% (n=22) said that their child did not (41.3% did not know).
- A fifth (20%, n=12) said that their child had been provided with information about adult mental health services or services available in the community. 46.7% (n=28) said no information had been provided and exactly a third (33.3%, n=20) said they did not know.
- 22.8% (n=13) said that information was easy to understand. 28.1% (n=16) said that the information was not easy to understand and 49.1% (n=28) did not know.

Parents/carers were invited to provide some thoughts about what a good transition service might look like. 30 parents/carers gave a response.

Some, who had already been through the transition had had a difficult experience:

"Not the one you have at the moment. It was useless. Promised her transition to adult mental health services, and then just dropped her like a stone. Got her medication through GP in the end. Left to sort ourselves. Terrible."

Another family was still waiting for the transition to take place after two years. Others had a big gap when transferring. In one case CAMHS continued to prescribe for the young person until the transfer could be completed.

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[4] It should be noted that the numbers responding to these questions is higher than those stating their children had transitioned, as anyone could answer the questions, not just those who had selected 'Yes' to the previous question.

Where children's services had been offered in-person for one young person the adult services were either online or phone which the young person was not comfortable with.

One family wanted the process to start sooner: "It needs to step in sooner to offer support, waiting for nearly 2 years, has meant that my son is now a lot more poorly. It feels like so many missed opportunities to help him, still waiting for medication appointments, this would be helpful now and we have no idea how much longer we will have to wait". Another parent suggested, "A phased transition to allow for delayed processing".

As with the other open text responses in the survey, good communication and listening to the young person's needs was repeatedly cited as being important:

- "Seamless, and fair waiting list transitions. Friendly and reassuring staff, more services catering to young people."
- "Clear and open communication at all stages. So far I have phoned numerous times over recent weeks and everything is still pending. Waiting times are unknown, I do not know if we can opt for 'right to choose' and speed up the waiting process."
- "My child was left with a big gap when transferring. We were told that CAMHS didn't know what they could do for her. However they were happy to continue to up the dosage of medication without any therapy work being completed. There has been no improvement for my daughter since coming into service at the age of 11 years."
- "The pediatrician passing information on to the adult doctor and the treatment and care being seamless, not having to fight for medication that has been given for 15 years and then having been seen once, never seen again despite being on restricted medication. My child has seen an adult doctor once in three years and is on controlled medication, how is that right?"
- "A phased transition to allow for delayed processing."

5.1.11 Other comments and observations

Respondents to the survey were asked to share any final comments or observations about any of the issues covered in the survey or in relation to healthcare.

It appears that the final comments in this survey were largely made by people who had bad experiences and may reflect energy and motivation already used in completing the survey.

Not being listened to

Some of those comments describe failures to listen, and a lack of respect towards children, young people and their families.

“When my son was seriously ill with a burst appendix, he was told by a reception member he should go home and see his gp on Monday as he had already been in to a&e the day before and had managed with the pain. He was told he didn't need triaging as he'd been in prior, and nothing had changed! His girlfriend tried explaining he was much worse and he needed some medical intervention as she checked symptoms online on the nhs app. This was met with a smirk, to be told that just because they have a phone doesn't make them a doctor! Then they said you youngsters always think you know everything, and they were told to leave, or security would throw them out! He was rushed to hospital 20 mins later in an ambulance to have an emergency appendectomy and partial bowel resection as he had burst his appendix days before, and it had infected his bowel. If the receptionist had triaged him, it would have saved distress and an ambulance and staff which all costs money! Playing God was how my son described it and said "if you or dad had taken me it wouldn't have happened and that's a fact.”

Another parent spoke about their daughter who had to wait years to be taken seriously about her “horrific periods”. If a person is only 15 or 16 this is a long part of their life.

For children and young people with neurodiversity there is a lack of understanding about their condition. One parent was told by a paediatrician “your ASD sons, 'don't look autistic… Who told you they were?' ”. Another parent asked that “All professionals should have a good understanding of autism and mental health issues and should not dismiss children’s pain because they are autistic and/or have mental health issues”

Waiting lists

Parents/carers reported very long waiting lists for all specialists but for mental health, neurodiversity and CAMHS they reported that these are “exceptionally long”, running into years, with accounts given of children ageing off the waiting list without ever having received a service. Many others have paid for private treatment and assessments given the concern that they felt for their children’s distress and risks associated with self-harm, eating disorders and depression. Even if you got to the top of the waiting list there was still a sense of despair that the help would be what was needed:

“Just that the service is failing children. Parents are having to fight and pay to help their children. Money, we don’t have. Waiting lists are too long and even then there is no guarantee of help”. This feeling was borne out by other accounts of inconsistent support, paperwork being lost, constant delays and cancellations of booked appointments and children telling their story as they move from one service to another.

"I have needed to access mental health support a few times and never felt able to continue with choosing an NHS route. I have gone private each time - I do not believe this is ok. My child's mental health is so important that I would do whatever I can, but I should not have to pay thousands in private care when I pay my taxes for access to the NHS."

There is a strong feeling amongst parents that CAMHS needs reform with one suggesting that LLR ICB should, "Outsource your mental health department to someone that can do the job".

Sadly, one person made this direct appeal: "Can you speed up getting her to see a psychiatrist as she really struggles with her depression and anxiety right now?"

Services are not able to cope with Mental health crises and one respondent observed that: "Mental health crisis help seems to be the police NOT the NHS which is a very scary situation for a vulnerable young person"

Some parents/carers had a strong sense of failure and breakdown in the services they had tried to access. "I absolutely dread my children being poorly and myself, as you never know whether you're going to be one of the lucky ones or be left to sort it out yourself. No one cares, no one works together, and the services are leaking money everywhere."

They talked about staff shortages, reduced accessibility, staff who were too stretched to behave with empathy and a fear, even amongst those who had had relatively minor encounters, that if you ever truly needed help it would not be there. "So far, we've been lucky. We've not needed mental health services. Across the last couple of years: we've been able to be seen regularly by an NHS dentist; the ambulance arrived swiftly when called; the high-dependency care worked; medications have been available to fulfil repeat prescriptions… However, sadly, I no longer trust that the NHS will be there to give an adequate and timely response every time we need it."

5.2 Key Findings

- The most commonly cited concern among parents/carers regarding their child's health was in relation to mental health (see Figure 28). The results are striking insofar as they replicate the most reported concern among CYP who also reported mental health as the health issue that matters most. (See Figure 7).

- There was a very clear consensus that parents/carers knew what health services to use for physical health conditions with 88.1% (n=566) of parents/carers agreeing or strongly agreeing that they would know what health services to use should their child become ill. (See Figure 29). This differs markedly about knowledge of which mental health services to use, where those agreeing or strongly agreeing fell to 50.5% (n=325). (See Figure 30). The data therefore indicates a pronounced difference in the knowledge and confidence of parents/carers in accessing physical versus mental health provision. The results parallel the views of CYP where 78.8% (n=1,399) agreed or strongly agreed that they knew which health services to access while 59.7% (n=983) said they would know how to contact mental health services. (See Figures 9 and 24).
- The results are strongly indicative that parents/carers perceive that healthcare professionals treat their children with care, with 68.6% (n=418) agreeing or strongly agreeing with this idea. (See Figure 33). This aligns with the results from the CYP survey where 74.4% (n=1,344) indicated that they are treated with care and concern (Figure 12).
- Note however that parents/carers were less likely to indicate that staff listen to their child (at 58.4%(n=360)). This differs somewhat from the findings from CYP 68.1% (n=1,231) of whom said that they felt listened to (Figure 11). Of some concern, around a fifth of parents/carers (21.8%, n=128) did not feel like healthcare staff listened to their child. (See Figure 32). Of interest, the same proportion of parents/carers did not feel that they were listened to (21%, n=128). (See Figure 34).
- The results indicate that parents/carers were generally positive about the health service that they had last used for their child (59.7%, n=364 good or excellent) thereby giving a positive endorsement of NHS services for children. (See Figure 35). The results are interesting insofar as young people were more likely than parents/carers to give a positive assessment of health services – 73.7% (n=1,335) rating them as good or excellent (Figure 13).
- It is clearly evident from the survey results that the NHS is not perceived to perform effectively with regard to timely access to onward referrals with nearly two thirds (63.3%, n=285) of parents/carers indicating dissatisfaction (of whom 44.7%, n=201 strongly disagreed). See Figure 36. Young people were less likely to give a negative assessment of the speed of getting an onward referral appointment, with a quarter (25.7%) disagreeing or strongly disagreeing. (See Figure 15).

- Moreover parents/carers indicated that the quality of transfer was poor with over half of respondents (55.2%) indicating that the service transferred to did not have details of their child's condition. (See Figure 37). The findings therefore indicate that the transfer of patients between NHS services is an area of concern and warrants further attention to understand how this can be done better for young patients. Again, there is a slight contrast with views of CYP here with one quarter (24.9%, n=334) disagreeing or strongly disagreeing that the service had their details. (Figure 15).
- The results tend to suggest that more can be done to improve the information that is shared with CYP following a health intervention. The results at Figure 40 demonstrate that over a quarter of parents/carers (28%, n=157) stated that their child knew what was going to happen to their care. Almost as many (25.2%, n=141) stated that they did not know. This lack of information continues with regard to staff giving advice to children on how to look after themselves. Nearly a quarter (23%, n=130) of parents/carers stated that their child was not given advice. See Figure 41. The picture that emerges therefore is one where patients appear to be leaving NHS care without the full information that they need in relation to their complaint. The results are again worse than those given by CYP where 17.3% (n=290) said that they didn't know what was going to happen next with their care (Figure 20) and 12.1% (n=202) indicated that they had not been given advice (Figure 21).
- With regards to discrimination, the results between parents/carers again differ from those of young people. 22% (n=122) of parents (section 5.1.8) indicated that their child had faced discrimination or a barrier compared to 9.8% (n=163) of CYP (Section 4.1.9). Note however the difference in the qualitative data that was then provided. Whilst parents largely reported issues regarding lack of awareness of the needs of their neurodiverse child, young people tended to report outright discrimination (racism, sexism, transphobia).
- While the survey highlights some shortcomings in relation to aspects of care (such as that highlighted immediately above) the overall assessment of parents/carers in the NHS is positive with just over half (52.2%, n=287) rating healthcare as excellent or good. (See Figure 42). This is similar to the results from CYP where 69.5% (n=1,135) reported healthcare as excellent or good. (Figure 23).

6 Voices of health and care professionals

This section sets out the findings from the survey of health professionals.

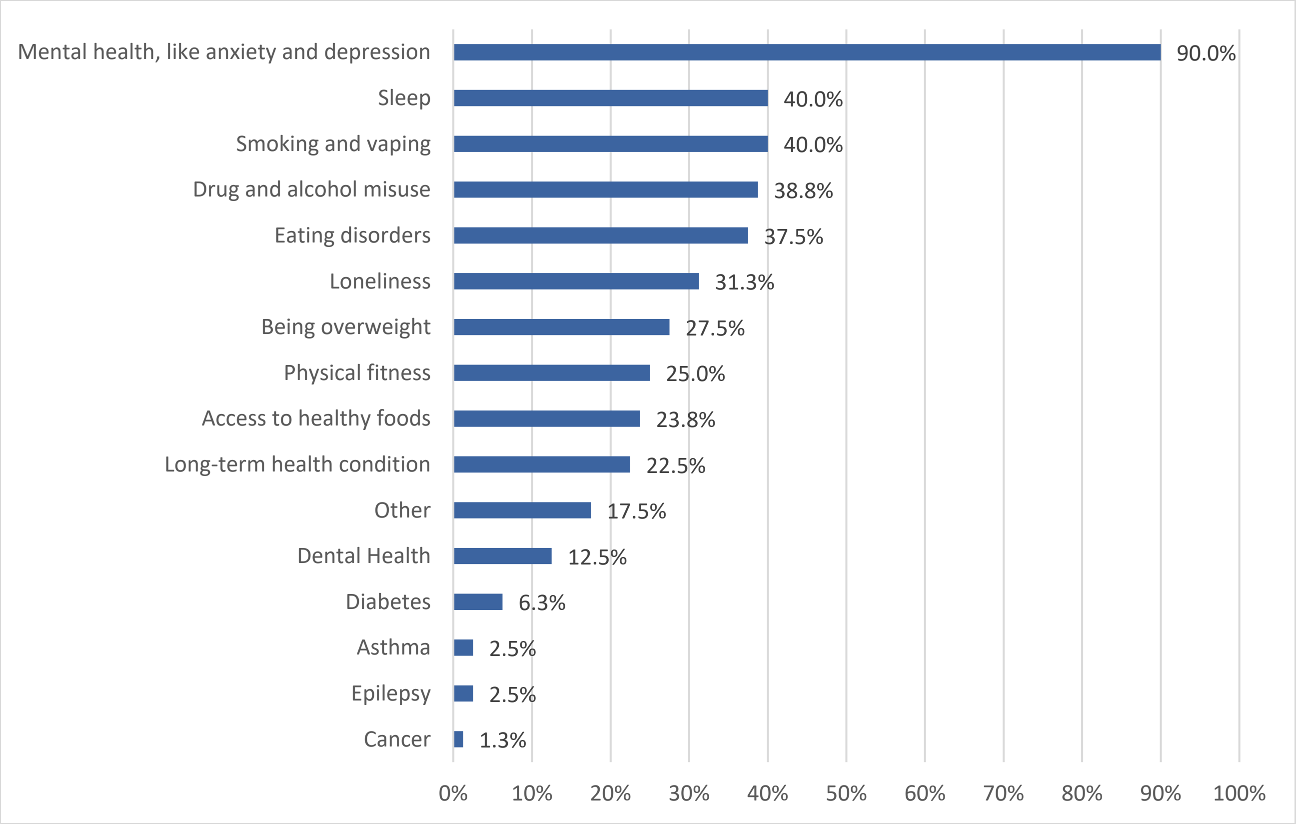
81 professionals responded to the survey.

6.1 Findings

6.1.1 Health priorities

Health and care professionals were asked to indicate which aspects of young peoples' health and wellbeing they felt need addressing most urgently. The results are set out at Figure 43.

Figure 43: What aspects of young peoples' health and wellbeing need addressing urgently



(Valid Total = 80. Note people were able to tick more than one option).

Condition	Number
Mental health	72
Sleep	32
Smoking and vaping	32
Drug and alcohol misuse	31
Eating disorders	30
Loneliness	25
Being overweight	22
Physical fitness	20
Access to healthy foods	19
Long-term health conditions	18
Other	14
Dental health	10
Diabetes	5
Epilepsy	2
Asthma	2
Cancer	1

Mental health was the most commonly given aspect of young people's health that professionals felt needed addressing, as cited by 9 out of 10 respondents (90%, n=72). Sleep and smoking and vaping were the next most commonly cited health issues with 40% (n=32) respectively.

17.7% (n=14) of professionals cited an "Other" option. All of the responses are set out verbatim below:

- "Healthy eating and drinking, sleep patterns and behaviours, emotional regulation and resilience."
- "Sickle cell, Thalassaemia."
- "Functional disorders in children and young people."
- "Parental support and education especially regarding parental responsibilities and our expectations of them."
- "Violence."
- "Body image."
- "Trauma."
- "Identifying young carers for support."
- "We feel like PMLD young adults are generally not given much thought or professionals do not know what to do with them. For example we had a parent take her 20 year old daughter to the

hospital as she was screaming and self-harming. The hospital ran some tests said there was nothing wrong and in no pain and sent her home. Mum asked what she should do as daughter clearly very distressed and they advised pain relief (even though they did test to rule this out) and again sent mum away when clearly they needed support."

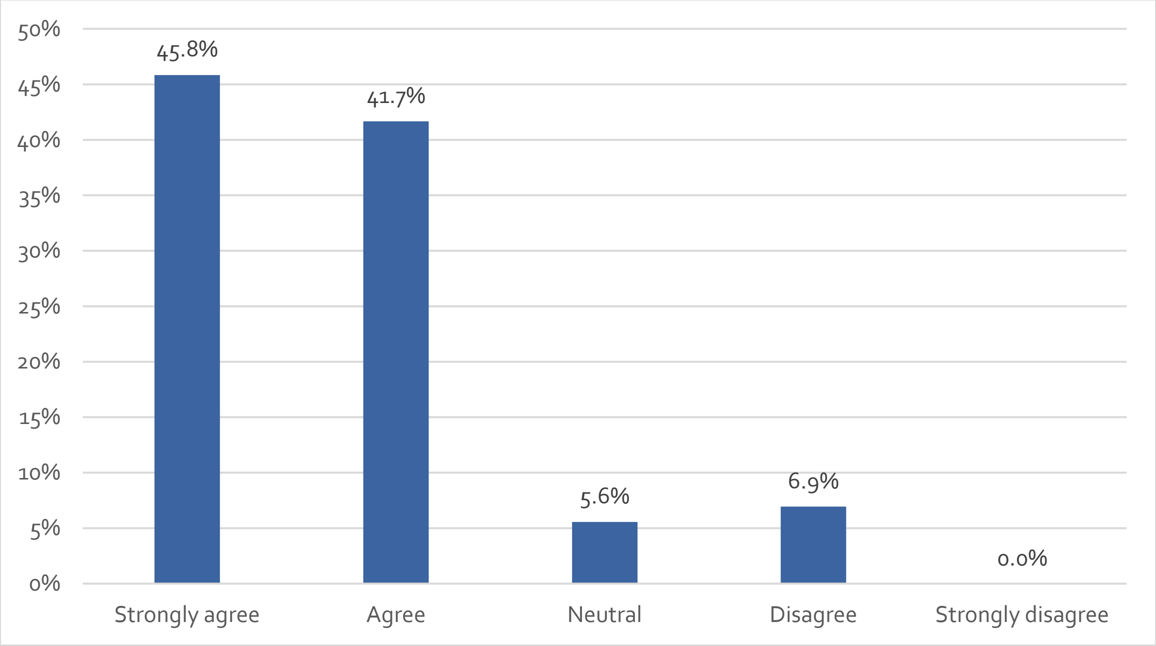
- "Isolation from peers and school life, impact on ordinary development, derailing outcomes and exacerbating mental health issues."
- "Neurodiverse conditions, Sensory Processing disorders."
- "Resilience building."
- "Neurodivergent conditions such as Autism and ADHD."

6.1.2 Confidence engaging children and young people

Respondents were asked to respond to the statement: Thinking about the last time you provided health services to a young person, to what extent do you agree with the statement: "I felt confident talking to the young person about all aspects of their care and treatment"?

The responses are set out below.

Figure 44: I felt confident talking to the young person about all aspects of their care and treatment



(Valid total = 72)

Assessment	Number
Strongly agree	33
Agree	30
Neither agree nor disagree	4
Disagree	5
Strongly disagree	0

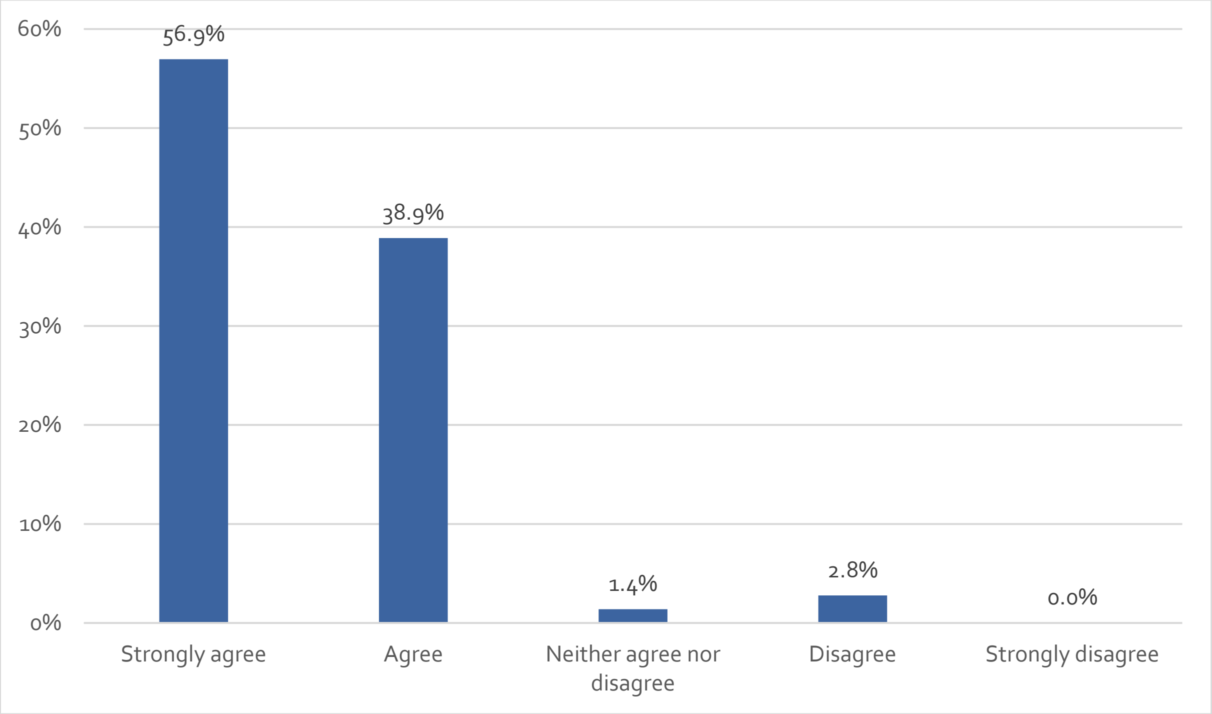
There was a clear consensus among professionals with 87.5% (n=63) of respondents stating that they agreed or strongly agreed with the statement. None strongly disagreed.

6.1.3 Young people involved in decisions about their care.

Professionals were asked to respond to the statement: Thinking about the last time you provided a health service to a young person, to what extent do you agree with the statement: "I felt confident in involving the young person in decisions about their care"?

The results are set out at Figure 45.

Figure 45: I felt confident in involving the young person in decisions about their care



(Valid total = 72)

Assessment	Number
Strongly agree	41
Agree	28
Neither agree nor disagree	1
Disagree	2
Strongly disagree	0

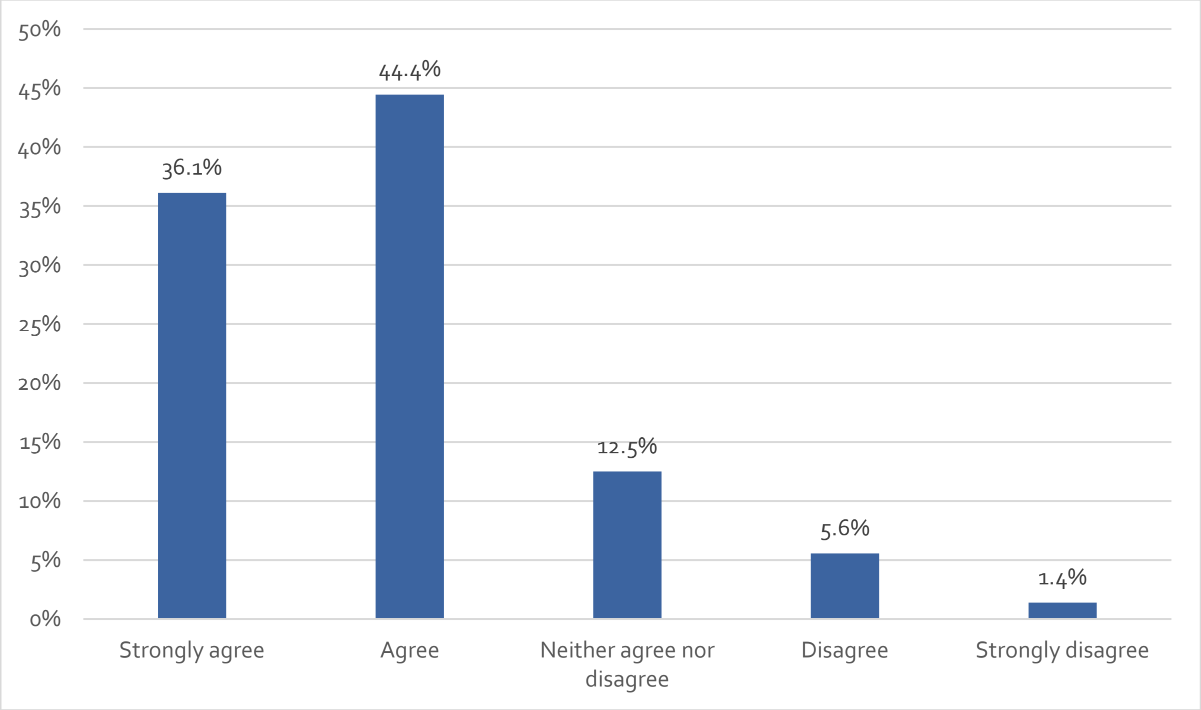
There was again a strong consensus among professionals with 95.8% (n=69) stating that they agreed or strongly agreed with the statement. None strongly disagreed.

6.1.4 Confidence in making decisions

Respondents were asked to respond to the question: Thinking about the last time you provided health services to a young person, to what extent do you agree with the statement: "I felt confident in making decisions about their treatment and care including onward referrals"?

See Figure 46 below for the results.

Figure 46: I felt confident in making decisions about their treatment and care including onward referrals



(Valid total = 72)

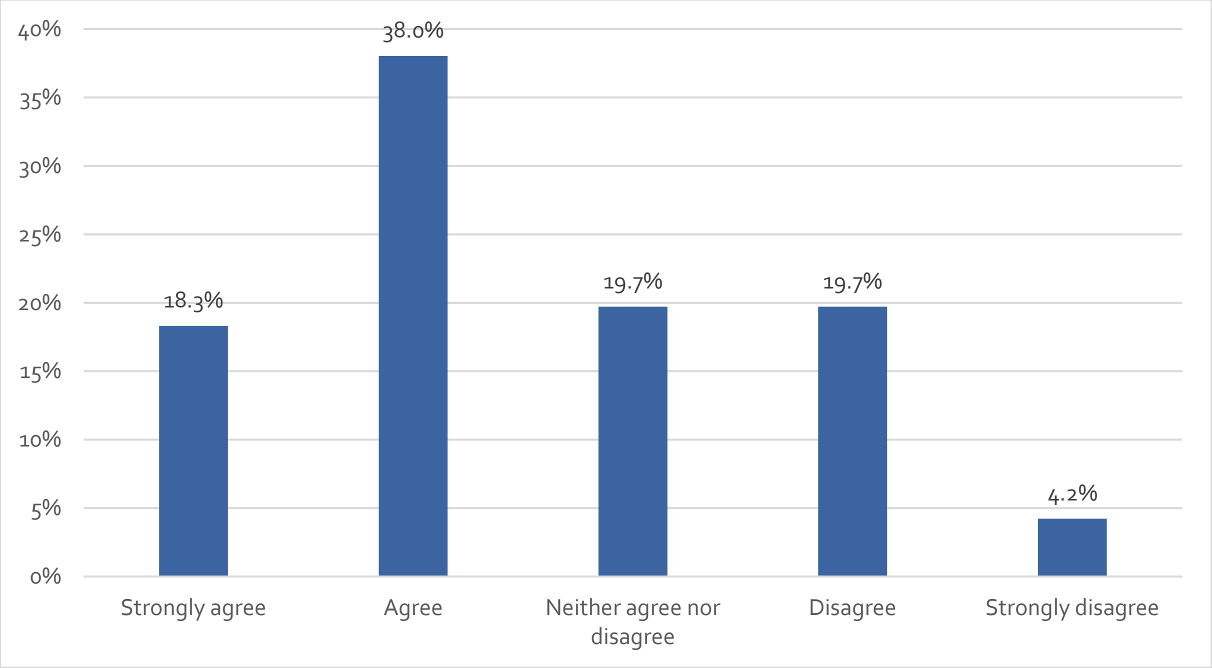
Assessment	Number
Strongly agree	26
Agree	32
Neither agree nor disagree	9
Disagree	4
Strongly disagree	1

Once again there was a very strong consensus among health and care professionals with 80.6% (n=58) reporting agreeing or strongly agreeing with the statement (albeit that those who agreed were greater than those who strongly agreed). 6.9% (n=5) disagreed or strongly disagreed.

6.1.5 Referring into other services

Respondents were asked to respond to the statement: Thinking about the last time you provided health services to a young person, to what extent do you agree with the statement: "I felt confident and was able to easily provide a referral into another service"?

Figure 47: I felt confident and was able to easily provide a referral into another service



(Valid total = 71)

Assessment	Number
Strongly agree	13
Agree	27
Neither agree nor disagree	14
Disagree	14
Strongly disagree	3

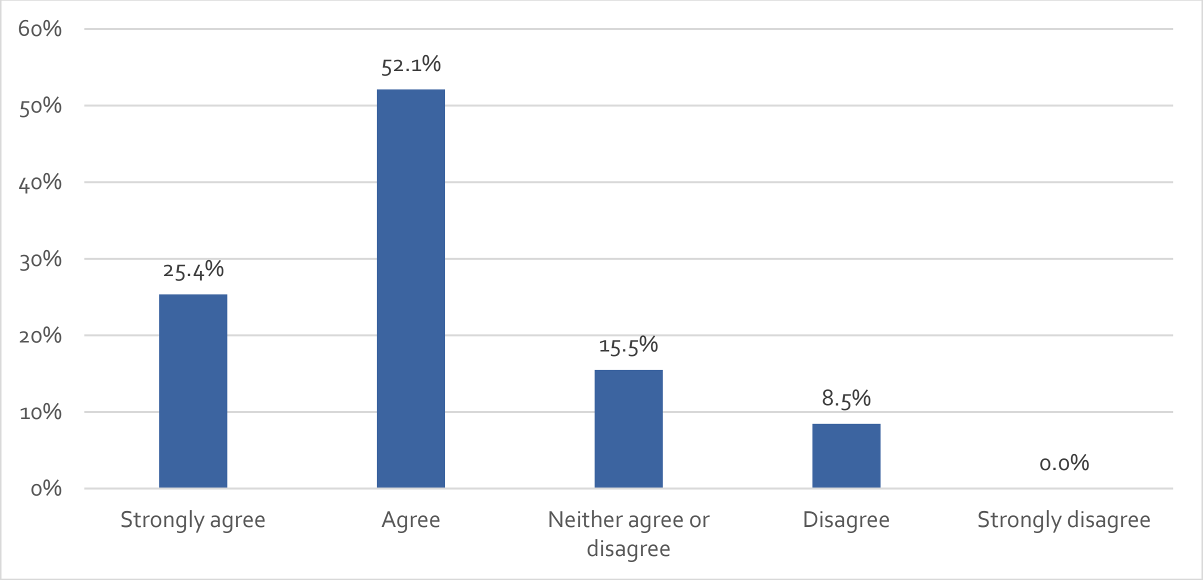
Just over half of respondents (56.3%, n=40) indicated that they agreed or strongly agreed with the statement while a little under a quarter (23.9%, n=17) disagreed or strongly disagreed.

6.1.6 Providing young people with advice

Respondents were asked to respond to the statement: Thinking about the last time you provided health services to a young person, to what extent do you agree with the statement: "I felt confident in providing the young person with advice on how to look after themselves after they left treatment"?

The results are set out at Figure 48.

Figure 48: I felt confident in providing the young person with advice on how to look after themselves after they left treatment



(Valid total = 72)

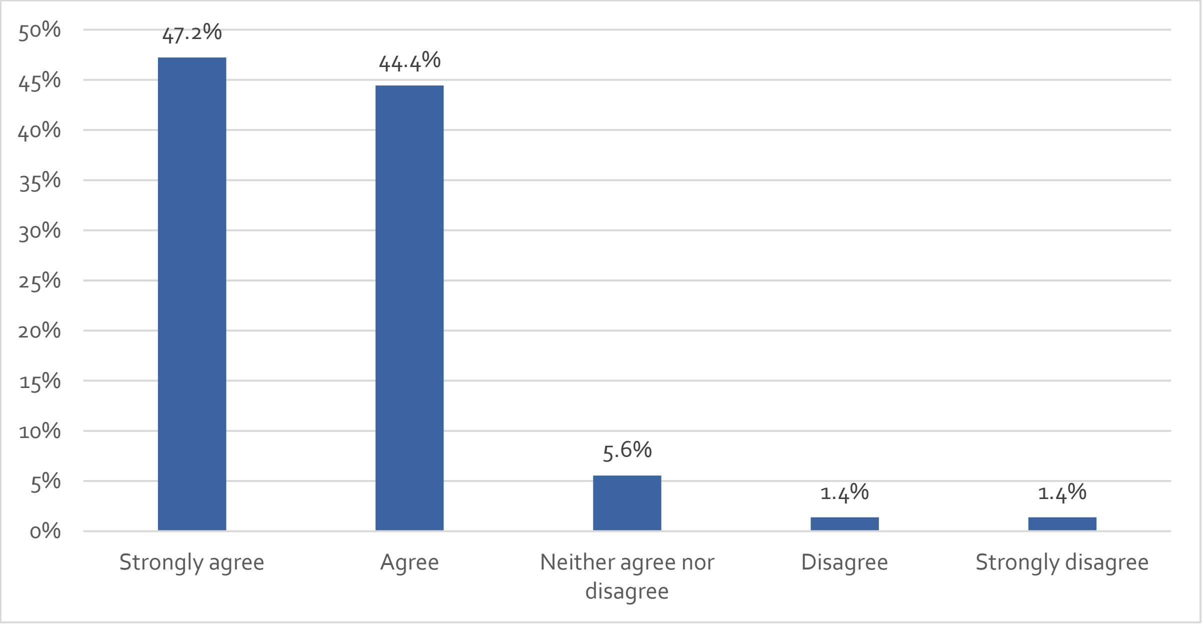
Assessment	Number
Strongly agree	18
Agree	37
Neither agree nor disagree	11
Disagree	6
Strongly disagree	0

The majority of professionals indicated that they were confident in providing advice to young people with over three quarters (77.5%, n=55) agreeing or strongly agreeing with the statement.

6.1.7 Working with family members

Those completing the survey were asked: Thinking about the last time you provided health services to a young person, to what extent do you agree with the statement: "I felt confident in building a relationship and communicating with the child's family member(s)"?

Figure 49: I felt confident in building a relationship and communicating with the child's family member(s)



(Valid total = 72)

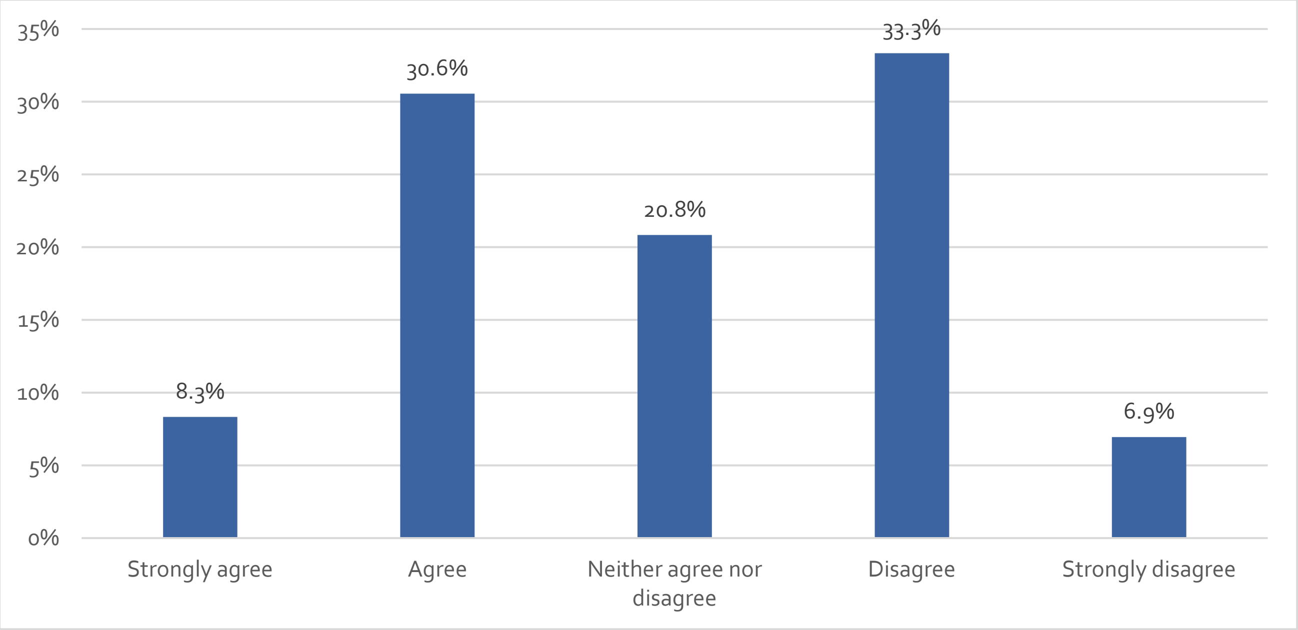
Assessment	Number
Strongly agree	34
Agree	32
Neither agree nor disagree	4
Disagree	1
Strongly disagree	1

There was a very clear consensus among professionals that they felt confident in building relationships and communicating with family members with 91.7% (n=66) of respondents agreeing or strongly agreeing with the statement.

6.1.8 Support for health and care professionals

Professionals were invited to respond to the statement: To what extent do you agree with the statement: "I have everything I need as a professional to help me in my role in supporting young people"? See Figure 50.

Figure 50: I have everything I need as a professional to help me in my role in supporting young people



(Valid total = 72)

Assessment	Number
Strongly agree	6
Agree	22
Neither agree nor disagree	15
Disagree	24
Strongly disagree	5

40.2% (n=29) of health and care professionals did not feel that they had what they needed to help them support young people while 38.9% (n=28) agreed or strongly agreed. A fifth (20.8%, n=15) neither agreed or disagreed.

Respondents were asked to explore their response to the statement in more detail. The key themes that were identified are set out below along with illustrative quotes.

Mental health

- "Access to the appropriate mental health services is limited and some of my young people just need someone to listen to them/counselling through difficult times. This not readily available."
- There is not enough psychological support for young people - school nurses do not provide enough services and need to be around more for drop in sessions. Young people need help to recognise when they have difficulties rather than waiting for them to say they want help."
- More resources needed specifically in mental health services, low level input for managing anxiety and low mood, managing emotions and navigating life as a teen /young adult. Emotional resilience overall needs improving."
- "I am not a mental health nurse - many of the young people I manage are struggling with school, friendships, social media, feelings of loneliness, self harming/feeling suicidal. There is very little support for young people's mental health and lengthy waiting lists. They need someone to talk to in a safe environment - sending to ED to see crisis team is often met with aggression or young people walk out. We have 2 psychologists in team, they have waiting lists of up to 6 months for our vulnerable patients-this seems unacceptable."

Collaboration and professional support

- "We work in partnership with agencies and professionals as part of our own supervision as well as supporting the needs of young people to ensure they are given the best advice and information for the care they require."
- "I am supported by doctors, psychologist, we have a good team."

- “I have support from the nurses and my manager.”
- “In my role, I feel well supported by managers and have the equipment I need to deliver sessions in school. I have received lots of training to develop my skills and knowledge too.”
- “I feel I have great links to specialists to seek advice and provide the support young people need.”

Issue around onward referrals

- “Because there are different services available for different aspects of health and it is not always easy to pinpoint the exact service needed. Often when making calls/referral you get passed on with a different number several times which is frustrating.”
- “The mental health services are not easily accessible for young children. I’m always unsure how to refer or what service will help the children appropriately.”
- “Difficult getting some YP support with onwards referrals due to other teams criteria e.g. CAMHS.”
- “Ability to onward refer and get swift support & action from the right services is something out of my control . But very frustrating for the child & family.”
- “Referrals to services for diagnosis of ADHD, autism or any neurodivergent diagnosis is extremely difficult at present. This creates stress & anxiety for people of any age and their carers.”
- “I am unable to refer to hospital services, and have to refer back to GP and ask them to refer on to these services.”

Resources

- “General lack of resources and staffing within the NHS - no computer or desk space to work from, poor staffing & lack of time to talk to young people properly.”
- “I don’t think we have the in hospital resources or facilities to support some of the things these people need; especially the 16+ age group.”
- “There are services that young person need to receive help from but I cannot provide this in a timely fashion due to long waiting list or lack of provision to refer. This is especially frustrating when there is no medical intervention I can offer to help and outside my work remit to help.”
- “Most often parents bring their children because NHS services are not available.”
- “Because my role, within an adult community learning disability service, is highly dependent on fully-functioning and coordinated support services for young adults receiving care, whether in their family home or accommodation supported by a registered provider. That coordinated

support is very difficult to get when social care services are so poorly funded, resulting in sub-optimal service provision from voluntary sector or private companies."

- "Lack of resources required for sessions in service, difficulties with staff recruitment means feeling overwhelmed and overburdened with extra work, therefore unable to provide 100% to CYP."

Lack of collaboration between services

"Sometimes there is a lack of understanding between different services about their roles and remit. This can cause divisions between different organisations, and even feelings of animosity. There is often a sense of 'passing the buck' with no services wanted to talk hold and coordinate the care of a young person. There seems to be no real guidance, plans or processes for that care coordination, for example if a young person has complex mental and physical health problems, and also difficulties related to their home life and education. It often feels like this role lands with CAMHS - who are not equipped, do not have the expertise of resources to coordinate such a variety of services."

- "I can support them but feel there is very little support from other services."

6.1.9 Discrimination

Respondents were asked whether they had witnessed any discrimination or barriers to CYP accessing healthcare. Nearly half (48.6%, n=35) of health and care professionals stated that they had witnessed discrimination or barriers, 37.5% (n=27) had not, and 13.8% (n=10) were unsure.

Discrimination

Respondents were asked to explore their responses with regards to the discrimination of CYP. The responses are set out below verbatim.

- "If we do witness anything, we are confident in our ability to follow protocol and reporting processes as well as ensuring the young people are not compromised in the provision of care they receive by following through with services to ensure there are no gaps and they are not further impacted or traumatised from any discrimination or barriers in healthcare."
- Working in CYP mental health, CYP from minority ethnic communities are vastly under represented in our patient population. Although attempts have been made nationally to increase awareness of common mental health problems, this has not reached the most isolated and hard to reach communities. It can sometimes feel like initiatives to improve access to services are almost lip service, so that organisations can tick a box to say they are acting on

inequalities, when actually minority communities can still struggle to access, or not wish to engage with these initiatives. In terms of the LGBTQ+ community I feel the barriers are related to lack of understanding, and reluctance to learn in staff members. I have experienced overt homophobia by a colleague, even though this was directed at me, within an office setting, it led me to be extremely concerned about how this attitude us reflected in the staff members work with CYP and their families."

- "There is clear unconscious bias and some conscious bias in the healthcare system, young people that frequently attend services can be labelled as "difficult" etc. Language barriers, cultural barriers all have impact on how some health care providers treat patients."
- "BAME cultures not fully represented in the service users accessing MH services. From experience, likely due to cultural belief systems from families not identifying/prioritising YP's mental health."
- "Protected characteristic groups are discriminated against in many ways - access to healthcare, timely referral, access to treatment."

Barriers

The question also addressed barriers experienced by young people. There was no single key barrier raised and so an illustrative selection of barriers that were identified are set out below.

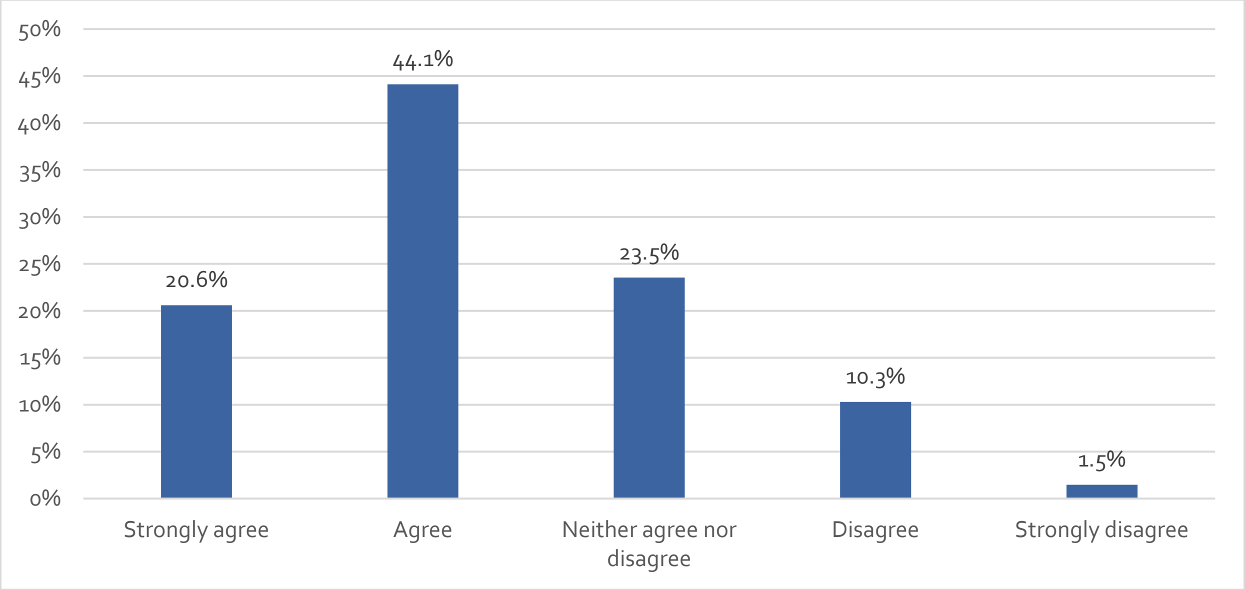
- "Young people often find it difficult to take the lead in their own care if parents have been managing their long term health condition throughout their lives."
- "Language barriers are the biggest difficulty and having access to the right interpreter."
- "Young people feel discouraged from accessing healthcare as they feel they don't matter and will just get put on a waiting list."
- "Lack of trauma formed approach for young. People who are victims or perpetrators of violence."
- "I don't think there are any actual active barriers to CYP accessing healthcare but I do think there are potential perceived barriers which we could manage better. Many of these are societal/ socioeconomic or cultural."
- "Access to services can be a postcode issue, who and how a referral is made can impact if it is accepted, parent engagement may mean child is not given full opportunity to access the correct support that is available for them. Lots and lots of issues and barriers."
- "We've now reached a point where young people have to have attempted suicide before they are even assessed."

- "Barriers: long waiting lists which means there is a lack of continuity for young people. Sometimes, young people feel spoken at rather than too if professionals address their parents more than them."
- "Young people not knowing where to go for support, schools should have more on offer for children and young people.

6.1.10 Working with other organisations

Respondents were asked to respond to the statement: To what extent do you agree with the statement: "I have a positive working relationship with other organisations who also engage, provide service or work with young people"?

Figure 51: I have a positive working relationship with other organisations who also engage, provide service or work with young people



(Valid total = 68)

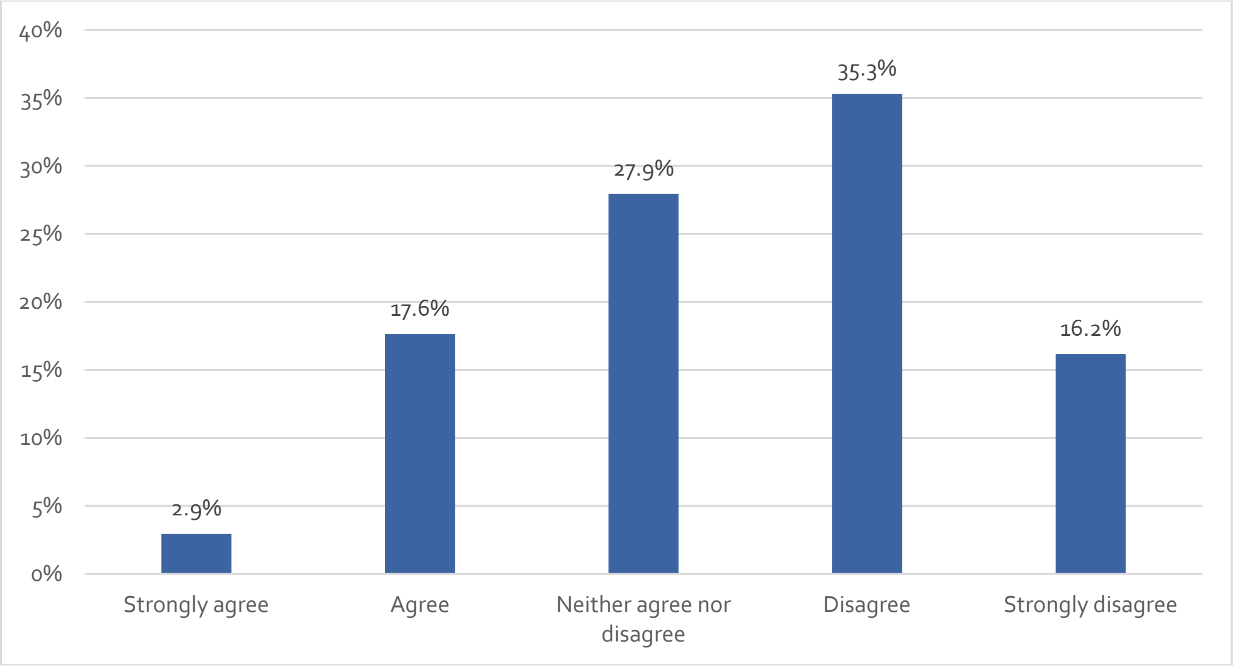
Assessment	Number
Strongly agree	14
Agree	30
Neither agree nor disagree	16
Disagree	7
Strongly disagree	1

Nearly two thirds (64.7%, n=44) of professionals reported a positive working relationship with other organisations, agreeing or strongly disagreeing with the statement. Almost a quarter (23.5%, n=16) neither agreed or disagreed.

6.1.11 Integration of health provision

The survey explored whether health and care professionals thought that services for CYP are integrated across health and care. The results are set out below.

Figure 52: Services for young people are integrated across the health and care system



(Valid total = 68)

Assessment	Number
Strongly agree	2
Agree	12
Neither agree nor disagree	19
Disagree	24
Strongly disagree	11

The results clearly show that health professionals do not think that services for young people are integrated with over half (51.5%, n=35) disagreeing or strongly disagreeing. Over a quarter (27.9%, n=19) neither agreed or disagreed.

6.1.12 Thoughts and observations about providing services to children and young people

The survey allowed respondents the opportunity to make any other observations about providing services to CYP. Fifteen respondents provided additional information. There were no consistent themes in the data and so a selection of quotes are provided below:

- “Yes services are integrated, but if the agency is unfamiliar with a 'softer holistic approach' they are likely not to refer or signpost, therefore, from our experience in working with partner agencies, it is important to know how other services that are not conventional are helpful and in fact help remove barriers and stigma that is perceived in society.”
- “A lot of services are under pressure, I appreciate that. There is a lot of disjointed working with service providers claiming it is not their job/role without trying to provide a solution or an answer for this child at the centre.”
- “Access to services outside of their 'disease' related treatments is limited.”
- “I don’t think we are as yet properly set up for the care of young adults with chronic conditions; 'transition' is only a part of it, our facilities, especially inpatients, are lacking unless they have cancer and that is unjust.”
- “All services that young person are not within same institution and this affects the input young person needs - like access to CAMHS if not for acute medical need.”
- “We need to advocate for our patients.”
- “We do not have access to each others’ record keeping systems therefore information missed as not able to find it.”
- “When I started out as a psychotherapist 18 years ago accessing services was easier, although the quality of those services was generally poor. Now access is almost impossible without at least a 1 year wait. Lower level issues are solidifying and causing lasting damage when they could be treated easily and quickly at outset.”
- “There needs to be more communication & working together with all teams & families. More communication & better information for families.”
- “Health and social care not always in alignment with child's needs.”
- “Health and social care is very disjointed, always difficulty in obtaining funding for certain aspects of child's care which leads to delayed discharge and maybe insufficient support in community for families. Families of children with complex healthcare needs have insufficient

help to assist them in the community especially as these children are living longer and require more care."

- "Services are not integrated, it can be very difficult to get hold of CAMHS staff-patients will be allocated a named CAMHS worker, I am rarely updated about what support the young person needs, services are working independently of each other. Several of my patients have not attended school - some for over 2 years, I have struggled to get hold of welfare officers, named social workers, services do not update health care professionals."
- "County offer differs to City Postcode lottery."

6.1.13 Mental health

Respondents were asked whether they feel confident in supporting young people to transition to adult mental health services or services available in the community.

Among those who reported that this issue was applicable to their role 47.3% (n=26) of respondents stated that they were not confident, 30.9% (n=17) stated that they were confident, and 21.8% (n=12) were "unsure".

Professionals were invited to share their experiences of supporting the transition. The responses generally related to a number of key themes:

- Differences between adult and young people's mental health access criteria,
- The impact of transition arrangements on CYP and their family,
- Lack of clarity about transition arrangements,
- The absence of transition arrangements.

Illustrative quotes for these themes are set out below.

Differences between adult and young people's mental health access criteria

The most commonly cited issue was the difference between adult and young people's services in terms of the criteria adopted and the nature of the service offer:

- "Majority of CYP with mental health difficulties accessing secondary services do not meet the criteria for adult services. It can be very difficult to help CYP and their families understand the remit of adult services, and how it is very different to child services. This is often met with anger and frustration from CYP and families, which feels misdirected. It can be hard to help CYP and their families understand and accept that there are other services than secondary MH care which may be best placed to support them."

- "A lot of patients who need to be transitioned are often missed and feel they have been dropped by children's services as they do not meet the adult services criteria."
- "The thresholds for YP and adults is very different with mental health and more support needed for 18-25 year olds."
- "I have worked in both child care and supported parents going through to adult services. I now work in adult care as a manager and have ongoing involvement in how transitions work. Again the transition criteria is very strict and requires a very high level of dependency and some of our service users I would have thought be 100% health are not due to the criteria which means they suffer as a result."
- "I feel referring to adult mental health services is an easy process, however it is noted that adult services have difficulties matching the offer children have received, noting children often requiring transition have had multiple services involved at the same time, often seeing patients every other day, where as adult services highlight this is not possible from their service and is considered this approach to have hindered the development of resilience in young people and causes reliance on service/revolving door."
- "Hard - having to cut down appointments so they get used to the new expectation of adults, and also the change in validation and care, feels like they get way more tough love in adults which is a change from the more softer approach in CAMHS."
- "I've been able to support and refer young people to adult services but have found mixed messaging on eligibility due on the exact age of transition. This created duplicity, confusion and made me appear unprofessional."

Impact on young people and their family

A number of respondents focused on what they perceived to be the impact of current transition arrangements on CYP and their families:

- "It's hard for the service user and their families."
- "Very poor, young people & families are exposed to lack of funding, no capacity , no support conversations often."
- "Young people can find the transition from a lot of support under CAMHS to adult services a challenge."

- “It's a really difficult process and it can be really hard seeing the effect of this upon the young person.”

Lack of clarity about transition arrangements

Some respondents felt that current transition arrangements are not clear:

- “Lack of knowledge of where to refer and long waiting lists.”
- “Confusion about how to access services - grey area - no one takes accountability.”
- “I have varied experience of supporting transition - opportunities to discuss a young person and have an integrated plan of support can be good - or can be very poor. It is not a consistent picture.”
- “Cumbersome and often frustrating.”

The absence of transition arrangements

Some respondents felt that there was largely an absence of transition processes:

- “That the transition process is non-existent and relies on the young person starting their journey again as an adult via their GP.”
- “In Primary care we are often left to see these cohort due to no other services available to support them when they are in crisis.”
- “In my experience, transitions are often very sudden, and young people and young adults are often left without services for their mental health particularly when they reach 18 - unless they are care leavers.”
- “The transition of young people between services is failing before it has begun.”
- “There is no transition they just get moved from one waiting list to another or drop off the system entirely.”

Learning disability

One respondent explored issues with regard to young people with learning disabilities, noting that transition here are also problematic:

- “I have supported transitions from children’s to adult services within the Learning Disability community and not specifically in Mental Health. A lot more emphasis needs to be placed on ensuring supportive transitions for this cohort, as their families and carers often feel as though they have been 'pushed off a cliff'. The problems with transferring Education Health and Care

Plans from children's to adult services just don't seem to be being addressed, with the 'education' aspects taking precedence and very little handover happening particularly in terms of 'care', which often isn't even documented in the plan. I have worked with a number of clients whose EHCP has been discontinued by the Special Education Service/local authority when an education provider feels they are no longer benefitting from the provision or is unable to continue offering them a place, whilst the person still has ongoing health and care needs. The provision of health services, such as Speech and Language Therapy, between children and adult services is so different that it is not feasible to continue to provide the same level of input which is documented in their EHCP (which often has not been being provided as recommended anyway due to lack of resources)."

6.2 Key findings

- The most cited health need among CYP that professionals indicated needs addressing is mental health (see Figure 43). This therefore constitutes a highly consistent message given that it was most cited also by CYP and parents/carers. Of some interest the results from the professionals parallel those of parents/carers with both groups indicating that the second most important area to be addressed is sleep.
- The results from health and care professionals very clearly indicate that they feel confident talking to CYP (87.5% (n=63) of respondents - see Figure 44). This finding, while a positive endorsement of NHS staff, is somewhat at odds with the views of CYP. Note that 68% (n=1,231) of CYP reported that they felt listened to (Figure 11). Note also a little over half (58.4%, n=354) of parents/carers felt that their child had been listened to by health staff (Figure 32). This also differs from the picture given by health professionals where 91.7% (n=66) felt able to communicate with family members. (Figure 49).
- There also appears to be somewhat of a disconnect between health and care professionals and young people in relation to the involvement of CYP. While 95.8% (n=69) of professionals endorse the idea that they are confident in involving young people in their care (see Figure 45) this drops to 79.3% (n=1,353) of CYP (of whom the majority – 55.5% (n=947) - indicated that they were involved in decisions about their care "a little"). (See Figure 16).
- There appears to be something of a disconnect between the views of health and care professionals regarding giving advice, and the views of parents/carers and CYP. While over three quarters (77.5%, n=55) of professionals indicated that they were confident in providing advice (see Figure 48) only about a third (32.4%, n=181) of parents and just over a half of CYP (52.6%,

n=880) indicated that they child had been given advice by a health professional. (See Figure 41 and Figure 21)

- Just over half (56.3%, n=40) of professionals indicate that they are easily able to refer CYP into another service (see Figure 47). From a parent/carer perspective though the picture shifts somewhat: the majority (63.3%, n=285) of parents/carers did not think that their child got an appointment quickly and only around a fifth (21.4%, n=95) stated that the service referred on to had details of their child's condition. See Figure 37. The results therefore show that, while professionals are confident in making referrals, the process of this is not perceived as smooth and easy by parents/carers. 25.8% (n=462) of CYP did not think they were able to access onward appointments quickly and 24.9% (n=249) felt that they had to tell their story again. (See Figures 14 and 15).
- The results from the professionals indicate that healthcare staff do not feel that they had the help or support that they need to carry out their role effectively, with 40.2% (n=29) indicating that this is the case. (See Figure 50).
- While the data regarding perception of discrimination and barriers is somewhat concerning (48.6%, n=35) of professionals stated that they had witnessed discrimination or barriers – see Section 6.1.9) the qualitative data accompanying the results tends to indicate that the issue is more to do with barriers, rather than high levels of discrimination existing. However, it remains the case that a number of respondents identified issues around discrimination in the delivery of healthcare to CYP.

7 Conclusions

A number of conclusions, drawn from the data in this report, are set out below.

7.1 Overall assessment of health services

CYP, overall, have a positive view of healthcare and health services. A large majority (73.7%, n=1,335) reported that the last health service that they had used was good or excellent (Figure 13) and a majority (69.4%, n=1,135) of young people rated their experience of healthcare overall as good or excellent (Figure 23). The views of parents/carers were also positive with just over half (59.7%, n=364) reporting that the last health service their child has used was good or excellent (Figure 35) and over half (52.2% n=287) giving an overall positive assessment (Figure 42).

While young people raised a number of issues of concern for them (explored below) it is evident therefore that, on the whole, young people have a positive view about health services and have had positive experiences in their interactions with healthcare.

We note though the different rates of satisfaction between parents/carers and their children. There is nothing in the data that would help to explain the difference between the views of young people and their parents/carers but it is clear from the research that parents/carers are less likely to be satisfied with health services than their children.

1. **Key finding: The majority of young people have a positive view of health services and report having had a positive experience in their last encounter.**
2. **Key finding: Parents and carers are generally less satisfied with healthcare for children than young people.**

7.2 Health concerns of children and young people

Mental health

A clear finding from the surveys of CYP, parents/carers and professionals is the concern regarding mental health which was the most commonly cited health issue reported across all groups (60.8% (n=1,103) of CYP, 92.1% (n=605) of parents and 90% (n=72) of professionals). (Figures 7, 28 and 43 respectively). Mental health also featured strongly as an issue in the participatory activities and was the most commonly raised topic. (See Section 3.2.1).

It was evident from young people that they do not feel that mental health is treated on a par with physical health and is not prioritised. Common motifs in relation to views on mental health include that it is not taken as seriously as physical health, that there is widespread under-diagnosis among young people and that there are insufficient services. Some young people explicitly drew parallels between physical and mental health services, noting the lack of support in the latter compared to the former.

While care should be taken in reporting based on a very limited number of statements, it is the case that more than one young person consulted reported not being engaged by mental health services having self-harmed or having reported thoughts of suicide. There was a sense therefore that even young people in explicit crisis were not able to access support for their mental health.

Sleep

Somewhat strikingly, both young people and their parents/carers identified sleep as the health issue that was most important to them after mental health. (45% (n=848) of young people and 43.7% (n=288) of parents/carers – see Figures 7 and 28). Note that sleep therefore ranks above all other conditions that might have been thought of to have been of a more pressing concern. The findings were further endorsed by professionals who also identified this as the second most important issue (39.5% (n=32) - Figure 43).

3. **Key Finding: CYP indicate that mental health is the health issue that matters most to them but do not feel that there are the right range of services in place to respond to their mental health needs and that more needs to be done to help young people with their mental health.**
4. **Key Finding: The key health issue of concern among parents/carers regarding their children is also mental health.**
5. **Key finding: Both young people and parents/carers identified sleep as the next most important issue to them.**

7.3 Knowing how to access healthcare services

The results with regard to young people's knowledge of how to access healthcare services are positive with a large majority (78.8%, n=1,399) reporting that they would know what to do should they become unwell. (Figure 9). The majority (59.7%, n=983) of young people also knew how to access mental health services. (Figure 24). Note that parents/carers were also clear that they would know how to access health services for their child (88.1%, n=566). (Figure 29). While half (50.5%, n=325) of parents/carers knew how to access mental health services for their child (Figure 30), the rate differs markedly for those for physical health services.

The majority (59.9%, n=1,118) of young people noted that the first thing that they would do if they had a health concern would be to talk to a parent/carer. Note that only 6.1% (n=114) would contact their GP. (See Figure 8). The results therefore very clearly illustrate the critical role that parents/carers play in young people's access to health services and that, to engage young people in healthcare, awareness raising must target both young people and those that care for them.

The results also show that nearly a quarter of young people would go online for information about health. This therefore emphasises the need to provide young people with information about the right sites to go to for information, to ensure that what they access is clear, accurate, timely and, ideally, points them towards locally available services.

The results indicate that there is scope to improve knowledge regarding how to access mental health services so that awareness is on a par with physical health services. This is all the more important given the heavy emphasis placed by young people on their mental health and getting the right support for this. (See Section 6.2.).

6. **Key finding: Most young people know how to access health services should they need them but are most likely to turn to parents/carers in the first instance. This therefore highlights the need to engage effectively with both young people *and* their parents/carers.**

7.4 Health services used

The most commonly used health services were dentists (74%, n=1,363) of CY) and GPs (72.9%, n=1,344). See Figure 10.

The results indicate a notably high use of emergency services with nearly a quarter of young people reporting having used A&E in the last 12 months.

While there is no data available that indicates why this level of usage is so high, it is possible that use of A&E is being driven by difficulties in accessing GP services (described below) and those young people who reported giving up on trying to get a GP appointment. This conclusion is however purely speculative. Note though that only 0.6% of young people stated that, if they were unwell, they would go to A&E first (Figure 8). This therefore tends to support this conclusion insofar as it indicates that young people are looking for support for their health elsewhere before turning to A&E.

7. **Key finding: Over half of young people had seen their GP in the last twelve months. A fifth had attended A&E.**

7.5 Waiting times and access

While young people's overall assessment of health services tended to be positive (see 6.1 above) , they raised a number of negative issues regarding health services. The most commonly cited of these was in relation to waiting times and access which was evidenced in both the surveys and the participatory activities.

A very strong theme through the participatory work was the difficulty in getting GP appointments which was widely reported as being difficult and time consuming. A number of young people reported failing to get appointments with their GP and some (worryingly) subsequently gave up trying.

Waits were also reported in relation to secondary care with frequent reports of waiting times of several months. Some young people reported waiting times of over a year, and some even of several years.

It is important to caveat these findings inasmuch as that long waiting times was not a universal feature of young people's comments and, in some cases young people reported quick access to healthcare including GP appointments the same day, and rapid access to hospital services.

The overall impression however is that young people have experienced long waits to access healthcare and find making GP appointments slow and difficult.

8. **Key finding: The most common complaint made by young people in relation to health services was long waiting times for both primary and secondary healthcare services. Young people also reported that they found it difficult to get appointments with their GP.**

7.6 Being listened to

A very strong theme emerging from the consultation was the need for young people to be listened to, to have their health concerns taken seriously, and not to have their worries dismissed (particularly on account of their age). Comments in the survey and from the participatory activities indicate young people are highly aware of their health needs, know when their health has deteriorated or is giving them cause for concern, and therefore when they need to access professional support. Given this, one of the most common reasons given for a positive interaction with health was that they were listened to and taken seriously. (See Section 3.1.4). Conversely, a commonly given reason for a negative assessment of healthcare was that they were ignored, dismissed or that healthcare workers did not take the time to listen to them.

Given the importance of being listened to, the results from the survey provide a positive picture with 68.1% of young people saying that they felt listened to. These results align with the views of parents/carers where around a fifth (21.8%, n=132) also indicated that their child was not listened to. (Figure 32).

These results should be read in conjunction with the findings from the professionals' survey whereby 87.5% (n=63) of respondents indicated that they feel confident talking to young people. (Figure 44). There is therefore a slight disconnect between the overwhelming majority of professionals, who report that they feel able to talk to young people, and what young people and their parents/carers are saying. We therefore surmise that there is a slight sample bias at play. Those professionals who responded to the survey regarding children's healthcare may be those who are more likely to engage effectively with young people. Or put simply, professionals who don't feel confident talking to young people didn't answer the survey.

9. **Key finding: Young people place significant importance on being listened by healthcare practitioners and this is integral to their assessment of the quality of healthcare.**

7.7 Caring and compassionate staff

The results from the survey make it very clear that being treated with kindness, compassion and in caring manner are of significant importance to young people. This was the most commonly given reason why a young person would rate their interaction with healthcare positively, and (where staff were uncaring) a key reason why they would give a negative assessment. (See Section 3.1.4).

The results from young people indicate that health services are treating them with care with just under three-quarters (74.4%, n=1,344) of CYP indicating that they were treated with care and concern. (Figure 12). (Note that the rate among parents/carers was however slightly lower at 68.6%, n=418 - Figure 33).

10. **Key finding: Being treated with care and compassion is a key factor in how young people judge the quality of healthcare.**

7.8 Next steps and advice

Given the importance of communication for young people (see 6.6 above) it is interesting to note that the survey indicates that not all young people were clear about what would happen next with their treatment. While just under a third (31.1%, n=550) of young people report knowing next steps, the most common response was that they "sort of" knew (39%, n=653). Nearly one in five (17.3%, n=290) did not know. (All data Figure 20). Parents/carers shared this view with just over a quarter (28%, n=157) reporting that their child knew what would happen next. (Figure 40).

Again there is a slight disconnect between the views of CYP and parents/carers and those of professionals, 95.8% of the latter felt confident in involving children in decisions about their care. (Figure 45, n=69). This would appear to provide further evidence of the sample bias that was noted above (see 6.6).

Note also that not all young people were provided with advice following treatment. While a little over half (52.6%, n=880) were given advice, over a quarter (26.9%, n=451) "sort of" were given advice and 12% 9n=202 were given no advice. (All data Figure 21). Of some interest, parents/carers were less likely to indicate that their child had been given advice (32.4%, n=181 - Figure 41).

The results from professionals are interesting to note at this point with 77.5% (n=55) of healthcare workers who responded to the survey stating that they felt confident in giving advice to CYP. (Figure 48). Once again, this would tend to suggest that the views of professionals who responded to the survey may not be representative of the views of healthcare workers more widely.

The results would therefore tend to suggest that there is scope to improve communication with young people about next steps in their treatment and how they can manage their own health.

11. **Key finding: A sizeable minority of young people leave treatment not knowing what the next steps in their treatment are.**
12. **Key finding: A small minority of young people leave treatment having been given no further advice.**

7.9 Onward referrals

The data from the survey tends to suggest that the issue of waiting times extends to onward referrals, with only a quarter (25.6%, n=457) of young people indicating that they got an onward appointment for diagnosis and treatment quickly. (Figure 14). Parents/carers were less likely to indicate that their child got an onward appointment quickly (20.9%, n=94 agreeing or strongly agreeing – Figure 36).

It is useful to contextualise these findings with the results from the survey of professionals which indicate that a fifth (20.5%) of respondents felt that services for young people are integrated. The majority (51.5%, n=35) did not think that services were integrated. (See Figure 52).

There appears to be an issue with the quality of the referral/handover process with only around a third (35.7%, n=479) of young people stating that the service they were referred on to had details of their condition. (Figure 15). Parents/carers shared this view about the quality of transfer, with 21.4% (n=95) indicating that the service had details of their child's condition. (Figure 37).

13. **Key finding: Young people and their parents disagreed that onward referrals to other health services were quick.**
14. **Key finding: Young people and their parents/carers disagreed that services that they were referred on to had the details of their condition.**

7.10 Support for professionals

The results from the survey of professionals show that under half (38.9%, n=28) felt that they had everything that they need as a professional to help them in their role in supporting young people. (See Figure 50).

The results are interesting insofar as, if our assertion that some degree of sample bias is true, then the data indicates that the majority of professionals who feel most comfortable working with young people (that is, professionals who responded to the survey) do not feel fully equipped and resourced to help them. This conclusion is of course conjectural given that it is based on our views of the sample of professionals who responded. Regardless of this however, it remains the case that the majority of professionals do not feel that they have everything they need to work effectively with their young patients.

The comments provided by professionals usefully illustrate what is preventing them from providing the help that they would like. The responses indicate that the main issues are: a lack of mental health resources, improvements to referrals, more resources and better collaboration between different health partners. (See Section 5.1.8).

15. Key finding: The majority of professionals do not feel that they have everything they need to help them in their role in supporting young people.

8 Appendix

8.1 Full breakdown of ethnicity from CYP survey

Table 10: What is your ethnicity?

Ethnicity	Count	Percentage
Bangladeshi	13	0.8%
Chinese	344	22.4%
Indian	106	6.9%
Pakistani	68	4.4%
Any other Asian background	17	1.1%
African background	31	2.0%
Caribbean	21	1.4%
Any other Black background	20	1.3%
Asian and White	47	3.1%
Black African and White	8	0.5%
Black Caribbean and White	21	1.4%
Any other Mixed or multiple background	26	1.7%
British, English, Northern Irish, Scottish, Welsh	704	45.8%
Irish	1	0.1%
Gypsy/ Traveller	9	0.6%
Roma	0	0.0%
Any other White background	24	1.6%

Ethnicity	Count	Percentage
Arab	15	1.0%
Polish	10	0.7%
Somali	4	0.3%
Prefer not to say	22	1.4%
Any other ethnicity	27	1.8%
(blank)	346	
Total	1,884	1,538

8.2 Full breakdown of ethnicity from Parent survey

Table 11: What is your ethnicity?

Ethnicity	Number	Percentage
Asian or Asian British - Bangladeshi	2	0.4%
Asian or Asian British - Indian	24	4.6%
Asian or Asian British - Pakistani	4	0.8%
Any other Asian background	0	0.0%
Chinese	2	0.4%
Black or Black British - African	4	0.8%
Black or Black British - Caribbean	2	0.4%
Any other Black background	0	0.0%
Mixed - Asian and White	3	0.6%
Mixed - Black African and White	3	0.6%
Mixed - Black Caribbean and White	3	0.6%
Any other Mixed or multiple background	3	0.6%

Ethnicity	**Number**	**Percentage**
White - British, English, Northern Irish, Scottish, Welsh	434	82.7%
White - Irish	5	1.0%
White - Gypsy/Irish Traveller	1	0.2%
White - Roma	1	0.2%
Any other White background	10	1.9%
Arab	0	0.0%
19. Polish	2	0.4%
Somali	1	0.2%
Any other ethnicity	1	0.2%
I would prefer not to say	20	3.8%
Blank	286	
Total	811	525

8.2 Limitations in geographic data analysis

As survey respondents were only asked to provide a partial postcode, the conclusions we can draw from this data are limited for two main reasons.

1. **Data Quality**

Since the question allowed free text responses, the input varied widely in format and accuracy. Many responses needed correcting, and some could not be used at all due to inconsistencies. This made it difficult to reliably analyse the geographical distribution of responses.

2. **Ambiguity of Partial Postcode**

Many partial postcodes cover multiple local authority areas. For example, LE2 2 has an almost equal number of postcodes in both Leicester City and Leicestershire County, making it impossible to determine whether a respondent lived in the city or the county. Similarly, LE15 spans across Harborough and Melton.

When analysing the data, we only recorded a local authority area/district for postcodes with a confidently determinable location. This limitation predominantly impacted postcodes on the border between two geographic areas, particularly Leicester City as it is centrally located in Leicestershire. While a 24.4% response rate for Leicester City suggests potential underrepresentation, we were unable to determine a definitive location for 170 valid postcode responses, so the actual number of respondents living in Leicester City may be higher than reported. Conversely, the number of respondents in Leicestershire County may be overestimated, as we did not consider postcode data from neighbouring counties (Nottinghamshire, Lincolnshire, Northamptonshire, Warwickshire, Staffordshire, and Derbyshire).

Table 12: Summary of geographical analysis from children and young people survey

	Number of respondents
Did not provide a postcode	797
Provided an invalid postcode	50
Provided a postcode that doesn't fall within LLR	18
Provided a valid postcode that we could use to categorise by geography	849
Provided a valid partial postcode, but it covers more than one local authority area	170
Total respondents	**1884**

City	207	24.4%
County	598	70.4%
Rutland	44	5.2%
Total number of responses we can confidently categorise by local authority area	**849**	

Blaby	39
Charnwood	56
Harborough	106
Hinckley & Bosworth	60
Melton	36
North West Leicestershire	26
Oadby & Wigston	174
Provided a valid partial postcode in County, but it covers more than one district area	101
Total County	**598**

Table 13: Summary of the postcode responses from the children and young people survey

First part of postcode	**Number of respondents**
CV13	4
DE11	2
DE12	1
DE74	1
LE1	16
LE10	45
LE11	21
LE12	17
LE13	31
LE14	10
LE15	96
LE16	17
LE17	3
LE18	57
LE19	14
LE2	303
LE3	37
LE4	40
LE5	85
LE6	3
LE65	3
LE67	38
LE7	87
LE8	45
LE9	41
NG13	2
NG33	1
PE9	2
Did not provide a valid postcode	862
Grand Total	**1884**

Table 14: Summary of geographical analysis from the parents and carers survey

	Number of respondents
Did not provide a postcode	202
Provided an invalid postcode	3
Provided a postcode that doesn't fall within LLR	2
Provided a valid postcode that we could use to categorise by geography	400
Provided a valid partial postcode, but it covers more than one local authority area	52
Total respondents	**659**

City	70	17.5%
County	306	76.5%
Rutland	24	6.0%
Total number of responses we can confidently categorise by local authority area	**400**	

Blaby	37
Charnwood	62
Harborough	50
Hinckley & Bosworth	38
Melton	17
North West Leicestershire	30
Oadby & Wigston	11
Provided a valid partial postcode in County, but it covers more than one district area	61
Total County	**306**

Table 15: Summary of postcode responses from the parents and carers survey

First part of postcode	Number of respondents
CV13	9
CV9	1
DE12	10
DE74	2
LE1	1
LE10	16
LE11	21
LE12	20
LE13	12
LE14	13
LE15	38
LE16	13
LE17	18
LE18	6
LE19	14
LE2	45
LE3	36
LE4	40
LE5	12
LE6	7
LE65	7
LE67	23
LE7	23
LE8	22
LE9	37
NG13	2
NG32	1
PE9	3
Did not provide	207
Grand Total	**659**