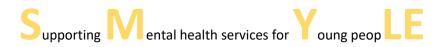


University for the Common Good





Understanding barriers and facilitators to engagement with mental health services for young people

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### 1 Introduction

# 1.1 About the SMYLE study

The *Supporting Mental health services for Young peopLE* study (SMYLE) was a research study conducted in 2020 and 2021 by a team of researchers from the Department of Psychology at Glasgow Caledonian University. The study was conducted in partnership with colleagues from NHS Greater Glasgow and Clyde (NHSGGC) Specialist Children's Services (SCS), the project funder.

The purpose of the commission was to explore barriers and facilitators to engagement, in its broadest sense, with mental health services for young people in the NHS GGC area with a view to making recommendations to underpin future service delivery.

There are a range of terms used to describe individuals who are older than children but not yet adults (e.g., adolescents, young people, teenagers) and these depend on things such as the legal framework and preference of authors. In this study we adopted the term 'young people' to refer to the population of interest; individuals aged 12 – 25 years old. This is in keeping with the view that they represent a group who are "older or more experienced children who are more likely to be able to make...decisions for themselves" (General Medical Council, n.d) and the focus of this study was on support available prior to the transition to adult services. When making reference to published literature we occasional adopt the terms of the original authors (e.g., adolescents) to appropriately convey their focus.

## 1.1.1 Steering Group

The development and progress of SMYLE was overseen by the SMYLE Steering Group. The Steering Group met bimonthly to: monitor and advise on progress against agreed objectives; advise on critical steps in the project journey, such as the recruitment of participants; and, advise and agree strategies for dissemination of study outcomes. Membership of the Steering Group is listed in <u>Appendix 1</u>.

## 1.2 About this report

This report outlines the background to the SMYLE study, the methods used to conduct the study, the findings of each phase, and the conclusions and recommendations made.

### 1.3 The impact of COVID-19

The SMYLE study was commissioned, and the original proposal developed, prior to declaration of the coronavirus disease (COVID-19) as a global pandemic (Tedros, 2020). Early modifications were made to the proposal following the UK Government's introduction of a first national lockdown on 23<sup>rd</sup> March 2020 (Johnson, 2020) and the impact of COVID-19 was listed as a standing item on the Steering Group agenda to ensure SMYLE was managed flexibly in response to the evolving context. The primary impact was a move to online working that remained in place for the duration of the study. To aid interpretation of the conclusions and recommendations, in this report we highlight where COVID-19 impacted directly on the delivery of SMYLE.

# 2 Background - setting the scene

Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community (World Health Organization, 2018).

The vision for a world where mental wellbeing is assured through the promotion of positive mental health has recently been articulated in the United Nations Sustainable Development Goals (United Nations, 2021); however, this is not a new agenda. The need for (early) intervention to establish positive trajectories across the lifespan has been a defining feature of public health policy for over a decade (Allen, 2011; Irwin, Siddiqi, & Hertzman, 2007). A burgeoning literature describes the development and testing of interventions that seek to either prevent or ameliorate factors known to result in poorer outcomes and promote assets to support successful development. The mental health and wellbeing of young people is of particular concern because "Happy and confident adolescents are most likely to grow into happy and confident adults, who in turn contribute to the health and well-being of nations" (Rao, 2001, p. 168).

# 2.1 Young people's mental health

However, global estimates suggest that between 10 and 20% of adolescents (10-19 years old) have a mental health problem, and adolescents are at higher risk than children (World Health Organization, 2020). Mental health conditions account for 16% of the burden of ill-health in adolescents, and suicide is the third leading cause of death in 15-19 year olds (World Health Organization, 2020). Moreover, it is thought that over half of mental health problems experienced in adulthood will have had early symptomology by the age of 14, but the majority will go unreported (World Health Organization, 2020), and there is a pattern of recurrence across an individual's life (Kessler et al., 2012).

While this underreporting of mental ill-health symptomology makes it difficult to estimate the prevalence and incidence at local levels, the combination of available survey data with data about referral and uptake of mental health support in Scotland points to a large proportion of young people experiencing negative mental health and wellbeing. For example, survey data show that in 2010 26% of S4 pupils (~15 years) reported emotional and behavioural problems, 24% reported conduct problems, 36% reported prolonged sadness, and only 33% reporting happiness in their life (NHS Health Scotland, 2013). In 2011 14% of 16 – 19 years olds reported symptomology indicative of a mental health problem, and 8% had behaviours suggesting alcohol dependence, and rates of drug-related disorders in the under 19s were 19.4% (NHS Health Scotland, 2013).

National datasets show an upward trend in referrals being made to Child and Adolescent Mental Health Services (CAMHS) in Scotland, with a peak of 10,193 referrals in the quarter ending June 2021. The quarterly waiting list for CAMHS exceeded 11,000 in 2021, and every quarter over 4,000 children and adolescents began treatment (Public Health Scotland, 2021). In June 2021 there were 28,988 children and young people receiving treatment through CAMHS (Public Health Scotland, 2021). These data highlight that there is a critical need to promote mental wellbeing, and prevent and treat mental health problems, in young people in Scotland.

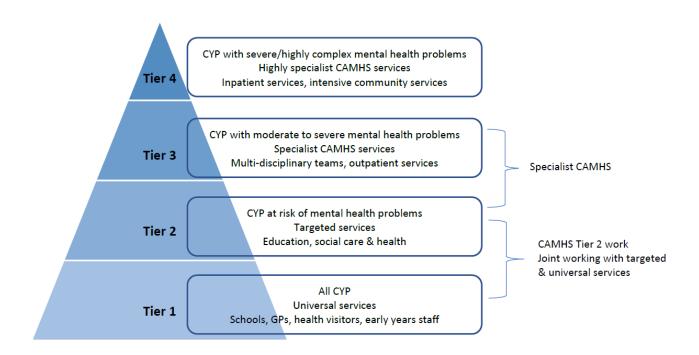
# 2.2 Mental health support for young people

Since 2006 Scottish policy, service provision and practice that impacts on the lives of children, young people and their families has been underpinned by the Getting It Right For Every Child (GIRFEC) approach: "making sure children and young people can receive the right help, at the right time, from the right people" (Scottish Government, n.d. a). Numerous policies and legislation support the provision of health and wellbeing services for children and young people in the NHS, education and third sector. These include the Children and Young People Act (Scotland) Act 2014 and the more recent Scottish Mental Health Strategy 2017 – 2027 (Scottish Government, 2017). For example, the Children and Young People (Scotland) Act 2014 requires a single planning approach for service provision, one that is outcomes driven and underpinned by an understanding of children and young people's wellbeing. The Mental Health Strategy 2017 – 2027 (Scottish Government, 2017) outlines 40 actions to improve service design and delivery. Of importance in the context of the SMYLE study is an acknowledgment that work is needed to improve access to CAMHS and to better integrate the whole system of mental health support for children and young people, including prevention and early intervention (Tiers 1 and 2, see below) (Scottish Government, 2017). The strategy is explicit in highlighting the need for "CAMHS [to be] available, accessible, acceptable, of a good quality" and that improvement "should also consider design of services and referral pathways" (Scottish Government, 2017, p. 24).

Mental health services for children and young people are described within a four-tier model (see Figure 1). At Tier 1 mental health support is universal, provided in services that do not necessarily have a primary mental health function (e.g., schools, social work), and providers do not need to be mental health specialists. Services at Tiers 2 to 4 are typically provided by mental health practitioners (e.g., psychologists, counsellors, psychiatrists), who offer diagnosis and consultation to children and young people referred with more complex needs. Child and Adolescent Mental Health Services (CAMHS) "are multi-disciplinary teams that provide...assessment and treatment/interventions in the context of emotional, developmental, environmental and social factors for children and young people experiencing mental health problems" (Scottish Government, 2020, p. 1). CAMHS is typically offered at Tier 3 and 4, with Tier 4 providing services such as intensive community treatment, day units and inpatient units (Information Services Division, n.d.; Scottish Government, 2020). CAMHS takes referrals for children and young people up to 18 years old, referrals for those over 18 years old are made to Adult Mental Health Services (AMHS). The aspiration for CAMHS is that it should be community based, and access to appropriate support should be quick and easy (Scottish Government, 2020). CAMHS is complemented by additional support through Community Mental Health and Wellbeing Supports and Services.

Referral to CAMHS is made in the case of a child or young person who is experiencing moderate or severe mental health problems, defined as "emotional, behavioural, or psychological difficulties of the child or young person which affect several areas of their life (e.g., home and school)" (NHS Greater Glasgow and Clyde Specialist Children's Services, 2017, p. 4), that cannot be addressed through other services. Referrals can be made by any agency who provides support for children and young people. Referrals are triaged to a prioritised waiting list, and the local delivery plan standard for CAMHS is currently 18 weeks referral to treatment (Information Services Division, 2019), with a first appointment scheduled for 4 weeks following accepted referral (Scottish Government, 2020). Data from the period 2020 – 2021 show a rising trend with 73% of children and young people in Scotland seen within 18 weeks (Public Health Scotland, 2021).

Figure 1: CAMHS tier structure



## 2.3 Mental health support service access

There is, however, growing awareness that some young people struggle to fully access mental health support services (MHSS), such as CAMHS. Historically, a fundamental barrier to access has been in rejected referrals. Indeed, in 2018 an audit of referrals to CAMHS in Scotland found that 1 in 5 were rejected (Scottish Government, 2018), and 'not accepted/redirected' rates continue to fluctuate around 20% (Public Health Scotland, 2021). These rates remain high, but changes have and continue to be made within the whole mental health support system to address this; for example, offering an initial appointment to all appropriate referrals, ensuring that referrals considered inappropriate for a service are redirected to an alternative, and by developing referral pathways to ensure appropriate first referrals are made.

While acknowledging the importance of rejected referrals as a barrier to securing appropriate support, there are a wide range of factors that mean that even when services are made available engagement is not optimal. For example, it is estimated that as many as 50% of young people who are in need of mental health support do not enrol in treatment, and of those that do enrol half again fail to complete it (Merikangas et al., 2010; Pellerin et al., 2010). In Scotland, in quarter ending June 2021, 14.1% of children and young people offered a first appointment with CAMHS did not attend (Public Health Scotland, 2021). In some periods over one-quarter of first appointments have been recorded as a 'did not attend' events (Information Services Division, 2018).

# 2.4 Engagement

Service access through an efficient and sensitive referral process is one of the first steps to ensuring that high quality mental health support is available and accessible to all children and young people in need. However, to ensure positive outcomes, access and attendance needs to lead to full engagement with the support/treatment pathway. This includes the engagement of both the young person and also their caregiver(s). Caregivers play a critical role in how young people access, attend, and engage with services and they have been identified as a key barrier/facilitator to young people's engagement and treatment outcomes (Staudt, 2007; Haine-Schlagel & Walsh, 2015).

A number of definitions of engagement exist and they share a fundamental understanding that "engagement represents an individual's multidimensional (e.g., social, cognitive, affective, and behavioral) commitment to treatment...[and it] is a dynamic process that involves the interplay among individual, familial, processional (i.e., provider-client), service organization, and ecological (e.g., availability of services in the community, sources of help typically sought by members of a group) factors" (Becker et al., 2018, p. 2).

Indeed, engagement, or indicators of engagement, can be usefully categorised as being attitudinal or behavioural. Attitudinal engagement refers to elements such as expectations about support/treatment demands and effectiveness and motivations to participate (Staudt, 2007). Behavioural engagement includes seeking support, attendance, and active participation with the demands of the support/treatment (both in sessions and any homework) (Staudt, 2007).

It is also important to acknowledge the temporal nature of engagement. For example, Becker and colleagues (2018) proposed the REACH framework that defined key domains of engagement as: relationship (e.g., therapeutic relationship); expectancy (e.g., expectations about outcomes); attendance (e.g., attending sessions); clarity (e.g., understanding demands of treatment); and, homework (e.g., completing practice exercises). However, while this can be helpful in scaffolding research into barriers and facilitators of engagement when the person is in treatment, the framework excludes engagement domains prior to any support/treatment enrolment (e.g., support seeking) and after the individual has left support/treatment (through completion or withdrawal).

Thus, barriers and facilitators can impact on different types of engagement (i.e., attitudinal and behavioural) and in multiple domains (e.g., REACH) that span the full trajectory of a young person's engagement journey (e.g., support seeking, attendance at support/treatment, cognitive preparation for support/treatment, and adherence to any support/treatment programme) (Becker et al., 2015). However, much of the literature focuses specifically on in-treatment engagement and this means that, currently, knowledge and understanding about other points in the mental health support seeking journey are more limited.

# 2.5 Engagement barriers and facilitators

There is some published work that has identified barriers and facilitators, and in this there is a general consensus that therapeutic relationships and collaborative decision making are critical in the engagement process (e.g., lachini et al., 2015; McPherson et al., 2017). However, while this understanding exists, it is important that barriers to and facilitators of engagement are explored in a contextualised way; sensitive to both the stakeholders they relate to and the context of the service delivery (e.g., geographical and sociocultural context).

For example, research has highlighted a disconnect in the ways different parties in the service user/provider relationship describe barriers and facilitators. Mental health providers often point to factors that exist on the side of the client, such as denial, lack of motivation and knowledge. Whereas service users are more likely to describe engagement barriers in the context of the provider, such as negative treatment experiences, lack of co-operative treatment decision making and blame (Buckingham et al., 2016). These opposing views make it difficult to address issues of ownership of engagement and difficult to implement engagement strategies.

In addition, it is noted that much of the literature about engagement with MHSS for young people has focused on the perspective of caregivers and other adults (Bone et al., 2015; Buckingham et al., 2016). This gives a limited voice to young people in relation to decision making about their healthcare (Bone et al., 2014). When young people have been included, they tend to be sub-populations (e.g., young people with psychosis) or recipients of narrow focused services or single interventions (e.g., lachini et al., 2015). Consequently, very little is known about the barriers and facilitators of engagement with a multi-disciplinary mental health service such as CAMHS, and even less is known about the engagement of young people in Scotland with MHSS.

# 2.6 The SMYLE study

## 2.6.1 Aims and objectives

The aim of the SMYLE study was defined by NHS Greater Glasgow and Clyde (NHSGGC) Specialist Children's Services (SCS) and the research team and subsequently operationalised in specific objectives. The aim was to explore barriers to, and facilitators of, engagement with mental health support services (MHSS) for young people (including Specialist Children's Services [SCS] and CAMHS) with a view to making recommendations to underpin future service delivery in NHS GGC and more broadly.

The specific objectives were to:

- 1. Undertake stakeholder engagement and involvement to: i) generate information/questions about engagement of young people and their families in MHSS; ii) imagine what would make an engaging service for the future; and, iii) build relationships to facilitate recruitment.
- 2. Explore young people's knowledge, understandings and experiences of mental health and mental health support seeking during COVID-19. Specifically seeking to understand the impact COVID-19, and related public health interventions, may have had on young people and their families with respect to their mental health and their access and engagement with MHSS, and explore options for support in the future.
- 3. Explore young people's perceptions and beliefs about specialist MHSS, and perceptions and beliefs about treatment effect/benefit. Including young people who are at a pre-engagement stage, those who have received a referral to NHS specialist services, and those who accessed non-NHS mental health support. Engagement will be conceptualised in a broad way and will include: process (e.g., referral process); practicality (e.g., transport, accessibility of online and telephone services); service context (e.g., culture, environment); and, the therapeutic relationship (e.g., relationship with therapist and support staff). Attempts will be made to recruit young people from areas known to have lower than expected levels of engagement with MHSS.
- 4. Explore the role of family, peers, and others in facilitating/preventing engagement (including attendance) with MHSS, including specialist mental health services.

- 5. Where possible, explore professionals' perceptions and experiences of working to engage young people in specialist MHSS.
- 6. In all aspects of the project, consider whether there are aspects of service provision, young people's perceptions and beliefs and/or socio-cultural issues that might widen the inequalities gap and/or promote disengagement (e.g., localised community issues, processes that promote engagement in some groups of young people but not others).

The objectives were addressed in three phases: a review of the literature, a stakeholder engagement and involvement phase, and the main empirical study.

## 2.6.2 Theoretical perspective

The research was guided by a critical realist theoretical stance; one that conceptualises social reality as multi-layered and seeks to explore the multiple mechanisms and structures generating social phenomena (Bhaskar, 1989). Through this theoretical lens, experiences of stakeholders can be linked to and explained by underlying generative mechanisms, including, for example, individual factors and beliefs (Oliver, 2012). This approach enabled an exploration of the social and individual barriers and facilitators to meaningful engagement with MHSS.

An important underpinning factor in the translation of the objectives of SMYLE into the study design was to give young people a vehicle to describe and explain their engagement with MHSS. While addressing the objectives was a key focus of the design, we worked to ensure that young people had the opportunity to tell their own stories. We recognised these stories might go beyond, or be different to, our initial understandings of the issues, which were developed using existing literature that, as we note above, has limited input from young people.

# 3 Phase 2: Stakeholder engagement and involvement

This section describes Phase 2 of the study; stakeholder engagement and involvement (SEI) designed to inform the development of Phase 3. First, this phase of the study is contextualised by providing a rationale for involving stakeholders. Second, the methods used to recruit and involve stakeholders are described, as are the governance and ethical considerations, and the data analysis. Third, the findings are presented alongside the conclusions and implications for Phase 3 of the study.

## 3.1 Stakeholder engagement and involvement: the context and rationale

### 3.1.1 Stakeholders

Stakeholders are "individuals or organizations who have an interest, personal or professional, in the topic" (Guise et al., 2013, p. 668). A stakeholder in health research is defined as "an individual or group who is responsible for or affected by health- and healthcare-related decisions" (Concannon et al., 2018, p. 459), this includes people who use health services and those who provide them (INVOLVE, 2012). There are multiple ways stakeholders can and should be involved, and attempts have been made to define different activities at different points in the research process. For example, INVOLVE (2012) differentiate between: 1) stakeholder engagement, as the provision of information and knowledge about research to stakeholders; 2) stakeholder involvement, as the active involvement of stakeholders in the planning and delivery of research; and, 3) stakeholder participation, as the more typical inclusion of people as the subjects of the research that data is collected from or about. In what follows, we use the phrase 'stakeholder engagement and involvement' (SEI) to reflect that, in the SMYLE study, the activities of the research team and the stakeholders are interrelated and contingent on each other.

### 3.1.2 Why involve stakeholders?

Expectations around SEI have grown in recent years, and the majority of research funders require the involvement of stakeholders as a means of enhancing the research process, contextual validity, and impact potential. As such, the purpose of SEI is to produce evidence that is timely, objective, rigorous, and developed and presented with transparency (Concannon et al., 2018; Cottrell et al., 2015). In addition, SEI can generate user/patient-centred outcomes that can help bridge the research-practice gap by increasing researchers' understandings of the issues, and decisional dilemmas faced by the public (Guise et al., 2013).

In some contexts, stakeholder engagement and involvement may be an end in itself; having an intrinsic rationale. In other contexts, SEI may be driven by instrumental imperatives; involving stakeholders in ways that are beneficial for the research (Concannon et al., 2018). This might be in making research aims and questions more relevant, methods and approaches more transparent and valid, and making findings more useful and thus more likely to be implemented in practice (Concannon et al., 2018). SEI is particularly important for research involving populations that have proved harder to reach, such as young people, because they can illuminate barriers and help formulate ways of overcoming these (Esmail et al., 2015).

Of course, alongside meeting the needs of the research process, it is important to acknowledge that stakeholders choose to be active participants in the research process for a variety of reasons. For example, personal experience with a particular service may lead to the desire to change its delivery. Also, the opportunity of having a voice or being able to give something back by helping others may encourage involvement (INVOLVE, 2012).

#### 3.1.3 Who to involve

A crucial step in any SEI activity is ensuring that individual stakeholder participants best represent the views of the respective stakeholder group(s). Thus, being transparent about who is involved and why they are involved is vital (Concannon et al., 2018), as is taking a purposive approach to the recruitment of individual stakeholders (Guise et al., 2014). To guide this, various frameworks have been developed, but in their *Practical Guidance for Involving Stakeholders in Health Research*, Concannon and colleagues (2018) acknowledge the overlap in these frameworks. The authors recommend a flexible application of the frameworks, noting that not all groups should or need to have a stake in all aspects of the research, and that stakeholder categories are not mutually exclusive. For example, stakeholders may have an interest as an individual but also as a representative of an organisation. This overlap between the stakeholder categories requires transparency in the purpose of the SEI and in the role of the individual stakeholder to ensure conflicts of interest are not created (Concannon et al., 2012).

### 3.1.4 How to involve

The extent of stakeholder involvement – the role of the stakeholders – differs across projects and different phases within projects (Concannon et al., 2012). INVOLVE (2012) differentiates between three approaches to involvement: *consultation, the* seeking of stakeholder views that are used to inform study team decision making; *collaboration,* which involves an ongoing shared decision-making partnership between stakeholders and the study; and, *user-controlled research,* which is actively controlled, directed and managed by stakeholders. Linked to this, the modes of involving stakeholders can be relatively simple, such as asking stakeholders to participate in research meetings or comment on research proposals, or they can be more sophisticated, like the use consensus methods such as the Delphi technique (Cottrell et al., 2015; Linstone & Turoff, 1975).

## 3.2 Stakeholder engagement and involvement plan

A SMYLE study stakeholder engagement plan was developed using the practical guidelines by Concannon et al. (Concannon et al., 2018). The purpose of Phase 2 of the SMYLE study was to undertake SEI, whereby stakeholders were invited to participate as consultants in the design of Phase 3. Specifically, the aims were to: 1) provide the research team with insight into stakeholders' perceptions and experience of mental health and mental health support services (MHSS); 2) inform the development of Phase 3 interview questions about engagement of young people and their families with MHSS; and, 3) provide insight into appropriate recruitment, data collection and dissemination methods, and build relationships to facilitate recruitment for Phase 3. It was also envisaged that this SEI would have intrinsic elements. Participation in the SEI activities may empower young people to talk about their experiences of mental health and mental health support needs, and professional stakeholders would have the opportunity to talk about their experience of working with young people.

## 3.2.1 Stakeholder groups and recruitment

Guided by the Cochrane Knowledge Translation Framework (Cochrane, 2017), three stakeholder groups were identified as having the appropriate knowledge and/or experience to make a meaningful contribution to the SEI: young people, parents and caregivers of young people, and professionals working in a mental health context. The inclusion criteria are defined in <u>Table 1</u>.

Table 1: SMYLE stakeholder group inclusion criteria

Young people	Young people aged 12 – 25 years old
Parents and caregivers	Parent or caregiver of a young person aged 12 – 25 years old
Professionals	Professionals (including volunteers) who provide mental health support to young people
	Professionals (including volunteers) who refer young people to MHSS
	Individuals with experience of engaging young people in MHSS and/or mental health research
	Individuals from organisations who engage with young people and families (e.g., youth clubs/associations staff, sport club staff, education staff)
	Representatives of mental health charities and NGOs focussing on children and young people

A purposeful sampling approach was taken to facilitate the recruitment of individuals who represented each of the stakeholder groups (Palinkas et al., 2015). Opportunistic and snowball strategies were employed in the following ways:

- Social media accounts for the SMYLE study were set up on *Facebook* and *Twitter* and used to publish advertisements about the study. Posts were designed to directly recruit participants and encourage sharing of the posts to wider audiences.
- Gatekeeper organisations were asked to cascade recruitment materials through their networks (including social media).
- The SMYLE study was promoted in Glasgow Caledonian University through official staff and student communication platforms (e.g., staff newsletter and email).
- An advertisement was placed on *People in Research*, a database that publishes opportunities for public involvement in NHS, public health and social care research.
- Members of the research team and Steering Group used their own professional and private networks to cascade information about the study.

## 3.2.2 Mode of stakeholder engagement and involvement

SMYLE Phase 2 took place over 4 weeks between 17<sup>th</sup> July and 19<sup>th</sup> August 2020. It is important to note that this was during the COVID-19 pandemic and UK public health measures impacted on the ways that SEI could be facilitated. Originally conceived as face-to-face activity, the SEI was redeveloped to virtual activity using the project website as the primary vehicle. Other changes were made in relation to the study recruitment and scope. Recruitment of individual stakeholders was widened from those living in Greater Glasgow and Clyde (GGC) to the whole of Scotland. The focus was also broadened from services provided by the NHS to MHSS available to young people in Scotland (e.g., school services, private counselling and third sector). That said, efforts were made to recruit as many young people and parents/caregivers with experience of NHS GGC CAMHS as possible.

Individuals who were interested in participating were provided with a participant information sheet (PIS) that was tailored to their stakeholder group. The PIS was accessed on the study website and, after reading, those who wanted to participate were asked to complete an online consent form and set up a user account with a unique log-in and confidential password. The online consent forms were checked by the research team and, where appropriate, the participant's account was approved to allow contribution to the discussion forum. Following provision of consent, participants were also asked to provide some demographic information.

Each participant was allocated to a private discussion forum for their stakeholder group; individuals within each forum could read the comments from, and interact with, other people in that stakeholder group, but not across groups. The decision to separate the groups was taken to maximise discussion amongst participants facilitated through homogeneity of experience. This was considered particularly important for young people who may have been reticent to contribute to discussions with professionals or parents/caregivers. It also allowed for the questions posed to be tailored to the stakeholder group.

Each discussion forum was structured so participants read a short vignette describing a young person who was experiencing mental health problems. They then navigated through a series of question prompts that linked to the vignette. Participants could leave comments in response to each question or choose not to respond.

The question prompts were designed to elicit responses on the following key topics:

- How mental health and mental health services are understood by SEI groups
  - Understandings about what mental health is in the context of young people
  - Understandings about what MHSS are and who they are for
  - Perceptions/beliefs about what mental health services do (e.g., understanding of treatment and prevention)
- The nature of engagement and disengagement of young people with mental health services
  - Experiences and understandings of (attempted) access, referral and engagement/disengagement
  - What currently works and doesn't work to engage young people (i.e., perceived barriers and facilitators of engagement) with mental health services
  - Understandings about who the key gatekeepers/facilitators of access and accessibility are (e.g., GPs, families, young people, school nurses)
  - The role of family and others in facilitating/promoting engagement with MHSS
  - Aspects of service provision that impact on engagement

- The design of SMYLE Phase 3
  - Strategies for the recruitment of young people and families to Phase 3
  - What young people, families and services/organisations would want to gain from Phase 3
     (i.e., health care decision making)
  - Who findings should be disseminated to

Stakeholders were invited to make as much of a contribution as they wished across the 4-week period of SEI.

### 3.2.3 Ethical considerations

Ethical approval was obtained from Glasgow Caledonian University's Psychology, Social Work and Allied Health Sciences Ethics Committee. All stakeholder engagement and involvement activities were guided by appropriate ethical and legal frameworks and published best practice guidance about stakeholder engagement and involvement (INVOLVE, 2018). In addition, the research team completed mandatory and appropriate research training such as Good Clinical Practice training and NSPCC training on how to keep young people safe online.

At all times, it was ensured that the processes of informed consent, confidentiality and anonymity were transparent and implemented. All participants were asked to provide explicit informed consent for participation prior to engaging in the online discussion fora. All young people were asked to consent to participating and for those under 16 years old permission was sought from their parent/guardian. All study data and documentation were managed in line with the requirements of the Data Protection Act (2018) and the General Data Protection Regulation (GDPR), as well as GCU's Data Protection and Privacy Policy (V1.2).

### 3.2.4 Data analysis

The comments stakeholders provided in the online fora were primary data, and these were complemented by demographic information to allow for a description of the stakeholders. Comment data were analysed using Framework Analysis (FA; Ritchie et al., 2003), a method for the management and analysis of qualitative data frequently used in health research (Ward et al., 2013). The key aim of FA is to produce structured outputs of summarised data through coding with an analytical framework. The analytical process was guided by the five steps outlined by Ward and colleagues (2013) and regular meetings between researchers were held to agree on recurring themes and patterns in the data (see also Heath et al., 2012). The data was downloaded, anonymised and organised to facilitate analysis using NVivo 12 (QSR International Pty Ltd., 2018). In step 1, Familiarisation, the researchers familiarised themselves with the data in multiple iterations of reading the fora comments. In step 2, Identification of an analytical framework, two members of the team independently coded the data and grouped codes into categories, summarising data with similar meanings and ideas. In step 3, Indexing, the analytical framework was used to code the full data set and the themes and sub-themes were refined. In step 4, Summarising data in analytical framework, a matrix was created in which rows represented themes and sub-themes, columns represented cases (stakeholder groups), and each cell contained the raw data. The data within each theme and sub-theme were then summarised. In step 5, Mapping and interpretation, both researchers went back to the original data set to interpret the data in its context. Last changes were made to the data and summaries developed to ensure enough detail was provided and to highlight any differences within each stakeholder group. Illustrative quotes were selected to provide an account of each data summary.

### 3.3 What we found: Phase 2

# 3.3.1 Recruitment and sample characteristics

As part of the recruitment strategy (see 3.2.1), five social media posts were created, and these were shared and retweeted by 91 individuals/organisations. Using the available analytics, it is estimated that 6,109 individuals were reached via social media posts and 956 people visited the study website. In addition, 38 gatekeeper organisations were asked to assist in the recruitment of young people, parents/caregivers and/or professionals. No further information was gathered about how the organisations cascaded information about the study or how this translated to participant recruitment.

All recruitment strategies yielded 60 successful study sign-ups (participants filling out the consent form) and 30 participants who left comments in the discussion fora: 14 young people, ten parents and six professionals.

# 3.3.1.1 Young people stakeholders

Demographic characteristics of the young people stakeholders can be seen in <u>Table 2</u>. The mean age of the 14 young people stakeholders was 19.3 years (SD = 4.0) and Table the majority identified as female and were in education, and all lived in Scotland Table. Over half of the young people had some experience with MHSS; either currently or recently receiving support/treatment.

**Table** 

Table 2: Demographic information – Young people (Phase 2)

		% (n)
Gender	Female	71.4% (10)
	Male	28.6% (4)
Location	NHS Greater Glasgow & Clyde	35.7% (5)
	NHS Lothian	7.1% (1)
	NHS Grampian	7.1% (1)
	NHS Forth Valley	28.6% (4)
	NHS Lanarkshire	14.3% (2)
	NHS Ayrshire & Arran	7.1% (1)
Employment and education	Employed	28.6% (4)
	Unemployed	7.1% (1)
	Attending school	42.9% (6)
	Attending university	21.4% (3)
Experience of mental health services	Some experience	64.3% (9)
	No experience	21.4% (3)
	Thought about seeking support	14.3% (2)

## 3.3.1.2 Parent/caregiver stakeholders

Demographic characteristics of parent/caregiver stakeholders are presented in <u>Table 3</u>. The mean age of the ten parent/caregiver stakeholders was 44.1 years (SD = 4.6), and Table the majority identified as female and were employed Table . Half of parents/caregivers lived within the NHS GGC region and about one third of the parents/caregivers had some experiences with MHSS for young people.

Table 3: Demographic information – Parents/caregivers (Phase 2)

		% (n)
Gender	Female	80% (8)
	Male	20% (2)
Location	NHS Greater Glasgow & Clyde	50.0% (5)
	NHS Forth Valley	30.0% (3)
	NHS Lothian	10.0% (1)
	NHS Lanarkshire	10.0% (1)
Employment and education	Employed	55.5% (5)
	Unemployed	33.3% (3)
	Attending university	11.1% (1)
Experience of mental health services	Some experience	33.3% (3)
	No experience	44.4% (4)
	Thought about seeking support	22.2% (2)

### 3.3.1.3 Professionals stakeholders

The mean age of the six stakeholder professionals was 35.2 years (SD = 13.0), 83.3% were female (n=5). All professionals were currently employed in posts in central Scotland.

## 3.3.2 Discussion forum findings

Three themes were coded in the analysis: 1) Understandings, perceptions and beliefs about young people's mental health, 2) Perceived barriers and facilitators to engagement with MHSS for young people, and 3) Design of SMYLE Phase 3. A number of sub-themes were coded within these. Table 4 provides an overview of the themes and sub-themes with exemplar quotes from stakeholder for the first two themes. Quotes were not included for the third because the comments left by participants were often just single words or phrases.

The first two themes relate to Phase 2 aims 1 and 2, and provide insight into the experiences of mental health and MHSS from each of the stakeholder perspectives, and they inform the development of Phase 3 interview questions. The third theme relates to Phase 2 aim 3, informing appropriate recruitment, data collection and dissemination methods. A brief description of themes and sub-themes is detailed below, and the implications for Phase 3 are discussed.

# DRAFT – Not for circulation

Table 4: Overview of the themes and sub-themes with exemplar quotes

Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Understandings, p	perceptions and beliefs about young p	eople's mental health		
Understandings of mental health	Young people and parents presented an understanding of mental health that acknowledges both the positive and negative. Focus on negative MH promotes stigma. Dissonance between how professionals perceive the understandings of young people with how it was reflected by the young people.	The condition of your thoughts and perceptions. E.g. having a good mental health day would consist of lots of positive outlooks and motivated thoughts. (YP, F, 25y, in treatment)  Just as important as physical health. It is the health of our mind, including mental disorders but also self-care and keeping our mind a positive place. (YP, F, 19y, in treatment)  Mental health is the well-being of your emotional state, mental state etc. It's something that some of us try to hide from peers and family because we may feel judged but it's important to talk about it so that we can keep ourselves healthy. (YP, F, 16y, in treatment)	the ability to function in a positive healthy manner, and cope with day to day life and any problems that may arise. (Parent, F, 40y, child previously sought support)  It is exactly like physical health: it can be good and bad at times.  Sadly, people often implicitly replace 'mental health' by 'mental illness' and the latter carries stigma. (Parent, F, 40y, child previously sought support)	I've heard young people saying their 'brains are broken'. (Professional, F) Young people are very aware of mental health, and are confident to use that phrase when chatting about how they're doing, such as 'my mental health is fucked'. Many acknowledge their own depression/anxiety using those terms'Meme speak' and joking about their own mental health is very common. (Professional, F)

Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Information and support seeking	Young people and parents presented a range of different people and places they could go to for information about, and help with, young people's mental health. Young people struggle to talk about mental health.  There was a disconnect in young people knowing that there were sources of support and feeling able to access them.	It seems a lot of people suffer in silence due to not wanting to be seen as weak or as an attention seeker. Some people don't want their parents to worry about them or tell their friends because they might not understand or really care. (YP, F, 17y, thought about mental health support)  Either family, friends, perhaps counsellors at school/uni. These might not necessarily be on a regular basis – if at all. (YP, F, 25y, in treatment)	Change of behaviour, sadness and a general retreat into themselves. A parent knows their child and what is 'normal' behaviour. (Parent, F, 51y, no experience)	
Knowledge of mental health support services	Young people's knowledge about CAMHS was limited. Parents did know about CAMHS but also held a view that it was difficult to access. CAMHS, or an appropriate gatekeeper, was not always the first port of call for young people with mental health difficulties.	I believe it is a mental health service/charity for young people. I think they must offer support and possibly counselling (YP, F, 25y, in treatment) Yes, I was under CAMHS until I was 18, however I had never heard of their services before I was referred. (YP, F, 19y, in treatment)	I googled it to find out what it means but have not come across the service or heard of it. Seems to not be advertised in an obvious way. (Parent, F, 41y, thought about treatment for child) I have not used the service, so I can't comment, but I have heard that there is a waiting list for appointments. A child in crisis should not be made to wait! (Parent, F, 45y, no experience)	

Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Expectations of mental health support services	Young people and parents construct mental health as something experienced across the lifespan with the potential for periods of poorer mental health. Professions felt young people and parents/caregivers were looking to be 'fixed'.  Professionals felt that young people and parents/caregivers can have unrealistic expectations of MHSS/treatment.  Unrealistic expectations make engagement difficult.			I think they [young people] expect support to solve all their problems, and are disappointed when they don't necessarily view therapy/counselling as helping. They expect staff to be friendly and have a wide understanding or various different issues affecting young people. (Professional, F) I think they [YP] expect mental health workers to be around for a while and this isn't always feasible Parents/carers can also have a mind-set of wanting to their children to be 'fixed' which can be difficult mind-set to have for all parties involved. (Professional, F)

Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Perceived barriers	and facilitators of young people's eng	agement with mental health support	services	
Barriers and facilitators to support seeking	Key barriers to seeking support were invisibility of mental health, lack of knowledge and information about mental health and MHSS, and a lack of appropriate signposting. Key facilitators included normalisation of support seeking and gatekeepers who were encouraging and supportive.	I think that there needs to be more conversation and signposting for services and avenues into these so that young people know they exist as I had no education of mental health or services until I was diagnosed and taken to professionals by adults. (YP, F, 19y, in treatment)  The shame and embarrassment of what they think the opinions of their peers will be. There is a huge thing about mental health in high schools and a lot of it is negative as peers that don't experience it don't think that it's serious and think that those who suffer with it are 'attention seeking'. (YP, F, 16y, in treatment)  The more normalised it becomes; the more people are willing to reach out for their own support. Hearing positive effects other people have had from receiving support would encourage young people more. (YP, F, 25y, in treatment)  The encouragement that it's not something to be ashamed of. (YP, F, 19y, in treatment)	Finally, it is not easy knowing what is abnormal about your teen's behaviour, especially if they are your first. (Parent, F, 40y, child previously sought support)  If a young person has been described all their life as being 'shy' they might not realise that what they're struggling to cope with as a teenager is in fact anxiety disorder. This lack of awareness could be exacerbated if the young person sees that their parents are just attributing things to 'normal teenage behaviour'. (Parent, M, 52y, child in treatment)  Fear, accepting your child has mental health issues is very hard. (P199; Parent, F, 51y, no experience) my daughter got therapy there however the waiting list has since increased so much that the criteria for a referral has changed a lot. The pre-therapy screening at the hospital is also very strict now (it seems you need to be suicidal to access treatment). (Parent, F, 40y, child previously sought support)	A lot of young people resign themselves to their poor mental health assuming it is inherent to who they are and the world they live in (Professional, F) Stigma amongst peers, pressure from parents, long waiting lists, unapproachable professionals that make them talk about things they find irrelevant. (Professional, F) Approachable teachers and GPs, peers saying they found it useful, it being promoted by influencers on YouTube. (Professional, F)

Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Barriers and facilitators of ongoing engagement	Key barriers to ongoing engagement were stigma, unmet expectations of treatment, poor therapeutic relationship, appointments that clash with other priorities.  Key facilitators included supportive others, positive therapeutic relationships, ownership in treatment plan.	They will tend to doubt themselves to the point that they think their problems aren't important enough and they may feel embarrassed and like they won't be taken seriously. Also, opening up makes you realise how real it is and that you really do need help, which can be a lot to process. (YP, F, 16y, in treatment)  Maybe even feeling as though the sessions are not helping.  Sometimes it is difficult to tell a counsellor to their face that they are not a good fit for you. (P169; YP, F, 25y, in treatment)  If the person they were seeking support from made them feel understood and important, make them feel comfortable and proud that they actually opened up. (YP, F, 16y, in treatment)  Travelling to appointments is hard. And explaining why I missed school. I didn't like that. (YP, M, 12y, completed treatment)	The young person and the counsellor being able to relate to each other is key. The young person needs to feel that the counsellor truly understands what they're experiencing I also think that the young person feeling that they are in control is key to them continuing to attend. That could come from the young person having freedom to discuss particular issues that are on their mind at the time, or have some ability to decide when appointments happen (Parent, M, 52y, child in treatment)	Unapproachable professionals that make them talk about things they find irrelevant (Professional, F)
Role of family and others in engagement	All three stakeholder groups highlighted the importance of the family in facilitating initial and ongoing engagement.	Fear of friends or family finding out and judging them. (YP, F, 19y, in treatment)	Being judged by others, particularly peer groups as someone who has 'issues' would be a determining factor and not knowing where to turn to for help. (Parent, F, other demographics not provided)	if other members of the family have had negative experience with mental health services and don't support he child going, they are unlikely to continue engaging. (Professional, F)

Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Design of the SMY	LE study Phase 3			
Potential stakeholders and gatekeepers	Stakeholders/gatekeepers were identified as schools, (mental) health care services and staff, MH charities and third sector organisations, and youth clubs.			
Promotion and recruitment activities	Gatekeepers should be asked to promote the study (e.g., as part of the wellbeing curriculum in schools).  Social media is a key vehicle for the recruitment of young people. Incentivise study participation. Recruitment material should highlight the aim of improving service accessibility and delivery.			
Data collection methods	Young people preferred one-to-one conversations or online surveys. Parents and professionals preferred one-to-one interviews and focus groups to exchange views.			
Theme/Sub- themes	Key findings	Young People's Comments	Parents'/Caregivers' Comments	Professionals' Comments
Dissemination and expectations of study outcomes	All groups hoped that study outcomes would improve MHSS for young people. Findings should be disseminated through stakeholders/gatekeepers. Present findings in attractive, clear, relatable and concise ways.			

## 3.3.3 Understandings, perceptions and beliefs about young people's mental health

Participant comments relating to their understanding, perception and beliefs about young people's mental health were reflected in four sub-themes: understandings of mental health; information and support seeking; knowledge of MHSS for young people; and expectations of MHSS for young people.

## 3.3.3.1 Understandings of mental health

The young people stakeholders were able to describe their understandings of mental health with language that suggested a mental health literacy, which could facilitate conversations about mental health and wellbeing. They referred to "emotional wellbeing", "resilience", "ability to cope" and "self-care" as well as "depression", "anxiety" and "eating disorders". However, while the young people were able to apply a language to describe aspects of mental health, they didn't go on to elaborate on this. This makes it difficult to know if they have a full understanding of mental health, or if this language is a representation of the internalisation of a mental health narrative without depth of understanding. For example, the young people didn't describe causes of poorer mental health or ways that people might work to improve their mental health. This is important because it might inform help seeking behaviours; for example, if young people construct mental health in a deterministic way they may be less likely to seek help.

Both parents/caregivers and young people perceived mental health as something that was as important as physical health and referred to mental health as having the potential to be impacted both negatively and positively. In particular, parents alluded to the potential for the narrative about negative mental health to mask the positive, which was presented as "misleading" and causing stigma; a problem some young people also described. This reinforces a need to explore both positive and negative aspects of mental health.

Professionals acknowledged that young people have a language to talk about mental health, and that some young people understood they had the capacity to change it. Interestingly, and in contrast to what the young people and parents/caregivers said, professionals framed young people's understandings of mental health as relating to mental health problems; they didn't describe young people talking about positive mental health. This may reflect the context of young people's interactions with professionals as being times when young people are struggling with their mental health, but further exploration of this is required.

### 3.3.3.2 Information and support seeking

A range of potential sources of information and support seeking were identified by young people; this included the internet, friends, GPs and schools. However, what needed further consideration was the extent to which these potential sources facilitate access to support/treatment for young people in need. Indeed, while young people were able to list potential sources of support, they also described that, in their view, most young people do not go on talk to anyone about their mental health. Indeed, the act of talking to another person about mental health was described as requiring "courage" and "trust" in the other person. Interestingly, only young people who were currently receiving, or had previously received, support/treatment mentioned professionals (e.g., GP, a teacher, therapist, or social worker) as someone young people would talk to about mental health, young people without experience of mental health support didn't make reference to professionals.

The support parents/caregivers received from friends or other parents tended to be about signposting to appropriate support services. The primary trigger for seeking help for their child's mental health was noted as being a change in behaviour or emotional wellbeing that could not be explained.

# 3.3.3.3 Knowledge of mental health support services

Although all the young people pointed to places/people that could be contacted for information or support for mental health, none of them provided the name of a specific mental health service, such as CAMHS. The young people who had no experience of MHSS were unaware of CAMHS, and even young people with experience lacked clarity about what CAMHS was.

The majority of parents/caregivers had at least heard of CAMHS. This knowledge was typically the result of researching MHSS or through friends' children having been referred to CAMHS. Interestingly some highlighted that the use of acronyms makes knowing what services are for more difficult and suggested that names of services should give a better indication of purpose. Additionally, where there was knowledge about CAMHS this was often positioned negatively, particularly around long waiting lists and strict referral criteria, which suggested parents/caregivers perceived the service as difficult to access.

## 3.3.3.4 Expectations of mental health support services

Professionals described young people and their parents as expecting mental health services to 'fix' mental health problems, and they acknowledged that often there is a mismatched or unmet expectation of MHSS, which makes engagement difficult. Professionals also noted that the unmet expectations of young people and their parents often extended beyond the outcome of treatment, to include operational service issues such as location, resources, and staffing.

This narrative of 'fixing' suggests professionals believe young people and parents construct mental health as an acute issue. However, this was not a narrative shared by young people and parents who, as above, presented an understanding of mental health as something experienced over the life course, albeit with the potential for periods of negative impact.

# 3.3.4 Perceived barriers and facilitators of young people's engagement with mental health support services

Within the theme of perceived barriers and facilitators three sub-themes described the data: barriers and facilitators to support seeking, barriers and facilitators to ongoing engagement, and the role of family and others in engagement.

## 3.3.4.1 Barriers and facilitators to support seeking

Across all three stakeholder groups there were similarities in the barriers reported, many of which echoed the issues raised in discussions about mental health more generally. Key barriers included the invisibility of mental health, lack of knowledge and information about mental health and MHSS, and a lack of appropriate signposting. Consequently, young people and parents/caregivers presented as being ill-equipped to recognise when mental health support was needed. For example, young people reported an initial problem not knowing they had a mental health problem, so they were unsure who to turn to for help.

Young people, parents and professionals also identified mental health stigma, as well as fear, shame and peer pressure, as key determinants of accessing support. Addressing this stigma, and normalising support seeking were identified as having a potential facilitative role in engaging with support.

Practical barriers were reported by both young people and parents, in particular financial constraints in relation to accessing private services and perceptions of long waiting times for NHS services. Parents also had a perception that referral criteria were overly stringent and could result in young people remaining unsupported.

Professionals and young people highlighted the role of others in support seeking. Professionals noted that young people's expectations of the therapeutic relationship with mental health professionals, or previous therapeutic experiences, could act as a barrier to seeking support. However, this could be countered by gatekeepers who were encouraging and supportive, and who sought to normalise the process of support seeking.

### 3.3.4.2 Barriers and facilitators to ongoing engagement

Young people and parents reported a number of barriers and facilitators to ongoing engagement with MHSS. Again the role of stigma, embarrassment and potential negative judgement from others were highlighted as important barriers and these were presented as being linked to concerns that problems might not be 'serious' enough.

A number of the young people felt that a barrier to ongoing engagement lay in the perceived effectiveness, or individual fit, of the support/treatment being offered. Professionals felt young people would disengage if they did not perceive the support as having the potential to benefit. Linked to this was the therapeutic relationship between the client and therapist. Parents believed that a good therapist-client relationship was the key to ongoing engagement. Professionals specifically highlighted lack of trust on the part of the young person as a barrier to building a positive therapeutic relationship, as was unmet expectations in that relationship.

Parents thought that families should have more control of treatment plans. Many parents criticised the lack of consideration of the individual family situation in the treatment plan and described regret and frustration that they had not been included more, and had not been provided with more 'tools' to manage difficult situations in the home.

All three stakeholder groups described clashes with education/employment and this presented competing priorities that some found difficult to overcome.

### 3.3.4.3 Role of family and others in engagement

A key facilitator of engagement linked to all the themes was the role of family, friends and important others. All three stakeholder groups described friends and family as having an important role to play in supporting young people's mental health; both support seeking and engagement with support services. Many of the young people highlighted the importance of interpersonal relationships through the support seeking journey, noting that others can be key in the normalisation process. However, while it was acknowledged that family and friends have the potential to be a support, the dominant narrative for young people was one of avoiding talking to them about mental health for fear of negative judgement. Moreover, professionals felt that families could present as emotional barriers if, for example, they did not 'trust' the support/treatment or they had had a bad experience themselves.

The nature of these relationships and how they contribute to the young person's mental health journey were identified as important for exploration in Phase 3.

## 3.3.5 Design of the SMYLE study Phase 3

## 3.3.5.1 Potential stakeholders and gatekeepers

Young people, parents and professionals listed the following groups as stakeholders and potential gatekeepers for Phase 3 of SMYLE:

- Schools and universities (including teachers/lecturers)
- Healthcare services and staff (e.g., NHS, GPs, nurses, private providers)
- Mental health professionals (e.g., psychologists, therapists, counsellors)
- Mental health charities and third sector organisations
- Youth clubs and associations (including youth workers)
- Sport clubs
- Parent council and forums and support groups
- Government bodies
- Children's Hearings Scotland
- Social work councils

### 3.3.5.2 Promotion and recruitment activities

Both young people and parents thought that promotion and recruitment activities should highlight that the SMYLE study would generate information to improve the delivery of MHSS, including accessibility, thus having the potential to improve young people's mental health. They thought it would be helpful to detail how the results and people's involvement in the study would contribute to this. Young people also though that incentivising the research participation with, for example, a £10 shopping voucher, would be a good way to motivate young people to participate and be a way of thanking them for their time. Social media and schools were considered good channels for advertising. A few young people suggested promoting the SMYLE study in the wellbeing curriculum in schools. Professionals agreed with young people and parents and further recommended advertising on social media as well as through CAMHS, GP surgeries, magazines for professionals, and on general public (e.g., supermarket) and school noticeboards.

# 3.3.5.3 Data collection methods

The majority of young people and parents preferred one-to-one conversations and surveys as methods of data collection, whereas professionals highlighted focus group discussion among peers. The three stakeholder groups suggested a range of questions that should be included to elicit data in Phase 3. The language used by the three stakeholder groups was considered useful in informing the construction of questions for Phase 3 to ensure they were meaningful and accessible to participants.

## 3.3.5.4 Dissemination and expectations of study outcomes

All three stakeholder groups believed that the findings from the SMYLE study should be disseminated to the previously mentioned stakeholders and gatekeepers (see Section 3.4.3.1). Social and traditional media and email were considered effective dissemination tools to reach a wide audience. The three groups of contributors felt it important that findings be presented in attractive, clear, relatable and concise ways. Infographics, charts, briefings and snapshots were mentioned as appropriate ways to summarise the findings.

The three stakeholder groups had high expectations of the study outcomes and expressed a wish that the findings would support better outcomes for young people through improved service delivery. Young people also hoped the SMYLE study could inform young people about when, how and where to seek help for mental health, and they felt the SMYLE study was a good platform for young people to have a voice about mental health. Parents thought it important that the SMYLE study was able to generate recommendations about how to improve MHSS and saw participation of parents as a good opportunity for self-reflection and the sharing of views and experiences. Professionals hoped that the SMYLE study would gather evidence from young people and parents on how to improve MHSS and, ultimately, improve young people's quality of life and support more efficient service delivery.

# 3.3.6 Summary of implications for Phase 3

Table 5: Summary of the implications for Phase 3 of the SMYLE study

	Implications for Phase 3
	<ul> <li>Explore individual understandings of mental health and antecedents and consequences of both positive and negative mental health.</li> </ul>
	Explore what would encourage young people to talk to others about their MH.
Understandings, perceptions and beliefs about	<ul> <li>Explore whether sources of help/information young people and parents access facilitate engagement with MHSS.</li> </ul>
young people's mental health	<ul> <li>Explore how knowledge about accessing MHSS, including CAMHS, could be improved.</li> </ul>
	• Explore preferences for MH support provision among young people and parents.
	<ul> <li>Explore the expectations and reality of support/treatment access and engagement for young people, parents and professionals.</li> </ul>
	<ul> <li>Explore barriers and facilitators in more depth with focus on identifying knowledge/understanding gaps and ways mental health support seeking can be de-stigmatised/normalised.</li> </ul>
Perceived barriers and facilitators to engagement	<ul> <li>Explore young people's treatment journey with a focus on engagement at each point, paying particular attention to how stigma is experienced during support/treatment, what makes a positive therapeutic relationship, how expectations around treatment ownership and effectiveness can be managed, and ways practical barriers (e.g., appointment timing) might be removed.</li> </ul>
with MHSS	<ul> <li>Explore what young people found unhelpful or difficult about the service(s) they accessed.</li> </ul>
	<ul> <li>Explore in more depth the role of the family in enabling or discouraging young people's engagement.</li> </ul>
	Strengthen relationships with existing gatekeepers.
	<ul> <li>Involve schools in recruitment of study participants and dissemination of findings.</li> </ul>
	Build social media accounts and followers.
Design of	<ul> <li>Incentivise study participation with a shopping voucher.</li> </ul>
SMYLE Phase 3	<ul> <li>Conduct one-to-one online interviews and/or focus groups.</li> </ul>
	Define recommendations for how the service delivery could be improved.
	<ul> <li>Ask gatekeepers from the recruitment and promotion stage to help disseminate findings.</li> </ul>
	<ul> <li>Present findings using infographics, charts and tables.</li> </ul>

# 4 Phase 3: Participant interviews

This chapter describes Phase 3 of SMYLE, which involved interviews with young people, parents/caregivers and professionals. The qualitative research methods are described prior to the presentation of the findings.

### 4.1 Qualitative research methods

### 4.1.1 Research setting

The original proposal for SMYLE was that it would be contained to NHS GGC; however, changes made to the study to allow it to continue during the COVID-19 pandemic included broadening the scope to people from across Scotland who met the inclusion criteria. That said, NHS GGC was considered the primary setting of interest, and specific attempts were made to recruit young people living in areas where engagement with mental health support services (MHSS) is lower than expected. Areas with low levels of engagement included neighbourhoods in Glasgow East (Tollcross, Denniston, Barlanark, Carmyle and Alexandra Parade), Glasgow South (Govanhill), and neighbourhoods in Clydebank (Hardgate, Faifley and Kilbowie). Given COVID-19 public health restrictions, and the unpredictability in relation to this, the study was conducted online.

## 4.1.2 Sampling and recruitment strategy

The recruitment of participants to this phase of SMYLE was informed by the findings from Phases 1 and 2. Purposeful quota sampling was used to ensure the recruitment of young people, parents/caregivers and professionals considered appropriate to addressing the study aim and objectives (Robinson, 2013).

To reflect the continuum of engagement, we identified a number of important subgroups of young people, parent/caregivers and professionals who were targeted for recruitment. These are described in <u>Table 6</u>.

A number of strategies were employed to recruit participants to Phase 3. Similar to Phase 2, the study was advertised on SMYLE social media accounts. Social media posts were designed to directly recruit participants and to encourage sharing of posts to wider audiences. In addition to this, gatekeeper organisations were asked to cascade recruitment materials through their networks (including social media cascades and newsletters). Advertisements were placed on *People in Research* and MQ Mental Health Research, both are databases that publish opportunities for public involvement in health and social care research. Steering Group members distributed information about the study within their networks. Snowball recruitment was also used, asking study participants to invite participation from within their networks; for example, young people were asked if their parents would be interested in participating.

Given the finding of Phase 2 (see Section 3.3), recruitment activities were also designed to involve schools. Following ethical approval, flyers were sent to secondary schools in Glasgow, and direct contact was made with five head teachers who had expressed interest in the study. Recruitment through schools potentially increased access to younger participants who are less likely to have social media accounts. Corroborating the views of Phase 2 stakeholders, recruitment through schools was more successful than the other strategies (see Figure 2).

Care was taken to recruit young people of different ages and with different gender identities. When recruiting parents, attempts were made to recruit fathers as well as mothers but it was acknowledged that fathers continue to represent a 'hard to reach' group in research about young people.

Table 6: Phase 3 target participant groups and subgroups

Young People (12 – 25 years old)	Purpose	Recruitment target	
In need of mental health support/treatment but who have not sought this out	To better understand how young people experience the process of seeking support and what prevents them reaching out to services	2	
In need of mental health support/treatment but who have been unable to access it	To better understand how young people make first contact with mental health services (including information seeking behaviour) and the challenges they experience in accessing the services	2	
Receiving support/treatment from MHSS	To better understand barriers and facilitators of ongoing engagement and the ways these might be addressed	4	
Referred to/sought support from mental health services but who did not complete the programme of support/treatment	To better understand what contributes to young people discontinuing support/treatment and how this might have been avoided	4	
Referred to/sought support from mental health services and who completed the programme of support/treatment	To better understand the engagement process including what facilitated and hindered completion of support/treatment programme	4	
Parents/Caregivers	Purpose	Recruitment target	
Whose child is in need of mental health support/treatment but who have not sought this out	To better understand how parents experience the process of seeking support and how they support their child	2	
Whose child is in need of mental health support/treatment but unable to access it	To better understand how families make first contact with mental health services (including information seeking behaviour) and the challenges they experience in accessing services	2	
Whose child is receiving mental health support/treatment	To better understand barriers and facilitators of ongoing engagement and the role of the family in this	2	
Whose child has been referred to/sought support from mental health services but who did not complete the programme of support/treatment	To better understand what contributes to young people discontinuing support/treatment, how this might have been avoided and the role of the family in this	2	
Whose child has completed a programme of mental health support/treatment	To better understand the engagement process including what facilitated and hindered completion of support/treatment programme and the role of the family in this	2	
Professionals	Purpose	Recruitment target	
Who provide mental health support/treatment to young people	To better understand practices that facilitate young people's ongoing engagement and explore engagement challenges experienced by professionals	2	
Who signpost to/are part of a mental health referral pathway for young people	To better understand the difficulties young people and families experience in accessing mental health services and what improvements could be made	2	
Service manager	To better understand service-level barriers and facilitators of engagement and the feasibility of alternative approaches	1	

### 4.1.3 Data collection

Potential participants were invited to sign up via the SMYLE website (<a href="www.smyle-study.org">www.smyle-study.org</a>) where they could access their group-specific participant information sheet (PIS), which described the study's purpose, the form of data collection and storage. After reading the PIS, potential participants completed an online consent process, which included telephone parent/guardian consent for those under 16 years old. At the bottom of each PIS was a link to the online consent form where participants had to opt into the study. When the consent process was complete participants were sent a short demographic questionnaire and, on return of that, interviews were arranged.

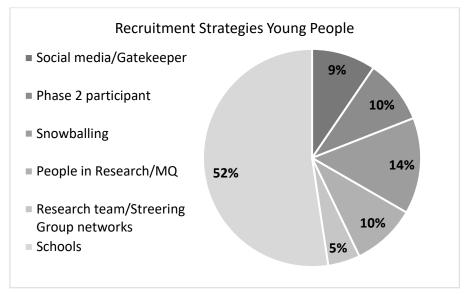
Interviews were conducted online using *Microsoft Teams* between December 2020 and May 2021. They were semi-structured, lasted 40-60 minutes and they were audio recorded to facilitate transcription. Each interview was guided by an interview schedule developed for each of the three participant groups. The interview schedules were informed by the Phase 1 literature search, with an emphasis on capturing data about multiple domains across the full trajectory of engagement (e.g., REACH), and informed by findings from the Phase 2 stakeholder engagement and involvement. Each interview schedule was developed in a way as to ensure that participants, particularly the young people, had the opportunity to tell an authentic story about engagement rather than reinforce dominant understandings within existing literature. After each interview, the participants received a £10 Amazon voucher.

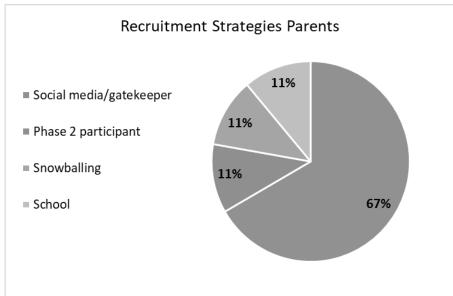
### 4.1.4 Ethical considerations

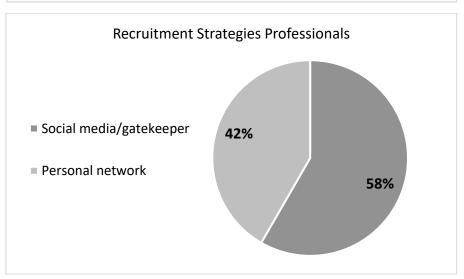
Ethical approval was obtained from Glasgow Caledonian University's Psychology, Social Work and Allied Health Sciences Ethics Committee as well as the Education Services Research Group (ESRG) of Glasgow City Council. As in Phase 2, the interview procedure was guided by appropriate ethical and legal frameworks (e.g., The Declaration of Helsinki [World Medical Association, 2013], the Economic and Social Research Council's Framework for Research Ethics [ESRC, 2015]). Although none of interviews elicited welfare concerns for the participants, and no participant asked to withdraw from the study, regular debrief sessions were held within the study team to give the interviewer the chance to process the content of interviews.

At all times, it was ensured that the processes of informed consent, confidentiality and anonymity were transparent and implemented. All study data and documentation were managed in line with the requirements of the Data Protection Act (2018) and the General Data Protection Regulation (GDPR, 2018), as well as GCU's Data Protection and Privacy Policy (V1.2).

Figure 2: Effectiveness of recruitment strategies (Phase 3)







### 4.1.5 Data analysis

Interviews were transcribed verbatim, anonymised, and transferred to NVivo 12 (QSR International Pty Ltd., 2018) to facilitate analysis. Data were analysed thematically, following published guidance about thematic analysis and applying a codebook approach Braun and Clarke (2006; 2021). This analysis was guided by the research aim and objectives and informed by critical realism. The key stages included:

- Familiarisation with the data through active reading of the transcripts to identify ideas, patterns and meanings.
- Determination of topics linked to the research aims.
- Production and application of themes and codes that had meaning in the context of the topics.
- Naming of the themes to provide meaning related to what each theme is about.

A theme is a broad category, or a story, that is usually built on through multiple codes and reflects shared meaning in the data relevant to the research aim (Braun & Clarke, 2021). The importance of a theme is not determined by the frequency of its occurrence but rather its meaningfulness to the research aim (Bryman, 2015). The process of analysis is not a linear one and during the analysis process, the research team was constantly comparing, contrasting and discussing the data, and refining the development of new codes and themes.

To ensure a rigorous process two members of the research team undertook the coding of the data with a third member of the team undertaking quality checks of sections.

## 4.2 What we found: Phase 3

In total 42 people participated in interviews in Phase 3 of the study, information about these participants is available in <u>Section 4.2.1</u>. Findings from the thematic analysis of the interviews with young people, their parents, and professionals are presented in an integrated way that highlights similarities and differences in the accounts of the three groups.

## 4.2.1 Sample characteristics

## 4.2.1.1 Young people

Twenty one young people participated in interviews during Phase 3, and their mean age was 17.4 years (SD = 3.1). As can be seen in Table 7, the majority identified as female (n = 17; 80.9%), were currently attending school (n = 15, 71.4%), and were from the NHS GGC catchment area (n = 13, 61.9%). Some young people chose not to provide their full postcode so it was not possible to use the Scottish Index of Multiple Deprivation (Scottish Government, n.d. b) to classify the neighbourhood they lived in, but those who did provide a full postcode came from neighbourhoods across the spectrum of deprivation with seven young people living in areas with high levels of deprivation. Information about the young people's experience with mental health services is included in Table 7. The majority of young people had sought treatment for their mental health but for some this was not through CAMHS.

## 4.2.1.2 Parents/caregivers

Nine parents participated in interviews. As no other type of caregiver participated, in what follows we refer only to parents. The mean age of the parents was 45.9 years (SD = 6.6), all reported their ethnicity as White, and the majority identified as female (n = 8; 88.9%). Most parents lived in the NHS GGC catchment area (n = 5, 55.6%). The majority of parents were in full-time or part-time employment (n = 7; 77.8%) and the others were full-time carers or in education. Like the young people, some parents chose not to provide their full postcode, those who did came from neighbourhoods across the spectrum of deprivation with the majority coming from areas with lower levels of deprivation. The children of the participating parents had varying experiences with MHSS and their mental health problems included anxiety, depression, autism, and eating disorders. Individual demographical information can be seen in Table 8.

Table 7: Demographic information for young people (Phase 3)

ID	Gender	Age	Ethnicity	Location	SIMD	Occupation	Self- identified MH problem	Experience with MHS	Type of service accessed	Experience with CAMHS
YP_1	F	22	As	Lanarkshi re	n/a	Full-time work	Anxiety	Currently in private counselling Currently taking medication Previously referred to CAMHS with no follow up	Private counsellor, medication	Referred to CAMHS but never contacted by service.
YP_2	F	16	W	Forth Valley	10	School	Eating disorder Anxiety	Completed CAMHS treatment	CAMHS	CAMHS treatment completed
YP_3	F	22	W	Grampia n	4	Full-time work	Autism	Currently receiving NHS counselling and online CBT Currently taking medication	NHS online CBT, NHS counselling, medication	No experience
YP_4	F	23	W	Grampia n	n/a	Full-time work	Anxiety	Currently taking medication Currently referred for NHS treatment Previously had NHS counselling	NHS counselling, medication	No experience
YP_5	М	19	W	GGC	n/a	Full-time work	Anxiety	Previously referred to CAMHS with no follow up Previously accessed mental health support group Previously had school counselling	Community mental health support group, school counsellor	Referred to CAMHS but never contacted by service.
YP_6	F	25	W	Lothian	4	Full-time work	Depression Breakdown	Currently taking medication Previously had online CBT Previously had NHS counselling	Medication, NHS counselling	No experience
YP_7	F	19	W	Grampia n	9	University	Complex PTSD	Completed CAMHS treatment	CAMHS	CAMHS treatment completed
YP_8	F	17	Af	GGC	1	School	Anxiety	Thought about seeking support	N/A	No experience

ID	Gender	Age	Ethnicity	Location	SIMD	Occupation	Self- identified MH problem	Experience with MHS	Type of service accessed	Experience with CAMHS
YP_9	F	18	W	Lanarkshi re	n/a	School	OCD	Currently in private counselling Previously discharged by CAMHS Previously withdrew from CAMHS treatment	CAMHS, private counselling	Discontinued CAMHS treatment
YP_11	F	17	W	GGC	2	School	Anxiety Depression	Currently receiving CAMHS treatment Previously had private counselling Previously had school counselling	School counsellor, CAMHS	In CAMHS treatment
YP_12	F	15	W	GGC	1	School	Anxiety Autism	Currently receiving support with school nurse Previously received school counselling Previously had rejected CAMHS referral	School counsellor, CAMHS	Discharged after first CAMHS assessment
YP_16	F	17	W	Grampia n	5	Unemployed	Autism	Currently referred to adult services Previously had CAMHS treatment	CAMHS, medication	Completed CAMHS treatment
YP_18	F	15	W	GGC	n/a	School	Anxiety Depression	Thought about seeking support	N/A	No experience
YP_20	М	16	W	GGC	1	School	Grief Trauma	Currently referred to CAMHS Previously had school counselling	School counsellor	On CAMHS waiting list
YP_21	F	17	W	GGC	n/a	School	Grief Trauma	Previously received school counselling	School counsellor	No experience
YP_23	F	17	W	GGC	1	School	Anxiety	Thought about seeking support	N/A	No experience

ID	Gender	Age	Ethnicity	Location	SIMD	Occupation	Self- identified MH problem	Experience with MHS	Type of service accessed	Experience with CAMHS
YP_26	F	14	W	GGC	1	School	Anxiety	Currently referred to CAMHS Previously received CAMHS treatment	CAMHS, community paediatrician	Completed CAMHS treatment, on CAMHS waiting list
YP_27	F	14	As	GGC	n/a	School	Anxiety Depression	Previously received school counselling Previously attended support group	School counsellor, community support groups	No experience
YP_28	М	13	W	GGC	n/a	School	Anxiety	Currently receiving school counselling	School counsellor	No experience
YP_30	F	15	W	GGC	1	School	Depression	Currently referred to CAMHS Previously had CAMHS treatment	CAMHS	Completed CAMHS treatment, on CAMHS waiting list
YP_31	М	15	W	GGC	1	School	Anxiety	Previously withdrew from CAMHS treatment	CAMHS	Discontinued CAMHS treatment

Af = African, As, = Asian, W = White

Table 8: Demographic information for parents (Phase 3)

ID	Gender	Age	Ethnicity	Location	SIMD	Employment	Child's MH problem	Child's experience with MHS	Type of service accessed
Parent_1	F	41	W	Lothian	8	Part-time work University student	Anxiety Depression Autism	Previously completed CAMHS treatment Current referral to CAMHS	CAMHS
Parent_5	F	34	W	Lanarkshire	n/a	Full-time carer	Autism	Completed non-NHS treatment	Third sector
Parent_7	F	47	W	GGC	10	Part-time work University student	Eating disorder Anxiety Depression	In CAMHS treatment	CAMHS
Parent_9	F	50	W	GGC	8	Full-time work	Anxiety	In CAMHS treatment	CAMHS
Parent_10	F	57	W	Ayrshire & Arran	9	Full-time work	Asperger syndrome	In CAMHS treatment	CAMHS
Parent_12	F	49	W	Highland	6	Full-time work	Asperger syndrome Anxiety	Child 1: Referred to CAMHS and school counsellor Child 2: CAMHS treatment withdrawn Withdrew from private counselling	Child 1: School counsellor CAMHS Child 2: CAMHS Private counselling
Parent_13	F	52	W	GGC	10	Part-time work	Eating disorder Anxiety Potential autism	Completed CAMHS treatment	CAMHS
Parent_14	F	41	W	GGC	9	Part-time work	Mood	Thought about seeking support	N/A
Parent_15	М	42	W	GGC	1	University student	Anxiety	Previously completed CAMHS treatment Current referral to CAMHS	CAMHS Community paediatrician

#### 4.2.1.3 Professionals

Twelve professionals participated in an interview. The mean age of professionals was 41.7 years (SD = 10.2) and the majority identified as female (n = 10; 83.3%). The professionals were from Edinburgh, Glasgow and Fife and, as can be seen in <u>Table 9</u>, they had a range of professional roles.

Table 9: Demographic information for professionals (Phase 3)

ID	Gender	Ethnicity	Role in young people mental health	Profession	
Prof_1	F	W	Service provider	Youth worker	
Prof_3	F	W	Provides mental health treatment	Trainee psychologist	
Prof_4	М	W	Signposts to treatment	Youth worker	
Prof_5	F	As	Provides mental health treatment	Trainee psychologist	
Prof_6	F	W	Signposts to treatment	Youth worker	
Prof_8	F	W	Signposts to treatment	Youth worker	
Prof_9	F	W	Signposts to treatment Provides mental health treatment	Clinical psychologist	
Prof_10	F	W	Service provider	Service manager	
Prof_14	М	W	Provides mental health treatment	Trainee psychologist	
Prof_15	F	W	Provides mental health treatment	Clinical psychologist	
Prof_16	F	W	Provides mental health treatment	Clinical psychologist	
Prof_17	F	W	Service provider Provides mental health treatment	Team manager	

### 4.2.2 Findings from interviews

As noted above, to facilitate analysis we identified topics that were linked to the research aims and objectives. Under each topic we described themes and sub-themes with accompanying illustrative quotes. This approach allows for consideration of barriers and facilitators to engagement within MHSS across the full spectrum of engagement points; prior to seeking support, during support seeking, and when support/treatment is in place. To give voice to as many of the participants as possible, we have chosen to present a large number of quotes in this section of the report. Each quote is accompanied by the gender and age of the participant, the child's experience of mental health services, and for parents we also present their child's mental health problem (more detail is presented in Tables 7-9).

The interviews we undertook with stakeholders were about both the barriers and facilitators of engagement. However, we found that in their discussions with us, participants were more likely to talk about negative perceptions and experiences, and this frames how we present the results. We take this approach to give authentic voice to participants, but also to allow the reader to fully understand the nature of the barriers and facilitators presented by participants. This will allow for more informed consideration of ways in which barriers can be reduced or removed, and facilitators promoted. It also creates opportunity for further exploration of individual barriers/facilitators and/or points in the engagement journey in future research or co-creation service improvement activities.

Following the presentation of results within each topic we present a summary, learning points and recommendations.

# 4.2.2.1 Topic 1: Young people's knowledge, understandings and experiences of mental health and mental health support seeking in the context of COVID-19

As noted previously, the SMYLE study was conducted during the COVID-19 pandemic and we sought to understand the impact COVID-19, and related public health interventions, had on young people and their families with respect to their mental health and their access to and engagement with MHSS. This was incorporated into the study to provide context to the interviews, which took place during the pandemic, and to further understand the impact of COVID-19 adding to the emerging evidence base about this.

# Theme: Impact of COVID-19 on young people's mental health

Young people, parents and professions spoke about the COVID-19 pandemic as having both positive and negative impact on young people's mental health and their ability to engage with MHSS. These were not simple, mutually exclusive positives and negatives but rather there was a narrative of juxtaposition where early positives became longer-term negatives, or where positives and negatives were experienced simultaneously.

The public health restrictions that had been placed on the UK population – lockdown – meant that young people had limited in-person social interaction beyond their home, and they were participating in home schooling. For some this imposed limitation was presented as reducing stress and anxiety associated with social situations, and in a way that removed their sense of personal responsibility for this. Often this was presented in the context of particular mental health problems linked to social anxieties and related difficulties (e.g., autism).

...it was kind of like almost a relief, like I wasn't doing my best like before, or even during COVID-19, so like not having to go out and see family and friends, or like make an effort all, like it kind of, like, put me at ease because I don't have to like put on a face, face to like face people. (YP\_30, F, 15y, Depression, CAMHS re-referral)

And so I think being off at the start of COVID was a relief to her because she is legitimately off school, in her eyes. (Parent\_9, F, Anxiety, CAMHS)

A number of young people who we've been working with before COVID, pre-COVID, who've had really bad anxieties, who struggled, have actually expressed feeling calmer and happier because things like going to school was a big trigger for them, things like being in busy places. (Prof\_8, F, Signposter, Youth worker)

While this sense of relief at not having pressure to engage in some social situations, including school, was evident in the accounts of the three groups, this was contrasted with accounts of the negative impact of COVID-19. The extended nature of home confinement created an environment where young people could over-think, where routine and social expectations about behaviour had been removed, where support was very limited, and where intra-family conflict was experienced.

...you're waking up and you're sitting at a desk in your own room... you're literally working in your own, the place that you cry, the place that you sleep, the place if you eat, if you eat, and it's just really struggling. And, it's, it's like no support is getting put through. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

With being in the house 24/7 knowing that there isn't an escape. You know I don't like school, but I didn't hate it either, school's kind of like an outlet for me, it's a place where I can go and not being at home all the time, because home isn't necessarily the best place to be. So when I was stuck in the house it was knowing that if anything happened bad today, if any argument occurred, if anything happened, then I don't have school to go to the next day, I'm going to have to stay in the same environment again the next day, and the next day, and the next day... Even if I don't say anything at school, you know school is just a place where I can be away from the house. I can at least see people, you know I can...go to classes, I don't have to have be in the same environment, the negative environment that I am in the house. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

I think just such a long time on her own, isolated in her room, all her thoughts are you know in her head, and you know she's fourteen, that's when you know you should be you know just chatting and dealing with life and, you know, instead she's thinking, she's over-thinking probably. (Parent\_12, F, Multiple MH problems, CAMHS)

It was also acknowledged that the transition back to school and other social situations was uncertain and could, in itself, cause a decline in mental health if young people were not prepared for it or supported through it.

I just have such bad anxiety and it's, it's made it worse because now I'm so scared to go out and socialise because I've not done it in so long. (YP\_16, F, 17y, Autism, CAMHS completed)

...that transition then from going back from, you know, being at home all the time, to going to school was almost too much too soon for her. (Parent\_15, M, Anxiety, CAMHS)

The virus and the public health measures impacted on young people's engagement with their support/treatment plan and this, in turn, impacted on their lived mental health experience. They reported that confinement to the home resulted in a lack of motivation and in some instances their ability to take part in support/treatment activities. Alongside this, they were concerned about their own health and the health of significant others, perhaps because worries expressed by these significant others were internalised.

...we were getting [child] to a stage where she was probably feeling better or well enough to at least start with behavioural stuff and start going to school. COVID hit and then her plan absolutely fell apart. (Parent\_7, F, Multiple MH problems, CAMHS)

towards the start of the lockdown I was really, really struggling because basically all of the contamination stuff had come true. I couldn't really do the ERP [exposure response prevention] anymore, because it was actually dangerous to like, because obviously that element potentially you could catch COVID. Because a lot of the things would be like pressing the button on a traffic light, but obviously with COVID around, you can't really do that safely. So a lot of the ERP kind of went out the window. (YP\_9, F, 18y, OCD, discontinued CAMHS)

...seeing like the panic, and my mum's quite older than other mums and she was really worried about that and she's meant to be like the role model of brave and like that figure, and like seeing that like how the fear like... (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

#### Theme: Impact of COVID-19 on access to mental health support services

Across the three groups of participants there was a view that the pandemic had raised the visibility of mental health as an issue, and that there was an increased acceptability of talking about mental health problems at a societal level.

Yeah because a lot of people were saying how they have to live during COVID is affecting their mental health, and how it is not seeing your friends every day...So everybody is talking about it now. It's a bit more normal when you say that your mental health has gone down. Because of COVID everybody understands. (YP\_8, F, 17y, Anxiety, no MH support)

...there's been a lot of chat over the media, the government, all the briefings about mental health...it's really adults, children, young people, everyone across the board, mental health, this is affecting us all...in different ways...so having, normalising the conversation about mental health and it's okay not to be okay has resulted in more young people going 'actually, I don't feel okay', or urm, or going to their guidance teachers at school and going, 'I need somebody to talk to', and then they get in touch with us. (Prof\_8, F, Signposter, Youth worker)

However, this public conversation about mental health had not necessarily translated into more young people gaining access to support. There was a perception and reality that during the early stages of the pandemic it was more difficult to get referred, that some services had closed, especially at Tiers 1 and 2, and others had to prioritise cases.

I think COVID changed it a wee bit because it wasn't that easy to visit my GP and things like that. So, I was left to deal with quite a lot of things by myself. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

Lack of services. Lack of trained services. Lack of visible services, especially during COVID. They were hidden to start with, but they are just invisible now. (Prof\_1, F, MH service provider, Youth worker)

Underpinning this was a sense that the pandemic had caused or further exacerbated lack of communication and co-ordination between different parts of the mental health support system. Indeed, parents and professionals were concerned that the impact of COVID-19 would be such that waiting lists for mental health support would grow.

So, you know there were already these ridiculous waiting lists and shortages, so I can, you know, I just think, you know the waiting list for CAMHS is going to be double what it was a few years ago. I don't know that, I'm just guessing, but that, as a parent, is how I feel it's like, actually accessing services is going to be more difficult because there's a greater need. (Parent\_12, F, Multiple MH problems, CAMHS)

#### Theme: Impact of COVID-19 on young people's engagement with mental health support services

The majority of the young people in the sample found virtual support (including online, telephone and email) difficult, and they described this as reducing their engagement with support/treatment offered. The difficulties young people reported were primarily related to a lack of privacy for virtual consultations. They were often at home with others, and they felt this impacted on their ability to be open and honest.

It's very awkward to say how shit you are feeling over the phone where people can't see the other person... It was telephone because Skype wasn't the best when I had everyone in my family at home as well... You can't have privacy in your house when you are living with other people all the time. Sometimes I would take calls in my car, just to get privacy to talk about things.

Whereas when you are at a GP room, it's obviously just you and the GP so you can talk about things. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

This was compounded by difficulties in managing the therapeutic relationship virtually, and in some instances managing elements of the support/treatment itself. Some young people felt virtual appointments were a check in rather than a support session, and that led to disengagement or total withdrawal.

I hated the online calls, they just gave me more anxiety, so I just ended up emailing her and telling her that I was okay with stopping the sessions, even though I really wasn't. I was still struggling but I told her I didn't want to continue, so that was the last I had heard from her. And then I just, I think I just deteriorated quite a bit. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

...we couldn't really do any of the activities or the skill building exercise because COVID was limiting everything. So, it was just kind of 'this isn't helpful, we're going in circles, it's pointless and I'd rather not waste our time'. (YP\_16, F, 17y, Autism, CAMHS completed)

I think it was the whole the family would be around and I wouldn't want to say much, or either say anything. You know it was so busy in the house, since I'm a young carer as well, meaning I have lots of responsibilities in the house. So, taking time out of counselling just didn't seem important anymore. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

It is important to note that, linked to comments above about lockdown providing a means of limiting social interaction, a small number of young people preferred virtual appointments or were at least willing to engage with them.

I did do a video call with her like I am now, which was better. I think when you can see people's face as well, it's more helpful because you can read their expressions. So that was obviously better than the telephone calls but definitely seeing someone in person is much better. I think as well because in person she could do the ERP [exposure response prevention] with me more easily, which worked well. (YP\_9, F, 18y, OCD, discontinued CAMHS)

Parents corroborated the view that engagement with virtual services was difficult, but they understood the challenges young people faced to be about the relationship with the professional the young person was working with rather than pragmatic factors such as privacy.

And then by the time COVID came along, I think it was just the lack of face to face. It's just the not, not knowing who you're talking to. Even though, even though she knew her worker because she'd only seen her a couple of times, she didn't feel that she had that relationship and it just felt really overwhelming to her. (Parent\_9, F, Anxiety, CAMHS)

Professionals' accounts acknowledged the concerns of young people around challenges, especially in relation to privacy and the therapeutic relationship, but they also spoke to this as a transitionary issue and acknowledged individual differences in relation to engagement. In the early stage of the pandemic virtual services had to be set up and this made provision more challenging, some professionals also felt that as virtual working continued young people were less likely to engage because of online fatigue. However, they saw virtual support as overcoming some barriers that might prevent optimal engagement with face-to-face support/treatment (e.g., transport, embarrassment).

I think it's been a real mix and it depends on the young person. I think that for some young people, seeing you face-to-face is really important and being in a room with somebody and being able to pick up on all those little things that happen in interaction that kind of get lost in the digital medium, I think that's been hard for some young people. For others I think it's really positive I think they've found the video calling easy and nice and its meant that they haven't come in, had to come into, you know, the CAMHS building where they might potentially see other young...I know that has been an issue for a couple of the people that I've seen is that they've bumped into people from school in the waiting room and I think for young people there still is that almost stigma or embarrassment about having to come to CAMHS, so I think it removes some of that. (Prof\_14, M, MH support/treatment provider, Psychologist)

## Theme: Impact of COVID-19 on mental health support service provision

Observations about the impact of COVID-19 on MHSS provision came, primarily, from professionals. One professional noted that while overall referral rates had not increased the urgency of cases had escalated and this placed a different pressure on services.

Well, our referral rates haven't went above where we would expect them to be normally. But what has changed significantly is the number of urgent presentations. That has increased. I think, I think easily by about twenty percent, or even more. (Prof\_10, F, MH service provider, Manager)

The need to move to a virtual service quickly and without much resource to do so was a, perhaps obvious, consequence of the restrictions of the pandemic. Professionals described the impact this had on short-term service provision as meaning that some young people had to be prioritised for continuing care while others had their treatment paused.

...we weren't set up for remote working at all. So, we had to quickly think of a way of supporting the most at risk families and had to put families on pause for a little while, while we tried to navigate getting laptops, phone, things like that, because we just couldn't, couldn't provide a service. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

Professionals often held mixed views about how the changes necessitated by COVID-19 had impacted on service provision. There was a view that virtual working had positive benefits in widening access to some families and in making some of the administrative elements of the role easier to manage. However, mirroring the experience of young people and parents, professionals found that support/treatment was more difficult to manage when the young person was not in the same room.

I'm not keen to keep the remote access as routine. However, I do think in terms of accessibility it should be an option for families to do things by phone...So, I do think that those things should be optional for families...I think face-to-face for therapy is definitely better, maybe dragging people down to face-to-face appointments for simply checking in not so good...it means that we're working at home sometimes and I think that is good, it means that we can focus. So, for today I'm having to write two legal reports so it's quite nice to have this to do today as a bit of break because I've not seen anyone, but it's also nice to be able to be, to be able to sit at home and focus on writing those reports without my phone ringing or people coming to my office door.

(Prof\_15, F, MH support/treatment provider, Psychologist)

#### Topic 1: Summary

The impact of COVID-19 on young people's mental health was mixed. For some the limitations around social interactions were positive but for others this was a negative experience. The same can be said for the provision of MHSS, in that service-level changes were received positively and negatively. There was a view that support seeking behaviours had declined and accessibility had reduced, but COVID-19 had offered a new platform for the public, including young people, to talk about mental health.

The shared experience and narrative about the pandemic's impact on mental health had facilitated an open public conversation. How this public conversation impacts on mental health of citizens, including young people, in the future is unknown. Much like the participants in this study, emerging evidence highlights a double-edged sword; opening channels of communication but simultaneously increasing things like worry and fear and, consequently, negative mental health experiences (e.g., (Thompson et al., 2021). However, there is real potential to use this public conversation to improve understandings of MHSS, including explaining the tiered structure of provision, with clear messages about how level of need is aligned within the structure, and how to negotiate access.

The perception that access to MHSS was reduced during the pandemic is evidenced in national datasets. During the early stage of the pandemic referrals to CAMHS were very low (reduced by more than 60% in June 2020 compared to June 2021), but they started to rise as services adapted their provision and as schools reopened, they fell again during the January 2021 lockdown, following which they began to increase (Public Health Scotland, 2021). This cycling trend was mirrored in the number of young people seen over the course of the pandemic even though the number of open cases remained relatively stable (Public Health Scotland, 2021). In addition, the waiting list for CAMHS across Scotland had increased (Public Health Scotland, 2021).

In the main, there was general agreement from young people, parents and professionals that the provision of support/treatment using virtual means during the pandemic had been a challenge for the professional and the young person. Although this was tempered with a view that virtual service provision had the potential to improve access for some groups who might find face-to-face more difficult. These contrasting views reflect those of many professionals who had to pivot their provision during the pandemic, and solutions to the challenges faced are starting to emerge (Feijt, et al., 2020; Johnson et al., 2020). In the context of the SMYLE study, the disparity in views held about virtual provision is likely to reflect the fact that it was enforced on both professionals and their young patients/clients because of the pandemic. Embedding virtual support as part of 'business as usual' provides opportunity for optionality. Professionals can be trained to undertake virtual support/treatment and to work with young people to determine the appropriateness of it for each individual patient/client.

#### Topic 1: Learning points and recommendations

- There is opportunity for MHSS and other agencies to capitalise on the public conversation about the impact of COVID-19 on mental health as a way of reducing stigma and illustrating how young people and families can access and navigate the tiered mental health support structure.
- MHSS should adopt a blended approach to service provision, with options for face-to-face and/or virtual support/treatment. Optionality must be agreed between the young person and service/professional and be sensitive to their individual needs rather than the decision about format being predetermined.
- Implement measures to better support young people and families to engage fully with virtual support/treatment. For example, ensure the virtual provision is acceptable to the individual's circumstances, provide guidance on finding safe therapeutic space, and ensure therapeutic relationships are well-established prior to, or during, the provision of virtual support/treatment.
- Mental health professionals require training to support their delivery of mental health services in virtual environments, including how to optimise the engagement of young clients.
- Provide signposted support for young people and families as they transition out of COVID-19.
- Review continuity plans to implement learning from COVID-19 to facilitate the provision of MHSS in times of crisis. This should include ensuring that services can remain open and delivering (some MHSS had to close during COVID-19, others had reduced capacity), and young people and their parents are fully informed about how support/treatment can be accessed.

# 4.2.2.2 Topic 2: Perceptions, beliefs and expectations about mental health support services and support/treatment

A starting point in the journey to engagement with MHSS, and support/treatment offered, lies in the perceptions, beliefs and expectations that young people, and their families, have about them. These cognitions drive how ready and willing a young person is to seek support/treatment when it is needed. A view that MHSS are not needed, are not appropriate, and/or will have no benefit to the young people will underpin disengagement from the outset.

#### Theme: Perceptions and beliefs about mental health support services

Young people and parents' perceptions of MHSS were underpinned by a view that services are underfunded and understaffed. This drives an understanding that MHSS are not a priority and can be difficult to access. This was presented as a structural issue rather than one that lay within services themselves.

I don't know if that's, you know, anybody's fault. It's down to how much, you know, funding the NHS gets from the government. And I know that, you know, mental health services are... again I think it's becoming better but I don't think it's a massive priority. I don't think it's as big a priority as it should be from the government, in, in terms of funding perhaps. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

Indeed, many young people and parents reflected a view that services were doing as much as they could with the resources available to them.

Although, like the nurses and the mental health team do work as hard as they can, there's not maybe enough of them to provide that service. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

The biggest barriers I think it comes down to money...I think, the absolute biggest barrier is money through these services. If there was enough money going into the services then they would be able to have enough counsellors, enough space, enough time, to make genuine connections and help these kids. (Parent\_1, F, Multiple MH problems, CAMHS)

However, while there was an understanding the services were constrained, parents were frustrated at the impact this had for their family.

I know the service. I know the massive pressure they are under. I know their waiting lists, I have privy to all that stuff, and so I understand. I understand. But as a parent, obviously, you just want your child to be looked after and supported. (Parent\_9, F, Anxiety, CAMHS)

Alongside a perception that financial constraints impact on the accessibility of MHSS, young people also described some uncertainty about the accessibility of services linked to individual need. There was a view that MHSS were only accessible to high-risk cases and this prevented some people seeking out support; whether that be CAMHS or other Tier 2/3 services.

...they had told me that I'm only having, aww this sounds so bad that I don't even want to say it, but she was like, 'you're only having thoughts of suicide, some people are making attempts so they need to help them first, so you will be waitlisted for ages'. And I was like 'aye, ok'. So that's why I gave up with the sort of thought of CAMHS... (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

Maybe some reassurance that anybody can talk to them. Because some people think you've got to be diagnosed with a mental illness. Or have something really bad going on in your life. So they maybe think that they're not one of the people who could talk about it. (YP\_8, F, 17y, Anxiety, no MH support)

Many young people described holding negative perceptions about what MHSS do before they accessed them. Even young people who knew others who had accessed services were reticent about how they might be useful to them. This was articulated as services not really providing support at all, through to concerns that they might result in the person seeking help being hospitalised against their wishes.

I was always, to be honest, too scared to open up too much to her because I had this fear in the back of my head that I was going to get thrown in a loony bin or something. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

That they don't really do much. They just kind of tell you to like, keep going and stuff like that and it might be motivation. But I mean if you have a problem and you want something done about it, usually they don't really do anything for you. (YP\_8, F, 17y, Anxiety, no MH support)

These negative perceptions about MHSS were reinforced by the perceptions of other people who informed the thinking of the young person.

[son] was very anxious, very worked up because he had spoke to a friend at school, or someone who he thought was a friend, and the friend had told him that we were taking him to the crazy doctor and the crazy doctor was going to fill him full of medication and would maybe take him away from me and things like that. (Parent\_5, F, Autism, non-CAMHS support)

Professionals supported the view that there were structural constraints on the mental health support system. However, some of the professionals who signpost young people to services felt that an increase in funding to CAMHS was not a simple solution and instead focus was need on early intervention and support other than CAMHS.

...but I don't necessarily know if it's they need to invest more money, I think it's maybe making, making courses, making the education more accessible, you know, seeing that there is this problem and we need to look at other ways to introduce people in to the services. But again, it's like the professionals are overwhelmed, inundated, so that's going to impact them. (Prof\_4, M, Signposter, Youth worker)

#### Sub-theme: Reputation, rumour and misperceptions about CAMHS

The majority of young people spoke about CAMHS in the context of rumour and reputation, which informed their (mis)perceptions about the service. First, they had conflicted views about how helpful CAMHS could be. Many had heard both positive and negative accounts and/or had had their own mixed experienced. However, young people prioritised the negative accounts over the positive ones, and some of this was perpetuated by information on social media.

Some people have like a very mixed reactions and will be like 'Oh my personal experience is like really, really good' and for other people it would be like 'They don't really help you'. (YP\_8, F, 17y, Anxiety, no MH support)

I think there's lots and lots of negativity towards CAMHS; my age generation anyways. You see it even on social media, like CAMHS, you hear it in person. People are like 'CAMHS is the worst thing ever'. Obviously I can't really say for that because I didn't really have any service from them, but from what I know people don't really think it's a great thing...But I do know one girl who has treatment from CAMHS and she still is and she thinks it's quite good. So I guess it sort of depends on what you're going for and who you're seeing, that sort of thing. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

Second, and linked to their views about structural constraints on mental health services, young people spoke about perceiving CAMHS as having long waiting lists that made it difficult to get support, and even when treatment was offered it wasn't always helpful.

Because I don't know how I'd be feeling, but he [friend] was put in for CAMHS in June and has only gotten an email about being seen and having a session for this week. So, I don't know if I would be willing to wait that long. Maybe I would feel different in that time difference. (YP\_8, F, 17y, Anxiety, no MH support)

I'd seen a lot of TikToks as well about, there's lots of like videos about it and it's like how people have been waiting ages on a long waiting list and that. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

...all the people that are waiting, it's been weeks, months, even years. So if I were put on the list I think it would take a long time and by the time that I got there, and then feel like they're not going to help me, I just like, 'Oh what's the point if I have to wait so long for no help?' So I don't think that, yeah, I would ever go to CAMHS for help. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

This perception that waiting lists for CAMHS were too long was also shared by parents. As noted previously, parents consistently spoke about CAMHS being underfunded and they believed this resulted in long waiting lists that, in turn, meant only children who were very unwell would be seen. They frequently referred to prioritising of cases. Some parents went as far as saying that the waiting lists were so long they saw no point in pursuing CAMHS as a support for their child.

I think the first thing anybody will go is, 'Oh, you'll never get seen by CAMHS', so that's the first. You know actually...it's barely worth trying, because the waiting list is so long that actually your child will be an adult before they get to the top of the list. That's definitely what my friends would say. So I think people don't try and access CAMHS because they really think, 'Do you know, if my child needs support, they need support now, not in eighteen months' time'. (Parent\_12, F, Multiple MH problems, CAMHS)

Professionals acknowledged that there was a negative perception about CAMHS. One professional in particular felt this could be turned on its head, and MHSS could use the media as purposeful vehicle to educate families about what CAMHS does and how it is placed in a tiered system of support.

I mean one of the key things I would want to put across is that I think CAMHS is, it gets kind of unfairly criticised but also overvalued, all at the same time. So, there is a belief that if there is any kind of mental health difficulties then CAMHS, you know, should be involved. But actually, we're only funded to see the most severe difficulties, and there are lots of great services in kind of tiers one and tier two, but I don't think the same value is placed on them. So, people, people really seek us out and really want to be accepted and be part of our service. Even though they perhaps don't understand what it is that they want from us... You know I think sometimes perhaps there could be some different press put out about what percent of the budget is spent on CAMHS, how many people actually work in teams... (Prof\_16, F, MH support/treatment provider, Psychologist)

#### Theme: Expectations about mental health support/treatment

Expectations about support/treatment, and the fulfilment of these, have an important role to play in engagement. The three groups of participants discussed expectations in the context of support seeking and referral to support/treatment, and then during the time support/treatment was being received. For many families there was not a single, linear referral to support/treatment pathway but multiple attempts at referral and, in some cases, multiple times receiving support/treatment. While there was considerable overlap in the expectations prior to and during support/treatment, these were presented as two distinct phases in support seeking.

# Sub-theme: Expectations prior to referral

When speaking about the referral to support/treatment process young people said very little about the administrative side, their focus was primarily on expectations about the services and the support/treatment they might, or might not, be offered. Irrespective of their experience with MHSS, young people had a consistent and shared narrative around their expectations. They expected to be seen quickly and for there to be quick resolution to the problem(s) they were experiencing.

When you are not feeling mentally well, you just want to get better. You don't want to be waiting for months trying to get help because then you just end up feeling like there is not anything you can do to get better. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

I don't want him in therapy for years and years of his life. I just wanted him to get help.

(Parent 5, F, Autism, non-CAMHS support)

So she didn't want to feel that she wants to kill herself. She didn't want to feel that she wanted to die. She didn't want to go so anxious, she couldn't leave the house. And she wants to be happy again... She, naively I think, wanted some kind of magic pills. (Parent\_7, F, Multiple MH problems, CAMHS)

Professionals felt that this expectation of a "quick fix" was often unmet leading to disengagement with the process.

So I suppose the expectation would be that they want somebody to support them and somebody to help them get through whatever period of their life is causing them some kind of struggle or upset. I think it's really hard because especially now because everybody wants everything fixed and they want it fixed yesterday. (Prof\_6, F, Signposter, Youth worker)

I think that for our services, there's often an expectation that young people and their families, they'll come in, there'll be clear goals and they will work through those goals and there'll be no deviation from that and that they'll be discharged quite promptly. The reality just isn't like that. You know people come in and, and maybe come in for one thing and we may think 'oh there's another difficulty there', or life events happen, you know life events come up. (Prof\_15, F, MH support/treatment provider, Psychologist)

Although young people were not always sure what support/treatment would involve, during early stages of support seeking there was an expectation of a diagnosis and an end point, and that the end point would be a resolution, or eradication, of the problem they were experiencing. In fact, many young people described getting a diagnosis, or "label", as key in the treatment process, and there was a sense that it would go some way in helping the young person understand themself.

Like if, no matter what they say I have depression, but maybe it, it was like, if they diagnosed me with like something it would maybe be like more treatable rather than just saying that I have a down day, lie in bed for the whole week. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

...she wanted an explanation on why she felt the way she did. And that was really, I think, for her it was like, you know, she wanted to just know, you know, say 'This is what it is', so therefore she can deal with it and move on. (Parent\_13, F, Multiple MH problems, CAMHS)

Parents also expected that MHSS should be able to provide a diagnosis and appropriate support/treatment for their child. However, in contrast to the way young people presented support/treatment, parents acknowledged that mental health might fluctuate across their child's life.

I hoped he would have somebody to talk to who was outside of our family. Somebody who was a neutral party that he could depend on and talk to, that would maybe reiterate what we have been trying to tell him. That it's ok to have bad days, it's ok to have good days, and it's ok to feel however you're feeling. You want to feel angry, feel angry. You want to feel sad, feel sad. I wanted him to have support and to understand that mental health. The way I think about it, if you broke your arm you would go and get help for it, you would go to the doctor. You would get a cast. You would get help. I believe mental health should be the same way. There should be support in place for everyone who needs it. I don't care who you are. At some point in your life you are going to be in some type of emotional turmoil. (Parent\_5, F, Autism, non-CAMHS support)

Some young people saw CAMHS as being a stage in their support/treatment journey, and a service that could potentially help "fix" the problem in a way that other services had not been able to. The service was often implicitly and explicitly described as a last option.

So, it was sort of my fault for like pushing away so many options, but at the same time I felt as if I had exhausted everything, because everything was just getting repeated, it was like everyone was just telling me to do meditation or exercise and I was like 'I've tried, it's not working'. So, I was, like, hopefully CAMHS will give me something more. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

Professionals noted that this view of CAMHS as the only or last chance for help can lead to unmet expectations. They felt that limited knowledge about tiered support meant that often families did not see support received prior to CAMHS as sufficient, and referral to CAMHS was the preferred end point for most families seeking support.

...in a funny way I think there's an over valuing of CAMHS, you know that we have powers to, you know, tell them to go to school, or behave differently, or not to be depressed. You know there's a belief that we have, you know, we have the ability to change things which often we don't have.

And certainly, for some people, not all, but for some people, there's the belief that the problem can be treated within the child and that if we do something to that child then, or give that child medication or something, effectively then that child will be okay. (Prof\_16, F, MH support/treatment provider, Psychologist)

So, it was about having that discussion as a community, you know CAMHS doesn't have the magic wand or the fairy dust that's going to fix everything, it's about...a whole system, can we work together to support everybody? So it was about changing... it was parents, it was about changing parents and carers views on the services that they access. And sometimes recognising that the interventions that they're receiving via universal and third sector services are actually enough and good enough, that they don't always need to come along to, they might not get a better service by coming to CAMHS. (Prof\_10, F, MH service provider, Manager)

Parents' narratives about their expectations of MHSS during the support seeking journey focused as much on the administrative aspects as it did on expectations about the support/treatment itself. Linked to their concerns about the length of waiting lists, parents acknowledged that MHSS, including CAMHS, needed to prioritise the young people who were being referred to them. They often spoke about children who they perceived as being higher risk, or in more need, than their own child. However, they expressed a fear that this would impact on the referral process for their child.

I know that there's kids in the world who are so much worse off but part of me can't understand how people can see these kids every day and know that, even if they just need a little bit of help. Would they not rather these kids who are asking for the help get it, before they get to the point that it's too far to go back? (Parent\_5, F, Autism, non-CAMHS support)

Parents were also concerned that if their child was receiving support elsewhere CAMHS would reject their referral, and parents of children with an autism diagnosis expressed concerns that this diagnosis would lead to a rejection. The source of information that led to parents having these concerns was primarily from other parents on internet-based support fora.

I have been advised many times to basically lie to CAMHS, to the link worker, and basically say that we are not accessing support elsewhere. Don't mention the school counsellor. Don't mention the psychiatrist because as soon as they know, it's really horrible, but as soon as they know that your child is accessing all these things in comparison to all of these other kids, you will be put at the bottom of the list....again it's not my experience but I am fearing this now, it's because the autism has been pointed out, that we will not be able to access therapy for depression or anxiety. Because CAMHS doesn't deal with autism. Now, I am actually worried that we will be rejected from the list. (Parent\_1, F, Multiple MH problems, CAMHS)

Some parents recognised that the journey into support/treatment could be difficult because their child was not able to engage in a way that they thought they would need to in order to benefit. This could be because they resisted discussing their mental health problem or because, in their view, it had taken so long to get a referral the progression of their child's condition made engagement challenging. Alongside this, some parents questioned whether or not the support/treatment that was proposed could meet their child's needs.

But I'm actually a bit at a loss because [son] won't engage and I think I don't really know what they can offer. (Parent\_10, F, Asperger's, CAMHS)

...you know I think life is not all about CBT, I think sometimes providing a young person with that opportunity to talk and listen to them is in itself enough. Doesn't have to be so goal orientated. which I think is the CBT approach. (Parent\_12, F, Multiple MH problems, CAMHS)

This limited knowledge about mental health and mental health support/treatment meant that parents and young people often had expectations that could not be met thus promoting disengagement.

I think that, again because the expectations vary so much, I think some people do have really unrealistic expectations of, of what is achievable in treatments. (Prof\_14, M, MH support/treatment provider, Psychologist)

#### Sub-theme: Expectation fulfilment

When talking about their experience of receiving support/treatment, young people shared views about whether they felt it worked for them or not. The young people who reached out for help with their mental health, and parents of young people who had sought help, had an expectation that they would be seen by a professional who would help them talk about the problems they faced, but also help them build coping skills and strategies. When this expectation was met young people spoke about the support/treatment as having had a positive impact, when the expectation was not met they described the support/treatment in negative terms and as not having been of benefit.

The guy who saw me, he left me like a tool kit. All these different strategies that he taught me to manage whenever I was feeling anxious about something. So, that was definitely really helpful. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

I didn't get anything from it because I just noticed I was going in every week, moaning about the week I've had and then leaving. Then the next week I would do exactly the same. There was no sort of coping strategies or methods, there was nothing like that that I took away from it.

(YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

They just kind of was like, 'Oh, talk about like your feelings', but I spoke about them but they never gave me like any proper solutions to deal with them. (YP\_30, F, 15y, Depression, CAMHS re-referral)

So, you know, obviously you really want her to go along for a number of sessions and then be fixed and everything's lovely, you know? I know that's not the case. And it may be that she, she might be unfortunate, and she may struggle her whole life. She's got on her dad's side a family history of sort of depression and various things. So she might be a bit unlucky in that respect. But actually, I would hope that there would be enough support and tools there to help her better manage some of that and so that she's able to function. (Parent\_9, F, Anxiety, CAMHS)

Referral to self-help or self-guided online support was described as unhelpful by YP, and parents reported that young people were much less likely to engage with these resources. This lack of engagement was primarily driven by a lack of personalisation of the resource; the expectation was they would be supported by a professional whose focus was on them.

...it was basically an online, an online version, which, honestly, for me was useless. Just personally I find it a lot more helpful to actually talk to somebody, and an online kind of computer programme is just kind of completely...took the, took the life out of it. I don't know just, yeah, it wasn't, wasn't the same. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

You always end up with somebody giving you a sheet with lots of links; [MHSS], all of those helplines and websites. My daughter not once has been on those things. I am sure it helps lots of people, but you can't assume just because you gave them a list of resources, online resources, that it's actually a service (Parent\_1, F, Multiple MH problems, CAMHS)

...you know, we're two very different people, dealing with two very different things, but the remedy is still the same. It's still funnelled into a one size fits all treatment, so the young people didn't go back. (Prof\_4, M, Signposter, Youth worker)

Even when young people were provided with self-help or self-directed support to complement support/treatment with a professional this was viewed negatively, as the professional avoiding their responsibility to the young person.

Like if you actually have humanity and compassion and use your ears and listen to people, and like, I don't know, I feel like that makes a better support than just here's a help book, go do it yourself. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

Acknowledgment of lack of engagement was not limited to self-help/directed materials. Some of the young people acknowledged that elements of support/treatment did not work well for them because they had not engaged in the way that was needed; for example, because the young person was too unwell or because they were not experiencing a positive relationship with the service offering support/treatment.

So, I mean she talked about anxiety and she talked how I can deal with it, but I felt it never really, personally I didn't want to get better. I wasn't in that place where I was too stubborn to even say, you know I thought I was okay, I was like... "No I don't really need any help." So having that negative attitude didn't really help anyway. So, I don't think it really helped me because I wasn't in the right place. (YP 27, F, 14y, Multiple MH problems, non-CAMHS MH support)

But by that time you know [child] was really not engaging with them really. And I think both [father] and I both felt it was almost getting, it was quite a waste of time going because it's just a check in really, there was nothing really kind of... and to be fair to them, [child], you know he's a tough nut to crack. (Parent\_10, F, Asperger's, CAMHS)

Like young people, parents had expectations in relation to the outcomes of support/treatment on their child's mental health. There were parents who offered some positive discussion about their child receiving support/treatment; however, many expressed the view the support/treatment was not meeting the needs of their child. These parents felt that they understood the root causes of the problem their child faced, and they had expectations associated with this. This impacted on their assessment of the effectiveness of the support/treatment and how they supported their child in this.

Not tackling any potential root cause of her anger and behaviour. Basically they worked on what [child] brought in to the session, which was the anxiety side of things. (Parent\_1, F, Multiple MH problems, CAMHS)

And I kept thinking 'Why don't you start doing it and see if she engages' instead of all this like, you know, why don't you just sit down and say 'Let's do some ratings of what causes you most anxiety'. I just felt 'Why don't you just start?' and it was like a year of doing nothing. They didn't build a relationship. They didn't complete an assessment. They didn't do any therapy. I wanted them to do something, I did want them to do something. I wanted them to recognise that, and I wanted them to maybe meet [child] where she was rather than where CAMHS were...But it didn't meet the needs, it doesn't meet the needs of my child. (Parent\_7, F, Multiple MH problems, CAMHS)

But I think the, the final straw for me, at a planning meeting at the school...the person from CAMHS said 'It's fantastic, we've made brilliant progress, you know [child] can now, you know, now knows how to recognise the panic attacks', and I'm thinking 'But we want to stop the panic attacks'. It's not, you know, this wasn't to me, as a parent, this was not a good outcome...

Because it wasn't happening at home, the panic attacks were absolutely associated with school.

So, at that point, I withdrew [child] from school. (Parent\_12, F, Multiple MH problems, CAMHS)

This view that their child's needs were not being met was sometimes reinforced by other professionals.

And we were saying to her 'Just force the issue and say I am the parent. I'm telling you this is what the reality is'. She was told to go to an online learning tool and tell her daughter to go for walk. Maybe listen to music and do breathing exercises. This woman said 'My daughter is telling me that she doesn't want to be here'. (Prof\_1, F, MH service provider, Youth worker)

Many of the parent participants reported feeling let down by CAMHS in particular. The expectation they had about the support/treatment their child would receive and the impact this would have on their mental health was not met. They described this as CAMHS saying that they could not support or treat their child, and this was particularly pronounced for parents of children who had an autism diagnosis.

CAMHS felt very clinical and hard...But it just felt very clinical and very 'Oh I can't help you, bye'. I think that's the difference was when we walked into [3<sup>rd</sup> sector MFSS] and when we walked into the carers centre they were very open and honest about, they might not be able to fully fix you or fully help you but we are going to try. Whereas CAMHS, they was just, they was not even trying.

(Parent 5, F, Autism, non-CAMHS support)

Professionals who offered support/treatment were acutely aware that the expectations of young people and parents cannot always be met while they are receiving support/treatment. Often this is because there are unrealistic expectations about what support/treatment can offer. They discussed the need for open communication with families in these instances.

...how I work, it's very collaborative process in terms of identifying what the need is...By the end of the assessment appointment I would kind of clarify what I think they were trying to convey to me through the discussion, what I think might be the most helpful approach to support their needs. But also have a think about what they were hoping to get from CAMHS as well, and trying to see if we can kind of marry them together in some way. Sometimes what they're wanting from CAMHS isn't something that CAMHS is able to offer. Or there isn't a need, there isn't a mental health need and that's part of my professional background and opinion is to be able to say to families 'Look I just don't think actually that you need any CAMHS support, you're doing really, really well', and that can sometimes be a bit of difficult conversation as well in terms of expectations. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

That, that can be very difficult and the word 'fixed' very often does come up, you know that families do seem to just want things to be fixed. I think it depends on how amenable the families are to thinking differently. And we try very hard to help families see that they've got lots, lots of different ways of coping and all we're really doing is really supporting them with that...What's very frustrating is when people come in wanting things to be fixed and wanting your opinion and then discount your opinion when you give it if it doesn't seem to fit their narrative. (Prof\_15, F, MH support/treatment provider, Psychologist)

As well as meeting their expectations in relation to outcomes, while their child was receiving support/treatment parents expected that the various services involved would work together but often perceived this wasn't happening. They described having to act as the conduit for this, and it frustrated them. Some professionals also noted that the disconnect in the system can lead to poorer support for a young person in need.

Like, if CAMHS had got in touch with speech and language and spoke to [professional], if they had got in touch with Doctor [GP] if they'd asked to see his records from then and what they were talking about it might have changed things. (Parent\_5, F, Autism, non-CAMHS support)

[child] at that point, was having huge questions to do with gender, and needed someone to speak to about that, and it wasn't dealt with then, and if you'd had a more joined up services, actually, you would have hoped that [child] would have had the opportunity to talk about those issues then. But that was, that wasn't part of the deal. (Parent\_12, F, Multiple MH problems, CAMHS)

In particular, we've had one young person that we've supported for maybe about 6 years now and they've had a very long history with multiple different services, really struggle with mental health, really poor mental health, lots of diagnoses in between...Sometimes it's been really a heavy load to support this young person but we've seen the value in being able to support them and I think when they've been in the right place to accept support then it's worked for them. But if there's been someone that they've potentially clashed with within the clinical side of things then it's been a struggle for them as well. (Prof\_6, F, Signposter, Youth worker)

#### Topic 2: Summary

Young people and parents held the view that MHSS were difficult to access. The challenges they described were both perceived and experienced, and were understood to come from underfunding of the mental health support system; this was corroborated by professionals. When discussing CAMHS young people and parents believed there were long waiting times and that only those considered extremely high risk were prioritised, which made access difficult, if not impossible. This perception of the (in)accessibility of MHSS ran contrary to what young people and parents expected from MHSS; that they would be seen and "fixed" quickly.

These views of young people and parents are reflected in national datasets that show waiting lists for CAMHS are a reality (see Section 2.3) (Public Health Scotland, 2021). Alongside this, prioritising cases are a necessary reality for services, higher risk or more severe cases are associated with shorter waits for CAMHS (e.g., Edbrooke-Childs & Deighton, 2020). However, there is little public information available about access and waiting list times for other services. This means that CAMHS waiting lists are over-represented in the media, and public conscious. Having information about other MHSS would potentially facilitate engagement with them if they could demonstrate capacity. This could, in turn, help alleviate some of the burden on CAMHS by facilitating earlier intervention.

The view that services are hard and/or slow to access can act as a barrier to engagement in different ways. For example, a belief that there is no point in trying to access them can prevent first contact with services (Iskra et al., 2018). Moreover, if young people gain access, their engagement with the service and the professionals who work in it may be predicated by a view that services cannot deliver optimally because of underfunding. This is compounded when knowledge about mental health is limited and expectations around "quick fix" go unmet.

As well as challenges related to accessing MHSS, young people described some uncertainty in relation to the implications of accessing services and support/treatment. Whether this was a belief that the support/treatment would not be effective, or a belief that it could result in undesirable outcomes (e.g., hospitalisation), the consequences are the same in acting as a potential barrier to accessing or fully engaging with support/treatment offered. This finding has been noted in other research as described as "fear of the unknown" (Bone et al., 2015). In the context of CAMHS, young people pointed to unhelpful information perpetuated on social media that took them a step further than fearing the unknown to instilling beliefs and expectations that, even if the waiting list can be navigated, support/treatment offered through CAMHS would not be effective. Indeed, recent research found that 27% of videos associated with the #CAMHS on *TikTok* were negative representations of the service (Chadee & Evans, 2021).

All of this adds to the expectations that young people arrive at services with, and almost certainly has the potential to promote disengagement. For example, if the young person doesn't receive an early diagnosis they may become disillusioned with the support/treatment process because expectation of a linear process resulting in a "quick fix" is unmet.

During support/treatment a number of reasons for disengagement were expressed but at the heart of these was a need to feel the support/treatment they were receiving was personalised. For example, self-help or self-directed support/treatment was perceived as impersonal and difficult for the young person to engage with. In addition, when the therapeutic content of support/treatment couldn't be translated to their everyday lives young people interpreted this as not meeting their needs. A systematic review has shown little evidence for the effectiveness of self-directed digital interventions for depression and anxiety in young people, and this has been linked to a lack of relatable and interactive content, with educational content being assessed as "boring" (Garrido et al., 2019). This links directly with the issue of personalisation highlighted by the SMLYE participants.

The disengagement that young people described had the potential to be reinforced by parents and professionals. This happens when they distrust diagnosis, or the support/treatment offered, and verbalise this to the young person. This is something that can be compounded if support agencies don't work together to support the young person and their family. However, professionals acknowledged that there will always be groups whose needs cannot be met by the agency they try to engage with, and there needs to be dialogue about this so the young person and their family understand why their needs cannot be met and where alternative forms of support might be found.

#### Topic 2: Learning points and recommendations

- Develop guidance, tailored to target audiences, on when mental health support/treatment should be sought (i.e., what mental health problems services can help with), and the appropriate tier of support/treatment. This could be in the form of online information or leaflets and should include guidance on how to match a mental health problem(s) to appropriate tier of support.
- Provide transparent, audience-appropriate, guidance about how the full range of MHSS can be
  accessed. This could be in the form of online information or leaflets and should include information
  about access pathways and criteria. This could be complemented with information about service
  waiting times to help manage expectations.
- Provide information about support/treatment demands that helps to set realistic expectations about what the support/treatment journey is like (including duration).
- CAMHS should develop a positive, educational social media campaign to inform young people, and families, about their remit, how support/treatment is delivered, and outcomes. This could include testimonials from young people who have received CAMHS treatment/support.
- There is a need to ensure that therapeutic materials, whether provided by a professional or self-directed, feel that they have been personalised for the young person. This could be achieved by ensuring materials are relatable and interactive, rather than being a simple educational tool.
- There needs to be a meaningful dialogue with parents and linked agencies to educate them about the support/treatment the child is receiving. This would facilitate better parental support of the engagement needs of the support/treatment plan.

#### 4.2.2.3 Topic 3: The engagement journey

A range of barriers and facilitators to optimal engagement with MHSS (MHSS) were identified in the interviews with young people, parents and professionals. Some of these were explicitly described as barriers and/or facilitators, whereas others were implicit in the conversations that the participants had with the researcher. These are organised into themes that describe discrete stages in the support seeking and engagement journey. To facilitate depth of analysis and understanding, and the usability of the finding of this research, we have organised the findings into sub-themes that describe barriers/facilitators within the context of key stages in the support seeking journey. This allows for observations and recommendations to be made in a way that facilitates targeted intervention to promote facilitators and remove barriers.

#### Theme: Acknowledging the mental health problem

A critical stage in the process of seeking support/treatment for mental health problems lies in the acknowledgment that there is a mental health problem, and that the young person would benefit from support/treatment. Both young people and parents spoke about an extended process of accepting that mental health support was needed, and part of this process was dealing with stigma associated with negative mental health.

Young people and parents frequently spoke about taking time to realise the young person had a mental health problem. The timeline young people spoke about was a cumulative one where they carried their mental health problem(s) over a period of time before they reached out for help; they referred to this as a struggle or a burden.

So, my mental health experience, I started, that started when I was 14 years old. I really struggled at a young age with my mental health, and just growing up. My mental health didn't really get better till roughly 16 years old. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

In hindsight I know now that she was probably depressed. The anger and challenging behaviour was just symptomatic of that. At the time, we didn't know. (Parent\_1, F, Multiple MH problems, CAMHS)

Often they sought support following a trigger event where, they experienced a critical point or a significant decline that was unsustainable. The types of triggers that caused participants to reach out for help were often suicide ideation or attempts, or periods of school refusal. With hindsight they acknowledged how long it had taken to get to the point of support seeking.

...I still remember the day, I came in and there was just, there was no one in the house actually, and I just thought this is the perfect moment because I just had a hard day and it was a full box of Ibuprofen I put in my mouth. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

She kind of experiences anxiety, low moods and self-harming and I had sought the support of CAMHS when she took an overdose of paracetamol. (Parent\_7, F, Multiple MH problems, CAMHS)

Yeah, sure so my daughter is just about to turn sixteen., We basically, you know, everything okay primary school, came to secondary school and then we realised there was, you know, there was something kind of going on. (Parent\_13, F, Multiple MH problems, CAMHS)

There were a variety of reasons offered as to why it took so long to ask for help. Some young people thought that the symptoms they were experiencing were a physical health problem or something typical of adolescent development.

I took me about a year to realise that I was having panic attacks as well. I thought I was getting an upset stomach, I was getting winded, and asthma. I put it down to everything else it could have been. I didn't know that that was a thing. It was never ever brought up to me. It was never an option. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

I have always known that I was anxious but I thought it was normal. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

Others young people did not acknowledge the issue until a significant other highlighted it to them.

At first, I thought that the appointment was literally just made because there was something wrong with my period. I didn't realise that it was because I had lost a lot of weight. I think my whole family realised that I wasn't eating much because for lunch I would have this mini, tiny side salad...But I didn't really realise that until I got there and then the GP weighed me and she was like 'You are quite underweight. That's not really normal'. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

Even when young people recognised that they were experiencing something that was a problem, or different to how they thought they should feel, being able to articulate this was not always an easy step for them. Some felt adults, such as their parents and GP, acted as a barrier to them fully acknowledging and articulating that they were experiencing a mental health problem. Some adults were presented as not taking mental health of youth seriously, or confusing it with patterns of development and thus downplaying it in the eyes of the young person.

My parents because they didn't believe that I had an issue. I did try to speak to them several times and it did circle back to the 'It's just a bad day. You will get over it'. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

Unfortunately, it took quite a while for doctors to actually discuss it with me...The doctor just kept putting it down to being a teenager and being a little bit more hormonal. I had one doctor at one point even telling me on a phone consultation when I was feeling really depressed when I was about 17 that I will grow out of it. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

...and I just said I'm getting increasingly worse, I need help, like what can you do? And the GP was basically just, in my opinion, not helpful at all. He basically just said that what I'm deciding is basically teenage issues. I had quite a lot of instances where I had to go to the hospital thinking that I had, well in my head, a heart attack but it was actually just, like, a panic attack. He said to help that he can offer, I think it's a beta blocker, I think that's it. That's all he said, and he was like 'Ok if you need help again, if you need to come back, come back'. But honestly after that I was just like I'm not coming back. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

The young person might try to undertake some self-diagnosis using internet sources or resources from school, but they do not always make an easy link with the literature and how/what they are feeling. This longer journey to realising support is needed means that early intervention is more difficult to achieve.

So then people will downplay their problems on themselves and be like, oh no, I'm not that bad. So they're not going to reach out for help until they are at breaking point. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

Not all the young people in the study were at the point of fully understanding their own mental health, and whether not they needed support. This was reflected in inconsistencies in their narrative about their mental health.

I see my mental health as pretty ok. I don't think my mental health is bad most of the time. I think I am pretty good most of the time... I just feel anxious in a lot of classes, every day. Like I just felt like I shouldn't be there, like I really needed to leave. I didn't like being surrounded by the people who are in their classes. (YP\_8, F, 17y, Anxiety, no MH support)

This young person (YP\_8) had spoken to friends who tried to reassure them that their feeling were normal. However, they had begun the process of researching this on the internet and storing the information for the future, and they had researched how to get a referral to CAMHS.

They were kind of reassuring me that it's not as big as I think it is. That what I'm feeling is like just kind of over exaggeration... it's just like something just in case, for the future. I feel like everybody should know. If you look it up online it's really easy to find the information. I feel like everybody should be able to access it just in case anything happens. (YP\_8, F, 17y, Anxiety, no MH support)

Parents also reported feeling challenged when their child was displaying behaviours or emotions that they couldn't understand.

Once we actually could put a name on...This year has actually been better, although her mental health has been declining, in terms of the family dynamics it has been better because we could actually name what was wrong. Depression, anxiety, autism. (Parent\_1, F, Multiple MH problems, CAMHS)

Indeed, parents found being given information about their child's condition resonated with them, particularly if they felt it was tailored for their situation. This supported them to better understand their child's condition in the early stages of acknowledging there was a problem.

...they offered us a chance to go...[to] a sort of six-week [charity's] kind of package thing, where you learn about Asperger's and autism and it was for parents of [child's] age group. So, we met other parents there who equally had a late diagnosed child. So, that was really helpful actually for [husband] and I, and it probably confirmed to me, the more I learnt the, the diagnosis was probably right, actually. (Parent\_10, F, Asperger's, CAMHS)

...but the parent helpline, it was quite reassuring to hear that actually, you know you're doing these things, the things that you're trying sound quite good. (Parent\_14, F, Mood, no MH support)

#### Sub-theme: Stigma

A critical issue in the acknowledgement of a mental health problem was stigma about mental health, and this impacted on how the young people managed conversations about mental health with others. In their interviews young people did not talk about denying that they had a mental health problem, but they frequently discussed downplaying it or not discussing it with others to avoid stigma. They wanted to avoid the negative judgement of others, even people that they were close to, their friends and family, and this impacted on their ability to get early intervention.

But my mum, she doesn't want to know that I am struggling, because, like I'm her baby, she doesn't want to know that. Same with my gran, they don't talk about it much. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

The key concerns in relation to stigma were almost polar opposites. There were concerns that some people might not take mental health problems seriously, and an opposing view that others would think the young person was more unwell than they were.

I think just the fear of talking to someone about how you feel, in case someone else judges you or you get called, like, attention seeking, or you just get made out to be, like, not how bad you are, as you say you are. Like if you feel your mental health is really bad and someone, like, just judges you off of that and says something about it, it stops you going to someone about your mental health, like get help for it. (YP\_18, F, 15y, Multiple MH problems, no MH support)

A lot of parents are still dismissive, a lot of young people canny speak to their parents unfortunately, because it's this whole thing of... you know, what have you got to be depressed about? (Prof\_3, F, MH support/treatment provider, Psychologist)

...especially, like, within the school and you say that your mental health is bad, they would be, like, 'Oh what's wrong?' They will automatically think that something is really wrong, even when it's not that bad. (YP\_8, F, 17y, Anxiety, no MH support)

For a few young people there was a real fear of the implications of telling family they were experiencing negative emotions, and this prevented them for seeking support within their family.

If my parents knew, I was always terrified of them just not supporting me or disowning me because I had mental health issues. So, I never reached out to my GP until I turned 18. In my household once you are 18, you are independent. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

When young people spoke about stigma this was in relation to how other people would judge them if they knew they had a mental health problem. They did not discuss stigma as existing within services. The focus of the stigma was the person who needed help/support. Parents also saw their children hiding their mental health problems from others because of concerns about the implications it might have for them. For example, young people were keen to keep discussions about their own mental health out of the school context.

But she's so embarrassed, she was mighty embarrassed that I might tell her teacher behind her back, which I don't like doing. But if she had known that I spoke to the teacher then everything would be 'But you told her'. So, it was important to keep that apart. And she is very, very worried that people might think badly of her if they know that she's struggling with these things at home.

(Parent 14, F, Mood, no MH support)

In school and stuff I would usually have appointments during the school day, I was always scared or embarrassed that my friends would find out. I didn't want them to know in case they thought differently or anything like that. Thinking of it now, I don't think they would have but back then I just felt like they would. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

Some of the girls, one of the girls specifically, she was adamant that no one would know. She would come before the class, the bell rang and then she would leave our session before the bell rang to get her next class so she wouldn't be seen as kind of leaving and coming, type thing. So for her I think there was a lot of stigma. (Prof\_3, F, MH support/treatment provider, Psychologist)

When professionals discussed stigma they acknowledged that young people experience it in the context of mental health, but the focus of their discussion was less on how they experience it and more about how it presented as a barrier to young people being able access mental health support. Professionals described the paradox of more open discussions about mental health being helpful but simultaneously highlighting the negative that, in turn, acted as a barrier to effective support seeking.

But still, I would say, ultimately, it's still going to fall down to stigma in some way, shape or form. Because school can be really informed and really enforce mental health, but I think, because as much as you're hearing this message and you know something is wrong, there is still this huge stigma or school pressure or peer pressure or social pressure going on that is probably really impacting... So I think it's a really complex mix. Will that ever be changed? I don't see that happening any time soon. (Prof\_3, F, MH support/treatment provider, Psychologist)

Professionals felt that the visibility of mental health services was a barrier to young people accessing them, especially if the service was in the school the young person attended. Changing the location or the visibility of the service could promote attendance by reducing the stigma associated with needing mental health support.

Which meant that they weren't seen, maybe the mental health worker going into the school, they could be going to a GP appointment or they could be going for whatever sports class were happening at the sports centre. So, for them it felt a bit less, for them it was about stigma, the area that they were. So it's about being creative in where they can be seen. (Prof\_10, F, MH service provider, Manager)

The way the services vary, you know, in the secondary school you walk in, you have the main building and then you have this in a separate building where they offer, so that not everyone knows what the young person is doing. But in this school, it's quite rare because I would go to the class door and I would call the young person. So the others know that this person is going to [service's name]. It's a very well-known fact that if you are having emotional problems, you go to [service's name] to talk it out... Especially with secondary students I think there is some shame associated with getting support. I think that can be a barrier. (Prof\_5, F, MH support/treatment provider, Psychologist)

#### Theme: Seeking support

Once a young person and those around them acknowledge a problem with mental health that they want to get support for, they described the next step in the journey as seeking that out. There were three important points in the support seeking journey identified as having barriers and facilitators to engagement within them. First, was identifying services that might offer help, support and/or treatment and then understanding how to access them. Second, once support services had been identified, families described having to navigate a referral process, this was particularly true in the case of CAMHS. The third important element of the support seeking journey was the waiting list; again, this was particularly salient in the case of referral to CAMHS.

## Sub-theme: Identifying services and how to access them

Many of the young people in the study reported that, at the start of their support seeking journey, they didn't know what services were available to them, or that there was a lack of available services. In addition to this, young people reported that they were often unclear about how to initiate contact with support services, and they felt that their parents also lacked this information. This delayed their support seeking.

Where I live it's not that rural but there aren't that many facilities. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

My parents didn't know CAMHS was a thing...I didn't know that there was support for young people back then when I was 14 and stared to get depression. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

Like I said, I had an open discussion with mum but she also didn't have any information on other services or where to go. She basically knew go to the GP and see what they say. That's all she knew. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

...I would be lost. I would be, like, I don't, I have no idea where to go, are there even places like for people who would help other than obviously if you're watching TV shows or whatever and you see people going get therapy or whatever, but other than that, I don't think so. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

There was contradictory narrative about the visibility of CAMHS. Some young people and families viewed it as a service that was hidden from them in their initial searches. In contrast, professionals felt it was almost too visible, seen by some young people and parents as the preferred service, even though others might be more appropriate.

When I looked online on Google there was nothing for young people apart from support groups and forums. But that was it. There was nothing about CAMHS anywhere. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

See, when I searched up CAMHS on the internet, there wasn't a lot of information to be honest with you. And it was quite a struggle to find the website. I actually don't know how I found it, but when I searched up CAMHS, it didn't first come up, it was like different things. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

...it's about changing parents and carers views on the services that they access. And sometimes recognising that the interventions that they're receiving via universal and third sector services are actually enough and good enough, that they don't always need to come along to, they might not get a better service by coming to CAMHS... (Prof\_10, F, MH service provider, Manager)

Indeed, professionals felt that young people and families were willing to reach out for help, but that problems existed in how they then access appropriate support.

So, yeah, I do think young people know where to get support, and I do think they ask for it, it's the experience of what happens after that, that is the problem. (Prof\_8, F, Signposter, Youth worker)

Professionals spoke about a confusion that exists in the support seeking journey. This might be articulated as there being too few services or too many services, but the end point was the same in that families in need, and some signposting professionals, find it difficult to navigate the support system.

Lack of services. Lack of trained services. Lack of visible services, especially during COVID. They were hidden to start with, but they are just invisible now. If there was somebody in my community who's struggling, they have not got a clue where to go. They would need to ask somebody, and I wouldn't know many people that would really know where to sign post them. Even schools. If they have not got anybody in the school, they would maybe make five phone calls trying to find somebody but even then. That's the issue that we have, it's not like any other service, if somebody broke their leg, they know where to go, they would take them to A&E or out of hours, make an appointment and get a nurse. That kind of clinical mental health services is invisible just now. (Prof\_1, F, MH service provider, Youth worker)

I think because mental health is so widely spoken about now there's almost too much. There's an influx of services, for example, we work in the local high school and in the local high school I can think of the NHS CAMHS service is there. We've also got things like our project called [service name] which is a drug and alcohol service but they do one-to-one type work. There are also things like a group that comes in to do something else that's kind of one-to-one therapeutic type stuff. There's us that are youth work services, there's the local authority youth work services, there's all these primary mental health care workers that are now putting into the schools to do one to one work. There's almost like, it could make it really confusing for young people about knowing where to go. (Prof\_6, F, Signposter, Youth worker)

One young person felt that services should be more proactive in identifying young people in need because they didn't always have the capability to seek help themselves.

They should have a better service, like support if it's, I don't know, somebody coming to their door and doing a welfare check or something once a month or doing something about it.

Sometimes you just need somebody to put their foot in and come to the door and say right, we need to sort you out, this is what we need to do. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

This was also supported by professionals. Youth workers spoke often about the need for services to "go to" young people rather than expecting young people to know services exist. This was presented as important in enhancing initial and sustained engagement. The notion of 'going to' young people could be where the service is located, by being in local communities rather than centralised provision, or through outreach work.

...so we done a lot of outreach, we went out in the street, we were out with our Y2K hoodies, out there, so they knew we were there because they knew they couldn't come to us... So, we went out and we were out two nights a week and we were also out around the school building when they were open at break and lunches. So we were there for advice and support, we were there if they wanted it, or we were there to show them that we were still there, you know that that consistency was still there. So that was one of the approaches, just to be as visible as possible... But again, I think it's about coming to the young person's community rather than asking them to come out of their communities. (Prof\_8, F, Signposter, Youth worker)

So, your outreach teams, your youth work teams, your early intervention teams and then your intensive teams, and I would make them more visible. I think visibility is key... (Prof\_8, F, Signposter, Youth worker)

In addition, physically going to young people there was a view that this could be achieved through more accessible and appealing branding, particularly in terms of social media visibility.

It's hard to appeal to young people...we've always found that the way that we get young people to engage is the gimmicky, make it fun, make it sexy. The branding. We did a rebrand and you will have seen on my emails that we've got a nice logo and we've kind of got things going, we use Facebook and we use Instagram. (Prof\_6, F, Signposter, Youth worker)

This barrier to initial support seeking was, however, different for families where the parent had professional knowledge of support services, through working in the NHS or linked service, or if they had had support for their own mental health, or had another child with mental health needs. Having knowledge of the system of support was helpful in facilitating access to support for their child.

...my mum's a practice nurse. So, she was very quickly able to say, you know, kind of, 'do this, go through this way or do this and this will get you the best kind of, you know, don't bother with this or do this', you know, offer kind of advice and a bit of guidance. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

I manage the [service name] for the city. So we've got [service] as part of that package. So she could access that. And I've also been working with the council and their counselling frameworks.

(Parent\_9, F, Anxiety, CAMHS)

After that, oh my mum did look for getting me a private cognitive behavioural therapist, because they don't really offer it to children and my mum was so set on paying for it 'cause she had actually had anxiety and depression and she had got CBT, and she thought it helped her...but then when the autism assessment came back with I did have it, then she was like, 'Well I'm not going seek CBT now because it might not even help'. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

Irrespective of the knowledge of the parent about how to seek support for their child, when parents were aware and acknowledged there was a mental health problem, they were important catalysts to young people gain access to support.

The first appointment I had no choice. That was my mum, she was adamant. I was saying to my mum as well, if she hadn't been so adamant, I wouldn't have gone. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

My mum, she was there for me constantly. She was the one who noticed it, she was the one who helped me. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

Young people talked a lot about schools and GPs as support service gatekeepers and parents saw their GP, or their child's GP, as the person they were most likely to reach out to. However, the narrative about making initial contact to ask for help/support was mixed, some young people were positive about these routes, but others expressed a reticence. Parents also expressed reticence or a negative experience of trying to seek support through their GP.

I mean for support for learning, there's so many teachers that do know about mental health and probably go through it themselves, pastoral care as well, they do know about mental health. But there's lots of teachers that haven't been educated in them. I know lots of teachers would be like, 'Yes we know what mental health is', but they don't really know it from a child's perspective. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

I haven't really talked to my GP about it, no. But I mean if, maybe school counselling is kind of my first, maybe, step. That's what I would maybe do first. But if it wasn't an option then I would maybe speak to my GP about it, yeah. (YP\_23, F, 17y, Anxiety, no MH support)

Because it feels like when you're talking to somebody like online about it and or you talking to somebody you know about it or somebody else that you feel comfortable with, it's different. But like with the GP's kind of like in in the past. She's only giving me prescriptions and, like, diagnosis for, like, physical illnesses. It will be kind of weird to talk about mental illnesses. (YP\_8, F, 17y, Anxiety, no MH support)

So, she's someone where, where we've been wondering what kind of support would potentially help her. We haven't, I've talked to the GP at one point and they've been very welcoming and said 'You can come back to us', we haven't gone down the route of saying 'I think she needs something' and having her seen by the GP et cetera. (Parent\_14, F, Mood, no MH support)

The GP surgery isn't particularly supportive of a lot of things, so I don't feel as if I would be able to go there. I don't actually know of any other service around here that I could go to, if I felt that I needed it. (Parent\_15, M, Anxiety, CAMHS)

Young people had different experiences of support in schools, some schools appeared to have a visible mental health support structure in place but for others this was newer or something that wasn't visible.

Our school just got a school counsellor but she is really busy so I don't know if there are that many options to get an appointment with her. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

When I was in school struggling, there was just nothing at all, there was just nothing. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

Ensuring that professionals who signpost young people and families to services know what services are available and what they could provide is important. It was suggested that this could be facilitated through better networking between professionals/services and having a named person who could act as a link between services.

A wee bit of partnership work...I'm not re-inventing the wheel here. A lot of it is partnership work and linking in with services that are working with young people, and promoting that whole person approach...I think partnership is definitely the key for us and our experiences anyway and the things that we have come across when we hear about young people engaging in services. We have got some young people that are engaging with services that we didn't even know that's what they were doing until they eventually told us 'Oh yeah I go and see my CAMHS worker like once a week', and we are like 'Oh right I didn't realise that was happening'. (Prof\_6, F, Signposter, Youth worker)

I think having direct access to, to mental health like CAMHS teams or, so we have a clear, maybe a go to person, you know, maybe a community link, you know, if there's maybe named person from, from the team... There may services out here that we don't even know about, you know that we could be utilising. It's about...networking. Maybe providing, like, networking events where you've got people at tables, and stalls and leaflets, and professionals could go and just find out more about what everyone does. Just something so simple, but actually it can make a big impact, you know having that networking day, and talk and speak about what they do, and linking, and potentially work together on pieces of work. I think they're really important opportunities. (Prof\_8, F, Signposter, Youth worker)

I think that's something myself and one of my colleagues have been very much discussing recently about like trying to get more of a one door entry system so that when people are referred that they come in, and we can give advice from point of entry that can maybe get people help quicker and to whichever service is the best at that time. (Prof\_15, F, MH support/treatment provider, Psychologist)

In describing how they engaged with support seeking, young people and their parents didn't offer much about engagement with third sector and charity-based organisations. When this was discussed, there was, again, a view that services weren't visible to young people.

I don't think there is any at all. In my community, apart from the NHS, we don't have community run clubs anymore. We don't have a place for young people to meet up and have fun...So, kids are more isolated. And as far as I know there is no mental health help either. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

I've looked for support groups, things like that, and there's nothing. Like, you can't find anything.

(YP 9, F, 18y, OCD, discontinued CAMHS)

Not that I know of. Maybe like the local church but like that's it. Like I never really been there, I don't go to church or anything like that, so I don't really know. But yeah, the local doctors, I think that's NHS and stuff down there. (YP\_31, M, 15y, Anxiety, discontinued CAMHS)

I didn't think there was services out there apart from CAMHS who could help us... There's not anything community wise like youth groups or community groups or if there is they are run through the church and that's not always good for somebody like [son]. (Parent\_5, F, Autism, non-CAMHS support)

Linked to this, professionals referenced a shift in the narrative around young people's mental health, that meant services that might previously have been referred to as something different to mental health support (e.g., youth work) were now part of the mental health support framework.

It's become more at the forefront of the delivery and very much a topic that we have started to explore a bit more in terms of young people and how they engage in different services that we offer. I mean, I think when we talk about mental health now, we can relate this to a lot of different bits of work that we do in terms of like, how young people can feel about themselves and we used to call it things like confidence building and self-esteem. These things are still there. But I suppose, the whole mental health topic perhaps maybe acts as a framework for how we deliver some bits of our work. (Prof\_6, F, Signposter, Youth worker)

What wasn't clear in discussions about this was how visible these services were to young people who might be looking for support with their mental health. However, it was noted that young people may attend, for example, recreational activities and in doing so service staff identify a mental health need that they can work with the young person on.

So you've got that group but then, as I say, you build relationships with young people. There might be certain things that are person-specific that you think 'Oh they'll maybe need a wee bit of support with this or a wee bit of support with that', and then obviously we've got some of the other groups. There's quite a lot there, you know, it can be quite meaty and there's a lot of conversations to be had and there's a lot of things that we could note and potentially look at other services that could support us to support that person. (Prof\_6, F, Signposter, Youth worker)

Professionals were of the view that funding models can make it more difficult for third sector and charity run support. Short term funding cycles reduce the opportunity for consistency of delivery and thus the visibility and accessibility of these services.

I think one of the biggest challenges is fixed term funding. That kind of moving sand, that what was there at one point is not there again, whereas actually it was a really good service that young people really benefited from. So, I think the problem is, yes they do meet the young people's needs, but the problem is the consistence of it, that it changes so quickly... (Prof\_10, F, MH service provider, Manager)

I mean less and less community based work services are open, I think were the only ones and they're shutting down please like us due to funding, there is, there is nowhere to go, you know.

(Prof\_8, F, Signposter, Youth worker)

...I think actually the biggest thing that would be most helpful for CAMHS, personally, is you know for there to be wider support outside of CAMHS, you know for young people. For you know, all of the services that used to be available, the support services that used to be available from when, you know from when babies were born, just don't exist anymore...So, you know we end up seeing young people who maybe would have got better support out in the community, but because the community support isn't there they come to CAMHS. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

I think part of the problem is, is there isn't a clear join up between Tier 1 and 2 and Tier 3 and 4. That we need a more explicit a pathway through, from those community services, into CAMHS and back down again. And because a lot of those community organisations are third sector, and rely on, on funding arrangements which very often run from year to year. We see them coming and going quite a lot so it's a constant changing landscape...But there also are a lot of organisations that do some good work and then they disappear. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

While the majority of the young people and parents who took part in the SMYLE study had sought out mental health support and had, therefore, been involved in discussions about treatment/ referral, this isn't always the case. It was noted that there were instances where referrals were made without the young person's buy-in, and this could have a detrimental impact on their engagement.

So, I think that if that hasn't been there and those conversations haven't happened right at the beginning, then that can result in a young person not wanting to, to be at the service. I also think one of the big things if they haven't fully agreed to come along in the first place and they're feeling coerced into it. They're not seeing the same issue that everybody else sees. (Prof\_10, F, MH service provider, Manager)

And parents and carers and teachers and things, and you know social workers, can find that very difficult, because they kind of just think 'Well I'm worried about him or her and I want them to come to CAMHS', but if they don't want to, then. (Prof\_16, F, MH support/treatment provider, Psychologist)

In contrast, services where the young person attends on a voluntary basis, particularly if the service has a focus on youth activities rather than specifically mental health, were considered by professionals as more likely to encourage engagement that facilitated discussions about mental health and mental health support.

It is very much kind of based on that voluntary interaction between young person and youth worker. I suppose it gives it a bit of a value. It's that young person's choosing to come along to our service, therefore we can start to build that relationship from that aspect rather than they've been referred in. So, therefore, we kind of have to work together, it's that sort of, there's a wee bit more to start that journey I suppose when we think about mental health. (Prof\_6, F, Signposter, Youth worker)

### Sub-theme: Referral – stepping on

Young people and parents saw the next step in the support seeking journey as the referral process, and they described their experience of referral as challenging. There were problems with communication between the young person and their family and the referring professional. These communication issues started early in the process and were experienced by some as thinking that it took too long to convince the gatekeeper, usually the GP, that referral to a support service was needed. There was a sense from young people and their parents that they were kept waiting by GPs, they weren't entirely believed or that they had to prove their mental health need over an extended period of time.

My GP looked at all the symptoms and it took months of going back and forth to the GP before I finally got referred to get the assessment. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

I actually ended up changing my GP. I got a lot more support from the new GP in that practice. Unfortunately, the new GP that I had wanted to get to know me a little bit before we went on with treatment...And then she had brought up that she wanted me to go and do an assessment for bipolar. Unfortunately, she left the practice. So, I got someone new who then wanted to get to know me again before we did all that. And then she left the practice. So, it's been one of those.

(YP 4, F, 23y, Anxiety, non-CAMHS MH support)

But I imagine that, you know, there are a lot of GPs that perhaps aren't particularly sympathetic or helpful in getting young people referrals. Obviously, you know, they're the main people that need to be doing it, so if you can't get past them it's like, well what can you do really? Again, one of the best facilitators is your GP! So, you kind of need, you need a decent GP really to, it's half the battle I think in getting anywhere you know, for younger people I think, obviously getting referred to the services like CAMHS. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

I opened the file and there was a letter from the deputy head in the file that basically said that [son] didn't need any support, that it was all in my head, that I was a pushy mum, that I was a detriment to his health, everything was my fault... The head of the speech and language says I take it you saw it and I said yes. She said you know I don't believe it now don't you and I said yeah but she went but that's why I was assigned your file... (Parent\_5, F, Autism, non-CAMHS support)

The majority of the young people had been referred to support services, including CAMHS, by their GP rather than other gatekeepers. Where the school was involved, it was often a recommendation to the family that the young person's GP make an onward referral rather than the school doing this. Indeed, the pattern of school referral to GP was described by some of the young people and parents in their interviews.

I think my guidance teacher had a meeting with my mum and basically the outcome was for me to go to the doctor. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

It was advised by them [school] but they couldn't do the actual referral, the GP had to do it.

(YP 7, F, 19y, Complex PTSD, CAMHS completed)

So we were referred through the school and our GP to CAMHS and it was about a year and a half before we actually saw anybody... This teacher was retiring and basically said I think you need some support, I think you need some help, go and speak to your GP. (Parent\_5, F, Autism, non-CAMHS support)

Professionals saw the communication challenges that young people and parents faced as resulting from GPs having a limited knowledge of the individual young person. While the majority of referrals to CAMHS were initiated by GPs it was felt that these might be better made by, for example, education staff who would know the young person better, a view substantiated by young people themselves.

...80% of our referrals come from the GP...really any professional that's involved with a young person can make a referral into the service. But what we find happens is, say for instance education, they will speak with the family, identify a concern and say 'Right, okay, go to your GP and ask for a referral to the service'. But it'll be far better if education just made the referral to us, because they're sitting with most of the information... (Prof\_10, F, MH service provider, Manager)

As a youth worker I can't refer a young person through an NHS provision, we still need to go to schools, speak to pastoral care workers, or contact social services, or social work departments who then has to work with the young person as a facilitator to get them more help. Because we're deemed as being, well, you're just a youth worker. (Prof\_4, M, Signposter, Youth worker)

So, I would normally, with the consent of the young person, would go to guidance, but I wouldn't know where to refer, if, I don't even know if I could, you know I don't know if I'd have to go through a GP. I would encourage a young person to go to GP. But I certainly wouldn't, I never have in my whole career, filled in a referral form for young people to the CAMHS services.

(Prof\_8, F, Signposter, Youth worker)

They [GP] didn't really know me or know anything about me. I don't think I'd ever met the person [GP]. You know, it's kind of like 10-minute interview where they asked lots of questions. He [GP] did agree to do the referral but was quite blunt with me that it probably wouldn't be accepted, and it wasn't... I think that having school staff able to do referrals to CAMHS would be of benefit.

(YP 7, F, 19y, Complex PTSD, CAMHS completed)

While acknowledging that they weren't always to best source of referral, blame wasn't placed with GPs, rather it was acknowledged that their capacity was limited in relation to supporting young people with mental health problems.

Yes, but you know it's whether GPs will pay attention to that. Because they have, they have very busy jobs. They have a short time to see people so it's a kind of knee-jerk reaction. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

However, it was felt that referral through GPs limited the range of services that the young person might be referred to, typically those located within the NHS (i.e., CAMHS), even if these were not the most appropriate. Referral from other professionals might increase the range of possibilities and given more opportunity to discuss individual need to ensure best fit between the young person and the service they are referred to.

So, it's really about really having that information at hand of what services are out there that are going to be the best fit for that young person. So for me it would be about those pre-referral conversations actually. Where would this, what's the right door for this young person to go through?... There's many referrals that are, that come into the service [NHS] that would be best suited elsewhere...So, there's sometimes other services out there that would be a better fit for young people rather than coming into a mental health service, having mental health records opened up. You know there may be other fits that would be better if conversations were to be had with them to help understand what the young person's goals were and what they were actually looking for. (Prof\_10, F, MH service provider, Manager)

Having the opportunity to make a self-referral to services was seen as a facilitator of engagement by all three stakeholder groups.

...so if students actually could self-refer themselves to a counsellor if they're in a bad position, or talk to somebody elected in the school who deals with mental health in young people, that would be excellent, I think that would really work. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

I guess I would design a self-referral, instant access services. So, you know, like, like your GPs, but not GPs, so you phone up, you said 'I need an appointment, you know I need to see a counsellor', and you get an appointment that day, and then you can carry on and have a regular block. You can self-refer to physio and have a block of physio. So, I would most definitely have a range of qualified psychologists, counsellors and have instant access to them...I think that would make it much more accessible, it would remove the stigma... (Parent\_12, F, Multiple MH problems, CAMHS)

I think every CAMHS service I've spoke to has not implemented self-referrals with fear of what that would do to their waiting list. But I think that, I think that if you had self-referrals, it would be really interesting to see the young people that came forward and felt that they required support. But, for me, it would be about whole system working...all professionals working together to meet the needs of, of our young people. (Prof\_10, F, MH service provider, Manager)

A few of the young people in the study were seeing private therapists primarily because, as noted above, their referral to CAMHS was taking too long and these private therapists encouraged the young person to pursue the referral that they were waiting for.

It's just trying to convince her [GP] that I need it. My counsellor suggested going back and talking to her [GP]. And I have tried...My counsellor has suggested psychiatric help and I keep trying to push for a referral. But my GP just won't do it. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

Then they suggested that I should go back to my GP for a referral back to CAMHS because I was going to need long term treatment and obviously the nature of private therapy is costly. (YP\_9, F, 18y, OCD, discontinued CAMHS)

Communication remained an issue after a referral had been made because there was usually a period of time, and in some instances an extended period of time, between referral and contact from the service they were referred to (e.g., CAMHS). In addition, some parents wanted interim arrangements for their child while the referral was being processed and had expected better communication about this.

I don't know if I was missed or...It was my GP that did it, but I have now changed GPs so I can't even ask him. Because I moved house. But I think I was there and they said that they were processing referrals. It's just, it took so long. I know it takes months, but it took too long for me. I needed support then and there. I just took it into my own hands. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

I think, it was in November 2019 that I had my first referral to CAMHS and it was only in December in 2020 when I heard back from them, and that was just to see basically what they could provide me with, and then it was, that was my last time I've spoken with CAMHS they said they'll put me on a waiting list and I've yet to hear back from them. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

Basically he went 'Right, ok, we will send a referral in and we will see what happens'. There was no follow up to it. There wasn't really great inquisition to it or anything like that. In all honesty it felt more like they were just sign and stamp. They weren't really overly interested. I find that with a lot of the GPs we had. (Parent\_5, F, Autism, non-CAMHS support)

...he [GP] said 'I will be speaking with a consultant at CAMHS as I am putting her on the referral list'. I understood that he was speaking to a consultant to agree on the phone, based on what the GP had on his file, that she could at least be prescribed some anti-depressants while she is waiting to see CAMHS. But that was completely false. It was not the case at all. (Parent\_1, F, Multiple MH problems, CAMHS)

Another communication concern for families related to their understanding of the referral criteria and their meeting of this. During the time between referral and initial assessment by the service there was concern that the young person might not meet criteria, and this was felt particularly in the case of family who had or were expecting a diagnosis of autism. They thought that they may be rejected on assessment.

...it's not my experience but I am fearing this now, is, because the autism has been pointed out, that we will not be able to access therapy for depression or anxiety. Because CAMHS doesn't deal with autism. (Parent\_1, F, Multiple MH problems, CAMHS)

In contrast, where a positive referral experience was described it was usually linked to positive communication.

Yeah, it was quite understanding like. He's been my family doctor for a while so he knew a lot of the background, then obviously I told him what had been going on within the past five months and...not that I want to say it was quite nice, but like he was, he started tearing up and in a way it showed that he was really understanding. Like that he'd understood what had happened basically. And then yeah, he was quite nice and made the referral. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

That's also when my P7 teacher kind of reached out to me...She would talk to me and make sure I was okay in the house and everything. And that was also when she referred me to a place, not really sure where, but that was when I figured out that I'm a young carer. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

Yes, so, so, the initial appointment with the GP was on, over the phone, and I think rather cleverly on the part of the GP, the GP decided she had to see her face-to-face to take blood to check for anaemia, because she said she was tired. Now, personally, my personal viewpoint completely, is that was probably a clever move on the GP to see her face-to-face in the current situation.

Because she could have asked the practice nurse to take her blood to be honest... And then, since then, the GP has been phoning her every ten days or so, for a chat. So yeah, today she spoke to her on the phone today, so that's all on the phone. And has done a CAMHS referral, but my understanding is the wait for that is months. (Parent\_12, F, Multiple MH problems, CAMHS)

### Sub-theme: Waiting list

Time spent on the waiting list for access to support was, as noted above, an anticipation of young people and families prior to active support seeking, but this turned into a reality for the majority of young people and parents involved in SMYLE. Being on a long waiting list was a negative experience for young people and this had the potential to impact on their engagement with services. Parents also reported a negative experience of waiting lists, but they never presented this as a barrier to continued engagement, indeed they were more likely to present long waiting times are resulting in increased need for support/treatment.

Young people were critical about the length of time they had individually spent, or were experiencing, on waiting lists and they were critical about the lack of communication in relation to this.

I think, it was in November 2019 that I had my first referral to CAMHS, and it was only in December in 2020 when I heard back from them. And that was just to see basically what they could provide me with, and then it was, that was my last time I've spoken with CAMHS. They said they'll put me on a waiting list and I've yet to hear back from them. (YP\_16, F, 17y, Autism, CAMHS completed)

They described the limited contact as causing stress, frustration and anger and, inevitable, many thought this compounded their mental health problem.

So, they could find a better way to do it faster because it is quite stressful not being able to get an appointment. Especially, when it's for concentration for example. Like for my sister because she got exams and all that. She wants to have sorted. When you are not feeling mentally well, you just want to get better. You don't want to be waiting for months trying to get help because then you just end up feeling like there is not anything you can do to get better. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

I was just left waiting, it was just like I was a number to them, like I was just a name. 'Ach we'll just help him when we've got time', that's what it felt like. And see waiting over 100 days, it takes less than 60 seconds for me to go into the cupboards, get paracetamol or jump out a window or something, something like that if I wanted to really end it. And waiting over 100 days for treatment after saying to the doctor, I don't think I could say anything worse, see if you say 'Ach, I'm on the verge of wanting to kill myself', I think that's really, that is, should be a red alert straight away if a young person is wanting to kill themself, and just, there was no support. There wasn't even a phone call to say 'Ehh, we're really busy the now', there was just no support at all. It was a horrendous experience. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

They sent us out a letter when we first were referred and told that they had received the referral, we were on the waiting list they would get in touch with an appointment. We didn't hear anything for roughly a year and a half if I'm remembering correctly. (Parent\_5, F, Autism, non-CAMHS support)

Some young people reported that they never received an appointment and had no explanation of why this was the case. There was also a sense of lack of empowerment around being able to question the length of time they were waiting.

I just never heard back. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

Personally I didn't kind of think to, I didn't think to ask really. I'd either, I'd either assumed that it had kind of been I don't know, forgotten about, or I was still on the waiting list. So yeah, I didn't, I didn't personally try and sort of check in with them... (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

Even young people who had a quick transition from referral to first appointment talked about the negative experience of others.

She [sister] had to wait quite a long time for her appointment. Hers took a really, really long time whereas mine was a lot quicker than other people I know have been there. I am not sure why mine was so much quicker than for other people, but I have heard a lot of people say that their appointment took quite a while for them to actually get one. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

As noted above, there was an acknowledgment on the part of families that waiting lists were unavoidable and there were people in more need than they were. However, this didn't stop them from feeling frustrated and angry about their own experience. For some their wait reinforced prior negative expectations and made them question the value of the service that they were waiting for and their willingness to engage with it. Alongside this there were young people who felt that by the time they reached the top of the waiting list their mental health had improved and this made them disengage, even though they may still have been in need of support/treatment.

My GP was also able to get me referred for CBT in person. But, as you know, these things have quite a lengthy waiting list, and it took about two and a half years until they had a space for me, which by then, I was kind of out of that period and didn't really need it anymore. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

...for that one appointment with CAMHS I was quite hesitant to even join it. Considering the fact that I know my mental health wasn't necessarily the greatest in December, but it was a lot better than what it was when I got the referral, and it had been over a year since I even heard from them. So that alone made me like question whether I was going to. But I thought maybe I'd just get, join the first meeting, maybe see what they said and then we'll see where we went from there. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

...what we call spontaneous recovery, you know they've actually, they come to the appointment because they've been waiting so long and they think 'Oh we don't want to cancel it', but actually through coming to the appointment and having the discussion they go 'Actually you're right, things are absolutely fine, they weren't eighteen weeks ago, and we thought we needed help and it was good to be put on a waiting list, but actually by the time we've come here, everything is sorted out'. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

Of course, there were young people who did not have a long wait, and for them, and parents whose children had received an appointment quickly (i.e., within weeks rather than months), there was a sense of relief that their wait was shorter than expected. However, this was often offset with an acknowledgement that others wouldn't have the same experience and, in many instances, while the young person had had a short waiting time for one referral they had experienced longer on other referrals.

I'm sure it was classed as an emergency at the time and I was seen within 3 weeks, which was obviously very, very quick in terms of the waiting list. The third time was over, how long was it, over 18 weeks it was, but it was okay because I already had the support there, I was in a very, very privileged and fortunate position where I already had support, but I can imagine that would be really hard for someone who didn't have that there. If that makes sense? (YP\_9, F, 18y, OCD, discontinued CAMHS)

We know there's like a 10 month waiting list. So we were lucky to get back in. (Parent\_9, F, Anxiety, CAMHS)

And actually, we felt quite lucky to just access psychology at the time [first request for referral] because of knowing that other kids had been waiting for even longer... This time we really wanted her to see somebody because a month ago she stopped going to school and she had the worst suicidal ideation... But because of that, we felt that we couldn't wait for two years, even if we were put on the waiting list, we were told that it would be 18 to 24 months now, the normal list. (Parent 1, F, Multiple MH problems, CAMHS)

While they were on a longer waiting list for support, such as CAMHS, some young people sought out alternative support. In some instances GPs offered medication and/or interim support, some sought support from third sector organisations, and others were able to pay for private support.

I was on the waiting list for a [CAMHS] counsellor but nothing was ever happening with it and I couldn't wait forever. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

So I had been on the waiting list for CAMHS from 2018 and then obviously nothing was happening so that's how I saw the school counsellor as it was a lot like having to wait (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

And the other thing that we did last autumn before we got back to CAMHS when we thought there was no hope, I was looking around for somebody privately thinking 'This just can't continue'. (Parent\_9, F, Anxiety, CAMHS)

But we got him into sort of private psychologist because CAMHS had a waiting time, and we were just so at the end of our tether really. (Parent\_10, F, Asperger's, CAMHS)

Professionals reinforced the experiences of young people and parents in relation to waiting lists. They expressed concern that a long wait for any type of intervention could lead to disengagement. In some cases this might result in young people not being referred on from one service to another more appropriate one.

Because your service is so oversubscribed that sometimes if there's a referral and it's not picked up quick enough then young people will lose interest and then they will forget. (Prof\_6, F, Signposter, Youth worker)

...we don't really want to hand these young people over to a services where they're going to be waiting six months to a year. (Prof\_8, F, Signposter, Youth worker)

The lack of empowerment that young people expressed in relation to chasing up or questioning their waiting time was a concern of professionals who felt that there would be young people at high risk "lost" in the waiting list because no-one was advocating for them.

I do think there's young people that either haven't been referred in or are sitting in our waiting list that haven't been flagged. And what I mean by flagged is that their voice hasn't been heard so that they could be in distress or going through a really difficult time, but no one is hearing that. So, they're sitting silently... I worked in a system where... as soon as a young person was brought into the service, they were allocated a case manager, a clinical coordinator. So, they already had someone to work with them so they would check in with them every few months if they hadn't been picked up for intervention. (Prof\_10, F, MH service provider, Manager)

Indeed, signposting professionals expressed concern that one of the reasons offered to young people about their wait was the severity of their mental health problem in relation to others.

For professionals to turn round to a young person and listen and say 'Yeah there's, there's people who are worse off that you'. Again, its trivialising. You know, no matter how small or how big a problem is, or what someone's dealing with, or what someone's battling, you're still trivialising to a young person...And then that young person becomes afraid to actually speak up to someone else because they think 'Oh well what if, what if it is maybe just I am overreacting, doesn't matter'. ...you know, that blew my mind when that young person told me that a professional had said this to her. That, yeah, 'There are people that are worse off than you so it'll be like a few months before I get back to you', you know, it's crazy. It blows my mind that that's accepted.

(Prof\_4, M, Signposter, Youth worker)

### Theme: Initial appointment and assessment

A younger person's initial appointment at a MHSS was often an assessment and formulation session. It was identified as salient in the context of engagement because getting a diagnosis was an important part of the support seeking process for young people and parents. Many articulated a view that support and treatment would only be beneficial if there was a tangible diagnosis that underpinned it. The diagnosis was presented as a validation of how the young person was feeling, something that they could use to talk to others about their mental health. Where the diagnosis was understood and shared between the young person and mental health professionals it was presented as a facilitator of positive relationships, but when it wasn't shared this was very much a barrier.

I would like to get a label on it to know what I am dealing with. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

I mean if you get diagnosed, I mean, let's just say you get diagnosed with depression and anxiety, you know that your feelings, these emotions, are because of anxiety and depression. But when you're not diagnosed, you always have to be questioning, oh maybe it's not anxiety, maybe it's not this, maybe it's just me, maybe it's in my head, maybe it's just hormones, maybe because I'm growing up. So, it's these constant questions you're having and you're not validating your feelings anymore because you just feel you're being dramatic. But whereas if you've been told that there is a problem here, and that it isn't just you, and you're not going crazy, you know you kind of have that sense of relief knowing that, oh okay, I'm only feeling like this because of this reason, I'm not going crazy. So, I feel like if you do get diagnosed, I feel that it's just kind of a, I mean at least you don't think that you're crazy. I mean you know why, there's a problem and you're able to deal with it much more quicker. You know you're able to say, 'oh, okay I've got depression, let's work on that'. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

Someone to sit down and assess me and rule out, is my autism is causing depression, is it something going on in my head chemically, Is it something else entirely? Just being able to see someone to get a diagnosis and to go 'Here is what you can do, this is guaranteed to help'.

(YP\_3, F, 22y, Autism, non-CAMHS MH support)

But the reason it didn't work was the diagnosis. Obviously if you don't get the diagnosis quite right, it is difficult to give the right treatment. (Parent\_1, F, Multiple MH problems, CAMHS)

Professionals who undertake assessment spoke about the need for a collaborative approach and there was an acknowledgement of a need to ensure that the young person understood the referral and what the assessment was for. This resonates with the approach that young people were seeking.

And normally, majority of the time young people have had a conversation with their parents, or they've maybe even instigated wanting to communicate with, for example, their GP about why they're coming to CAMHS. So that conversations already been had. But just as part of my own kind of practice, I would always check in with young person before I started the assessment just to see what their understanding of why they were there today. Because sometimes depending on their age, that understanding, or the parent's decision, they haven't actually had that conversation with the young person. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

Although there was an acknowledgement that not all young people are prepared to engage, and this can be a barrier to effective assessment.

So, we, I think we'll get the young people that will come in and don't want to be there at all, and it's mainly parents and the education, other people in the systems around young people that are concerned and want something to change. So I think some young people come in and don't enjoy the appointment, they feel very, very stressed. (Prof\_14, M, MH support/treatment provider, Psychologist)

Professionals also acknowledged that full assessment can take time, it can be complex and this impacts on the speed of diagnosis. They saw this as a necessary process but one that caused frustration for families.

...it's not allowed to make the diagnosis at that first appointment. An early diagnosis is you know, diagnosing as soon as possible is absolutely essential. If we could be diagnosing prior to someone coming into CAMHS that would be our ideal. You know there should only really be coming into CAMHS if there's an additional question about complexity of their mental health. But they can't be diagnosed simply by that one initial assessment appointment. The initial assessment appointment in CAMHS is around deciding whether or not they need to come into CAMHS or not for their mental health. (Prof\_15, F, MH support/treatment provider, Psychologist)

Some young people and parents felt that they hadn't had an appropriate assessment or a diagnosis, or there was a disconnect between how they felt, how people discussed their mental health, and the support/treatment that they received.

I told them as much as I could because I felt like CAMHS was a last resort for me to get help basically. So I had told them everything I could, but they never gave me a diagnosis or anything though, they said that would come afterwards but they said they knew how important it was to get me to see someone. So they said that was definitely going to happen, they said they were promising me that I was going to see someone and that I would get a diagnosis of some form... I had been on the NHS website and like researched all sorts of mental illnesses to try see what I resonated with more, and see what my symptoms were. Because, no one like wanted to give me a diagnosis or anything, I've still not had one. I still just get told I've got low mood so, low mood and anxiety. But, yeah, it's like, no one want to tell me I've got depression, but at the same time that's what I'm getting treated for. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

I felt like I just wanted a diagnosis because I thought a diagnosis would be great, I've got a diagnosis, I have help. About a year after the diagnosis I'd be a lot more normal. And I mean, a year after the diagnosis and I just feel the same. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

He tried to re-diagnose me with Munchausen, trying to accuse me of having Munchausen. But I don't, I know I don't. I know I have a very serious mental health problem. (YP\_16, F, 17y, Autism, CAMHS completed)

So then they didn't ever complete an initial assessment, to be honest. And as far as I see it, it was never completed appropriately. And I had a lot of frustrations with the service that they offered...

They were very much 'OK, let's do our assessment questions'. Which I do understand. But for [daughter], that was really difficult because she doesn't feel she has a relationship with them.

She found that a real challenge. And another challenge that [daughter] felt was very quickly they said, they referred her to talking therapy. 'You need to do talking therapy, and you can't talk [daughter] so what we're going to do?'. (Parent\_7, F, Multiple MH problems, CAMHS)

One of the parents spoke, in an implicit way, about their own honesty in the assessment process and that they hadn't been honest with the professional conducting the assessment because they felt the line of questioning was too focused on autism and not on mental health.

But I felt the chat quickly turned to 'Is there anybody with autism in your, in your family?'... So, to be honest, I didn't, I just said 'No' although I do have a nephew who's severely autistic...So, we never mentioned anything, because I just thought, you know, I don't want to do down that route because we want to see, you know, we're not here for that, we're actually here to discover what's kind of going on with, you know, with my daughter. And you know, why she's self harming and blah, blah, blah... We were actually at the stage where we just thought, do you know what, we're going, we're actually going to take her out of it and just go, you know, possibly go private, because we just didn't feel as if like, we just felt as if all the sessions were focused on going down the autism route, and being tested. (Parent\_13, F, Multiple MH problems, CAMHS)

This resonated with some of the discussion from professionals who described instances when families disagreed with their assessment.

What's very frustrating is when people come in wanting things to be fixed and wanting your opinion and then discount your opinion when you give it if it doesn't seem to fit their narrative.

And that's actually true of other agencies as well as, you know, with our families. (Prof\_15, F, MH support/treatment provider, Psychologist)

A number of the young people and parents spoke about the outcome of their initial assessment as them not being assessed as appropriate or eligible for CAMHS, but families didn't feel supported in this process. Even if they were linked to another service the explanation and transition was a negative experience. This was particularly the case for young people with autism diagnoses. While they were able to receive a diagnosis for their autism, they found it difficult to get support for comorbid mental health problems.

When I went to CAMHS it was about an hour and a half, basically just asking loads of questions and they concluded that they couldn't assist me on why I was there which was for anxiety. They decided that autism assessment would be more suitable. So they completely discharged me and then I was sort of left with no help for about two years until I actually got the assessment...The diagnosis was great because I got the answers, but then it was in a way pointless. I thought when I have a diagnosis everyone wanted to be there to help, there's going to be so much more easy access because I have a label. They can now see that I do have something and it's defined but no, nothing. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

Then she was like 'I don't think we can help yous'. He's a lovely child, and I do see why you feel the need for the help. But, and that's when she started going into the list about we haven't had the police et cetera. She said 'You just don't meet the criteria, and I'm very sorry for that but there's nothing we can do about that, and I'll get some information sent out for you to see if we can help you with any further services', and the information was never received. That was basically like the end of the meeting. (Parent\_5, F, Autism, non-CAMHS support)

Mental health support providers acknowledged the challenge in helping young people who have been assessed as not appropriate for the support they offer to understand the reason for this, and provide support in any transition to another service.

So, for example, if it was the case that things had improved, then I would just report that back and see if the families agree with that and say 'Well you see therefore, I'm not really sure if there's anything else, as a CAMHS services that we need to do because things are going so well'. If there's a bigger issue in terms of me having a think about another service that would probably be better served, then I would need to have a conversation with them you know, about whether it was social work or sometimes, you know, a medical professional. I would say, you know, I actually think it would be better for me to communicate with that services first, you know... Personally, I would never discharge someone at that stage if I was thinking of referring them onto another services. So, what I would do is I would, I would hold that family on my case load and talk to the professionals initially just to make sure that they were actually going to be taken on by that team. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

Professionals who signpost young people to MHSS had a sceptical view of the assessment process. There was a view that assessment and treatment planning was too generic and this was a barrier to engagement on the part of young people.

So anyway the two young people spoke to, to other people, the conclusion was that they were suffering from mental health problems. The two of them went to speak to a professional, separately, but they were both given the same treatment, even though their problems were very different. One was very much a clear case of depression, the other one was serious anxiety. It's still funnelled into, a one size fits all treatment, so the young people didn't go back. (Prof\_4, M, Signposter, Youth worker)

#### Theme: Mental health support/treatment

When young people have been allocated to a support or treatment plan there are several elements where engagement can become less than optimal. This begins with allocation to a particular support/treatment type and young people's views on and experiences of this. Alongside this are the various demands that the support/treatment type places on the young person. The attendance requirements, their understanding of the demands of the treatment including any self-directed requirements (homework), the environment that the support/treatment is offered in, the relationship with the therapist, and the discharge process.

# Sub-theme: Type of support/treatment

Having agency and being part of the decision making about the type of therapeutic intervention they receive was important to young people and parents. Professionals acknowledged that young people are not a naïve client group and that they have knowledge and preference about their treatment and that this needs to form part of the conversation with young people to optimise their engagement.

...it seems to be that young people seem to know lots and lots about lots of different therapies now. I think that's been the case for a while, but I think with social media now, we have young people that are coming in, telling us sometimes exactly what they need, and sometimes, you know, they're absolutely right...(Prof\_15, F, MH support/treatment provider, Psychologist)

However, for many this was perceived as missing in their support/treatment journey. Consequently, when young people discussed the support/treatment that they received, many of them focused on negative perceptions and experiences; elements that they did not like or did not feel worked for them. In some instances this was a psychotherapeutic intervention, and others a pharmacological intervention.

The types of things that young people raised in relation to a negative experience of psychotherapeutic interventions included not feeling that the therapy was compatible with them as an individual. For example, that group-based therapy was something that they could not participate in.

When I went, there were other people there but they were all, even though they all had difficulties with their eating, the people seemed quite confident and I just wasn't. I was just really scared to talk to anyone. It just made me feel worse. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

This issue of compatibility was also made in relation to the young person's mental health condition/problems. As noted above, young people and their parents had often undertaken their own research about treatment options, both prior to and while they were receiving support/treatment, and they had set expectations about this. When these expectations weren't met this led to a disappointment that could promote disengagement.

... after seeing the private therapist for a while, I knew that CBT and ERP were kind of the, the way forward, and I did that with her and she had sort of said 'When you go back to CAMHS this time, tell them, make it clear that this is the sort of treatment that you're looking for because it worked for you, if they ask you're looking for this'. And I did make that clear, I was not offered it, I was offered DBT which I'm going to be honest, didn't do anything... It was, again, very much to do with mood, instead of actually tackling the issue that was there, so it didn't help either...I read up on it, I made sure I knew, I read the guidelines on it, I looked at the NICE guidelines before I went, I kind of had an expectation that that would be followed to an extent but, no. (YP\_9, F, 18y, OCD, discontinued CAMHS)

It didn't work for me. CBT on its own isn't designed for a neuro-diverse brain, it's just not. It's not going to work. So, I was going through CBT and I was almost being forced to teach myself these things that I just can't do. So that had a negative impact on the fact I was being fed information and told I'm wrong for thinking this way, and I need to fix it when it's just how my brain works.

(YP\_16, F, 17y, Autism, CAMHS completed)

Parents frequently spoke about treatment incompatibility and, while it is not possible to substantiate this with the current data, it is likely that if shared with their child it would further compound the young person's negativity about the support/treatment.

She can't do CBT. She just can't. She isn't even aware of her true emotions or feelings. (Parent\_1, F, Multiple MH problems, CAMHS)

When the issue of support/treatment offering being incompatible with the young person was raised this was often linked to a limited offering. CAMHS, in particular, was described by some as not offering a diverse enough range of treatments and having too much focus on CBT as a therapy irrespective of the diagnosis.

I think that's where like CAMHS seems to fall down it's so, it's CBT or it's nothing. (YP\_16, F, 17y, Autism, CAMHS completed)

One size fits all box. (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

I feel like there should be lots of variety of things that people could go get help for because everyone's different... (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

I think it was cognitive behavioural therapy that I got put forward for, which just didn't kind of help either because it was just, almost like, all mindfulness this, that and, like, the next thing and, like, that's not helping... Don't want that, that's horrid, doesn't do anything. I don't know what other type of treatment there is because I've never been exposed to it, I guess. But I just, I just hope there's, like, another sort of thing that can, like, keep me happier. (YP\_30, F, 15y, Depression, CAMHS re-referral)

They just kept flogging that horse of 'It's got to be CBT, it's got to be CBT'.

(Parent\_7, F, Multiple MH problems, CAMHS)

Some young people chose to manage the issue of choice and compatibility by seeking support in the private sector. However, there were additional complexities here in that the increased flexibility and choice could be difficult to navigate.

So, I suppose there is more choice when you go for private. Whereas if it doesn't quite work with them, it's quite easy to say 'I don't think the relationship is working. I am going to try to look for another counsellor'... I think the hardest part was choosing the counsellor. When it's private, you have the choice of everyone. Making sure it was the right person for me. At the time, I was only comfortable with a woman. I wanted to make sure they were actually able to support me. You had to look at who they could work with. You needed to look at the costs because some people charge like into the hundreds, and you find that that's not really accessible. But you also don't want to go too cheap because you are thinking 'Why are you so cheap?'. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

In terms of private therapy, the advantage is that you can pick the person's specialism. So, if you type in the words 'art' and 'autism' then you have got a list of local counsellors or therapists with a speciality in that and you will know that your child will respond well. I am not sure we can be that picky with CAMHS and, actually, I don't think we would be listened to when saying that I think that art therapy would be really good for her...But at least the private counsellor you can pick their preferred way. So already as a carer or parent you have more of a say straight away because as a family you have chosen the method. (Parent\_1, F, Multiple MH problems, CAMHS)

Moreover, engagement with private services could further highlight the perception that CAMHS had more limited support/treatment options, and thus not be able to fully meet the needs of young people.

...I knew that CBT and ERP were kind of the, the way forward, and I did that with her [private counsellor] and she had sort of said when you go back to CAMHS this time, tell them, make it clear that this is the sort of treatment that you're looking for because it worked for you, if they ask you're looking for this. (YP\_9, F, 18y, OCD, discontinued CAMHS)

The need for the range of support/treatment to be as broad as possible, to ensure suitability across a wide range of young people, was something that professionals also supported. They recognised that there needed to be greater consideration given to the fit between the young person, their mental health need, and treatment/support they are offered.

Personally speaking, and not speaking as a manager, one of my biggest bugbears about the NHS is their limited view about intervention options and treatment options. It's not creative enough, and I mean creative in the literary sense. You know it's all talking therapies and if you're working with a young person 15 year old, 12 year old, 5 year old, whatever age it might be, and expect them to put into words how they're feeling about something that they don't have words for, then that's when you get people saying 'They're not engaging'... It's not that they're not engaging, is that they don't, they don't actually have the words to do it. (Prof\_10, F, MH service provider, Manager)

Being able to discuss negative views and experiences in relation to the type of support/therapy with their therapist or a related professional was an important part of a re-engagement process. It helped to build a sense of agency in the relationship between the young person and the person who is offering support/treatment.

I thought about it over the weekend and then I went back and told her that it made me feel a lot worse. She realised that it did because when she weighed me, I lost quite a lot of weight from the last time she saw me...We both realised that it wasn't maybe the right thing. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

So, she [counsellor] recommended I try CBT for anxiety but every time I tried to read the book, it would trigger a panic attack. Interviewer: Did you ever discuss this with her? I did but nothing came really out of it. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

Professionals who offer support/treatment noted the need to take a therapeutic approach that was flexible to meet the needs of young people as the therapeutic journey progressed. As more information becomes available to the practitioner they may adapt what they do to support the young person.

...as a clinical psychologist you're trained in a number of therapeutic modalities that, actually I tend to take a blended approach anyway. So I might do a little bit of CBT and refer to it as CBT, but you know within that, and depending on what comes up, because obviously you don't get all of the information in the assessment, with the young person. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

I think what we end up doing quite often is quite an integrated approach, which means that yeah, you're using a lot of different strategies from a lot of different models to try and meet the needs that young people are bringing. (Prof\_14, M, MH support/treatment provider,

Psychologist)

However, this might not be explicitly communicated to the young person meaning that they remain naïve to the changing approach. That said, mirroring the experience of families, professionals noted that CBT remains a dominant offering, but primarily because it is considered an appropriate approach for many of the mental health problems that young people present with.

I think we, we do need to be giving what the evidence-based practice is, and there is a lot of evidence around for CBT in a lot of cases. As the cases become more complex there's live evidence for anything so, you have to work in a more individualised way. So...I have a waiting list where I've written beside some of them 'CBT' and some of them I've written 'Individualised CBT', so they may have CBT underpinnings, but the actual work is far more individualised. (Prof\_15, F, MH support/treatment provider, Psychologist)

While medication was a positive choice for some of the young people in the study others found being on medication as part of their treatment difficult to manage, and this could lead to them choosing not to adhere to their prescription. They experienced the side effects of the medication as having a negative impact on their daily functioning and they talked about having to make a choice of whether or not to take the medication.

That one used to give me quite a lot of brain fog, so I had to be quite careful when I was taking it.

I couldn't take it when I was studying because I wouldn't be able to concentrate. If I had something due, I wasn't able to take it. But, also, I wouldn't be able to take it too late at night because otherwise I wouldn't be able to wake up in the morning.... With the medication I kind of have a love-hate relationship... I didn't need anti-depressants but I was getting them prescribed and this one gets you a little bit sleepier. And it does help. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

So she's been on three different kinds of medication. She's been on fluoxetine, where it made a really, really, she couldn't sleep at night. It really affects their sleep, and that was horrendous for her... And she wanted to change that. They wanted to change that. And then they tried sertraline, and that had a lot of depressive negative thoughts, and really suicidal thoughts, and just feeling awful. So she wanted to come off of that, understandably. (Parent\_7, F, Multiple MH problems, CAMHS)

This sense of conflict about taking medication was not just about the day-to-day management of it, but also whether or not to continue with it as a treatment option and conflicted thinking about this could be reinforced by conversations that the young people had with others.

I had a doctor who kind of suggested that, you know 'You can't be on these forever, and you know, it's just a, it's just a temporary solution', and such and such. And then in, in other times when I've been, I had a doctor who actually said 'That's nonsense! If you, if you need to be on medication because you feel like it helps you then, that's a personal decision'. Personally I don't, and again this is probably, yeah this is down to me. I could, I could come off my medication if I wanted to. I'm just kind of scared of having a relapse really. But yeah I have had kind of, conflicting opinions from different doctors who have said you shouldn't be on it long term, or if you need to take these for the rest of your life, that's fine. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

## Sub-theme: Clarity about support/treatment plan

Young people and their parents want to have a full understanding about the support/treatment that was planned. Important detail included the planned duration and the content of the sessions. Having this information helped the young people to manage their expectations about what would happen and what was expected of them.

With the first treatment I wasn't really sure what was going to happen. How long it would last or anything. She just seemed to explain that all to me throughout the whole process of it. Whereas the second treatment, before we properly started, he explained how long he thought it would take me. What it would contain and all that. What would happen...The second definitely made more sense. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

...there's kind of a bit of a feeling of the unexpected, not knowing what to expect and what it'll look like. (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

she's not told me much, she's not told me how long she's planning on seeing me for or if she would rather get me on medication than see me. I don't even know what she is going to talk about next week. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

I don't know what type of therapy it was, I don't know. It seemed to revolve a lot around talking so probably sort of talking-based. (YP\_9, F, 18y, OCD, discontinued CAMHS)

Lack of clarity about the support/treatment was a barrier to engagement for young people. It had the potential to impact on therapeutic session; for example, the willingness of the young person to be open with the professional they were working with. It also impacted on young people's ability to apply it in their own lives.

I think if I have had more information about what the counselling sessions would have been about, I would have felt a bit more comfortable. If I had known that I could have been as open as I want, that I won't get chucked in a hospital. I don't know why I thought that. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

It wasn't, the DBT was not explained very well, at all. When she did begin it, I didn't really understand what it was I was supposed to do, and I didn't know how to apply it either because, she often gave examples of applying it to when your, your sort of mood goes up and down, which wasn't the case for me, so I didn't really know when to apply it or how to apply it. (YP\_9, F, 18y, OCD, discontinued CAMHS)

Parents also reported concern that lack of clarity about the support/treatment plan would impact on their child's engagement.

...they referred her to talking therapy...and I did think 'Can you explain what that means? I'm not sure [daughter] understands why. What does it mean by talking therapy?'. And they didn't satisfactorily ever do that...Everything they have suggested has been kind of veiled in mystery of 'You must do talking therapy and you can't talk so you can't' and I'm like 'What do you mean talking therapy? We're talking now'. (Parent\_7, F, Multiple MH problems, CAMHS)

The professionals who provide mental health support/treatment agreed on the need for the process to be explained to young people but professionals who signpost young people to services expressed concerns that this is not always managed in a way that is accessible to the young person.

...because a lot of the early sessions that you would have with people is explaining that and getting them used to that (Prof\_14, M, MH support/treatment provider, Psychologist)

...but I do feel for most young people it's not been a positive or an understandable process for them, where it's explained to them in a way that they appreciate. (Prof\_8, F, Signposter, Youth worker)

One service manager suggested an alternative approach.

I think the gold standard for me would be that they, they receive some sort of written care plan...I mean that's kind of very general, but I would expect something of that that nature to go to the families. I don't know that that always happens. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

Alongside this, there was a view that open communication promoted clarity of understanding, and this could be managed better by professionals taking time to explain the support/treatment before embarking upon it. Allowing for questions to be asked and answered and supporting young people to fully understand the language of mental health support/treatment, which they acknowledged could be new and complex.

So, counselling, the first time I ever got counselling was actually terrible. And I think that one way, if a person is getting counselling for the first time for it to be explained properly, you know to calm them down, maybe ask some questions. Not really, kind of, go straight into it and make the person say too much and then when they say too much then you get mad at them or something like that. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

I feel like maybe at the very start when I didn't know exactly what was going on, I was a bit sceptical about going, it was a bit like 'Ah I don't necessarily think I should I go', but I think about, after a few weeks and I actually found out who they were, properly, I was fine going, like I was happy to go. (YP\_28, M, 13y, Anxiety, non-CAMHS MH support)

Yeah, he did use like quite big words. But I know, I knew what they meant but maybe other people don't and maybe they have to, not dumb it down, but make it more, make it more simple for people to understand instead of using the, these words that they've never heard before that can obviously alarm people to be like 'Woah, what's happening?'. (YP\_30, F, 15y, Depression, CAMHS re-referral)

It was important that this open communication and the ability to ask questions about the support/treatment was ongoing, especially between sessions with a professional.

If I have got questions, I give one of the admin ladies at [service] a phone and ask them. If they don't know they say 'Sorry, what's your email? I am going to find out and send you an email about it'. They are absolutely amazing with getting back to me. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

Yeah, yeah, she did explain that it was, like there would be so many sessions. That, like, things might work for me, things might not, sort of thing. 'Just take your time with it, try and process it all' and that she's always there, she's like a phone call away, sort of thing, if I ever really needed someone to talk to and stuff. (YP\_31, M, 15y, Anxiety, discontinued CAMHS)

The extent to which parent should be involved in the support/treatment plan was an issue that was presented as having positive and negative. Some parents felt excluded from the explanatory process, and that they had to rely on their child to provide them with the information.

I mean, I think it would have been good to have a session with parents to explain the actual process of what's going, what's going to happen, you know, how are we going to deal with this...So maybe I think like, you know, an information session would have been fantastic. If we sat down and said 'Right okay, this is what we're doing and this is how its' all going to work', rather than I felt we, everything was just played by ear. (Parent\_13, F, Multiple MH problems, CAMHS)

Well, I don't remember it. I don't want to say I wasn't given it. Perhaps it was explained to me but my recollection is that she had her thing going on with CAMHS and we had nothing to do with it. I didn't have a clue. I think I did know how many sessions. I probably knew that. I think it was like 10 or something like this. But I wasn't really aware of the set-up. I am lucky that [child's name] talks to me a lot. I am sure at the time she did tell me...I just don't remember being part of it. (Parent\_1, F, Multiple MH problems, CAMHS)

Some parents felt that information they held about their child and their mental health would usefully inform the treatment/support that their child was receiving, but there was no mechanism for them to be involved in this; they felt excluded from the process and that this was a barrier to the progress their child was making.

It feels to me that healthcare professionals are just not interested in hearing from the parents. I can't get my head around that... And the parents know about a lot about their child, so it could be useful to the therapist... I wasn't really impressed but I guess the psychologist can't work on something that the child is not mentioning. (Parent\_1, F, Multiple MH problems, CAMHS)

Whereas other parents felt they were included, and that this was positive in the therapeutic process.

Like, if he wanted me to know something she'd go 'Right mum come on in' and she would sit the two of us down. She's like 'Do you want me to tell her or do you want to tell her and I can help you?'. And a lot of the time he'd be like 'You tell her'. So she'd start explaining one or two things but she'd keep looking at him as if to check 'Are you ok with me telling her?'. (Parent\_5, F, Autism, non-CAMHS support)

Indeed, young people both acknowledged the benefit of their parents being involved, and expressed concerns around too much involvement. There were boundaries of acceptance of parental involvement that included them needing to know what the support/treatment plan involved, but not hear the detail of individual sessions.

I am not sure if it's mandatory for the therapist to tell people's parents everything. But I am pretty sure quite a lot of people would maybe be scared, or they don't necessarily want their parents knowing why they were feeling a certain way. If there was an option to not have parents told everything that had happened. That might encourage more people to go. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

I don't think I probably had a parent, like, come to the appointments and stuff with me, because that makes me really uncomfortable. But they used to be good to have someone to bounce off after the appointment, or even before the appointment. Just kind of gather all my thoughts together. (YP 16, F, 17y, Autism, CAMHS completed)

Indeed, professionals saw parents as a key facilitator of the support/treatment process and there was recognition that they needed to be informed about what their child was receiving and how they could support them.

There new some parents that are great and they will take their kids to appointments and they will be really part of that whole thing and then there's some parents that just don't know what to do because that was never anything that they experienced when they were a teenager. (Prof\_6, F, Signposter, Youth worker)

...so I think more support through CAMHS mental health services for parents on how to support their child through this process...But have a programme for parents where they are, they are hearing about how they can support their young people, what strategies they can use. That might be a nice option for those who really want to, who just feel they don't have the skills.

(Prof\_8, F, Signposter, Youth worker)

...there's resources there for parents within CAMHS, and I think it absolutely does come under our remit. If you're trying to take a whole child approach and think systemically, you have to not just do the one-to-one work, you have to think about who's around them and the people who are most likely to be around young people, most of the time, are their parents. (Prof\_14, M, MH support/treatment provider, Psychologist)

But they also acknowledge a fine line exists between involving the parent and managing the therapeutic relationship in terms of trust and confidentiality.

...you'll be having a lot of, like, conversations with parents about, they'll be wanting to know how it's going and what they can do and sort of, like, it's a fine line between what you can tell them, and what you can't tell them. To respect the young person's confidentiality. So you, yeah that can be a difficult conversation to navigate because you understand why the parents want to know but you also have to respect the wishes of the young person. (Prof\_14, M, MH support/treatment provider, Psychologist)

### *Sub-theme: Homework*

A lot of support or treatment would normally involve an element of homework, which might be practice or the application of the support/treatment to real world settings. Young people often referred to not undertaking the homework tasks fully, there was some engagement, but they acknowledged that it wasn't always full engagement. Some young people described psychological barriers to undertaking it, and others described their views about effectiveness as a barrier. Elements of homework that the young person was comfortable with, or they felt worked, were attempted, but elements that they didn't feel comfortable with, or they judged as ineffective, weren't.

Part of me just forgot doing it but then at the same time I didn't really like writing down what I was eating because I didn't really want to think about it back then. Nowadays I wouldn't have a problem with that but back then I was just self-conscious about it. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

So, I do have to do little activities every day when I get home. I do try to find a quiet space to completely do it but sometimes I don't always get it done. But I do try...I think it's because I already know it...I am already practising that from years ago and I am still doing it until this day.

I don't find it helpful at all. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

The grounding stuff I still do until this day when I am having a panic attack. That does help. I still got the book, I just can't read the book. I will one day. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

Another barrier that some young people discussed was the prioritising of homework within their day, or the additional burden it presented.

I tended to rush it and not actually like, you know, kind of just ended up doing it the night before, and not really putting much effort into it to be fair. I think because I was that exhausted from like school and sort of living with all that. It was kind of like the last thing on my priority list. (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

Not all of the young people remembered homework being part of the support/treatment that they received, and this was something that they felt was missing for them.

There was never any like 'Ok here's what we can do for when you're overwhelmed and your breathing's really heavy and you're like oh here's a breathing strategy'. There was nothing like that at all. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

No, nothing like that [homework]...I feel like writing stuff down, if she gave me like a journal or something like that, I feel like, and then maybe we could have talked about it. If I wanted her to read it or anything like that, I feel like that would have been really helpful for me at the time.

(YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

I don't think I ever got homework. I think it was just like... like take yourself, go sit, go sit in your room or whatever, like if you're feeling stressed, you're outside or whatever, go up to your room, sit for five minutes, read a book or try like to just calm your body down, go for a nice warm bath, take like, drink some tea, watch a movie, just something that relaxes you really. (YP\_31, M, 15y, Anxiety, discontinued CAMHS)

Linked to their knowledge and understanding of the support/treatment plan, an important facilitator of homework was parental support and monitoring.

My mum was really helpful. They always made sure that I did what needed to be done. My mum went out and bought me a notebook and all that for my diary. They were just really supportive as well about the whole thing. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

However, what parents often described was a lack of confidence and/or capability in supporting their child with this.

So, what happened was that I was supposed to support her at home with her CBT homework, but I was never told how to. There was zero communication with us carers. I think that was a problem because you don't know how to pick it up. It's not that I didn't want to help, but I didn't know how to. (Parent\_1, F, Multiple MH problems, CAMHS)

So I'm trying to do that myself, but I don't have a degree in psychology, or in counselling, and nine times out of ten I don't feel like I know what I'm doing. (Parent\_5, F, Autism, non-CAMHS support)

Professionals obviously saw homework as an important element of the support/treatment that could also be an important indicator of engagement.

...there's the expectation that there'll be homework, there'll be stuff for you to practice in between appointments. This isn't going to work as well unless, unless you are able to take on board the things and practice them in your real life. Because yeah, I usually put it to people that we have, we have an hour together, and that's a lovely hour, and it's really helpful to talk, but al lot of the work happens outside of that hour in your sort of life outside of the appointment, so it's going to be really important that you try the things outside. So yeah, that's usually how I would end my sessions by setting some homework and explaining that and making sure that they young people understand what it is I'm asking them to do and what I think that might help... If they are doing the things you're asking them to do I think, outside of sessions, that's probably another big sign. (Prof\_14, M, MH support/treatment provider, Psychologist)

#### Sub-theme: Attendance at appointments

Attendance at appointments for mental health support/treatment was problematic for many of the young people in the study. Difficulties arose both in terms of the time or timing of the appointments and logistics around transport. Importantly, the young people didn't just face pragmatic difficulties in relation to this, but they were also associated with additional emotional labour. Young people spoke about the majority of services operating within standard business hours; daytime on weekdays. This was problematic for some because it meant that they had the task of prioritising appointment attendance over things such as school attendance. This prioritising was both cognitively and emotionally difficult.

And she obviously works during the day, weekdays. She doesn't work weekends. That was the issue, scheduling time. Sometimes, it would be really difficult... The scheduling was probably the biggest barrier. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

It would have been better if there would have been a certain time after school that I could have gone instead. Then I would have to had to explain anything to my friends at school. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

As long as I get out of maths, defiantly. It depends which subjects it's during, or if it's after school on a, on a dancing night. Like if it's on a dancing night then I'll just be like really bored. And if it's during like one of my favourite subjects then, like, I'll be pure mad before it, and I wouldn't like want to go because I like the subject too much. But if it's one of the subjects I absolutely hate then I'll be fine. (YP\_26, F, 14y, Anxiety, CAMHS re-referral)

Prioritisation decisions could be influenced by other people. When young people felt that significant others, like teaching staff, didn't support them taking time away from their studies, this could act as a barrier, but support from others was seen as a facilitator.

...I would love to do it at night, in my own time...when you're in school and you're struggling, and your subjects are all different, taking a subject out to go to a counselling session, you just felt like the teacher hates you. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

No, my school were quite, they knew so they were quite chilled about it. (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

A key 'other' in the context of attendance was the young person's parent. Some young people felt a real pressure from parent to attend their appointments, they acknowledged that they might not have continued had this pressure not been there.

Especially with the fact that sometimes I do feel like giving up and sometimes I feel like there is no point talking to the doctor. I know that they won't let me do that. There is no chance they would let me not go to the doctor. I think they would drag me there if they had to. I think that is super important. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

But this wasn't necessarily a positive experience at the time, for some it was an unwelcome pressure, even when, after treatment was completed, the young person recognised the value in this.

Because my parents wouldn't have let me stop... I got better it, but that's taken quite a lot of family therapy...My parents would drag me to appointments and things but I wouldn't let them be involved... (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

Professionals also saw how emotional preferences can impact on the ability of the young person to engage. For example, if the young person is unable to share their need for mental health support with others this creates barriers in their ability to access services and appointments.

They're in school Monday-Friday, so in order to get, in order to get to speak to someone it needs to fall within say, 9am until 5pm, Monday-Friday. So they couldn't necessarily take time off school. They weren't trusting of the teachers to explain why they needed time off school, so the parents couldn't contact the teachers because a lot of young people don't tell their parents.

(Prof\_4, M, Signposter, Youth worker)

An important element was the closing of each support/treatment session, and how this is managed can impact on how young people feel about their attendance. Young people spoke about the emotional labour associated with sessions and the need for time to adjust afterward. Appointments that happened during the day were challenging because young people could struggle to make the necessary emotional transition back to school or other activities.

I missed one class a day [to attend counselling], but because it was so early in the morning I feel like after it I felt so down I just would go home anyway. I would feel like I can't sit through classes after having that experience, so I would just go home and be like, so yeah, I would just miss that, most of that day to be quite honest. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

...maybe some young people are like, that's such a big distance for me to go sit for like two hours, be sad, and come out being even more sad because of memories and past stuff that they'd had to bring up. I feel like they should give you some time at the end to be like collect yourself and know that you're not a bad person or whatever, instead of just being like 'Right, therapy's over, bye, there's the door'. That's quite, that's really overwhelming... at the end I'd always have like tears in my eyes, and they were like just about to fall and he'd be like 'Right, times up you need to go' and I'm like 'I can't go out looking like this'. (YP 30, F, 15y, Depression, CAMHS re-referral)

Because I was having appointments once a week, and then of course after the appointments I'd feel quite crappy, wouldn't want to go back to school, so we'd go to [restaurant] and we'd get pizzas there, and cookies, and we'd just relax, have time to ourselves and not have to worry about school or work or doctors' appointments. (YP\_16, F, 17y, Autism, CAMHS completed)

Some parents noted a negative impact on engagement with appointments was the process of appointment scheduling. Rather than having a set day/time, subsequent appointments were made at the end of the previous one or in some cases they were notified via letter or telephone at a later date.

...the next session was always pencilled it at the end of the session...you know there was no consistency, that's how I kind of felt. There was no consistency...Things do change obviously, but you know you're, you're being seen very week. Whereas we were kind of 'Well, hold on I'll look at my diary and I'll try and fit you, you know, what about here and then?'. And I think, especially because kids are at school, they need to know when they're going to be in and out, because you can't have them missing lessons. Because then that just creates a kind of an anxiety. (Parent\_13, F, Multiple MH problems, CAMHS)

Logistically travel to and from appointment wasn't always that easy for young people who relied on public transport and/or other people to drive them. Conversely, having someone to facilitate transport or being able to attend without an extended journey was presented as a facilitator of attendance. The majority of the young people who couldn't drive themselves relied on their parents to take them to appointments.

At the time, when I first started, I wasn't driving. That was a huge source of my anxiety. So I was trying to avoid it as much as I could. I would try to take as much public transport as I could which was quite long-winded. I would have to leave for the council session at least two hours in advance. That was a huge hindrance for me. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

Yes, it's like 20 minutes away but, and obviously I'm only 17, I don't drive. But my gran's took me the two times that I have been. So she drives me there and then takes me back home again... she has just told me anytime that I need her to take me she will take time off work to get me there.

(YP 11, F, 17y, Multiple MH problems, attending CAMHS)

Personally, I was actually really lucky in the place that I lived at the time, the surgery was literally across the road from me, which was oddly convenient! So, yeah, I literally had to put shoes on and cross the street. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

However, families can face competing priorities related to the inflexibility of the appointment system or the ease with which the young person could travel to an appointment.

Not really attend but it's just all scheduling. Sometimes I would have to pick up my sister from school. I think that's the biggest thing, trying to find the time because counsellors work weekdays like everyone else. I think that has been the hardest thing, trying to make time for it...So if I had to do things like picking up my sister from school, that would impact that because I wouldn't be able to do anything. And at that time, I had to pick her up every day because that's just the way that responsibility fell for me. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

I have a disabled brother who needs care 24/7, so it was also the times we could go to appointments, because we can't go to a two o'clock appointment because we have to be home for three. And then my dad works, so he wouldn't get home until about three o'clock, five o'clock even sometime even eight o'clock at night. So, we couldn't go after three because my dad wouldn't be home to take care of my brother. And my brother can't come because he doesn't like leaving the house. So, it was very restricting. (YP\_16, F, 17y, Autism, CAMHS completed)

Towards the end of my second treatment, my dad had got cancer. Which meant that my mum had to drive him to...Glasgow every day. So, it was a little bit more difficult. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

Fundamentally, having to manage appointment attendance alongside everything else was difficulty for young people who were already struggling with their mental health.

I would have rather stayed local, I used to have to travel about forty minutes to go to appointments. So, I had to take a lot of time off school, which had an affect on my education. Which then had an affect on my mental health, and I had to spend all my spare time doing school work to catch up to get help with my mental health which was part of, it was a vicious cycle of just trying to just carry too much things. (YP 16, F, 17y, Autism, CAMHS completed)

It's a weird one, that somebody with depression and anxiety has to overcome all these barriers that are inherent to their illness to access the therapy. And when they make it, they are exhausted. (Parent\_1, F, Multiple MH problems, CAMHS)

Not all the young people found the logistics around attendance difficult. When they felt that attendance was likely to benefit them, and they had the support from others to make it possible, attendance at sessions could be prioritised over other demands. This was the case even when other barriers remained in place; for example, fear of stigma.

My mum would drop me off... I would say for me it was relatively easy because I was desperate to get better. So, I wanted to go to the appointment so that I could work on getting better...I would usually have appointments during the school day, I was always scared or embarrassed that my friends would find out...I would pretend that I was at the doctors for some random reason, or that I had a dentist appointment because I was scared of anyone finding out about it. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

She'll go into the appointment herself, but she would be reluctant to get there on her own. She has real anxiety about, she doesn't mind walking about on her own but she has huge anxiety about using public transport. You know, even going up to the reception desk and all that kind of thing is completely overwhelming for her. So, yeah, up until, the times we have gone in, I have gone in and taken her to the waiting area, sat with her and then she goes into the appointments.

(Parent\_9, F, Anxiety, CAMHS)

Parents also spoke about how they tried to find ways of managing this in dialogue with the MHSS.

CAMHS were actually really accommodating with that and would kind of, because [daughter] found it difficult leaving school, and it wasn't about peers, it was about her anxiety about needing to be challenged by an adult 'Where are you going?'. So you know, they would schedule it so it was just after lunch. She would come home at lunchtime and be able to go then. Or they would schedule it first thing in the morning. (Parent\_7, F, Multiple MH problems, CAMHS)

...it was fine because we just used to make the sessions, like, you know, try not let it interfere with school. So certainly the ones in east CAMHS we would make the sessions for late in the afternoon... When it was West CAMHS, it was actually easier to do, we had a, we tried to kind of have a, a set time, so it was nine o'clock...and then she would go back into school. (Parent\_13, F, Multiple MH problems, CAMHS)

Professionals were acutely aware of the issues that young people faced in relation to appointment timing and transport.

And again, maybe it's just a case of just looking at, we need to run this organisation Friday, Saturday, Sunday, Monday, Tuesday, or you know, over the weekend and in the evenings. So, yeah, being flexible with time, doesn't have to be Monday to Friday, 9 to 5...I would look at time differences, look at the weekends, and set it up in a very non-clinical way. (Prof\_3, F, MH support/treatment provider, Psychologist)

Glasgow's a big area, sometimes there's three buses that people have to get just to get to the clinic, so I think that that can be a barrier. (Prof\_10, F, MH service provider, Manager)

However, ways of overcoming this is challenging given constraints that exist both in terms of how services are delivered and in meeting preferences of young people and families.

Another reason would be that limited option of where the young person can be seen. Some young people would prefer to be seen in school, some young people want to be seen in clinic, some are offered home patients, not many in Glasgow I have to say. It's a very clinic-based model in Glasgow, at the moment. And it's trying to work out what's best for the young person and balance that with service needs as well. (Prof 10, F, MH service provider, Manager)

Some young people spoke about bringing mental health appointment to education or employment settings as a way of reducing barriers.

Yeah it is for the counselling because I can just book a room at work...and then I have to attend because it's during work hours and because I have booked it, I have got to attend it. I am quite a bugger for not attending things. For phoning up and saying 'Sorry I can't make it today' and then never going back. So, at least when it's during work hours, my managers will make sure that I go to it. It is really easy. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

They were during school, so she would just give me a time and I would go see her like every Wednesday and she would tell me to come back whatever time that she had slotted me in for that week. And then the school have wee cosy rooms that were just, they've got chairs and little lamps and pillows and stuff...it would be, like, we would get a little pass and would just show the teacher that we had an appointment and they would be like, they need to let you leave. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

... even if I do forget they'll just phone, like, my teacher just to say, like, '[young person] needs to come down' and that will be fine. They don't mind, like even if that did happen, I'll only be like five mines late so. It is quite easy to remember, even if I do forget then there is still, I still end up do going. (YP\_28, M, 13y, Anxiety, non-CAMHS MH support)

This highlighted a contrast between support services offered through schools and those available out with, such as CAMHS. The narrative of the young people suggested that when support was offered in school the school were able to oversee some of the logistical issues. However, they had no control over appointment scheduling when the young person received support/treatment elsewhere.

...it [school counselling] was during school hours, but they always made sure it wasn't a subject that was as important as like core subjects, like maths and English. So, it was always something like drama or, like, subjects, like, that that weren't like core to the curriculum. (YP\_28, M, 13y, Anxiety, non-CAMHS MH support)

The narrative of those professionals who had experience of working in school mental health provision was similar to the young people who had expressed greater flexibility in school-based services.

In the primary school, again, they are very supportive of it. The teachers are very accommodating. And they adjusted very well. I feel they've worked really hard to destigmatise the idea of getting help and therapy. So I'm really pleased about that. So I think that the practical challenges involved are very little. (Prof. 5, F, MH support/treatment provider, Psychologist)

...because the timetable that I would work on would change almost, I think it was like every fortnight, or every three weeks. So, I might see the student for the first period, and then three weeks later we might change to the fourth period...That was just depending on, I think, the student's rota. (Prof\_3, F, MH support/treatment provider, Psychologist)

This notion of schools having greater flexibility and/or better knowledge of the needs of the young person was also extended to third sector organisations. Professionals who working in the third sector felt that their ways of managing attendance disengagement was more sensitive to the needs of young people seeking mental health support/treatment. They felt that NHS services were rigid in their approach to managing missed appointments and that young people were too quickly discharged. In contrast, they felt that their organisations were more willing to be flexible.

We always say to young people 'If you mess up, or if you don't turn up or you make a mistake, that's okay, let's just start again tomorrow'. Whereas I think with mental health services, I think if you don't attend that appointment or you don't engage with that processes, there is a, from what I've heard, a strike system. (Prof\_8, F, Signposter, Youth worker)

Schools and third sector providers were viewed as being closer to the young person and able to initiate engagement activators in a way that larger organisations, such as the NHS, are not. For example, the ability to remind young people of their appointment closer to it was something that professionals felt facilitated attendance at sessions.

... but I really have to remind young people every single day, remember this is on Tuesday.

Especially because now they are not just turning up. So it's that instantaneous, 'This is happening now, oh yes so it is!'. Whereas if you're saying I'll meet you in four weeks' time, young people, they just forget because it's not happening right now. (Prof\_6, F, Signposter, Youth worker)

There was a feeling from some of the professionals that the appointment system, especially as it linked to discharge, lacked sensitivity to the complexity of young people's lives, especially those experiencing mental health problems. However, this was presented with an acknowledgement that it might be necessary given things like waiting lists and the need to create opportunity for those on the waiting list by discharging young people who were not attending.

You don't get everybody because things happen, but I think it's ok to opt out as long as you get an opportunity to re-engage. You come for three weeks but you can't come the next week because something happens but 'Away you and get back on the waiting list'. Why? Something happened in their life. Give them another wee route. 'No, no. They need to go back. They need to start from the beginning'. (Prof\_1, F, MH service provider, Youth worker)

...another two appointments are sent out, and if they don't attend those other two appointments then it is discharged from the service. Some of the staff really struggle with that, but the rationale behind it is purely down to waiting list numbers, and for us to try and have some kind of through-put and not have cases open that are maybe not wanted, or not ready to engagement with the service. (Prof\_10, F, MH service provider, Manager)

Now that's, there's flexibility in that. So for example, if you were worried about a young person there's no way that you're going to comfortably discharge them because they've not responded to a letter... But again, you know, majority of the time the policy's there for a good reason. And actually, sometimes people don't want to have that difficult conversation, like I said, where they say 'I don't want to come', so they just don't ever respond again...and we need to be fair with the families that we're seeing, we can't have preferential treatment for people. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

They just, I think they discharged me because they, yeah, they discharged saying that if I didn't go to the sessions, that I didn't need them, and I'm wasting, like, other people's time and, like, someone else could be getting that spot, and I'm like, but I need it, I physically can't do it today...

(YP\_30, F, 15y, Depression, CAMHS re-referral)

One professional highlighted the need for monitoring of attendance against engagement. There was concern that regular attendance might mask limited engagement with the support/treatment itself.

...but I think attendance doesn't necessarily mean good engagement. I think you do get, I mean the majority of young people attending does mean that they're engaging. But you know I think, I could think of quite a handful of people who just...attend...they just attend but the engagement isn't really here. And I think sometimes, especially for families that have been seen for quite a long time, it becomes this kind of familiar, a bit like a safety blanket you know and I think that, that's difficult as well because you then need to have a conversation about 'I know you keep attending and that's fantastic, but actually what is it that you're getting from this, this session?'.

(Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

#### Sub-theme: Environment

The physical environment that mental health support/treatment is provided in was highlighted by all three groups of participants as being important to facilitating engagement. This included the location of the service setting and the physical space, environment, the service occupied. In terms of location, having to go somewhere new or unfamiliar was described as negative and a potential barrier to engagement. Indeed, some young people felt that consistency in where they went for support/treatment would have helped them in the process and community-based services helped manage issues around familiarity.

I think the familiar environment. If it would have been my own GP, somewhere that I was used to being. Like I said, to me it sounds a bit silly that going to a different GP makes me a bit anxious. I think at that age, being somewhere familiar would have helped me to be a bit more relaxed.

(YP 4, F, 23y, Anxiety, non-CAMHS MH support)

...that was quite intimidating, because it was a change, and I suppose you sort of develop a routine about going, sometimes, it just helps you feel a bit better. (YP\_9, F, 18y, OCD, discontinued CAMHS)

...you know other mental health services could be more community based. You know so in an environment that a person's used to, that they can come to a person's house, take them out for, you know go out for a coffee somewhere, go and sit in a park and I think those things will open people up more to talking about things. (Parent 15, M, Anxiety, CAMHS)

Some professionals felt that providing support/treatment in a dedicated mental health space was better than provision in school or home because it helps to compartmentalise the sessions from other elements of a young person's life. Others disagreed with this to an extent, feeling it is better to take the support/treatment to the young person.

I think that one of the positives about a clinical model is that it takes the young person away from home, school, any other. It gives them a kind of blank canvas, someone new that they can, it's neutral and that they're able to go wherever they need to go with regards to their emotional feelings. (Prof\_10, F, MH service provider, Manager)

We always send them to a clinical place, we send them to a hospital or whatever, sometimes you maybe need to take the service to where the young person is comfortable...It's not to say that they might not go into a clinical setting, but I think you need to do the initial three or four weeks in an environment that is safe and then encourage them. (Prof\_1, F, MH service provider, Youth worker)

Parents felt that the when the MHSS building was busy, especially when the service was in a shared space, this created stress that was a barrier to young people being ready to engage with their therapeutic session.

Part of it was the setting. She found it anxiety provoking to get into the building. So, it's a lovely building, it's the one that won awards in the Gorbals hub. So it's lovely. But the waiting room is shared with paediatric speech and language therapy. And so there's young kids in there, and they're noisy. As soon she goes in, she feels stressed. (Parent\_7, F, Multiple MH problems, CAMHS)

...he finds all that really stressful he wouldn't sit down in the waiting room, he'd stand in the corner. (Parent 10, F, Asperger's, CAMHS)

There was an interesting contradiction in professionals feeling that shared clinical space could be a barrier, but also that sharing clinical space created opportunity to share the support/treatment for the young person. It was also seen as a way of developing the comfort associated with familiarity of the space that young people spoke about.

The barrier to it is wherever the building is, what does the building look like, who the building's shared with. All of that can be big factors in a young person coming into the building. So one of the buildings I used to work in was shared with sexual health and when I done a bit of a survey with some of the young people they said 'I don't want to come in there when there's pregnant people sitting waiting, when people are sitting there pregnant waiting to get ultrasounds and stuff done and they might be thinking that I'm pregnant'. (Prof\_10, F, MH service provider, Manager)

I would love to have different services accessing our building to deliver bits. It would be a great way of making it accessible to young people as it's somewhere where young people feel comfortable and could use a facility that's not under any other attachment. This is a place for a young person to go and feel a bit more comfortable. (Prof\_6, F, Signposter, Youth worker)

I always try and book the same room for the young person each time I see them so there's just that familiarity so I think that helps to, you know that even though the room might not be exactly how I want it to, they have a reference point and it's familiar to them and they start to feel relaxed over time. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

Environments that were seen as 'clinical' were considered unwelcoming and in some instances caused negative reactions such as fear. Even when a young person was attending an NHS service such as CAMHS they didn't expect it to have a medicalised physical environment.

At first, I was a bit scared because it did look like a hospital. Quiet, clinical and all that stuff... It was the whole waiting area. It was so plain white and the chairs were the same ones that you see at the hospital. It felt like I was waiting for a dentist appointment. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

Like it shouldn't look like, I mean obviously it's going to be a doctor but it shouldn't be like so, like if they were going to go into a room a, it shouldn't have like all that stuff, the doctors stuff, because it makes you feel like, not that you've got something wrong with you, but you've got something that you need like help with. Obviously, you need help but you know not in that way, you just need the support to help deal with it. (YP\_18, F, 15y, Multiple MH problems, no MH support)

The walls were white I think the carpet was blue or like a grey-blue tone. The seats were like blue and there was like a small desk in the middle, the room was like quite large. It was just, it felt very, I don't know the word but it was quite horrible to be like, it felt like an insane asylum, you know like the olden days like... yeah it was like, it was like that, it was so strange, it was awful.

(YP\_30, F, 15y, Depression, CAMHS re-referral)

It [CAMHS] was really intimidating, I just remember always being intimidated by it. But that's probably because it was new to me as well...All I remember, to begin with, it was in this, this room, it was nice, it was bright, it had a big window and then the rooms kind of changed and it was like a cupboard almost, with no window and I remember just being scared. There were sort of bars on the windows and what not, I get that they were there for a reason but I just remember being really intimidated by it. (YP\_9, F, 18y, OCD, discontinued CAMHS)

You know for something like CAMHS maybe a clinical setting's too formal and, you know, too cold I suppose. But if it's the only option that she's got, then it's all that we can have. (Parent\_15, M, Anxiety, CAMHS)

It was the view of young people that something less clinical would help engagement by making them more relaxed.

Inside the place, I would try to make it look more welcoming. More homely, more relaxed almost, so that people when they are there and are waiting for their appointment didn't feel quite so scared to go into that. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

So I actually experienced two different environments within CAMHS because the CAMHS team that I was with moved sites... So the first one, it wasn't exactly fit for purpose. It was like an old, like a nurses home with, like, little rooms and things like that. But the second one was lovely, it was bright, and it had been designed specifically for CAMHS. So that was like, big corridors with like, lots of side rooms and each side room had toys and stuff. (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

The types of issues within the environment that were highlighted by young people was the colour of the space. White was associated with clinical whereas colours were seen as welcoming. Chairs that were comfortable rather than functional were described as helping the young person to relax, which helped them engage better with the therapeutic session.

I don't know like, probably bright because like, bright colours are more like happy colours than a dark room and black and that. Because like the brighter, it just like puts you in a happier mood if you know what I mean. Because it's like bright colours like cheers you up and stuff. (YP\_18, F, 15y, Multiple MH problems, no MH support)

...and there's a like a few like drawings on the wall and some posters of mental health and things, and things that you can feel good about it. (YP\_28, M, 13y, Anxiety, non-CAMHS MH support)

Like comfortable, like not somewhere where you have to sit up and be professional...The community centre has a bunch of couches and comfortable chairs. And some posters around that calm you down. When you are the GPs you are in a room with a table and a chair and you are sitting there, telling them what's wrong. You are just having to sit up the whole time which feels uncomfortable while you are talking. (YP\_8, F, 17y, Anxiety, no MH support)

The school have wee cosy rooms that were just, they've got chairs and little lamps and pillows and stuff. So they're supposed to be the rooms for people to go and calm down or whatever, so it was like in a, the setting was fine and everything... Oh no! It's [CAMHS] like a wee hospital room. It's just she sits at her desk with her big spinny chair and I'm on another wee chair like away from her and it's just a big white room, it's not cosy or anything. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

...change the music in the waiting room. The music is so annoying, it's the same little chime over and over again. Put on the radio, like BBC Radio One, you know it's not going to have any bad words in it, it's got comedy, it's got music, it's up to date with the times, it's got music from the olden times, it's got everything. (YP\_16, F, 17y, Autism, CAMHS completed)

A number of the young people suggested that stress toys that they could touch in a session, or being able to bring their own comforter, would be helpful.

Like, stress toys, some people get really stressed really easily, the squishy things or like the bubble wrap ones. (YP\_31, M, 15y, Anxiety, discontinued CAMHS)

...or even if they let you bring in a comfort item... it kind of felt almost like an interview so like 'Oh I can't, I can't bring a teddy to an interview, I'll look childish, this will look stupid. I can't do that'.

(YP\_30, F, 15y, Depression, CAMHS re-referral)

She had stressed toys and squishy toys. Like sensory toys and he seemed to take a liking to this one particular toy on the first session, so she made sure that was the toy that was sitting out for him every time he came. (Parent\_5, F, Autism, non-CAMHS support)

Privacy and confidentiality were also associated with the environment. This was particularly linked to support in school and the need for the room the young person attended being somewhere private.

...yeah that was not peaceful at all because there was the people going through the corridors there was, it was just like a room that we have in the school, so there as lots of children walking by and when the bell goes it was loads of pupils and stuff...somewhere quiet where no people are walking by and like anyone could look in and see what's happening. So for some privacy I would say. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

In addition to the physical environment, the people who worked in the physical space that the young people attended were important to making them feel welcome. Indeed, this could offset the negative views about the physical space.

But once you got to know the people who worked there, they were all really nice. The people I spoke to were really friendly and really good, so that made it feel less intimidating. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

I would say it was just a normal GP office. It might be silly, but with it not being my usual practice, it made me a little bit uncomfortable. It sounds a little bit weird but I know my practice, I know the receptionist, it was a little bit weird for me. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

But with person C they were quite professionally dressed. And I feel like in an environment, in a hospital, yeah you look professional, you should, but in a mental health, they should have less of a stricter uniform. They should be able to wear comfier clothes, more day-to-day clothes that you would wear if you were just going out to the shops, something like that. Because you don't want to be in a room where you feel like you're talking to a doctor. You want to feel like you're talking to a friend...and they were all sitting in their fancy suits and skirts and pants and all that jazz and, just, it always felt like we were never, we were never level they were always ten levels above me. Where you should feel level with the person you're talking to. It's like trying to talk to a giant, you can't really do that without having to scream and shout at them to get what you need. You shouldn't have to do that. (YP\_16, F, 17y, Autism, CAMHS completed)

Many of the issues that young people raised in relation to the appearance of physical space were also acknowledged by professionals. For example, the need for rooms to be familiar and welcoming, and have things that young people can connect with in them, like toys and posters. Importantly, professionals highlighted the negative impact that a poor environment can have of the delivery of the therapy, it is more than an issue of aesthetics.

Yeah because if you've got like a big doctor's bench in the corner and there's a big curtain and all these like medical machines in the corner I kind of wonder, yeah, does that put people at ease? Probably not... And also, I know in the psychodynamic model it's important to have the therapeutic frame so you have like the same room with the same layout at the same time each week and that very, very rarely happens in CAMHS. That's because we have all the pressures on room bookings, we have so many people to see that you can't always get the same room at the same time. (Prof 14, M, MH support/treatment provider, Psychologist)

I think for younger children obviously like toys and play stuff like that. But you know obviously in COVID and pre-COVID we weren't really allowed to have a lot of toys and things like that...I think just having pictures and posters and, you know, more comfy chairs, just things like that that make them feel a bit more comfortable. But again, all of these things within the NHS are quite difficult, because everything needs to be wipeable... (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

I think the building I work in would be a really good example of not being good. It's a very old building that we were temporarily meant to be in...So, we're stuck in this old building where, it's had a coat of paint, that's one thing, but there are so many corridors, there are so many doors, it's, it's not necessarily a welcoming, friendly environment. We have put some pictures up, we put some artwork up which helps a bit. We've had to bring in our own, you know very often staff have brought in their own toys and other things from home because we haven't had those in the clinic...It, a number of young people with autism have said to me that just the sheer number of doors, the narrowness of the corridors, the brightness of the lights and the way that the door is bang and they're hard to push open and they, the winding concrete floors and the narrow stairwell, alternatively a lift which makes strange noises. These are everything that goes against a good clinic. (Prof\_15, F, MH support/treatment provider, Psychologist)

I think so we moved two years ago into a brand-new building and the fact we've got like, you know, clean walls and unstained carpets and just like a level of respect for young people.

Whereas before we were in a pretty dingy environment, you know the chairs were, you know, a bit torn and stained and, you know, so you just felt it wasn't a very welcoming environment.

(Prof\_16, F, MH support/treatment provider, Psychologist)

Professionals also noted the importance of the waiting area and the staff who work in there.

Where we were before...it had a welcoming welcome area, our current welcome area is vast and drafty. We had a welcoming waiting area where our CAMHS own admin staff were also the reception, which is how some of the personal aspects would come in. They would know the faces of these young people coming in. So, sometimes I've even got a call saying '[name], so-and-so has come in, they're on the street, they're really upset they're not got an appointment, they're usual worker's not here, but I know that you did a cognitive assessment, and you know them, can you come down and see them'. And I think that makes a difference, we had a separate waiting area for teenagers that we had for little kids, which meant teenagers didn't feel like they were surrounded by kiddie toys, little kids didn't feel scared of big scary teenagers, you know, as they saw them. (Prof\_15, F, MH support/treatment provider, Psychologist)

So, I think, you know, people being welcoming, including the reception staff. I mean just now we have a lot of kids coming into see because they're high-risk, and we've got these awful like cones in front of reception and kind of like police tape, so that nobody stands too close to reception, and it's absolutely horrible, the most unwelcoming thing I can imagine. (Prof\_16, F, MH support/treatment provider, Psychologist)

Young people and professionals felt that having young people contribute to creating a better environment would be beneficial.

Splash a bit of colour on the walls, they could even change the floors or like put paintings on the floor or get some of the patients to do stuff and contribute to it. Because I know if I was given opportunity to decorate or like have a little bit that I've done myself, even that would have a positive impact on my mental health. Because I could have that thing that people are going to see and I'm going to be proud of it, because I've been able to do that. (YP\_16, F, 17y, Autism, CAMHS completed)

So, it's hard to think of what we could do within the context that we're in already. I mean we've tried to do things like make clinic spaces more, more inviting, we've had young peoples' artwork on the walls, we've had projects where we've had sort of creative workshops where young people have been involved in making artwork for the clinic space. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

And another thing is we seem to have lost the way with engaging with the people that we work for, our young people or families. We're not having focus groups, were not involving them in interviews. I know that in in some service that there have been young people on interview panels for in-patient units for example and for staff, and I think that those are all really, really good ideas...But we, we don't ever ask them to come in and help us to look at how bad our building is, for example and what we can do to make think better. (Prof\_15, F, MH support/treatment provider, Psychologist)

## Sub-theme: Relationship with therapist

The relationship the young person shared with professionals offering mental health support/treatment was the most frequently discussed factor that could act as a barrier or facilitator of engagement. Professionals saw the therapeutic relationship as key in the process of engagement and in treatment effectiveness.

Young people choose to come to use our services and the main thing...is because they know us. We speak to them like people, we treat them like people, we know every problem or every issue that they've pretty much got because they open up to us. (Prof\_4, M, Signposter, Youth worker)

I think it is that about building an effective relationship with the young person, because, I mean, the therapeutic relationship is ultimately where the kind of change happens. (Prof\_16, F, MH support/treatment provider, Psychologist)

The stories of young people and parents were very similar in this context. However, young people didn't speak about their parent's relationship with professionals, only their own, whereas parents spoke about the relationship between the professional and their child and the separate relationship they had.

...obviously sometimes you just don't, you don't gel with people. Not everyone gets along, and that's fine, but I was really, really put off, so I never went back. (YP\_9, F, 18y, OCD, discontinued CAMHS)

I think what every counsellor should hear once is, get to know the person and not the mental illness. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

She was just quite blunt and to the point. She wasn't very interested in like hearing about what actually my problems were. It was very much like 'Right here's a workbook. Worksheet. Do the worksheet.' kind of thing and there wasn't much actual just like talking and things. I just didn't really get on with her... I think it genuinely it was just that lack of a therapeutic relationship. And, you know, she just wasn't particularly interested in listening to me. She just wanted me to kind of fit the book, do the six sessions, or however many is they give to you, and then be discharged from the service. (YP\_7, F, 19y, Complex PTSD, CAMHS completed)

At the heart of the therapeutic relationship was a need for it to be built on open channels of communication where the young person felt they had the space to talk rather than be talked at, but also that this was handled in a confidential way.

Having somebody who's approachable and easy to talk to and like rather than somebody who's wants to get down to business, like strictly find out stuff. I would like someone who's patient and will take their time with what you're telling them. (YP\_8, F, 17y, Anxiety, no MH support)

I feel like it was just very, the conversation might be like dry. You know the... I didn't feel like she felt interested in what I was saying or engaged or anything. I feel like she was just like 'Okay I'm here to listen to you and then I have to leave.' kind of thing. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

From day one she basically said to him 'Anything you say to me is a secret between you and me, and if you want me to share that with mum you just let me know and we can invite mum in and we can talk about it'. She said 'But otherwise it's just you and me, and I'm your friend, you're my friend and we will just talk'. And he loved it, he adored her. (Parent\_5, F, Autism, non-CAMHS support)

Trust was key, young people needed to feel that the professional believed what they told them. Young people spoke about the therapeutic relationship as something that took time to build, it required investment, and when it had been established that made it possible to engage with the support/treatment and gain benefit from it.

I think having that level of trust, it would have been a lot easier to open up. Longer session.

Seeing her a few times more like once a week would have been easier to build up that relationship...The trust. I think trust is absolutely everything when you are discussing your mental health. Especially when you are young and maybe a little bit insecure about how you are feeling.

(YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

Although she liked the worker when she first met her, she subsequently felt really let down by her and didn't trust her. And I think that probably played quite a big part in her not wanting to engage. (Parent\_9, F, Anxiety, CAMHS)

Professionals also spoke about a need to take the time to get to know the young person. However, it was acknowledged that this wasn't always promoted because of things like time pressures that are linked to waiting lists.

I try to be very aware of the child's likes, dislikes, their world, their personality, all of that. Just being a little aware, attuned to it. Because each young person is so different and so unique. Just being aware of that and just be mindful of the child. (Prof\_5, F, MH support/treatment provider,

Psychologist)

I think for clinicians to feel that they've got to be seeing people and getting through the cases as quickly as possible they, I think they don't do terribly much building of relationships. Whereas I think if you step back and think, say 'Well do you know what, the main thing here is that I'm a clinician, I don't care what the external pressures are on this, I need to see this young person'.

(Prof\_15, F, MH support/treatment provider, Psychologist)

Trust within the relationship was undermined if the young person felt that the professional wasn't invested in them. For example, if the young person was asked to, as they described it, repeat information across sessions. This was interpreted as the professional having forgotten, having not taken the time to prepare for the session.

The same thing happened during the third session with the notes. I went in and she said 'I've not read your notes again, can you remind me what you said last time'. And, you know that way where you just feel like you're really not being taken seriously, because it was just, I don't know, it just didn't, it wasn't right. (YP\_9, F, 18y, OCD, discontinued CAMHS)

And then when I met her yesterday she was like 'Oh that was my fault, I wasn't paying attention when I made your appointment, and I sent you the wrong link'. So I was like 'Okay'. And yesterday she just repeated, like yesterday she sort of, it was the exact same as the initial appointment, because she said she didn't have my notes from the first one. So she just needed me to repeat everything to her from November, because she had forgotten everything. So I was like, it feels like I'm not getting anywhere, so I don't know what's going to happen. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

The management of early conversations were critical in laying the foundations of the relationship. Young people found discussing their mental health difficult and to do this with someone they didn't know was even more challenging. They wanted to have established at least a preliminary relationship to allow them to open up and engage with the therapeutic process.

...children just feel they don't, you know, they don't want to let their emotions out anymore, sometimes. Even me as well, we like to, kind of, keep our emotions to ourselves, keep our feelings to ourselves keep them compacted. And the minute you go somewhere to let your feelings out it's really scary because, you know you're actually talking about your feelings, it's real, it's reality. And for some children I think that's definitely very scary talking about real problems, the problems that you've avoided for so long. Another thing is just, it's just, sometimes children just don't want to talk to anyone. Sometimes it's actually very hard work to even talk to someone about your feelings, because sometimes your feelings are so mixed up and so confusing that you don't actually know how to describe it. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

...stuff like 'How often do you self-harm, is it not at all?', sometimes suicidal thoughts, 'Have you ever thought about stuff?'. Yeah it was lots of stuff like how often do you feel sad, or how often do you think about suicide and questions like that. And I think going into a session and that's the first thing you see is people asking you those sorts of questions was not very good. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

Young wanted to feel that there was a bi-directional relationship between them and the person they were working with.

I don't think there was a relationship there. I feel like I, I feel like I knew her name and then that was it. I feel like I didn't really know, and I don't think she knew me. She knew what time I had to go and what subject I had after that session, but other than that I don't think there was any bond or relationship with her at all. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

This could be facilitated by the professional offering the young person some insight into them as a person.

She was really good at relating to herself, and like how she had struggled and how she got therapy as well, and like completely normalised it. Because at first I was so, like, I felt embarrassed to be going to see someone and I knew she made me feel completely fine, and like she actually she remembered stuff about me. So I was telling her about my friends and like who helped me with what, and she would remember people's names and she would remember what I had told her the week before and stuff so I always felt cared for and stuff. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

But if you were told that you were going to meet this person for X amount, or so many weeks, it would be nice to get to know them, and even if they shared a bit about them as well so that you just tell everything to them. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

The need for the young person to know about the professional they were working with prior to support/treatment was highlighted as a facilitator of relationship building.

...things maybe like, you are going to see so and so, here's a bit of a biography about so and so, so they understand, you know. So obviously I would have a referral about them, but they don't know anything about me. So there is automatically this shift in power...So, there might need to be a bit of a, here's some generic information about your practitioner, here's what they look like, here's what they're interested in, so you have a sense of this is who I am seeing, I know a bit about them. (Prof\_3, F, MH support/treatment provider, Psychologist)

There was both implicit and explicit reference to the therapeutic relationship being a mechanism of effectiveness in the support/treatment process; the support/treatment was only possible when a positive therapeutic relationship was established and maintained.

Young people reported a number of instances when they felt the therapeutic relationship had broken down as a consequence of the professional or the service. Examples of this included instances where the young person felt left down or even abandoned by the individual professional; if they took a sabbatical, went on parental leave or left the service. In other instances the breakdown was a consequence of actions at service level; for example, when the professional was accompanied by a another person (e.g., trainee or supervisor).

No, and I was like, I've just told this woman my full life story and she's just left me. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

I think she felt really let down by her worker in the service because she's had no input really. I mean, she did believe the worker had been off sick, clearly, but the fact that we were never told anything. There was no communication. If it hadn't been for me, being a pain in the backside and phoning all the time to see what's happened and what's happening. So she felt really let down and ignored, which clearly when you're feeling crap about yourself is not very helpful. (Parent\_9, F, Anxiety, CAMHS)

A similar experience was recounted when the young person moved service. For example, if they had interim support while they were on the waiting list for CAMHS.

...as much as I really want the support and to try and like find coping strategies so that I don't feel the way I feel, I just get anxious, like actually trying to start something new. And I think it was literally just because I had seen my school counsellor for a year and then she disappeared, so I am like so scared to start seeing anyone else. It's like when you're trying to dredge up all the things you've went through so that they can try and work with you, it's like you have to re-live it all again, so I just get sort of, anxious about that. But the CAMHS worker has not even asked for any of that she just, I'm not sure. (YP\_11, F, 17y, Multiple MH problems, attending CAMHS)

These disruptions in the therapeutic relationship impacted on young people's ability to remain engaged. Disruption to engagement occurred because the young person felt that the investment that they had made in the relationship with the professional was lost, especially when they had been working with the professional for a long period of time.

But she also went on a sabbatical over the summer which kind of ended the relationship because she wasn't going to be there. I don't feel like talking to three years of work with a new counsellor. I didn't want to go through it all over again. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

Right so, the second time the relationship was good to begin with, I did trust her...I did trust her enough that I would speak to her, and then another person was brought into the room and I felt quite intimidated. I remember being brought up to the room and being told that there was going to be someone there and that if I wanted to they could be asked to leave. It felt a lot like she didn't want them to leave so I didn't want to cause any trouble as such, so I just, I left it. And I remember I was in such a state, and I just didn't trust them after that...I was very, very scared to go back and that's kind of when obviously my mum saw the state of me when I got home, I was still in a state, and she phoned up and said that I was being discharged. (YP\_9, F, 18y, OCD, discontinued CAMHS)

There was a reticence about having to 'start afresh' with a new professional, often because the young person felt they would have to re-explain themselves to the new professional. This was presented as taking time away from the therapeutic process and additional emotional labour. There was a view that an established relationship facilitated the effectiveness of the support/treatment and a fear that if the young person had to work with a new professional they would need to recount things that they had already shared and that this would take time. The new professional wouldn't have the knowledge of the young person that they needed to provide effective support/treatment; this would take time to re-establish.

I am sure she has notes and stuff and then it's easier for her to remember everything. I don't have to go through everything, I can just say someone's name and she knows who it is. I don't have to give an explanation every time I mention them. Having the same person has been really beneficial for our relationship. Also, to help with the flow of things. So, when I come back and start talking about this people, she knows what happened and how I felt about stuff. So, we can talk about the present, the here and now. We don't have to do too much stuff about the past.

(YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

Parents supported the view that having too many professionals was problematic and, as well as supporting what the young people had said, they described this in the context of their child's need for consistency and routine.

Because [son] doesn't deal well with people coming in and out of his life. He's had too many people coming in and out of his life. His life revolves around structure, dependability and I can't keep having 50 billion counsellors re-telling stories a million times. (Parent\_5, F, Autism, non-CAMHS support)

Professionals shared the view of young people that transfer from one professional to another was a critical point that had to be managed well, otherwise it had the potential to fracture the relationship between the young person, the professional and the service.

And if we're transferring our young person from one to someone else, you know, if there's a member of staff leaving, in the past we very much used to have a hand-over session, or more you know, where we would introduce them and we would dovetail the starts and ends of therapy. That just doesn't happen now, a member of staff finishes on their day, to other members of the team are going in the next couple of weeks and their young people that they leave will go onto an internal, back onto an internal waiting list. You know so not only do they not have a chance to meet someone before the person goes and develop a relationship, they just go straight back onto a waiting list. Because there's no people available to take them over. So, we've lost, it seems really strange, it seems since we developed systems that were meant to make things better, since we became part of the CAPA system, and systems came about to make things better, I actually think it's made so many important factors worse and the important factors are around the more personal factors of the care of the families and children. (Prof\_15, F, MH support/treatment provider, Psychologist)

Some young people did report a positive transition between professionals and that was facilitated by a process of explanation, so the young person understood the reason for the change.

...and then when I heard that she was pregnant and that I was getting swapped over to someone new, that was, I was quite scared about that. I didn't know if I shall continue going because it was a new person. I didn't want to learn again how to trust someone all over again. But it turned out to be ok. I was just scared about it at first that it was a new person who knew everything about me but I didn't know anything about them... I think she told me like two weeks in advance. It was a bit of a shock, but then I had a little bit of time to explain about the person I was getting.

(YP 2, F, 16y, Multiple MH problems, CAMHS completed)

The nature of the relationship they shared with professionals wasn't the only important element, young people also talked about the characteristics and behaviours of professionals as being important because they promoted or disrupted the building of a positive relationship. The characteristics and behaviours that young people described as facilitating the relationship and thus helping support their engagement included empathy, genuine, friendly, someone who listens, non-judgemental.

She does a great deal of listening to me. That is really helpful. But then she suggests things like maybe I should seek psychiatric help or see if there is anything online, a resource that I could use.

She's been absolutely amazing. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

Smile, even if you've had a really hard day. A smile when you're calling for someone in the waiting room can have a big difference. Like 'okay I want to see you, I want to communicate with you, and I want to help you'. Most of them come in with miserable faces. It's like I understand you may have had a really hard patient ten minutes before me. But it's my time and you're taking that away. (YP\_16, F, 17y, Autism, CAMHS completed)

She didn't judge you for anything, if that makes sense, you know, some, no counsellor actually ever does judge you. But you know the way she was listening to me and the way she was sitting there, you know she actually wanted to listen to me, you know, it wasn't just her job, she did it because she actually cared if that makes sense. And every other counsellor I've been to, they were only there because of their job, they were only there because they were getting paid...So, I think the one thing different about her was that she genuinely wanted to help me, if that makes sense. And I felt that I opened up to her, you know, I was able to say whatever I was feeling, I didn't ever feel the need to hide anything. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

... I mean she was a very warm, you know, and easy to chat to person...and [child] did right from the beginning. I can remember the day of the first assessment when [child] saw her first on his own, I could hear chat, chat, chat. Now [child] will either close down and not speak or will talk nineteen-to-the-dozen, and it was definitely the latter. So, [child], right from the beginning found her comfortable to speak to, and I think that was probably more to do with her personality that anything else. (Parent\_12, F, Multiple MH problems, CAMHS)

Alongside this, there was a distrust of formality, it was viewed as hindering relationship building and consequently the young person's ability or willingness to open up in sessions. Formality was described in different ways that included how professionals dressed, how they presented and how their workspace was arranged.

And it was just, see just having a conversation and not having someone behind a notebook just sitting with their legs crossed and talking to you, it was just, it was more comfortable. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

I feel like they should just like dress like normal. Like not in like full doctors' outfits or hospital stuff, like they should just dress like everyone else. You know what I mean? So, you feel like they're a normal person that you can trust and talk to and it's not someone that's, you know what I mean? I can't quite describe it but...So, you feel like they're just talking to another human being. (YP\_18, F, 15y, Multiple MH problems, no MH support)

...I don't judge people based on style or anything but if people could dress how they want to dress and not have to like wear a uniform to work it just kind of, it would make me feel more at ease because once again I'd see them more friendly and that they're not just doing this because it's their job. (YP\_30, F, 15y, Depression, CAMHS re-referral)

...but I think for me with [professional] he's got a very, a very kind or unassuming but quite firm approach. So, I look back, they went to a meeting at school that I wasn't a party to, but there was this plan made between them and he's obviously made [son] you know sort of join in with it and agree it, because it's signed Mr Smiley and [son]. (Parent 10, F, Asperger's, CAMHS)

She was very, I mean I can normally talk to anybody to be honest, you know, even I found she was very, very closed very... just very, very business-like. You know it's like 'I'm here to do business and then, you know, I'm back out again'. I felt at times it was a little bit as if it was a meeting and you know, if you said anything, I just get the reaction she wasn't actually particularly pleased. (Parent\_13, F, Multiple MH problems, CAMHS)

The need for informality and contextual understanding was also reinforced by professionals.

...there was one [young person] that said to me 'They don't talk like you guys, they don't talk like us, they talk like all posh'. And, and I can understand that's a barrier, to a lot of these young people...a sense of humour, every time you work with people you need to have a sense of humour. I think that if young people can have a joke with you and a giggle, you know, like, you're halfway there, they like that. I think that being friendly, being real, being a real person...spending a wee bit of time, 'What do you like to do? Oh, I like to do that too'... (Prof\_8, F, Signposter, Youth worker)

Humour was also seen as a helpful facilitator and a way of breaking down formality.

...somebody who is kind of non-judgemental, kind of asks the right questions. I think lets, lets the person talk without being sort of too, doesn't sort of asks questions without being, sort of, too invasive, but lets them talk how much they want I suppose. Somebody with a sense of humour is really important for me as well. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

I feel like a good therapist should try and understand you as a person and not just your mental health. Like I think they should get to know you, sort of like a friend sort of way, but not like a friend... open and like friendly. Like I don't want them to be like oh, serious. Like obviously you need to have your serious moments, but I feel like you should almost joke in a sense about it.

(YP\_30, F, 15y, Depression, CAMHS re-referral)

Like young people, professionals acknowledged the role of humour in helping build a positive relationship. Other techniques used included age-appropriate play and a focus on the interests of the young person. These were seen as important in helping to level the power imbalance that exists between professional and young person.

I use a mixture of humour, and I try and use their interests wherever possible. I try and make jokes about myself so they feel there's not, I'm not in a position of power compared to them, so I think that can help. For younger kids I use a lot of play based engagement. So, you know sometimes it might just be that instead of having an assessment session where you're just asking lots of questions, you actually just do a lot of play...So, it's a bit of trial and error, there's no specific question, specific answer to that because it's really tailored to the young person but, but that's part of my job is to be able to do that, so. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

And knowing when... I think there's something about playfulness as well, with young people. I think you, you have to be able to also pick up on their sense of humour and the bits that they're saying that are intended as jokes and then yeah, offering your own humour when that feels appropriate and useful. Because I think yeah, it, I know certainly in the sessions where it's gone wrong for me have been ones where it has been overly serious for too long, and it's felt like a really grim slog for young people...(Prof\_14, M, MH support/treatment provider, Psychologist)

Parent and young people often presented age as a relational barrier and a reason that positive relationships weren't build. Age was associated with formality and lack of contextual understanding, describing professionals as too far removed from their age group to be able to understand their situation.

I feel like the woman that I had she was quite old compared to me so I feel that we couldn't relate on anything on that level. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

...somebody maybe with a common interest or understands where [son]'s at in his life, you know. somebody maybe a wee bit younger. (Parent\_10, F, Asperger's, CAMHS)

I didn't feel I had like kind of a good relationship with her. Then we went to [place] CAMHS the mental health nurse we saw, I don't know she was just, she was, she was younger and I'm not saying, because it shouldn't be about age, but she was definitely younger and just seemed a lot more, definitely seemed a lot more caring and lot more, you know she would listen, she would take your opinion on board, she would listen, you know just definitely the listening thing I think was quite important. (Parent\_13, F, Multiple MH problems, CAMHS)

I think it's its finding common ground finding something they can relate to each other with. If, you know, if it was somebody that had an interest in music...or something like that, that they can kind of, I suppose, kind of talk about aside from everything else that's going on, that would be a big thing for [daughter]...So yeah, it's, she, I think she needs somebody who's you know, not, not too young, but not too old either. Maybe someone that's kind of closer in ages with myself and her mum you know...She just needs someone who's relatable for her. (Parent\_15, M, Anxiety, CAMHS)

While young people almost always referred to the characteristics of the professional, there was less comment on how they contributed to the relationship. When a young person did describe their role in the relationship they acknowledged that they might have made it difficult for the professional, but this was associated with them not having the time to establish a different relationship.

I wouldn't say that I had too much of a relationship with her. I saw her once every two weeks. I think I am quite difficult to build a relationship with. I don't think I helped matters... She was very open with me though and you could tell that she was really trying to kind of reach me a little bit.

But like I said, I only see her once every two weeks for like half an hour. It was mostly just discussing my panic attacks that last two weeks. It was never really an opportunity to actually get to know her or build a relationship. It was basically in, discuss what we have to discuss, out again. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

Professionals recognised the need for open communication, investment in the relationship with that individual young person, trust, and the need for the professional to present relational characteristics and behaviours.

Again, the person-centred approach could only come from actually knowing about the person rather than what their medical case is or what their history is, get to know them... We speak to them like people, we treat them like people, we know every problem or every issue that they've pretty much got because they open up to us. And it's not always about because we can help, it's just because they need to speak to someone. (Prof\_4, M, Signposter, Youth worker)

And I think the genuineness, and the honestly, and being very upfront and warm with people is how you can try and maximise the likeliness they'll come back and see you again. And letting, I think letting young people talk as well, like trying not to dive in so much and just hearing what they have to say is probably very like a really important part...People need to feel heard for them to start to develop a relationship with you. (Prof\_14, M, MH support/treatment provider, Psychologist)

Firstly it's trust. What, the line of work I'm in, the fundamental thing that we get is trust from the young person. (Prof\_4, M, Signposter, Youth worker)

One of the things presented as helping support a positive therapeutic relationship was acknowledging the young person as the expert in their own lives rather than reinforcing the position of the professional as expert. As noted above, having agency in the development of a treatment/support plan was important but this had to be reinforced in how the treatment/support was offered; in the therapeutic sessions and conversations.

I think that one of the most important things is to be heard and to be recognised that you're the expert, not the clinician. Because the clinician's only there to facilitate, it's the young person that's the expert in their own life. They know themselves better than anybody else. So, I think that if the young person is treated like a, like an equal then that's going to help engagement, if they're involved in the decision making process. (Prof\_10, F, MH service provider, Manager)

Because if you can't, if you're not, if somebody is just, not dictating, but if somebody is just making decisions on your behalf based on what you are telling them, why on earth would you engage? Because you're missing your autonomy, so as much as you can come to your sessions and do things, it's just like 'What ownership do I actually have in my own progress, in my own getting better, or my own support for myself?'...You, you know, you're knowledgeable and an expert in you as a person, and I have a bit of knowledge in the models that we could be using together, and we will come together and decide what's the best thing for you at this time...

(Prof\_3, F, MH support/treatment provider, Psychologist)

As an example, and linking back to the issue of communication in the referral process, it was felt that the treatment plan could be too focused on the information that came through during referral, rather than on the needs of the young person.

That's the big thing that I always say to folk, you do things to, you never do them with them. You can only do something to a person for so long before they vote with their feet and say 'I am not coming back'. But see if you do it with them, you shape it with them, you get a better engagement. (Prof\_1, F, MH service provider, Youth worker)

...when we get referrals into the service, we're told what people think the problem is. And I would hope my staff don't do this, but I'm sure there's some if you them meet with a young person and say 'Okay so your problem is X, Y, and Z, this is what I think is going to make the difference'. I know for myself I would be like 'Well you go away and fix it then because you know, I don't think that's what my problems are'. So I think that really thinking with a young person 'Okay so, what do you want to see different?'. You know, and 'What would different look like for you? How would you know that things had changed? How would you know that you feel better?'. So I think really involving them in their own care, and their aspects of it, and their goal making would really help engagement. (Prof\_10, F, MH service provider, Manager)

Indeed, a particular barrier to relationship building are instances where the young person isn't attending mental health support/treatment of their own volition.

I think if a young person is like coerced into coming, yeah it's really the parents who told them they need to, I think it can be harder to, and you have to do a lot more work at the start to build that trust and that relationship. (Prof\_14, M, MH support/treatment provider, Psychologist)

...it's difficult during sessions if you feel a young person's is not engaged, even though they're coming to every appointment. And sometimes I'll speak to them about, you know 'You don't seem like you want to be here', and tell them that they don't have to be there, it's not compulsory. And that's often interesting, they'll often then express that they've been made to come by their social worker, their mum, whoever it is. And when I say, 'Well that's not the case, do you want me to speak to them and tell them that you don't have to come back?' they often then seem to decide then to engage on the basis that it's now their choice to engage, rather than they're being made to engage. (Prof\_15, F, MH support/treatment provider, Psychologist)

And that's difficult because I think parents think 'Oh that's my child, I should just be able to kind of make them'...You know it's not like taking antibiotics for an infected toe, doesn't matter if you believe in antibiotics or not, they will do their action. Psychological work and mental health work, often there has to be an investment from the person that you're working with. (Prof\_16, F, MH support/treatment provider, Psychologist)

Families didn't speak much about choice in relation to professionals, but this was something highlighted as being important by professionals. There was a view that services had to be open to the needs and preferences of the young people that they were working with.

It's, it depends on the family. Or the, the clinicians use of supervision as well. So if you have a young person, depending on the age of the young person and the family, so depending on the interventions that are being offered, if you have say a family unit, just for the ease of it, or a young person that says 'You know I really don't want to work with that person, I would rather work with a male, or I would rather work with a female, or I've just not clicked with that person, I want to work with someone different'. They absolutely have that choice to work with someone different. (Prof\_10, F, MH service provider, Manager)

In addition to discussing what they felt underpinned a positive therapeutic relationship, some professionals spoke about how they assessed whether or not this was in place; whether it was working.

So, I think if a young person is happy to come into a room and talk to you and will, will chat, and will look pleased to see you. Sometimes we give them sets of homework exercises, small bits and pieces to practice, for example practicing the breathing exercises or whatever. If they can come back and they're telling you that the times that they did that, or even just telling you about their life in general, or the fact at they, you know they, at the moment they're coming back and telling us how pleased they are to be back at school. Then then that generally means that we've built up a relationship with them and that gives us a good grounding to be able to engage with them.

(Prof\_15, F, MH support/treatment provider, Psychologist)

This assessment of the therapeutic relationship wasn't something explicitly discussed by all of the professionals, it tended to be implicit in their interviews.

#### Sub-theme: Discharge

Discharge from support/treatment is a critical step in the process, because it is the point at which the young person has to manage their mental health without the support of the professional. This requires ongoing engagement with elements of the support/treatment, which, if not attended to, could result in relapse.

Professionals described a variety of reasons for discharge. The positive scenario was when the young person had completed the support/treatment plan and it was the right time for them to be discharged, this was considered to be a shared decision. The alternatives were when the young person disengaged or stopped attending, or when the family had taken the decision to remove the young person.

So, usually the decision for discharge is a joint decision. Unless, so a young person can decide that they don't want to come along anymore, and a family can decide that they're not going to bring the young person along anymore. It can be an agreed amount of sessions that there are going to get, that probably less so, but it does happen. (Prof\_10, F, MH service provider, Manager)

When young people felt that discharge included the opportunity to return for support, should it be needed, this was viewed as more positive than cases where they felt cut off. This was further helped when the young person had a sense of agency about the process.

She can kind of do an ending but it's not that abrupt like the six-week thing at uni where it was like 'Ok, that's the end of your sessions. Ok bye'. It's an ending that both of us have agreed on.

(YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

No, we, they did tell us that you know, that she would be, kind of they were heading towards it. I have to say that, you know, the mental health nurse we did see, she was quite good at keeping in touch...So no, she did tell us that it would be, kind of, you know, it would be, kind of, gradual and then gave us a date when like the last session was. (Parent\_13, F, Multiple MH problems, CAMHS)

She said oh you're fine, so you don't have to come anymore. And then that kind of upset me because I really did like the sessions. (YP\_5, M, 19y, Anxiety, non-CAMHS MH support)

However, even when discharge was a mutually agreed point in the support/treatment journey, young people still worried about their ability to manage their mental health.

I was a little bit scared because I didn't know if I would manage to cope with it. But, at the same time, I definitely felt like I was ready. I wanted to try, I wanted to see if it was the right thing to do. And it was in the end. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

There were instances when the young person thought they had been discharged because they had received their quota of support/treatment, rather than feeling that they were ready for this.

Well the only reason I didn't see her was because you're sort of restricted to eight. The first time you ever see them it's like a mini assessment to see if you need four or eight weeks, and every time it would always come back eight weeks for me, but once you'd done the eight weeks it's sort of like 'bye bye'. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

Parents described situations where their child had been discharged because of lack of engagement and they found this very frustrating because they felt the disengagement was part of the mental health problem and something that needed to be addressed in the support/treatment plan.

And basically the worker said 'If you don't, I can't see you. You're not allowed to come in face to face. So if you won't engage online, then I am going to discharge you. That's what we've been told to do'. So I said 'No way. Absolutely no way'. (Parent\_9, F, Anxiety, CAMHS)

Other young people discharged themselves because they felt that the support/treatment that they were receiving wasn't helping them.

But I ended it after eight weeks because I didn't feel that it was helping me at all. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

While professionals described the need to make efforts to re-engage a non-attending young person this was a challenge and there had to be a finite end point for discharge so appointments could be released to others on the waiting list. This wasn't an approach that professional felt comfortable with but they acknowledged the need to ensure young people on the waiting list could be seen.

Oh yeah so if someone misses two appointments now without given prior notice we're encouraged to discharge...Something that's been happening recently is there have been case load reviews going on because of, the sort of, strain and tension within the services, and yeah, the need to free up more capacity I suppose. So I think at the moment people are speaking with their line mangers about each individual case on the case load and, and trying to have a bit more of a plan around how many more sessions are we going to offer...Yeah, I think they've been trying to encourage a bit more of, what do they call them, like letting go discussions. (Prof\_14, M, MH support/treatment provider, Psychologist)

But again, I think, we don't want to be forcing people to come, but we've, recently we've lost that balance between that and giving them the choice. Because at the moment, the way the system is, it's simply if you're not engaging you're disengaged, goodbye... It used to be we'd set up a three-month grace period you know. When that used to happen, that was okay. At the moment that can't happen because that person's place has been picked up you know, has been scooped up by someone else and they're sitting in another part of the system waiting for the initial assessment which would be the best part of a year wait. (Prof\_15, F, MH support/treatment provider, Psychologist)

Sometimes discharge was associated with an expectation that the young person would be transferred to a different service. This worked well in some instances but in other instances the young person thought that the referral on was forgotten about.

So yeah, I think she was definitely, but again, discharged but [service] had been put in place. I don't know how I'd have felt if [service] hadn't been put in place. (Parent\_13, F, Multiple MH problems, CAMHS)

Yeah, then obviously I said I was referred for in-person CBT but that never kind of materialised really. So, yes, once, once my kind of weeks finished up, there was no kind of mention to me that anything else through the NHS would have been available really. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

Parents worried about what would happen when their child reached 18 years old, because at that point they should be referred to adult services, and they were concerned that this wouldn't happen, or would happen in a way that did not meet their child's needs.

So I'm anxious, I guess, because she's 18 in August. She'll be kicked out in a number of months.

And if we don't get some headway with some stuff, I don't know where we're going to be.

(Parent\_9, F, Anxiety, CAMHS)

Some young people had an expectation that after they had been discharged someone would be checking in with them to ensure that they were managing. There was disappointment when their expectation wasn't met.

...it was just kind of a case of like 'Ok, off you go, like, that's you now, enjoy'. Yeah, I, I don't remember kind of anyone following up with me about the counselling. I definitely at the time had regular kind of check-ins with my GP about how I was getting on with my medication, but yeah, in terms of the kind of, sort of feedback on, yeah check-ins on how I was doing otherwise then no, not really. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

# Topic 3: Summary

Acknowledging that a young person has a mental health support need is a long process for both the young person and those around them, and often involved the young person reaching a critical point before support was sought. There were two key barriers in relation to this. First, young people and families have a limited understanding about negative mental health symptomology and how that might differentiate from other things such as developmental trajectories. Even when information was sought out it wasn't necessarily accessible. Second, some young people perceived adults who could facilitate support seeking (e.g., GPs) to be a barrier.

Alongside this, stigma about mental health problems was a particularly important barrier to the process of acknowledging a mental health problem exists, that support is needed, and then beginning the process of seeking support. Stigma was described in a number of different ways but the end point for young people was that if they believed others would judge them negatively for reporting mental health problems and this acted as a barrier to them seeking support.

Difficulties identifying mental health symptomology, unresponsive gatekeepers and stigma are recurrent themes in the literature investigating barriers to young people's engagement with MHSS (Gulliver et al., 2010). The consequence is that young people can miss the opportunity for early intervention that might have prevented further decline and a need for more intensive services (e.g., CAMHS). Improving mental health literacy at a population level using psychoeducation has the potential to remove these barriers and facilitate a more responsive approach (Becker et al., 2018).

When the young person, and their family, embarked on the support seeking journey they faced additional barriers. The first of these was in relation to identifying appropriate services. They reported a lack of visibility and a limited availability of services (potentially perceived, potentially real). Key within this was that young people and parents showed a lack of knowledge about non-CAMHS (e.g., third sector) support services; this further highlights the invisibility of many parts of the tiered support system. There was an identified inequalities gap that was driven by the knowledge about MHSS within families. Families where there was a parent with knowledge about MHSS found support seeking easier than those without this knowledge. Linked to this, some families had helpful links with signposting professionals/organisation and other did not, the former facilitated support seeking.

There is very limited research about how young people navigate their way to MHSS, but the negative experiences that the participants in the SMYLE study shared resonate with this. Young people and their parents report limited knowledge about support services and this can cause them to delay making contact or make inappropriate contact (Gulliver et al., 2010). They often make contact with multiple people prior to a final gatekeeper, with some reporting contact with up to 15 people prior to referral (MacDonald et al., 2018). Parents are frequently the facilitator of support seeking and their involvement is associated with shorter delays in a young person's referral (MacDonald et al., 2018), which means that they would be an appropriate target, alongside young people, for information to help guide them.

When MHSS have been identified, referral into the services was a delayed process for many of our young people. They expressed this as gatekeepers delaying the referral. Stakeholders also felt that the referral process could be better facilitated by offering self-referral and encouraging referral by a wider range of professionals than GPs, because others potentially had a better knowledge of the individual young person. Indeed, there is evidence of self-referral resulting in shorter treatment delays (MacDonald et al., 2018).

However, even after referral had been made, young people experienced delays before assessment, and a key facilitator of a positive experience during referral and waiting list was communication from the service with the young person and their family. Lack of communication was more likely to be associated with a negative experience, it impacted on trust and expectations that young people have, and this had the potential to impact on positive engagement when appointments were made available. It also compounded mental health problems.

The expectations that young people and their parents had prior to receiving mental health support were carried into their support/treatment. They had expectations that at initial appointments they would receive a diagnosis, and this would guide the support/treatment they were offered. Receiving an explicit diagnosis, and one that the young person and parents agreed with, was an important facilitator of engagement with the assessment process and subsequent support/treatment. A positive assessment experience has previously been identified as any important facilitator of engagement because it supports positive relationship building (Beckeret al., 2018).

Linked to this need for a shared understanding of diagnoses, young people and parents frequently spoke about the need to feel they had agency in the support/treatment process. This included wanting to have input to the type of support/treatment they were offered. If they disagreed with the diagnosis, accepting and engaging with the resulting support/treatment was challenging. Disengagement with support/treatment was more likely to happen if the young person felt that it was incompatible with them as an individual, or how they assessed their mental health need. Importantly, this issue of incompatibility was potentially promoted by parents when their own expectations of what their child's needs were weren't met. Incompatibility of support/treatment was often perceived to be caused by services having limited options of the support/treatment they could offer rather than the best option. Building a sense of agency could be supported by professionals using positive expectation management practices; including enhancing motivation for the support/treatment, realistic goal setting and promoting positive views in relation to effectiveness and outcomes (Becker et al., 2018). There are also tools available to support the assessment and monitoring of cognitive preparation and motivation for support/treatment (e.g., Patient Motivation Inventory; Nock & Photos, 2006).

The need for clarity to support engagement extended beyond diagnosis and support/treatment options to the need for clarity about the detail of the support/treatment plan offered, including any homework. Young people described better engagement when they understood what support/treatment sessions would involve, and this was supported by parents also having clarity about the plan. Unfortunately, many of the young people in the study reported that this level of clarity was missing from their experience. It is not clear if this had been missed or if it had been described in a way that wasn't fully accessible to the young person, but young people spoke about the need for professionals to promote clarity of understanding through questioning and the translation of new and/or complex language/terminology. Young people didn't always understand the need for them to engage fully with homework, consequently they didn't always prioritise it. This is an important insight because previous research has identified homework as a facilitator of engagement (Becker, et al., 2015). An important facilitator of homework in this study was parental monitoring, and that required the parent having clarity about what was expected and the confidence to support their child in this. Modelling, reinforcement and monitoring are important in supporting young people to engage with support/treatment (Becker et al., 2018) and ensuring parents are confident and competent in this is essential (Lawrence et al., 2021).

The barriers and facilitators of attendance at support/treatment appointments were multiple and they mirror previous accounts in the literature (Gulliver, Griffiths, & Christensen, 2010). Barriers were both perceived and experienced; some young people perceived there were multiple barriers, but they overcame these and attended appointments. However, even when barriers are removed they have an impact on engagement because they increase the negative cognitions associated with seeking support/treatment. The facilitators of attendance were linked to an explicit dialogue and attendance planning between the young person and their family, the service, and other stakeholders such as school staff. This helped overcome logistical and emotional barriers and made attendance possible and positive. This type of attendance promotion can be supported by psychoeducation and a positive assessment and formulation process (Becker et al., 2015; 2018). Bringing MHSS closer to young people, in school and local communities, was important but it also required thinking through emotional barriers to attendance; for example, ensuring there is safe space that allows the young person to transition from appointment to other activities.

The environment that appointments are offered in was important to how young people engaged with support/treatment while they were at appointment. There was agreement across the three stakeholder groups that spaces needed to be welcoming and comfortable, as opposed to clinical and overly busy. The environment of the waiting room, and the staff working there, was just as important to young people as the appointment room; it set the tone of the visit. There was a view that services should be involving young people in the design of space. Other research suggests that the involvement of young people in service design should not be limited to the physical appearance of the service but extend to other fundamental elements (e.g., Collins et al., 2017).

Young people and their families felt the relationship between the young person and the person providing support/treatment was the most important barrier/facilitator of engagement when support/treatment is being offered. Full engagement was only possible when there was a positive therapeutic relationship in place. This involved open communication, trust, feeling listened to, and the professional being invested in the young person. Young people wanted to feel like they knew the professional they were working with. Continuity in who the young person worked with was important, but it was acknowledged that it isn't always possible. Young people told us about times disruptions to the therapeutic relationship were managed well and other times when they were mis-managed; the latter impacted on those young people's engagement.

Discharge support/treatment was highlighted by young people as another important point in their support/treatment engagement journey. Discharge could be viewed as an appropriate next step or, conversely, as happening before the young person was ready for it (e.g., because they had reached their quota of appointments). This was important because it impacted on how young people engaged with their support/treatment learning in the future. Some young people were discharged because they had not engaged with the support/treatment and parents found this difficult to understand because they felt the disengagement was part of the mental health problem that support/treatment should be addressing. Like other points in the support seeking journey, agency in the discharge process was important to how young people experienced it. There is little evidence in the literature about how to better support the discharge process, the young people in SMYLE highlighting its importance provides the impetus for research about this.

# Topic 3: Learning points and recommendations

- There is a need for psychoeducation that facilitates engagement with early interventions. This includes accessible guidance on mental health symptomology to help young people, families and relevant others (e.g., teachers, GPs) identify risk at an early stage, and guidance that encourages early support seeking.
- Services need to ensure that published information about mental health is fully accessible to the target audience. They could, for example, engage consumer/patient panels to co-produce information and suggest suitable publication vehicles.
- Work that is underway in relation to reducing stigma about mental health needs to be continued and used to inform service delivery. For example, changing the narrative about mental health services in school from something negative to something positive could facilitate engagement.
- MHSS should be visible and proactively promote accessibility to young people, families and signposting individuals/organisations. This would further support a 'right support at the right time' approach, facilitating access to the whole system. This should include better online presence and services adopting an outreach approach.

- Services should develop a communication plan to ensure young people are kept informed about their referral and the stage they are at in relation to this. This could be managed through a set of customisable, standard template communications (e.g., SMS or email).
- Referral pathways need to clearly articulate who the gatekeepers are in the process and encourage early referral to appropriate services. This should include encouraging referral through frontline professionals (e.g., teachers and youth workers) and having routes to self-referral.
- Introduce a case management system where each person on the waiting list is allocated a link person within the service who can provide reassurance and signpost to additional or alternative sources of support.
- Ensure the diagnosis, including the process, is discussed explicitly with the young person and their caregivers. A rationale or explanation of the diagnosis also needs to be explicit, and steps need to be taken to ensure the young person understands and accepts this. There needs to be a shared understanding, and this should not be assumed.
- Young people, and their caregivers, need to fully understand why a particular support/treatment plan is in place. This needs to be explained in the context of the young person's understanding of their mental health need. It is important that services value the young person's views in relation to support/treatment planning.
- Introduce written support/treatment plans for families that are explained in a joint session with the professional. This would allow for questioning, and assessment of the young person's, and their family's, understanding of the demands of the plan. It would provide opportunity for professionals to work to build parental confidence to support their child with, for example, homework activities.
- Services need to consider different delivery models that include evening and weekend appointments and the introduction of appointment reminder systems.
- Services should work with young people and their families to support them to develop a proactive
  attendance plan. This might include supporting them to overcome perceived attendance barriers
  (e.g., family priorities, perception of stigma) and/or experienced barriers (e.g., lack of appropriate
  transport). This might need to include attendance planning with, for example, the young person's
  school to ensure wrap around buy-in and support.
- Services should provide safe space where the young person can transition from their support/treatment appointment back to other activities (e.g., school classes). This might include dedicated time at the end of appointments that include casual conversation.
- Working with young people to create welcoming and comfortable environments for appointments. Particularly attention needs to be paid to waiting areas and consulting rooms.
- It would be helpful for service providers to develop videos of the support/treatment setting so young people can familiarise themselves with this prior to attending. This could offset some of the concerns/fears about attending, help prevent non-attendance, and encourage engagement by allowing young people to focus on the session and content of it rather than environmental distractors.
- Mental health support/treatment needs to include explicit time for relationship building. This
  includes ensuring the young person understands the bi-directional nature of the relationship and are
  coached to participate. This could be supported by providing young people with a short
  biography/video introduction of the professional they are working with.

- Introduce assessment of the therapeutic relationship. Ideally this should be done with a third party rather than the professional, so the young person has opportunity to describe elements of the relationship that is not positive for them.
- Any change to the professional they are working with (e.g., leave, absence) needs to be explained to the young person and there should be a planned transition that is discussed with the young person. This would include opportunity for new relationship building.
- Discharge processes need to be clear for young people and their parents. This could be facilitated through an explicit discharge plan that explains why discharge is happening, how additional support/treatment can be sought at the time of discharge or in the future, and clarifies any onward referral. It might also include information on how the young person can continue to use their support/treatment learning in their everyday lives.

# 4.2.2.4 Topic 4: The role of family, peers, and others in facilitating/preventing engagement

A recurring theme across all topics was the role of other people in facilitating or creating barriers to young people's engagement with mental health support/treatment. We do not seek to reiterate this here. Rather in this topic we highlight what young people and parents told us was important in managing relationships within their families and the potential for this to impact engagement with mental health support/treatment.

# Theme: The role of parents / family

It was evident throughout the interviews with young people, parents and professionals that families, especially parents, have an important role to play in supporting young people with their mental health. Not all the young people felt their relationship with their parent, and other close family, facilitated conversations about mental health but, for those who did, parents were presented as instrumental in helping identify formal support/treatment when needed, and in supporting the implementation of the support/treatment plan. Young people spoke about how their relationship with their parent(s) facilitated or prevented discussion about mental health. Parents tended to speak more broadly about the wider family context and the impact of their child's mental health on family relationships and functioning.

Underpinning the support that parents offer young people is the parent-child relationship and there was a recognition that this is both important and fragile when a young person is experiencing mental health problems.

Sometimes, if I am feeling really bad, then it can be quite difficult for them to cope and they kind of tell me to be a bit more positive 'Why are you being so upset? There's nothing wrong'. So sometimes it feels like they don't quite understand. (YP\_1, F, 22y, Anxiety, non-CAMHS MH support)

I struggle to talk to my parents about it because sometimes they just, they don't understand. Like I tell them I'm upset and they're like 'Why?' and I kind of just don't have a reason for it and...and then if I didn't have a reason they're kind of just like 'Oh, are you faking this?' and I'm like 'No, I don't'. That's something I'd never like do, that's like a horrible thing to like fake. (YP\_30, F, 15y, Depression, CAMHS re-referral)

And you know we just made sure that you know, she knows how much she's loved and wanted, and we just want to help her. (Parent\_13, F, Multiple MH problems, CAMHS)

Much like the therapeutic relationship, when young people felt that their parents were supportive and had, at least some, understanding of their condition this provided a supportive environment that facilitated the young person pursuing and engaging with support/treatment.

At first, I didn't really want to because I was a bit scared. But then I had a chat with my mum about it and I really thought it through. Then I realised that if I did have problems with my eating that it was probably better for me if I just went. Even if it wasn't that nice, if I actually went and put myself through it, it would be better off in the end... They were just really supportive throughout the whole thing. I spoke to my mum about it afterwards and she said that she did find it really difficult and that she felt really bad for me because she felt that she could have done more when I was younger so that I don't have to go through it. But I wouldn't have even known that at the time because she managed it really well. She was just really supportive throughout the whole time. (YP\_2, F, 16y, Multiple MH problems, CAMHS completed)

Other young people just didn't feel that they had the relationship with their parents that would facilitate conversations about mental health.

I don't know why, she probably hates me for saying that. But I feel like my mum would be the last person I would want to be like 'This is what I'm feeling', yeah. At that time, she knew that I was going [to counselling] and she knew that I came home afterwards, and she was there to make sure that I was okay. But other than that, it was more like, yeah just kind of leave me alone type...I feel like I just don't have that relationship side of us. I feel like I just couldn't tell her anything. I don't know why. I don't know what it is. (YP\_21, F, 17y, Multiple MH problems, non-CAMHS MH support)

Within the context of mental health, the way that the parent-child relationship was formed was, at least in part, associated with the parent's own experience of mental health. The intergenerational transmission of negative attitudes towards mental health was a barrier to helpful conversations about mental health.

My family were never really supportive to begin with. My dad grew up in quite a strict family. Growing up like 'You're having a bad day. Mental health doesn't exist. You're crying for nothing. It's for attention'. My mum was quite the same way. But then when I turned 18 and started seeking my own help, and when I had my breakdown, they kind of went 'Well, I have got my daughter here crying. She has self-harmed before'. I've got the scars to show them. So, I think that kind of changed their mind... And then my mum, I think she went to the doctor because she...got quite anxious. She still does quite anxious. The GP gave her medication for it and explained what anxiety is...He [father] told me, he opened up to me one day and said 'This is why I don't feel like going out much anymore, because I feel like everyone is looking at me'. And I just went 'You've got anxiety. This is anxiety. This is mental health'. And I think this opened his eyes as well. He is scared and terrified. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

In contrast to this, young people whose parent(s) had their own lived experience of mental health problem felt that they were better prepared to understand and support their situation.

I had a very open communication with my mum who also has a history of mental health issues from about the same age...my mum understands because she's gone through it. Bless my dad, he tries but he doesn't understand. He tries his best to be there. He tries his best to be there when I need to talk to someone. He doesn't always get it. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

It sort of just comes naturally now to speak about it, and my mum did share with me that she had experienced that and battled it on her own... She experienced it and she sought treatment for it. So I sort of thought, right ok if mum has sought treatment and she feels a lot better and her issues are all gone, or gone to a great extent and they are hardly there anymore, hopefully I can maybe seek that. (YP 12, F, 15y, Multiple MH problems, rejected CAMHS)

They [family] were really open about it [support seeking], there was, depression and anxiety basically runs in my family so I think that there is that level of understanding within the whole family. (YP\_20, M, 16y, Multiple MH problems, awaiting CAMHS)

The key support person within a young person's family wasn't always their parent, it could be a grandparent or another close family member. But in essence the importance of the relationship, if they had one, was the same.

...I've never rally spoke to mum and dad about getting help from anywhere, because like I'm not, I am close to them, but I just never really went to them because I'm not, like, that close with them. I went to my gran, and my gran was getting, was getting, has offered to get me the help I needed if I want the help... So, I went to my gran, I'm really close with my gran about everything.

(YP\_18, F, 15y, Multiple MH problems, no MH support)

Young people didn't talk much about the impact that their mental health had on the wider family environment; however, this was something that parents discussed in their interviews. Parents didn't always describe the direct impact on their child's engagement with support/treatment, but implicit in what they said was that managing a child with a mental health problem in a wider family context was complex and required significant time and emotional investment. This in itself has the potential to impact on a parent's ability and willingness to oversee their child's engagement.

A difficult issue for some parents was the way that their child's behaviour impacted on their relationship with the child, and with others in their household.

But also our family unit, with my husband now, [child's] stepdad, who brought her up and obviously loves her very much, we have been at breaking points. Not in terms of divorcing or anything like that but, for example, my husband disengaging from [child] because he just couldn't take the hurt anymore. We were literally bullied for eight years. It's awful living in that atmosphere. At some point you reach your won breaking point because you are a human being. I have missed days of work because I couldn't concentrate. (Parent\_1, F, Multiple MH problems, CAMHS)

And it's, it's really, it can be really strong at home. I mean there are days when we hardly hear anything apart from shouting and grunting from her, and it's, thank god it's, you know, it doesn't happen outside, it's reserved for those closest to her. (Parent\_14, F, Mood, no MH support)

Parents expressed particular concern about the impact on siblings. They worried about having to, in their eyes, split their time between siblings and that someone was always missing out. They were also concerned that they were too lenient with the child who had a mental health problem, treating them differently to their siblings. It impacted on the parent's ability to manage their child's behaviour, even if that was part of supporting their mental health (e.g., encouraging school attendance or regular meals).

So it's had a huge impact on her little sister because I'm just not as available to her. Which has been really, really hard and makes me question how we got here because actually her little sister's very dyslexic... And [sibling] really struggled with that and there was a lot of 'You love her more than me'. There's a lot of '[child] just needs to get up and go to school' and 'You're too soft mum. This is your fault'. A lot of blaming me for the fact that [child] is not well and is not able to do things. (Parent 7, F, Multiple MH problems, CAMHS)

Oh she was angry about something and then refused to come to eat, we said 'No, we're eating all now, this is, you know, food is not an option, sorry can you please come and eat your lunch, now'. She refused and we said 'Right okay, you have two options, you can come and eat with us, or you can sit in your room and think about it, but you're not interacting with us, and you're not doing anything else, because we've asked you to eat and to join us at the table'. I mean at some point we finished and then we kept her sister away from her, and then she felt horrible and felt we weren't treating her like a human being and we weren't considering her feelings, ignoring her. (Parent\_14, F, Mood, no MH support)

There's always things that can come up. You know, there's three children here, they've all got, they've all got their needs and, you know, there's only two of us to go between the three. So yeah, it's kind of difficult, you know. (Parent\_15, M, Anxiety, CAMHS)

Parents felt they had a role as protector, they had to protect the child with a mental health problem but also others within the family, and this extended beyond siblings.

It's distressing. And so that's hard because you're going to feel like you're not being able to be honest. And the level of her suicidality sometimes, I haven't disclosed to my family, particularly because they're not here. They're not here to assist in that way. And actually it would just devastate them, particularly because they can't do anything. It's less about stigma. It's just about trying to support them...So that's, that's really hard. It's a very isolating place to be. (Parent\_9, F, Anxiety, CAMHS)

As noted at various points above, young people and professionals acknowledged the critical role that parents play in supporting the practical side of engagement with mental health support/treatment. This was something that parents themselves acknowledged.

I suppose my job, a parent's an enabler you know, it's my job to enable her to take part in those things, to do those things' and use those things. And the same with the services, it's my job to enable her to access those services and to make the best possible use of them. (Parent\_14, F, Mood, no MH support)

However, there were things in the lives of the parent or the family that could act as barriers to them being able, in their own eyes, to support their child. A breakdown in communication, or differences of opinion, between members of the family who support the young person were perceived as acting in a way that inhibited the parent's capacity to support their child. For example, when the young person's parents were separated.

Also, I am divorced so we are also dealing with her dad and stepmother, so the four of us are trying to sort things out. You have to be on the same page, which we were not until two months ago...it is very difficult to also having to negotiate with your ex about the best approach. These kind of things. When they don't see the same things. Very complicated. (Parent\_1, F, Multiple MH problems, CAMHS)

In contrast, a supportive extended family network who were involved in supporting the young person and the parent was seen to be facilitative.

We've got my parents, we've got my brother and my sister and my niece. I've got three wonderful best friends and their loving partners who all love and support [son] and try to be there for us as much as possible and I know not every child has that... We were told, when we were going to CAMHS, that they only needed to speak to me so she drove us there and drove us home, and she was not amused when I told her what had happened in the meeting. She has encouraged me as much as she can to try and get help. (Parent\_5, F, Autism, non-CAMHS support)

As noted above, parents spoke about lacking competence and confidence to support their child in terms of the mental health support/treatment they were receiving. However, they also spoke about feeling they had reduced capacity to manage other elements of their own lives and other family demands.

...if the parents are not supported to cope with the children's challenging behaviour to do with their mental struggles. If the parents fall apart, what happens in the home? Who is there for them? No one. (Parent\_1, F, Multiple MH problems, CAMHS)

Parents had to manage competing priorities, especially their own employment and time to look after their child. Both emotional time and time associated with ensuring the child's safety and treatment/support plan. Some had the opportunity for flexible working but in other cases they had to reduce their work to look after their child.

[Husband] has actually, my husband has retired expressly to be at home for [child]. So that was a huge change for us in the last couple of years... So, trying to get him [child] to school was really stress, so if [husband] was on an early shift it was down to me to try and get him out, so it was really stressful trying to get to work. So that was horrendous. Every, it was just very, very stressful for both of us. (Parent\_10, F, Asperger's, CAMHS)

My work is really flexible. So, yes, I can do all of that. Had it been her dad, who's not working at the moment, but before he lost his job, he worked in Edinburgh. So that would have been impossible for him and his work. It was not the same flexibility. So, yeah, we're lucky because of our circumstances. (Parent\_9, F, Anxiety, CAMHS)

...can't always guarantee that that time's there because, you know, things can be volatile at home. You know, one of them can get quite physical and aggressive at times, you know, the other one gets very emotional at times, and you're constantly trying to support somebody. And then, obviously, there's other appointments around them as well, and then, just now, trying to finish dissertations and assessments and things, and then I've got my mother that's terminally ill. You know there's always, there's always a lot going on on top of that with the house. And we're talking to, talking to schools all the time, talking to therapists, the nurses the other services that they access, the carer centre, and, you know, so we are busy. But I try to organise my day as much possible to fit, to suit the children, you know, rather than to suit me. (Parent\_15, M, Anxiety, CAMHS)

Professionals were also conscious of the impact that competing priorities have on parents.

So, they don't have the means to practically get them to where they need to be. Maybe they've got lots of children, maybe they've got infants, maybe they've, you know, we've got young people who are young carers in our case load. We've got young people who have got single parent families and there's maybe five, six children in the home. (Prof\_8, F, Signposter, Youth worker)

Yeah sometimes there's a time consideration so parents might be working flat out and just not be able to have the time or the resources to support their children like they'd want to. (Prof\_14, M, MH support/treatment provider, Psychologist)

Many of the parents felt that they needed support to help them manage the complexities that having a child with mental health problems brings to a family. They wished that services such as CAMHS were able to provide this alongside the treatment/support the individual child received. They felt that to support their child they needed to build their resilience and that of their family unit as a way of supporting the child with a mental health support need.

I think sometimes the more you're capable of doing it yourself, the more you're left to do it. That takes its toll. (Parent\_15, M, Anxiety, CAMHS)

So that was the other thing that I was thinking, whether it would be potentially useful to see if there was any support for parents to get. To learn how to deal with the repercussions for you, if it's difficult at home, or if you have constant tension at home. (Parent\_14, F, Mood, no MH support)

You know these are things that, actually that's something that I would have wanted help with CAMHS with and it was never offered. Like how do we, how do I process with my child, how do I support [sibling] through this? (Parent\_7, F, Multiple MH problems, CAMHS)

I think through the whole experience at CAMHS, nobody...has ever, ever said 'How are you? How is the rest of your family? Is it anything we can help with?'. I know the service is not for me, or the rest of the family...yeah, that opportunity to ask. Actually planned, a planned appointment or offer an appointment to the parents. Or 'Here are some things you can access' or 'Here are some services as a parent you might want to go and speak to if you're struggling'...Any kind of parental support. I think it's a massive gap, which seems to be such a no brainer when you think the parents are the ones, or the carers are the ones who are trying to hold it together. And actually, when [daughter] saw a private psychologist who was really good, and I had a couple of calls with her at various points to talk through stuff. And she asked me how I was. I said to her 'You are the first person in the last three years who has asked me that is not friends or family. You are the first person who's asked me how I am'. That just seems just very fundamentally wrong, you know. (Parent 9, F, Anxiety, CAMHS)

However, there was very limited discussion from professionals about the work they did with families to encourage positive and supportive relationships. These were often presented as external to the support/treatment plan.

They might be open to a parent and the parent will say right you know what, let's get this sorted now, let's do whatever needs to be done. There are a lot of parents that will be dismissive, and they'll not take it seriously, and then that can kind of become a problem because the young person feels vulnerable, they feel neglected, they feel isolated, they feel alone. (Prof\_4, M, Signposter, Youth worker)

Not every kid has the opportunity to sit round the dinner table on an evening and chat about their day. I think parents have a role to play but we need to make sure as professionals that we support that young person to help their relationship at home as well, I suppose. (Prof\_6, F, Signposter, Youth worker)

...but I think it's difficult because like sometimes parents want to be really involved, but the child doesn't want that, and that's really difficult thing as a professional to kind of navigate. (Prof\_14, M, MH support/treatment provider, Psychologist)

# Theme: The role of others

Many of the young people spoke about receiving support from their friends and they valued this. However, confiding in peers wasn't something that they always felt comfortable with. There had to be a trusted relationship in place before the young person felt they could confide in peers and, some felt their peers could only really understand if they had their own experience of mental health problems.

I reached out to friends because they also suffered from mental health. But they went through GPs. They didn't get referred to CAMHS either. They were given tablets and whatnot to try self-help materials. I reached out to them to see how they coped. And they gave me a couple of hints because some things work for others but not for myself. (YP\_3, F, 22y, Autism, non-CAMHS MH support)

I've got one really close friend and we are quite similar. She has diagnosed anxiety but because my autism and I think I still have symptoms of anxiety, it sort of overlaps. I feel like we just sort of rant to each other. But with my normal friendship groups in school it's not something I really talk about but within my close friends we sort of speak about it. (YP\_12, F, 15y, Multiple MH problems, rejected CAMHS)

Friends could be a promoter of engagement with mental health support/treatment.

One of my friends was like really eager for me to, so like I was talking to her and that's when I was like, I realised that it's not normal, and then she was like 'Nah'. She said 'We can get you help'. (YP\_8, F, 17y, Anxiety, no MH support)

And I had a very close group of friends. A very small group of close friends and they were all aware. My best friend at the time kind of familiarised themselves with how I would start behaving when I started to get anxious and low moody. He knew what was coming...But I do think had I not had my friends, especially when I was younger, I think I would have taken a lot longer to go forward with going to my GP. (YP\_4, F, 23y, Anxiety, non-CAMHS MH support)

But perhaps the most important role for friends was being an emotional support and providing support for the young person to manage situations that they found challenging. This was particularly important in the context of school.

Yeah, my friend, one of my friends actually she's, like, she's been to CAMHS as well and stuff. And we've both had a really, not similar, but stressful experience with just everything and stuff. So we kind of like have that talk and stuff about, like we can both take each other's advice, what to do, what not to do sort of thing, who we can speak to and stuff. (YP\_31, M, 15y, Anxiety, discontinued CAMHS)

And sometimes you don't really want to talk. In some of my classes my friends aren't with me, so I don't really want to talk in these classes. It's just really stressful to be in a class where you don't really want to do anything. (YP\_8, F, 17y, Anxiety, no MH support)

Some professionals spoke about the importance of peer support for young people and the need for services to promote positive peer relationships in the support process. This was helpful for young people who were receiving mental health support, but it also provided a way into formal support for young people in need.

I think if you can get a group of pals to go together, you've won a watch. Their pals are their biggest support network... But I don't think we use a young person's support group enough. You need to appreciate that sometimes we are not young, and I keep trying to remind some of our staff that. You might need experience, but you don't know what they are living through. If they are talking to their pals and they are telling their pals; build that support around their friend network. (Prof\_1, F, MH service provider, Youth worker)

The other thing is also that if someone who's been through the service and has benefited from it, they obviously bring their friends along. So, they were dropping in. It's always like 'Oh, you can get your lunch here and let your friend know that we can talk'. (Prof\_5, F, MH support/treatment provider, Psychologist)

# Topic 4: Summary

Other people influence how young people engage with mental health support. The primary relationship described in the SMYLE interviews was the one young people held with their parents. Those who felt their parents were willing to discuss mental health, and to support them, described being better equipped to engage with support/treatment. However, parents often struggled to manage multiple and competing relationships within the whole family, not just the child with a mental health problem. This had the potential to impact on how they perceived and experienced their family relationship and their ability to support the child with mental health support needs.

Alongside relational issues, parents had the potential to provide practical support that promoted their child's engagement. Parents described a range of factors (e.g., relationship with partner, employment) that impacted on their ability to support their child, and thus encourage optimal engagement. Managing both the relational and practical issues associated with having a child with mental health problems was described by parents as effortful; however, there was very limited evidence of mental health professionals working with parents to help them manage it.

Outside of the family, friends were an important source of support for young people, but like the parent-child relationship only some relationships facilitated discussion about mental health and engagement with support/treatment plans. Friends tended to be seen as support emotional rather than practical support.

Previous research has demonstrated that relationships such as the parent-child relationship and young people's friendship have an important role to play in mental health and the promotion of positive outcomes (McPherson et al., 2014). How relationships impact on mental health, and how they work to facilitate engagement with MHSS remains open to investigation because there are multiple views on this (Logan & King, 2001). For example, the parent-child relationship is considered causal in both the aetiology of mental health problems and in mental health support engagement. However, the participants in the SMYLE study have offered their own views on this such that positive relationships between young people and their parents and friends engender a sense of support and this is presented as facilitating engagement.

# Topic 4: Learning point and recommendations

- Services should produce parental support packages with the aim of building confidence and
  competence in parents of young people who need mental health support. This should address issues
  such as building stronger/supportive relationships, sibling support, facilitating difficult conversations,
  and supporting a young person in treatment. Support packages could be generic or
  support/treatment specific.
- There needs to be clear signposting of parents to groups that can support them in their parenting role. This could be promoted through other parent testimonials.
- Services should produce support packages that help young people to understand and support peers when they are receiving mental health support/treatment. This might include how to open up conversations, strategies for coping with difficult information, and also how they help find support for their friend and/or themselves. This could be delivered in school curricula.

# 4.2.2.5 Topic 5: Structural factors promoting dis/engagement

In the themes that have been presented in other topics a range of barriers and facilitators that existed at the level of the service and/or the individual mental health professional have been described in the context of the point of the engagement journey. Alongside this, professionals spoke about structural factors that contributed to their ability to promote engagement at any point in the young person's journey. These are themed as barriers/facilitators in how professionals might encourage engagement and service-level constraints. Deprivation is an addition structural factor with the potential to create inequalities in engagement and we sought to draw out participants' understandings of this.

### Theme: Professional factors

Professionals described ways they might monitor the engagement of the young people they work with. This included monitoring attendance, monitoring the young person's engagement with planning their support/treatment, and their engagement in each of the sessions.

I think from a clinical perspective you'd be able to tell a young person is engaged if they were actively involved in their care and really taking part in their care plan. I suppose the, the core part of that would be coming along to appointments as well... I think for me really taking part in the clinical discussion parts, and coming along to the appointments that are offered, and the shared decision making, would be a sign that they're engaged. (Prof\_10, F, MH service provider, Manager)

...you know you can really gauge, as a clinician, if someone's not engaging...So, I think that there's, there's quite a lot of kind of personal markers that I think make it clear if things aren't going the way that you'd want to. And sometimes that can be, sometimes that can be because you need a tweak in therapy, and sometimes, actually, it's just that they don't need you anymore...And other times it's, there's a kind of evasiveness because maybe they're working up telling you something difficult, or they're not feeling that things are working in the way that they would want to and you need to have a conversation about that, so I would always lean into that conversation. (Prof 9, F, MH support/treatment provider/signposter, Psychologist)

While this monitoring was often based on professional judgement, professionals also felt that data had a role to play. Data would include attendance data but be more than this, there was a recognised need for data that was about the impact of the support/treatment being offered on the mental health outcomes of young people.

So, the actual stripping it way back from what I see as the real engagement of people really taking part in their care planning, to the nuts and bolts of who's attending appointments and who's not attended appointment, would be down to data and the outcome measures, and noticing baselines, improvements, not improvements. Feels like we're missing a trick there actually, as I'm talking about it out loud. (Prof\_10, F, MH service provider, Manager)

The extent to which the young person engaged with their support/treatment plan was considered important and one facilitated through the therapeutic relationship. However, there was an acknowledged lack of training that focused specifically on engagement. While it might be embedded in training offered to professionals, it isn't necessarily addressed sufficiently.

There is training, is it all, is it about, that in particular, I don't think it is, but I think it's probably encompassed, but it's an interesting point. Whether something solely on engagement would be, probably the next step. I think maybe looking at our families that are coming along to appointments it might be worthwhile probably having a look at their engagements and what our staff are actually doing. So yeah. (Prof\_10, F, MH service provider, Manager)

I think it [training in engagement] would be part and parcel of basic clinical psychologist, clinical training. But I, I can't speak for other professionals and all I can say is I can't think of any ongoing post-qualification training available. But it would be you know, something that you would pick up regularly in supervision. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

Where professionals found the disengagement of a young person challenging it was important that they could speak with colleagues about this, primarily to help identify strategies to re-engage the young person.

We also have team supervision, so we can bring cases to the team and discuss them. So, if it was someone that I thought engagement was an issue for I would always probably bring them to the team. Because I think sometimes there's things that you haven't thought about to try and hook them in, or you know especially if it's someone you think, 'Oh they could really benefit from the work'. I think it's really helpful to get your team on board to think if there's anything else. But you know sometimes they say, you know, 'Look, [professional], you've done all the things that you could possibly have done, I thank actually you've given it your best shot and they're trying to tell you that they don't want to come, but they're maybe too shy to tell you, to tell you that', and I think that does happen. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

I think for me, I would be thinking about it in my reflections on each of the cases I'm working with, I'd be talking about that in supervision and saying like 'This person feels like this, they've engaged really well and we're doing all this exciting stuff. This person I'm finding it more difficult to engage'. So, I would tell my supervisor... (Prof\_14, M, MH support/treatment provider, Psychologist)

Professionals described re-engagement as a difficult task that required multiple contact points, as opposed to a single event. However, they had to balance attempts to re-engage people with their right to remove themselves from the support/treatment.

I guess, you know, really just try and keep in touch, you know, 'We're here for you, we'd like to see you again', you know, and sometimes that might be, you know, 'You can come in again in a weeks' time, that will give you a weeks' time to think about, you know whether or not you want to continue working with me', you know, it might give people break. And it difficult because we want to sort of listen to young people and if they don't want to come anymore, then ultimately that is their decision...So that is quite tricky, to kind of get the balance right where you're trying, you know, because a lot of people don't want to be intrusive but if somebody doesn't turn up for an appointment, you know do you phone them to say 'Where are you?' Do you write to them, you know what do you do, do you organise another appointment? And it's that very much that's where we'd say it's dependent on the situation. Because there'd be some people who...had very good attendance and I phoned them and it turns out you know they kind of completely forgot, by mistake. And there are other people who have not come and I'm thinking 'Well, I'm not really sure that they want to come', and it feels intrusive to phone up. (Prof\_16, F, MH support/treatment provider, Psychologist)

For example, one particular strategy a few professionals spoke about was writing to the young person who is disengaged to try to re-engage them.

...so if I can't get through to a young person I will always try to write them a letter to say like "This is where we've gotten to, this is how I felt it was going, this is what we were working on. I'd be still really keen to keep doing that work or to hear from you about how we can do that differently, so can you give me a call and then we can put that through"...it doesn't always work...I'll never know for sure what went wrong with that particular piece of treatment. Or maybe it went really well and they just didn't need anymore. But yeah, so yeah, I think talking to young people being open to the idea that you've made some mistakes and how you can avoid those mistakes or fix it for them, and if you can't get through to them then I think sending a personalised letter to yeah, encourage a conversation, or let them know that that's an option.

(Prof\_14, M, MH support/treatment provider, Psychologist)

# Theme: Service-level constraints on engagement

In their interviews, professionals also highlighted a number of issues that they felt impacted on their working environment and, consequently, had the potential to impact on how they supported young people's engagement. A key issue was the limited capacity that professionals have to think about the delivery of the service. This limited capacity for service improvement means that services and individual professionals don't have time to work through ways in they could affect better engagement of the young people who use their service.

I think that sometimes clinicians are caught up in that, that hamster wheel in that they just feel the pressure rather than thinking 'Okay I can step off that wheel to see how else can we best support the people that are engaging with our service'. (Prof\_10, F, MH service provider, Manager)

One bit of work that I've been doing over the last couple of years is thinking about care bundles about how people get allocated and how we provide a system of stepped and matched care that's appropriate to the child or young person and is easily communicated to them and to their families. But that's not all together in place yet and, again we, you know, when waiting list pressures pile up then these things, we turn into more of a crisis management mode and we just see people as and when we can. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

And in reality, most people feel that they don't have the time to devise innovations either. Or to write up things that they're doing to help inform future therapy. (Prof\_15, F, MH support/treatment provider, Psychologist)

However, professionals also noted that they found change that is imposed on staff, rather than them being co-creators of it, had the potential to cause stress in the workforce. So, where change is being made it is important that professionals are part of the decision making.

I would like us to have a stable set of managers, for once...over the course for the past ten years, I think our teams had seven different service managers...every time a service manager comes in, with one exception...instead of stopping and watching for a bit to see what's working and what's not working, and asking the staff what's working, what's not working, they come in with a grand plan. They seem to think 'Whoever's been in my job beforehand has got it wrong, I need to change everything', and everything changes. And so, as clinicians were left trying to do our job while trying to deal with all these changes when nobody has actually asked us what might work...

We're very pleased to see that our service managers are asking us, as senior clinicians in particular, as to how we can helpfully deploy that resource rather than simply making that decision for us which was happening before. (Prof\_15, F, MH support/treatment provider, Psychologist)

A key issue impacting on capacity for creative thinking was the emotional labour that professionals have in their work with young people with a mental health problem. Without time and opportunity to deal with this, capacity for creativity and innovation is limited.

...you know that feeling of standing with somebody ready to jump, or feel they have no value in life. Somebody needs to capture it and put it into manuals because it's not the best feeling in the world. And the bit I struggle with is how that impacts on the workers that I've got. They've got to take themselves out it, pass it on, and maybe go back into a service. I say to them 'Go home. Make yourself a cup of tea. We'll phone you later. How do you feel? Do you want to speak?'

That's massive. (Prof\_1, F, MH service provider, Youth worker)

...I think it's really important for our profession to be able to have some psychological space ourselves, to be able to process things and to not have our own reminders of things because we are only human. And we're very good at containing other people's emotions, but that doesn't mean that we don't have our own. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

You know I suppose, people taking account of that fact that we do really, you know, we do really difficult work, we very rarely see anybody who's having an okay time, we're all day, every day we're dealing with people feeling down, feeling suicidal, feeling anxious, and you know that can take its toll on staff. (Prof\_16, F, MH support/treatment provider, Psychologist)

An important sign of difficulties in managing capacity are waiting lists and these were a reality for many of the professionals in the study. Professionals highlight two ways in which service delivery could be reconfigured to alleviate some of the capacity issues. First, it was felt that better use could be made of group-based therapies, which increase the number of young people who can be seen at any point in time.

...you know for certain presentations that we see a lot of, maybe being able to offer more groups so, you know, that they could initially start off with the group, see how they got on, and then if they needed more one-to-one support then they could come and have more kind of one-to-one therapeutic support. I think that might be helpful for some young people. We do have some groups but they are quite limited. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

Second, and linked to barriers/facilitators above (see <u>Section 4.2.2.3</u>), improved inter-agency communication with clear referral pathways was thought to be critical for alleviating burden on some services but in a way that ensured young people were being referred to appropriate service for their mental health need.

We work quite closely with the CAMHS service in our area and the guy that's the head of the CAMHS service in our area is a big advocate of youth work. He's done loads of training with loads of different teams across [east of Scotland] and I really get on board with that as a whole service approach...The joined up approach is the way that we need to be doing things. I'm a big advocator of that. I'm a big advocator of as much as we can an open dialogue about the young people that we work with and how we support them and making sure that it's the right fit for that young person. Yeah, and being part of that conversation for us very much in the youth work sector, is having that seat around the table. (Prof\_6, F, Signposter, Youth worker)

So, it's about having that discussion as a community, you know CAMHS doesn't have the magic wand or the fairy dust that's going to fix everything, it's about, as a whole system can we work together to support everybody...that link with other agencies is really important, because I think at the beginning of the pandemic, people went back into their silo. People went back into their own way of working...So, they're focused very much on our own services and how we were going to manage our own caseloads that we forgot to look outwards to say actually, how we're continuing to network with everybody else around about us? And that network with different services and families is actually, the engagement part is the really important part of it all.

(Prof\_10, F, MH service provider, Manager)

There's often quite lot of different agencies trying to decide who should be the right agency to work with the young person because of the complexities, where it would be my view that we need to be working coherently together to be able to work out who, which agency should be taking the lead at any one time and which agency's referral need to be involved. (Prof\_15, F, MH support/treatment provider, Psychologist)

Changing the narrative from mental ill-health to positive mental health was seen as another way of facilitating better understanding of what services can offer help and support.

...there has been a lot of emphasis maintaining mental health, but I wonder if that has been entirely helpful. Whether it should have been, the sort of message from the government and from other sources, quarters, should have been more about building resilience and not having that, so the kind of, emphasis on mental health. I think the terminology has been important. So people, I think more generally see themselves as having, or they label themselves as having mental health problems and so they, they see CAMHS as, as the resource to go to. Whereas really the, there isn't the understanding that CAMHS is, is there for moderate to severe mental health difficulties. So I don't think people understand the level of our thresholds. (Prof\_17, F, MH service provider & support/treatment provider, Manager)

Morale was something that many of the professionals spoke about. While for some this existed as internal to the service they worked in for others, CAMHS workers in particular, it was an external pressure that they felt as individuals, and which impacted on how they might work with others.

In terms of the organisation, it was kind of difficult to do that [be flexible in therapeutic approach] because again the manager was very micromanaging...Other managers in other kind of places were a bit more say, flexible. (Prof 3, F, MH support/treatment provider, Psychologist)

And actually CAMHS get scapegoated for everything but actually, it's only because we're the service that's still standing and all the other services don't exist...You know I think we do an exceptionally good job, that we do a very, very good job, but we, you know, all these reports that come out are just, yeah, they don't, they don't actually represent what's going on, and I think that's really sad. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

...that feels quite demoralising I think, because we're all kind of in a system where we're trying to work very, very hard to meet the needs of the young people and feeling like we're not doing that with these really long waiting times, and that there does feel like there's this, I don't know, it's become a very difficult situation... (Prof\_14, M, MH support/treatment provider, Psychologist)

The need for services and professionals to be mindful of the context of young people's lives was raised a barrier/facilitator in therapeutic relationship building and bring young people on board to help design a better service delivery environment was considered important. This is further extended as a generic barrier/facilitator in that some professionals felt that services and individuals working in services needed to be better educated in how to communicate with young people.

... I'm kind of not really afraid to get alongside the language that young people use...you know I'm quite happy to, kind of, yeah, reciprocate their language. You know if they've used it then obviously paraphrasing, I think is just so important... whilst I think a lot of adults sort of say, "well I was an adolescent one day, you know a few years ago, and I know how it feels" and actually we have no idea how it is for these adolescents...it's a totally different life that they experience from when I was an adolescence. So, I find it really unhelpful to say that, you know, 'I know how it is'. I know how some of it is, but I don't know how it is to have social media and all of that stuff, I didn't have that when I was younger. (Prof\_9, F, MH support/treatment provider/signposter, Psychologist)

For example, one professional noted the benefit of young people being part of training of staff.

This particular young person, I had got them to develop a training package with me about working with LGBT and transgender young people, and we went and delivered it to [employability service] people to open up the language that people are using when you are working with LGBT or transgender young people that could increase people's knowledge. It was a really, really good exercise actually...That was some of the barriers that they'd experienced in working with different services so it was quite interesting. (Prof\_6, F, Signposter, Youth worker)

# Theme: The role of deprivation

In the analysis particular attention was paid to the identification of issues that help understanding in relation to factors that might widen the inequalities gap in relation to the dis/engagement of young people. It is important to note that very few participants raised deprivation as a barrier to engagement; however, when prompted some examples were offered. Deprivation was described as impacting the living conditions of individual families, on how communities are experienced by those who live in them, and the availability and delivery of services within them.

There was a view that mental health could be compounded by living conditions and that this wasn't always addressed in the services available in places of need.

See your big areas like Denniston, that's all big posh flats and all that stuff...my main outlook was supporting communities that needed us, because that is the point of charities and support, to support communities that are struggling and people that are struggling, and try and give them a bit of support and help them, and that's what I went for, I went, I want to go to Haghill, I want to go to these areas. (YP 5, M, 19y, Anxiety, non-CAMHS MH support)

Especially in the poorer areas where people are affected, or their mental health can be affected, not just by, you know, things like depression, or schizophrenia, or whatever else. But also, by their, you know, how they live their lives. Living in poverty, or in poor housing, overcrowding, all of these things affect people. It all affects mental health and people don't see that. Authorities and services don't see that either... all these things lead to worse situations, worse outcomes and the need for more services to be put in. (Parent 15, M, Anxiety, CAMHS)

Young people's experiences of living in areas of deprivation were described in the context of personal safety and the impact this had on issues fundamental to mental health. For example, feeling safe being outside, whether that be for recreational purposes or to get themselves to mental health appointments.

I've, like I live in Glasgow in like a rough kind of area...Like I'm always constantly asking my pal 'Do you want to go out with me?' because I can't go out myself. Like trying to get my mum and dad to come with me down to [supermarket] is, even though [supermarket] is across the road from me, I just can't go anywhere myself. (YP\_26, F, 14y, Anxiety, CAMHS re-referral)

Deprivation was presented as affecting access to, and engagement with, mental health support both directly and indirectly. While access to CAMHS and third sector organisations is free at the point of access, families acknowledged that the accessibility of other non-NHS support options was limited by cost. Private counselling in particular was only available to those young people who could afford it, and the number of sessions that could be attended was driven by affordability rather than mental health need. As private services were often used to help young people while they were waiting on NHS services, this means that young people who cannot afford private services may be without support when they are on the waiting list.

...I had to kind of seek out counselling that was — what's the word? — as close to free as possible.

I just didn't have the money for counselling through privately which is quite expensive obviously...I think kind of, long term, the issue of paying for it really was enough to sort of, put me off. Which is a shame, because if it had been, you know, a bit less expensive or free then I definitely, I would have kept going. (YP\_6, F, 25y, Multiple MH problems, non-CAMHS MH support)

We don't seem to be able to find anything that fits that bill without it costing an arm and a leg. We found [name of private] clinic in Glasgow but they were wanting £55 a session and I just don't have £55. It's just not realistic at all. (Parent\_5, F, Autism, non-CAMHS support)

...none of the young people, definitely, that I work with can afford to go and see a private counsellor, because it's ridiculously expensive. The young people don't have access to that kind of money, a lot of parents don't. (Prof\_4, M, Signposter, Youth worker)

Money indirectly impacts on access and engagement through things like access to transport to appointments, telephone credit to contact services in crisis moments.

...and travel again. Midlothian, depending on where they've got to go, if they've not got the money to get the bus, and that's the reality for a lot of our young people and families is that they are living in extreme poverty that getting a bus...(Prof\_8, F, Signposter, Youth worker)

I think in terms of accessing our services, deprivation is an issue. Even though a bus, you know, it might not cost much to get a bus for somebody, the timing of their appointment, if it's the day before their pay check comes through, that can make a really big difference. (Prof\_15, F, MH support/treatment provider, Psychologist)

For me I think that where inequalities that come in, I think the ones that are in the service and are being seen, I don't think that there are the gaps. However, I think that whilst families are waiting to be seen, that there can be discrepancies in...if families feel able to phone to tell you that there's been a deterioration, then that would be managed quicker, but if families don't feel able, or don't have credit in their phone or, you know, if there's a real poverty issue then I think that they are disadvantaged because they're not able to communicate that there's been a deterioration. (Prof\_10, F, MH service provider, Manager)

Deprivation was also associated with more complexity in families, and this was viewed has acting as a barrier to engagement with mental health support because complexity can obscure need, and families and individuals often have to prioritise where their energy is directed.

Joe Blogs is sitting in his bedroom crying because he can't, he's not coping but because it's masked by, you know, the chaos potentially around them. It's a lot clearer cut when they come from a nice settled home and that young person's not coping, oh god, that's much more, you're much more aware of that and you can see it much more visibly, whereas when there's so much else going on in young people's lives it can be missed when there's, when there's other traumas and there's other issues that are facing them on a daily basis. (Prof\_8, F, Signposter, Youth worker)

Young people and professionals also presented the case for a cultural deprivation that is sustained by cultural norms. For example, ethnicity and religion were identified as impacting on the willingness and ability of families to engage with mental health support. This manifested in families not acknowledging or providing a safe space for young people to discuss their mental health

I'm Asian, I'm in a brown culture, if that makes sense, that's quite a big thing. So, what that really means is that parents, they don't really believe in mental health as in children, as in that children don't really go through anything to, they don't really need the help, which is, which is why I've always got the support from school, I've never you know asked mum and dad for counselling or asked my mum and dad for any help. (YP\_27, F, 14y, Multiple MH problems, non-CAMHS MH support)

YP: Because in my family is well, my mum is really religious so I know that if I said I was having mental health problems, she just told me to pray more. Interviewer: So you wouldn't feel comfortable telling her about it at all? YP: Not really, no. Interviewer: Do you have someone that you could talk about your mental health? YP: Not in the house, no. (YP\_8, F, 17y, Anxiety, no MH support)

There's this cultural belief that if someone is suffering with mental health, or is battling mental health, then they are weak in their society, and it's exclusion, it's expulsion, it would bring shame onto their family, it would bring shame to their area where they grew up. So yeah, it's one thing as a language, but secondly it's the cultural beliefs and the cultural recognition of what the effects are, whether that be mental health...the cultural acceptance, you know. If a young person comes out and says to their parents 'I am depressed', again it sounds archaic, but it could be a case of 'Oh well, you're bringing shame onto our family because you're suffering with depression'... (Prof\_4, M, Signposter, Youth worker)

Professionals also spoke about cultural barriers to engagement that exist in families linked to their religious beliefs.

...the mother removed the child from the service because she wanted her daughter to go to more of a Christian counselling service rather than within school. So obviously that was her choice, however, that student did come back and have a conversation with me, she wasn't particularly happy about it, and she was actually quite upset. (Prof\_3, F, MH support/treatment provider, Psychologist)

# Topic 5: Summary

In the interviews participants described a number of structural factors that impact on how professionals and services might work to promote engagement in young people. The starting point for this was being able to monitor engagement in an explicit and systematic way, using data and clinical evaluation, which wasn't always done. Monitoring in MHSS is most often done in relation to attendance and outcomes and assessment of both is not always considered a positive by professionals (Norman et al., 2014). Support for monitoring from the professionals in the SMYLE study may reflect a different attitude in relation to this, or perhaps a view that could change if more systematic monitoring was introduced. Given what professionals said about imposed decision making, the implementation of systematic engagement monitoring would need to be co-created with them.

Alongside data-driven engagement monitoring, there was a view that management of engagement and disengagement needed to be more explicit in training that professionals received, and form part of regularly clinical reviews with colleagues where good practice can be shared. This need for training when new monitoring systems are implemented in MHSS for young person has previously been highlighted as both essential and welcomed by professionals (Hall et al., 2014). It is important to reflect, however, that there is very little research about the use and acceptability of engagement monitoring in services that sit outside the NHS. Monitoring is resource intensive and has most meaning is if it is used consistently with appropriate information sharing; thus, the potential for it to be introduced across all parts of the mental health support system for young people is highly aspirational.

Professionals described a number of constraints they felt impacted in their ability, or that of the service, to facilitate better engagement in young people. A key issue was a lack of creative capacity of services staff to develop engagement strategies and interventions, or change the way services were delivered, to affect better engagement. There were also a range of external pressures. Professionals highlighted the need to promote better inter-agency working and understanding of the remit of MHSS to ensure better referral pathways and address some of the negative perceptions about MHSS. Doing so helps with better signposting to appropriate services and enables clearer onward or sideways referral, with the potential to impact public expectations and the moral of service staff (e.g., Cortina et al., 2019).

Deprivation was highlighted as an additional structural barrier to engagement. There were two types of deprivation acknowledged; economic and cultural deprivation. Economic deprivation was presented as having the ability to contribute to mental health problems but also in how people seek support; for example, preventing attendance because of safety fears or limited access to transport. Alongside this were cases where young people were prevented from engaging with MHSS because of beliefs about mental health that are perpetuated within communities (e.g., religious communities). MHSS were presented as lacking sensitivity to the impact of these types of deprivation and thus creating an inequalities gap. This has the potential to be managed through the involvement of young people and their families in future service improvement activities to ensure that services are appropriately formulated to maximise engagement of their stakeholders. This study and others highlights the willingness of stakeholders to participate in this and the value of hearing their views (Idrees et al., 2021).

# Topic 5: Learning points and recommendations

- Services should embed the collection and review of data about engagement and use this to support engagement interventions with young people. This could be done using a validated engagement assessment tool and one that links engagement needs to engagement strategies and interventions.
- Professionals would benefit from training focused on engagement strategies and from ongoing peer support in the sharing of good practice in engagement and re-engagement.
- There is a need to involve staff in the development and implementation of innovative engagement strategies and interventions.
- There is a need to develop better inter-agency working and have clearly defined referral pathways with a matrix of tier support services.
- Services would benefit from better promotion of service remit and positive outcome stories. This has the potential to improve staff moral as well as public perception.
- Engage young people and families in service design and service improvement. This would be
  particularly important in ensuring the sensitivity of service to the needs of individuals from particular
  communities (e.g., neighbourhood and cultural communities).

# 5 Conclusions

To the best of our knowledge this study is one of the first to give full consideration to the barriers and facilitators of young people's engagement with MHSS in Scotland, and in the context of the COVID-19 pandemic. The results have been presented under five topics of investigation:

- 1. Young people's knowledge, understandings and experiences of mental health and mental health support seeking in the context of COVID-19
- 2. Perceptions, beliefs and expectations about MHSS and support/treatment
- 3. The engagement journey
- 4. The role of family, peers, and others in facilitating/preventing engagement
- 5. Structural factors promoting dis/engagement

This approach to the analysis and presentation of the findings was to allow for consideration of barriers and facilitators to engagement within MHSS (MHSS) across the full spectrum of engagement. It enables the reader to focus on the point in the engagement journey of concern to them, read the detail of the results, the summary of findings and the learning points and recommendations.

A key strength of the SMYLE study was its focus on stakeholder engagement and involvement in both the development of the study, and then in involving stakeholders to generate data to inform service improvement. Young people, their parents and the professionals who work with them have important views on how services could be improved, and they have been able to suggest better ways for services to operate. Working with these groups to improve service delivery rather than imposing this without consultation is a key recommendation from the SMYLE study. A key limitation of the SMYLE study was in the recruitment of participants. This was challenging and likely affected by the COVID-19 pandemic resulting in the temporary closure of agencies that would have been able to support recruitment. Mirroring much of the research in the field, the participants were a self-selecting group who had, in the main, had negative experiences of mental health support provision. However, this provided us with a rich data set that highlighted areas for improvement rather than reinforcing existing norms of practice.

Linked to this, we acknowledge that some of the recommendations that we have made should already be part of service delivery practices and procedures, but importantly the young people and parents in the SMYLE study continue to raise them as barriers to engagement. Services will need to review the implementation of their own practices and procedures and consider whether there are different ways of working/delivery that can better promote engagement.

In summary, we found that young people and parents tended to focus on the negative elements of their engagement journey in the stories they told about this. However, this highlighting of barriers was helpful because knowing what these are will allow services to work to reduce or eliminate them. Across all the topics, we found that communication and relationships were critical in the engagement journey. Services were highlighted as having poor communication with the groups that they serve, and poor communication with each other. This poor communication meant that the mental health support system was difficult for young people and parents to navigate, and it prevented them from making use of the full range of services and from accessing early intervention. It prevented effective multi-agency working, and this impacted on how professionals and services worked together. When young people had contact with services, good and regularly communication about their referral and then their support/treatment plan promoted a positive experience and better engagement.

# 6 References

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# 7 Appendices

# 7.1 Appendix 1: SMYLE Steering Group

Julie Metcalfe (Chair) NHS Greater Glasgow and Clyde

James Egan replaced by Lynn Naven Glasgow Centre for Population Health

Barry Syme Glasgow City Council

Alex Cumming Scottish Association for Mental Health

Crisantos Ike Young people representative

Caitlin Tawse Young people representative

Rachel Harris NHS Greater Glasgow and Clyde

Kerri McPherson Glasgow Caledonian University

Kareena McAloney-Kocaman Glasgow Caledonian University

Pia Faeth Glasgow Caledonian University