IMHN Coproduction and Community Engagement: Community Mental Health Transformation Programme

January 2023 – March 2024

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# Context

The NHS Long Term Plan describes a:

“new community-based offer [that] will include access to psychological therapies, improved physical health care, employment support, personalised and trauma-informed care, medicines management and support for self-harm and coexisting substance use…and proactive work to address racial disparities.”

Local areas will be:

“supported to redesign and reorganise core community mental health teams to move towards a new place-based, multidisciplinary service across health and social care aligned with primary care networks.”

New place-based community mental health model will enable people with mental health problems to:

* access mental health care where and when they need it.
* manage their condition or move towards individualised recovery on their own terms.
* contribute to and be participants of their community.

It intends to modernise the existing CMHS by integrating primary and secondary care to increase the amount of mental health care you can get from the NHS within a GP or community setting.

NHS England published the Community Framework in 2019 and 12 sites were awarded funding to be test sites.

Surrey and Borders Partnership NHS Foundation Trust were selected to lead two early implementer sites in South Frimley and Surrey Heartlands.

Vision? Provide people with mental health needs with the right care when they need it.

Who is it for? Everyone aged 18-64 and 65+ in Surrey Heartlands Integrated Care System (ICS) and South Frimley ICS catchment.

# IMHN involvement

As part of the Community Mental Health Transformation Programme (CMHTP), Surrey Coalition of Disabled People was commissioned to employ three Co-Production & Community Engagement Officers to work within the Independent Mental Health Network (IMHN), to utilise their direct lived experience expertise to support the improvement of community mental health services, including development and delivery.

Project focus: Understand how suitable health and wellbeing services are, what barriers people face when seeking and accessing support, experiences and needs of specific demographics, and how the existing mental health support offer in Surrey and North East Hampshire can be improved.

Community engagement focused on Surrey and North East Hampshire residents aged 18+ alongside more detailed engagement with the following unseen/unheard demographics: Carers, LGBTQ+, Men, Neurodivergent people, and Older Adults (65+), supported by learnings from Surrey Minority Ethnic Forum/IMHN projects.

Findings will support the Community Mental Health Transformation Programme to understand how well services are working and how they can be improved to better meet the needs of everyone in the community.

# Project timeline

Project starts: The IMHN employs two part-time Co-production and Community Engagement Officers and one full-time officer in January 2023. Each officer has lived experience of the mental health system.

Community Connectors: 17 Community Connectors are interviewed in February and March 2023 to understand how the Community Mental Health Transformation Programme GPimhs and MHICS services map their clients’ needs. Published in May 2023, the report produced 11 recommendations and identified challenges with maintaining up to date lists of services, the sharing of relevant information, and the use of digital tools.

Online survey: Conducted from 17th April 2023 to 5th November 2023. Aim to collect a wide overview of experiences accessing health and wellbeing services, the barriers to seeking support, and areas of improvement.

255 responses:

* 28% Men
* 44% Neurodivergent
* 13% LGBTQ+
* 21% Older Adults
* 36% Carers

The survey was shared via organisational network, community forums and meetings, and leaflet sharing.

The survey was anonymous with the option to leave contact details should the participant wish to be involved in additional focus groups and co-design work. Respondents were asked to respond to 3 questions and 5 statements with space for additional comments.

Engagement: Demographics were assigned amongst the team and officers headed out into the community to talk with people and dive deeper into the topics being raised in survey responses. Officers presented at various events e.g., Pride in Surrey, Royal Holloway, University of London, and National Autistic Society ASPIRE Groups.

Focus groups: Participants from community meetings and forums are invited to take part in demographic specific focus groups to contextualise survey findings. 4 Neurodivergent focus groups were held in August 2023, 2 Carers focus groups, and 1 Older Adult focus group were held in September 2023.

Recommendation working groups: Team invited professionals and lived experience experts from previous focus groups to attend four working groups and co-design recommendations.

November 2023

* Introductory session to introduce the project to the group.
* Working group 1 covered information before and after appointments, information about the service and about you.

December 2023

* Working group 2 covered GPimhs/MHICS access, self-representation, and how to keep people updated.

January 2024

* Working group 3 covered diversifying services offered, peer support, and targeted communications.
* Working group 4 reviewed recommendations as a group.

Present findings: Team refines recommendations, create final outputs, and presents findings in system meetings during February and March 2024.

Project ends: IMHN contract ends March 2024.

# Survey data

Quantitative data: response trends from different demographic groups were compared to identify distinctions about how satisfied different groups were with the services they had accessed.

40% 'Agreed' or 'Strongly Agreed' that they felt listened to and respected by service providers

34% 'Agreed' or 'Strongly Agreed' that they felt that service providers understood their individual needs

43% 'Agreed' or 'Strongly Agreed' that they were concerned about discrimination, prejudice, and assumptions being made by their service providers

Respondents were asked to identify, from a list of multi-select options, where they would go for support if they were to **struggle with their wellbeing**:

* 50% selected GP
* 18% selected No one
* 65% select Friends, Family, Partner or Spouse

Percentage of each demographic group who would go to their GP for wellbeing support:

* 30% aged 18-25
* 37% aged 65
* 46% Men
* 48% Carers
* 54% Neurodivergent

40% of all survey respondents in Surrey and NE Hants ‘Agreed’ or ‘Strongly Agreed’ that they felt listened to and respected when discussing their needs with organisations providing support.

This statistic broken down by location:

* 20% Hart
* 67% Rushmoor
* 34% Waverley
* 47% Guildford
* 50% Surrey Heath
* 36% Runnymede
* 38% Spelthorne
* 36% Elmbridge
* 29% Epsom and Ewell
* 47% Reigate and Banstead
* 86% Tandridge
* 32% Mole Valley
* 7% Woking

“Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual?” (Percentages of 255 residents)

* Friends and Family: 65%
* GP: 50%
* Safe Haven: 9%
* Charity Services: 18%
* Peer Support Groups: 12%
* Community Leaders: 4%
* Emergency Services or 111: 7%
* Crisis Line or SPA: 10%
* No-one: 18%
* Other: 10%

Qualitative data was analysed in 1 month increments throughout the data collection period. In the first three months, analysis took an inductive approach to coding, then moved onto deductive coding.

**Top 10 responses to Q2 in the online survey**

“What do you feel are **potential barriers** to you **seeking support** when you are struggling to cope with day-to-day life?”

* Communicating the issue
* Wait times
* Hard to access
* Lack of understanding
* Lack of time
* Availability
* Bounce
* GPs
* Isolation
* Stigma

**Top 10 responses to Q3 in the online survey**

“What would make **accessing** health and wellbeing **support easier** for you?”

* More information
* Availability
* Preferred method of contact
* Wait times
* Seeing the same person
* GPs
* Bounce
* Listening
* No support available
* Crisis

Reflexive thematic analysis produced over 60 codes categorised into 10 key themes:

* Diversity & Assumptions
* Communicating the Issue
* Access & Availability
* Bounce
* Mental Health Stigma
* Crisis & Prevention
* Holistic Needs
* Lack of Information
* Choice & Autonomy
* Connected Systems

Survey respondents by age:

* 11% 18-25
* 11.4% 26-34
* 36.5% 35-54
* 20.4% 55-64
* 20.8% 65+

“Do you support someone experiencing mental or physical health difficulties who couldn’t manage without your help?”

* Yes – 35 respondents
* Yes and Disabled – 53 respondents
* No – 144 respondents
* Unsure – 15 respondents
* Prefer not to say – 4 respondents

Survey respondents’ gender identity:

* Female - 167
* Male - 70
* Non-binary - 5
* Transgender Female - 2
* Transgender Male - 2
* Gender non-conforming - 1
* Prefer not to say - 5
* Other - 2

Survey respondents’ sexuality:

* 80.3% Straight or Heterosexual
* 13% LGBTQ+
  + 15 Gay or Lesbian
  + 14 Bisexual or Pansexual
  + 3 Asexual
  + 1 Questioning
* 6.7% Prefer not to say

NOTE: Gender and Sexuality are separate data categories in data analysis.

Survey respondents by disabilities and neurodivergence:

* 4.9% Disabled
* 10.8% Neurodivergent
* 38.9% Disabled and Neurodivergent
* 45.3% No

Breakdown of Neurodivergent conditions:

* 77 Autism
* 38 ADHD
* 15 Dyscalculia
* 7 Dyslexia
* 11 Dyspraxia
* 1 Tourette’s
* 12 Prefer not to say
* 10 Other

# Theme 1: Diversity and Assumptions

All demographics have experienced assumptions being made about them based on:

* diagnosis
* lack of diagnosis
* appearing ‘well’
* struggles that providers don’t understand (e.g., caring responsibilities or neurodivergent symptoms).

Residents felt that training about diverse needs was lacking and impacted by high workforce turnover. They want services to prioritise individual needs instead of assuming needs based on an individual’s demographic.

Topics in this theme:

* Age\*
* Appearing well
* Assumptions
* Carers\*
* Discrimination
* Diversity
* Culture/Language
* LGBTQ+ \*
* Physical disability
* Prejudice
* Serious Mental Illness
* Understanding Neurodivergence\*
* Young Adults\*

\*Demographics focused on within this project, see key takeaways for more.

**Assumptions** like appearance, mental health stigma, heteronormativity, and diagnosis-based biases can impact how well people are listened to.

Assumptions about mental health needs based on presentation, affect carers and neurodivergent individuals who feel unheard when seeking help.

Many residents said that they had not experienced **discrimination** in healthcare settings. However, several residents said that assumptions and judgements are more common, especially regarding disability or diagnosis.

Participants expressed fear when disclosing neurodivergent conditions due to stereotypes.

Residents expressed dissatisfaction with current **diversity** training, calling for better understanding of diverse patients' intersectional identities and cultural backgrounds in mental health care.

Residents emphasised the importance of individualised support to improve experiences and avoid assumptions.

Residents noted prioritisation of certain disabilities, poor understanding of **physical disability impact**, lack of accessibility, and discrimination against disabled individuals.

Residents with both **serious mental illness (SMI)** and Autism/neurodivergence face challenges accessing treatment due to poor handling of SMI episodes and assumptions based on their diagnosis. Symptoms of SMI can hinder support access, leading to isolation.

Some residents felt their **age** influenced how they were treated by services, with concerns being dismissed or expectations being based on age. Focus group participants highlighted a lack of support for career women with poor mental health.

Residents emphasised the necessity for extra support for **young adults** to identify their needs and select appropriate services. One resident expressed that young adults are expected to achieve more due to their age, leading to their condition being overlooked. Another resident highlighted the need for additional spaces for young adult recovery. The focus groups included only one young adult due to low survey engagement and scheduling conflicts with daytime sessions.

**LGBTQ+** individuals face discrimination and assumptions, with issues like coming out and gender identity often overlooked. Concerns include lack of discussion and inclusion of LGBTQ+ topics in services, fear of practitioners not respecting LGBTQ+ identities, limited local services, and LGBTQ+ groups being primarily in religious settings.

There is a lack of awareness and support for **neurodivergent** individuals, especially women who mask their symptoms. Residents seek sensory-friendly spaces, visual aids, and proactive communication accommodations like notes before appointments. Autistic residents mentioned limited effectiveness of Cognitive Behavioural Therapy (CBT), and insufficient proactive accommodations for communication differences.

**Carers** expressed concerns about assumptions made about them, lack of awareness of their rights, and insufficient support. They desire understanding, flexible appointments, drop-in support, and proactive assistance. Action for Carers was commended, with one carer highlighting the support from physical health practitioners.

Carers face unique challenges as mental health caregiving is stigmatised and unpredictable. Many carers rely on friends and family and seek assistance in managing responsibilities without added workload. Carer assessments should be non-judgmental and consider various holistic factors. Mental health support for carers is crucial.

**CASE STUDY**

See Detailed Report for case study feedback about young adult neurodivergence experience.

# Theme 2: Communicating the issue

Participants in the survey identified communication as a key barrier to receiving appropriate support.

Some residents, especially those with dyslexia and other neurodivergences, found it challenging to verbally articulate their mental health struggles.

Time constraints and lack of understanding were key barriers to effective communication in initial appointments, particularly with GPs.

Speaking to someone unfamiliar with your issue was a barrier to communication and feeling understood.

Residents often felt dismissed discussing mental health symptoms with non-mental health practitioners or GPs, leading to a loss of faith in the system's ability to help them.

“I think these organisations rely too heavily on algorithms and guidelines, failing to hear the individual” (LGBTQ+ Neurodivergent Female aged 26-34, Mole Valley)

**Lack of understanding**

Survey raised a lack of empathy and understanding from services that leads to feelings of frustration. The impact mental health, neurodivergence, and physical health have on people’s lives are often not accommodated or addressed.

Focus group participants discussed a lack of trust in psychiatrists and counsellors due to respect and understanding issues. Trauma and late diagnosis of conditions like Autism and ADHD can lead to anxiety and low self-esteem. These experiences are often dismissed.

**Listening**

Residents shared that professionals sometimes overlook clients' lived experiences, leading to a reluctance to seek help. Concerns may be dismissed due to not having a diagnosis or preconceived assumptions.

Survey responses had varying options about listening quality, with lived experience and local practitioners often listening better.

Residents want to be heard and taken seriously. Some organisations may struggle to listen due to limited resources, and some practitioners follow protocol too strictly, hindering how much people share.

Residents seek open, empathetic environments with individualised support from volunteers or those with lived experience.

Focus groups: people are more inclined to open up to a professional if they are listened to with empathy and respect. Professionals should consider additional training in compassion-focused therapy, and value lived experience insights from individuals and their caregivers. Even if consent to share information with a caregiver is not given, professionals can still offer general advice on supporting someone with a specific diagnosis.

**Seeing the same person**

In the survey, residents expressed that having a consistent contact person positively impacted seeking support, feeling understood, and communicating mental health concerns openly. They desired a named contact to build trust and improve continuity of care and service quality.

Neurodivergent people shared that seeing the same person regularly provides predictability, trust, and safety, and increases the likelihood of recognising changes in mood or symptoms over time. Sudden changes in professionals can be difficult. Introducing a new team member during transitions can aid in building trust and easing the process.

Whilst GPimhs/MHICS currently provides support through a consistent community connector, there is room for improvement across services.

**Communication**

Communicating the issue posed a significant barrier to receiving support for residents, especially for neurodivergent and disabled individuals. A vast majority of neurodivergent individuals found CBT talking therapies unsuitable. Choice with communication methods (face-to-face or over the phone), recording conversations, and having more time were suggested as ways to help people articulate their situation.

Suggestions for professionals to consider:

* Allow time for people to process questions and information.
* Ask one question at a time.
* Consider reasonable adjustments.
* Encourage individuals to share their experience without bias.
* Clearly explain information and confirm comprehension, especially regarding emotions and feelings.
* Explain jargon and medical terms.
* Write down important details.
* Recognise that unwell individuals may not conform to social norms, and refrain from reprimanding them for expressing themselves e.g., with strong language.
* Respond to emails promptly.
* Consider offering scheduled phone calls for carers' support.

# Theme 3: Access and Availability

Access and availability was a large topic of discussion among survey respondents. It was raised as both a barrier to access support and a popular thing residents wanted to see improved.

Residents desire flexible services that could offer a variety of options (online, in-person support accessible via public transport, and out-of-hours appointments).

Concerns included:

* physical accessibility
* accommodations for neurodiversity
* transportation costs

Lengthy wait times was one of the largest topics discussed by survey respondents. Waiting times had consequences like putting people off accessing support, people’s needs changing whilst waiting, and being left to wait with little information or communication.

“Access. As in, availability when you need it, not 6+ weeks later. It takes a lot to ask for help, and if it's not there when you need it, you're less likely to ask again, until you stop completely.” (LGBTQ+ Neurodivergent Female aged 26-34, Mole Valley)

**Lack of time**

A top 10 reason for not reaching out for support across all survey respondents, primarily commented by ages 26-64 and women. It was also a popular comment among carers. Lack of time and resources from the system were mentioned as barriers.

**Wait times**

Respondents faced challenges with appointment availability, long wait times, and limited out of hours support resources due to various factors like disability, caring responsibilities, and employment status. Wait times were a significant barrier to seeking support, especially for neurodivergent individuals awaiting Autism and ADHD diagnoses, impacting their mental health. Consideration for ongoing needs during wait times was highlighted as essential.

Top 5 topic discussed by survey respondents. Residents ranked wait times as the number 1 obstacle, ranking it 4th in desired improvements behind more information, availability, and preferred contact method.

“I can’t use public transport and all the mental health service have been moved out of Epsom so getting to any face to face is impossible for me.” (Neurodivergent Male aged 35-54, Epsom and Ewell)

**Transport**

Those in mid-Surrey, men, gay and lesbian individuals are particularly affected and desire easier access to community groups and drop-in hubs without needing to rely on costly transport to out of area services or inaccessible and unreliable public transportation.

Carers, neurodivergent people, and older adults all cited transport as barriers to accessing support.

**Cost**

Residents in South West Surrey, gay people, and lesbians commented on cost more than other groups. Some people are unable to access neurodivergent assessments due to cost.

**Accessibility**

Issues raised include:

* Physical accessibility of venues.
* Reasonable adjustments for sensory needs.
* Reasonable adjustments for neurodiversity.
* Lack of accessible transport or home visit options.
* Need for safe places that support independence.

Southwest Surrey residents listed accessibility as a top 10 priority for improving service uptake.

**Availability**

A top 10 concern across demographics in survey responses, ranked in the top 5 barriers for seeking support. North East Hampshire residents had fewer mentions due to a lower response rate, leading to no clear consensus on key issues in that area.

Included lack of availability for out-of-hours, local, or face-to-face support. Some individuals avoid seeking help to not burden limited services.

# Theme 4: Bounce

Several residents told stories of experiencing bounce, or how they perceived they would experience it.

People describe being referred around in circles and not finding a service that they met the requirements for, or one that offered them meaningful outcomes, which resulted in the feeling that there was no support available to them.

**GPimhs / MHICS**

During engagement, most residents were unaware of the GPimhs/MHICS service but when asked how the system could be improved, suggested improvements very similar to these services. Mixed responses from people who have used the service. Some felt the communication methods were not neurodivergent friendly and no reasonable adjustments were offered or made. There was praise for having one point of contact, quick referral, and no need to retell story.

**Unknown outcomes**

Residents frequently experience a lack of response from services, or a lack of action taken after referrals had been made. Residents didn’t want to wait so long for updates on action being taken, especially when in crisis.

Carers highlighted the importance of completing carer assessments and improving the information provided to them, noting that current documents are lengthy, repetitive, and lack clear guidance.

“People not understanding my needs, trying to push me to other services (I can end up going round in circles), having a repetitive response every time I reach out over a period of multiple years...” (LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Mole Valley)

**No support available**

Top 5 concern for all residents. Number 1 topic mentioned in survey’s additional comments. Neurodivergent individuals and carers ranked it in their top 5. Residents aged 65+ was the only age group, and men the only gender, to not have this topic in their top 10.

* Mentions of no support available for neurodivergent adults, parents of children who have been sexually assaulted, or unpaid carers.
* Absence of local mental health support.
* Need for easily accessible support through simple referral procedures.
* Challenges for neurodivergent individuals include ineffective CBT talking therapies and insufficient trauma-focused care.
* No ongoing support for lifelong diagnoses or after discharge.
* Lack of support after crisis or suicide attempt.
* Frustration from absence of easily accessible support, particularly for those with dependents and additional challenges.
* No help available for autistic adults without learning disabilities.
* Need for specialised neurodivergent support instead of signposting to general charities.
* Older adults highlighted the lack of local community spaces.

**Bounce**

Top-ranking topic among all survey participants. Individuals aged 26-64 of all genders from various areas in Surrey consistently provided feedback on this subject. Neurodivergent individuals consistently shared their thoughts on this topic.

Carers seek a designated organisation to support them throughout the process of accessing assistance and conducting follow-ups.

Neurodivergent individuals highlighted gaps in the system for autistic individuals without learning disabilities and those with both Autism and mental health requirements.

The hurdles of not meeting criteria or having to retell their story are significant barriers.

Autistic individuals are sometimes directed to services unsuitable for their needs, creating a divide between mental health services and neurodivergent diagnoses.

Topics discussed included:

* Inconsistent services
* Unaligned referrals
* Disconnected services
* Lack of response and follow-up
* Listening without producing outcomes
* Exhausting available resources
* Inadequate and incorrect signposting
* Repeating stories
* Feelings of being overlooked or neglected due to these issues

# Theme 5: Mental Health stigma

Popular reason for residents not seeking support, after themes of communicating the issue, lack of information and access and availability.

Mental health stigma impacts access to support:

* Internally: feeling like a burden, shame, and that mental health is your responsibility alone.
* Externally: fear of judgement, including experiences of being seen as attention-seeking or difficult by professionals or others.
* Societal: fear of consequences affecting child custody or work, as well as not feeling like you can prioritise seeking personal mental health treatment due to others relying on you in your personal life or at work.

“Other people reliant on me - family, work; negative feelings of self (self-blame, shame, self-criticism - other people cope, why can't I?); stigma (could it affect my job, future jobs, people's impressions of me)” (Female aged 35-54, Surrey Heath)

“Not wanting to dump trauma on people and worry people with my own problems”. (LGBTQ+ Male aged 18-25, Rushmoor)

“I feel that sometimes reaching out for support may be used against me for getting my son back. Worried they will see it as I can't cope.” (Disabled and Neurodivergent Female aged 26-34, Waverley)

“People never listening. Fear of someone sending police or ambulance out when not needed. Fear of my family finding out how bad I am.” (Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead)

**Stigma**

Top 10 reason for not reaching out across all survey respondents.

Top 10 barrier for 26-64s, carers, and those who said they wouldn’t reach out for support.

Top 5 barrier for 18-25s, women and neurodivergent people when reaching out for support.

Stigma (primarily around mental health and other diagnosis) was a top 5 comment relating to reasons that people felt discriminated against or that they received judgment or assumptions.

Joint number 1 reason (with wait times) for Trans/non-binary people not to reach out, and joint 3rd for gay people and lesbians.

**Burden to others**

Some individuals feel like a burden to others, especially to their family, leading them to avoid seeking help to not add to their family's mental load or worries. Neurodivergent people are prone to rejection sensitivity dysphoria, low self-esteem and feeling like a burden.

**Judgement from others**

Residents fear being judged as weak, failures, or attention seekers, and avoid seeking support to prevent negative perceptions from family, staff, or peers.

**Fear of consequence**

Some residents fear seeking support due to concerns about potential negative impacts on child custody, job prospects, and workplace perception.

**Personal responsibility**

Top 10 reason for not reaching out for support for those who responded that they would reach out to no one for support.

**“I can’t be helped”**

Feeling like they can’t be helped was a top 10 reason for 18-25s not reaching out for support.

**Shame**

Top 10 reason for not reaching out for support for 18-25s, women, gay people, and lesbians. Shame was only mentioned in Q1.

“A sense of shame, not wanting to be a burden. Pride stopping me from asking for help.” (Female aged 65+, Carer, Guildford)

# Theme 6: Crisis and Prevention

Residents said that they wanted more accessible early prevention-based services.

Residents faced challenges accessing GP appointments and mental health support, often delaying until crisis. Some believed meaningful support was hard to obtain without reaching a crisis point.

Some residents cited mental health symptoms and fear of escalation as barriers to seeking help.

There is an insensitivity to people reaching out for help when entering the system at a different point than where the system wants residents to be. (e.g. person told to call 111 who were dismissive and said to call GP instead which had a negative impact on this person’s mental health).

**Crisis**

Several residents felt mental health services were only available when someone is in crisis, with mixed feedback on crisis support. Some find crisis lines unhelpful, were rejected from A&E, and felt Safe Havens aren’t nice places to be. Suggestions included more drop-in centres, improving crisis service accessibility and the sensory environment, and for crisis services to be able to follow up.

Focus groups highlighted a lack of intermediate support for individuals not in full crisis, with a feeling that CMHRS only support people before or after.

There is a subjectiveness to what “crisis” means, causing people to end up at the wrong support service.

**Prevention**

Residents want support to be available when you recognise your mental health is worsening before it reaches crisis. They want community-based drop-in locations outside working hours and ongoing support after intensive support to prevent relapses.

Focus groups highlighted the need to have care plans for all individuals, not just those with severe conditions. The community often lacks care beyond crisis support, requiring individuals to seek help when they are most vulnerable.

**GP**

Residents reported challenges accessing GP appointments for mental health, citing short visits, lack of caring or informed GPs, and limited awareness of community services/groups. Positive experiences included seeing a trusted GP who understood their needs.

Across all focus groups, participants expressed anxiety about medication changes and mismanagement, leading some to avoid seeing GPs. Despite having good relationships, older adults still faced challenges finding the right GP. GPs were seen as gatekeepers to services, with appointment times considered too short.

**Difficulty gaining appointments**

Residents frequently commented on how it is difficult to gain appointments, especially with the GP. One person said that is it so bad that you don’t even try unless your condition is urgent.

**Fatigue**

Fatigue and burnout were cited as barriers to seeking support, made worse by symptoms of ill-health (for example, insomnia).

**Fear of escalation**

Some residents feared reaching out due to escalation.

Residents didn’t want to be sectioned or have emergency services sent to them due to a misinterpretation.

This prevents people from being honest with call takers and reflects the lack of trust in the system.

**Isolation**

Some residents felt isolated, hindering their ability to seek support due to social anxiety, lack of connection to community services, and information.

Services for older adults often prioritise addressing isolation and loneliness.

Focus groups highlighted isolation in rural areas, decreased mobility, and society anxiety as challenges faced by residents. Adult Social Services praised for enabling isolated individual to go out once a week for a few hours.

“Making phone calls is very difficult so the crisis line is unhelpful. I am also unable to travel so cannot get to Safe Haven. I often become non-verbal when struggling to cope.” (LGBTQ+ Disabled and Neurodivergent Female aged 26-34, Guildford)

# Theme 7: Holistic Needs

Residents praised charity services for listening to them, offering flexible access and holistic support.

Flexibility was especially valued by those with diverse needs like carers and neurodivergent individuals who struggle with complex referral methods and deal with co-occurring conditions.

Peer support groups and charities were highlighted as valuable resources within communities.

“I constantly get turned away and not listened too. I now feel it's pointless reaching out.” (Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead)

**Charities**

Residents felt charities listened to them and offered holistic support with specialised advice and guidance. People expressed the need for increased funding as VCSE sector is heavily relied on and trusted. Carers praised Space2BU for providing practical support and guidance. Charities were commended for their accessibility, clear administration, and accurate information. Positive feedback in Older Adult focus group for Mary Frances Trust but had concerns about online accessibility.

**Hard to access**

Many face challenges accessing services due to criteria not being met or being autistic. Difficulty accessing face-to-face appointments, finding local services, and flexible options like drop-ins or out-of-hours services.

Carers and neurodivergent individuals struggle to access support due to transportation or out-of-area services. Older adults find transport management challenging and rely on volunteers or face affordability issues.

“Services need to be better at helping people build full and positive and active lives, not just focus on medication and promoting crisis services and dealing with relapses.” (Male aged 35-54, Rushmoor)

**Holistic needs**

Peer support groups offer practical and social support, reducing isolation. Residents seek more access to groups and more assistance in finding them. However, some find established groups exclusive.

Carers appreciate relaxed and non-judgmental services like wellbeing prescriptions and the ability to drop in and out of support.

Residents want holistic support addressing all their needs, not just individual issues, to build long-term sustainable mental health and lifestyle support.

Those with overlapping diagnoses felt that no services could cater to their complex needs.

“Services mostly seem to treat all clients (or potential clients) as if they have reduced capacity or are unintelligent. They don't seem to take the necessary holistic view needed for Recovery to work. They seem to have a fixed idea of what people's needs are and not really listen to people or work collaboratively with them.” (Male aged 35-54, Carer, Rushmoor)

“There needs to be more focus on "wellness" and on a holistic view of people's issues, and helping people build happy and healthy and sustainable lifestyles; and less focus on illness and crisis” (Neurodivergent Female aged 55-64, Hart)

“Allow other areas of my life to be explored, enable a long-term view, open the future.” (Disabled and Neurodivergent Female aged 55-64, Carer, Elmbridge)

# Theme 8: Lack of information

Residents primarily searched for information about services online, rather than from their GP or in the community.

Challenges include difficulty finding information on access, wait times, and outdated service details.

Some feel overwhelmed navigating information, while others struggle to know where to start when seeking support during distress.

**More information**

Many people have to do their own research into what is available. Residents desire a centralised, up-to-date information source with accurate eligibility criteria, wait times, and care pathways. They seek more details on local initiatives via GPs, easy access to care records, practical support advice, and a care passport for neurodivergent individuals.

Focus groups identified various challenges:

* Outdated and physical health-focused leaflets in GP waiting rooms.
* Anxiety due to lack of information on appointments including location, parking, and sensory environment.
* Inconsistent online information about Safe Havens.
* Lack of clear signposting to services and outdated information.
* Difficulty finding relevant information online.
* Carers seeking more information on cared for person care and support services.
* Individuals tend to seek information on conditions and services only when needed, often while occupied with caregiving duties, and require help from others to gather information.
* Professionals require more details on triggers and coping strategies for effective support.

“More obvious care pathways for people experiencing mental health problems. People are often not motivated to seek help, are unsure of the best way of getting it, and faced with a complex network of different services...” (Disabled and Neurodivergent Male aged 55-64, Carer, Hart)

“Knowing where and how to access services. This could be through advertising i.e. posters or leaflets at GP surgeries, hospitals, libraries, CAB, even supermarkets.” (Female aged 55-64, Carer, Elmbridge)

“More advertised information in the community.” (Female aged 65+, Waverley)

**Not knowing what is available**

Residents feel overwhelmed by navigating information, unsure where to start or access resources, and conversations with staff can be inefficient if needs don't fit standard options. Desire for a central access point for local information.

Signposting:

* Lack of online group signposting
* Carers groups rely on word of mouth
* Professionals need better knowledge of services
* Support on how to access the signposted service is needed
* Good signposting knowledge by diagnosticians
* Older adults may benefit from posters in community locations

# Theme 9: Choice and Autonomy

Residents wanted to have a say in their treatment, have a choice of how they access the service and contact organisations, and have access to all their information.

Transparency about care decisions, corrections of errors and notes, and understanding individual needs for reasonable adjustments are key to support individual needs.

However, across the demographics of survey respondents there wasn’t always a clear consensus of how each group wanted to access services with different individuals, including those in similar situations, often wanting different things.

Suggestions included consistent workforce who could understand and accommodate them, with a focus on autonomy and confidentiality.

**“**The service is not accessible. It’s not transparent how decisions are made, and referrals and people (are) left to wonder what’s happened” (Disabled and Neurodivergent Male aged 65+, Carer, Woking)

**Choice**

Residents desire more service options (e.g., one-to-one or group), local support, longer appointments, and clearer information about eligibility criteria. Focus groups found a lack of awareness about the Right to Choose service for Autism assessments. There are concerns about the suitability of CBT talking therapies for everyone and that mental health services can take a ‘one size fits all’ approach.

**Comments about workforce**

* Criticism included staff, especially senior clinicians, lacking empathy and being judgmental.
* Issues arose when professionals were unprepared for appointments, requiring autistic individuals to explain their condition repeatedly.
* Concerns were raised about professionals laughing at unexpected comments and the need for proper introductions.
* Mental health teams would benefit from specialists in each condition, including neurodivergence.
* Concerns about high staff turnover reducing continuity of and quality of care.
* Staff need support to know how to make reasonable adjustments for mental ill health.

**Preferred contact method**

Residents had diverse preferences for accessing appointments, services, and communicating with practitioners, including online, over the phone, face-to-face, text, local options, advocate accompaniment, and social media support groups.

Neurodivergent individuals prefer contacting services via email or text, with online appointments offering convenience and accessibility. Older adults prefer telephone contact or in-person appointments due to technology limits. Understanding and empathy are needed for missed calls due to caregiving responsibilities. Online booking forms may pose challenges for those with executive dysfunction to explain symptoms accurately enough to access appropriate support.

**Confidentiality**

Three individuals expressed concerns about data protection and information sharing. One person working in the NHS feels hesitant to seek support due to knowing the workforce.

**Autonomy**

Residents want their care to promote autonomy and choice. This includes transparent decision making, clear plans, seeing and understanding patient notes, being able to contribute to and correct patient notes, open communication, having a say in your treatment, and being given all the options (not just put on a path of standard practice).

One person said that they felt like they weren't a part of the GPimhs discussions about their treatment.

Focus groups discussed person-centred care that tailors treatment to individual needs, and empowers choice and involvement in decision-making.

People desire involvement in decisions regarding their care (preferring to submit statements for consideration at MDT meetings rather than feeling excluded), accessible summaries of discussions, and the ability to easily correct errors in notes.

Professionals explaining decisions on medication and interventions allows individuals to challenge misassumptions and highlight overlooked factors. Those who have accessed GPimhs/MHICS want to have communication with the person prescribing their medication.

**Recovery College courses could benefit from specialist instructors with deep expertise rather than broad but shallow knowledge.**

# Theme 10: Connected systems

The challenges faced by individuals utilising various service systems, including charities, public services, and long-term physical and mental health services, highlight the complexity of managing care paths across different systems for both patients and caregivers.

Many disabled residents and caregivers expressed the necessity for integrated mental and physical health systems to collaborate and coordinate care programmes effectively.

Improving signposting and awareness between different services is crucial, especially for commonly co-occurring conditions like:

* eating disorders and Autism
* learning disabilities and mental health issues
* learning disabilities and neurodivergence
* neurodivergence and sexual assault/abuse

There is a demand for interconnected services that offer consistent care and consider the difficulty of managing both physical and mental health conditions. Moreover, it's essential to recognise that individuals with mental health conditions might also have undiagnosed or diagnosed neurodivergent conditions.

**Physical Disability**

Several disabled respondents said that there is a poor understanding of how sensory loss and physical disability impacts mental health.

Conversely, one respondent expressed frustration about professionals assuming poor mental health issues due to physical disability.

Residents feel left alone to cope, judged that others think they are over-exaggerating, and that people don't understand/aren’t well informed about disability, especially brain injury, in mental health services.

“Services are very boundaried and there is a complete lack of someone being of charge and overseeing someone’s care. This means provision is splintered and un co-ordinated, resulting in the carer having to act as an unpaid team co-ordinator but without access to the funds and resources.” (Neurodivergent Female aged 55-64, Carer, Waverley)

“It can be tricky to access some forms of mental health support when you are limited by physical health issues.” (Disabled Female aged 26-34, Guildford)

Mental health [services] are not set up to help those who have physical disabilities or comorbidities - both of which often go hand in hand” (Disabled Female aged 35-54, Carer, Waverley)

# Key takeaways

**LGBTQ+ community**

* Lack of specific support for LGBTQ+ experiences and needs.
* Survey responses included prejudice, homophobic, and transphobic views.
* Misassumption that LGBTQ+ needs are already being met.
* Lack of existing engagement between LGBTQ+ community and the system.
* Young LGBTQ+ people want access to mental health services and support that address gender identity related issues.

**Men**

* Lack of community spaces that aren’t sport clubs or paid activities.
* If men aren’t seeking support - how can we target service awareness to loved ones instead?
* Tricky to find existing forums to promote community engagement.

**Neurodivergent**

* Autistic individuals face withdrawal of existing mental health support post-diagnosis.
* Effective support requires clear communication and consistent, long-term support from the same person or consistent source.
* Mental health professionals need better understanding of autism and neurodivergence, including challenges faced, communication difficulties, masking impact, and trauma from stigma.
* Neurodivergent residents consistently raised that CBT talking therapies are not effective in their current form. Autistic people often have alexithymia (difficulty recognising and identifying emotions) and may lack the cognitive flexibility to challenge their thinking patterns, making this therapy style ineffective and inaccessible as CBT is based on the interactions between thoughts, feelings, and emotions.

**Older Adults**

* Whilst mental health support is not specifically labelled, VCSE organisations are already utilising place-based holistic community support.
  + However, they need statutory support to continue this work to a high standard.
* Social activities are attended mainly by women, even when marketed to all.
* Lack of age-tailored mental health forums like ATLAS or Amplify Mindworks.
* Support for older adults often focus on loneliness and Dementia.

**Carers**

* Lack of provision for localised carer respite.
* Need to distinguish between mental health carers, neurodivergent carers, and physical health carers as each group has different needs.
* Concerns around older adults who are carers, the support for them, and resources for when carers are unable to care for their person.

**Young Adults/University students**

* Lack of safe spaces and awareness on how to access support.
* Want for local community groups and spaces.
* CBT talking therapies are not suitable for those with language difficulties (at least 50% of adolescents referred to CYP mental health services have these).
* The transition from under 18 to 18+ is a huge time of change for all.
* Young Adults are being asked to do everything on their own for the first time with little to no guidance yet expected to have it all together.
* Issues affecting university students include social media; pressure from family, peers, culture, and society; isolation/loneliness; lack of structure; accessing pharmacy/GP in university area; difficulties finding information.

**Co-production**

* True co-production is a lengthy and continuous process that requires continual support from system professionals and sponsors.
* Whilst the team referred to their own lived experience insight throughout, due to time constraints, resident involvement aligned more with co-design principles.

**Feedback from lived experience experts**

“I very much value the opportunity to share my lived experiences for the benefit of others.”

“I find this project incredibly interesting, and I have enjoyed participating in the discussions about recommendations. I am really grateful to have been able to join in! Thank you!”

“I didn’t know my lived experience insights could actually be helpful.”

“The focus groups have made me feel my mental health struggles can have a positive impact.”

“It was a bit hit and miss as many people had a story to tell and I felt at times this was an offloading process!”

“It felt like an incredibly productive use of my time, being able to contribute to such meaningful discussions and feel listened to is something that some similar groups haven't managed to achieve!”

“It was incredibly empowering,”

“I am so grateful that I was able to be a part of this project.”

“I felt welcomed, valued & heard.”

“The sessions were friendly, kind, compassionate, structured & well administered.”

# Recommendations

**Implementation of these recommendations:**

We recognise that the current financial landscape will limit the ability to implement many of these recommendations, however, we hope the mental health system will think innovatively as to how the suggested changes can be implemented within the current structures to create a more accessible offer for Surrey residents. For recommendations which no funding solution can currently be found we hope commissioning teams from the ICBs (Surrey Heartlands and Frimley) and Surrey County Council (SCC) are maintaining a forward plan of need knowing which gaps in the system exist which these recommendations can be added to. Consistently review and add to the Joint Strategic Needs Assessment (JSNA) based off local research such as this report which highlights areas of future commissioning needs.

## Information

1. Review existing good practices of information sharing happening in the system and offer a standardised approach across the area for information sharing before the appointment. For example, who the clinician is, what to expect i.e., ‘this appointment is to introduce the service and assess your needs’, including a way to submit accessibility needs.
2. Review existing support directories, and if those are not adequately meeting people’s needs, then consider alternative options. For example, there is an assumption that Surrey Information Point fills this need, although people find it difficult to navigate, often out of date, and not relevant for MHICS teams in North East Hampshire.
3. Research existing community magazines in each district and borough. Use their lessons learnt to provide support to the residents who create these and support the expansion of more local community magazines that can include information about mental health and wellbeing support across more areas in Surrey and North East Hampshire.
4. Contact people on GPimhs/MHICS waiting lists and other community mental health services to update on waiting times. Community Connectors should keep information about waiting length for signposted organisations and maintain this list to increase transparency on speed of service upon referral.
5. Promote the availability of mental health services to support loved one’s mental health needs as well as the primary client, which could include providing information to help loved ones understand the primary client’s diagnosis.
6. Expand targeted marketing of mental health services to include those within the primary client’s support system as residents are less likely to independently source support for themselves when they need it and could be encouraged to do so by friends and family.
7. Provide information prior to the first appointment about the clinical and community staff the client will see. This could be either in the appointment communication or by directing to staff profiles hosted on service provider or SABP websites. We recommend staff profiles include a person’s name, role, photo, and suggest including pronouns, and if the professional is comfortable, other relevant information, such as if they are neurodivergent, to allow clients to understand if a professional has shared lived experience.

## Improving current service offer

1. Include LBGTQ+ services as standard practice when signposting people to support.
2. Include services for parents, siblings, carers, loved ones as standard practice when signposting people to support.
3. Review commissioning of LGBTQ+ services within Surrey and North East Hampshire as there is currently a lack of tailored support with a need to create welcoming spaces for LGBTQ+ specific experiences.
4. Improve the relationship and communication between physical health care providers and mental health care providers at primary and secondary levels to increase holistic approaches to care across the Surrey and North East Hampshire system that look at individual need and the whole person.
5. Community Connections, peer support providers and commissioners to review geographical boundaries of peer support meetings and work together to ensure equality of offer across the area.
6. Signpost people to Community Connections peer support groups, or other commissioned providers, whilst clients are on clinical waiting lists to help bridge the gap and help prevent bounce or escalation of need.
7. Community Connectors and GPimhs/MHICS Lived Experience Practitioners should have a list of minority ethnic specific support including nationwide services, especially ones with access for non-English speakers.
8. Community Connections providers to work with minoritised ethnic communities to co-design mental health peer support groups with specific provision by age, gender, religion, language etc. For example, a group specifically for older adult Muslim males, new mothers, or Nepalese speakers. These should sit within spaces already used by those communities. Many residents felt they wanted groups of people who understood their experience of living in Surrey and North East Hampshire and were at similar stages of life. Residents who do not have English as their first language find it extremely difficult to use mental health services, however peer support provision could be established within the area in non-English languages which work with communities in collaboration with Community Connections providers who have knowledge and experience of offering mental health support.
9. Update the online information SABP has about LGBTQ+ specific issues (including gender related issues) to ensure that the signposted information includes both local and national support services.
10. Identify and promote community created spaces that act as safe spaces for people not in crisis but with wellbeing needs to help tackle isolation e.g. volunteering opportunities, Women’s Institute, Libraries, Men in Sheds, Andy’s Man Club, Scouting and Girl Guides, Sports Clubs.
11. Review how information about newly commissioned or changed mental health support services is shared with professionals across the system – especially the GPimhs/MHICS Community Connector professionals – and review how key information websites are accurately maintained.
12. Offer a variety of therapeutic options so the most effective approach can be identified, as every individual’s needs will be different. Recognise that some interventions can be inappropriate for certain people, for example many autistic people feel CBT does more harm than good, unless specially adapted for them. Educate people on the various options available, to empower them to choose what is most suitable, and promote a more holistic approach to mental health.
13. Mental health services should hire highly trained Autism specialists and practitioners with lived experience of neurodivergence, who can understand the person’s context without them needing to explain their neurodivergence. This will help improve trust and engagement, increase insight into how neurodivergence and mental health are interconnected, and the challenges people face. Lived experience insight will also help make sure that support or therapy options are appropriate for neurodivergence needs.

## Appointment and access

1. Review the sensory environment of facilities (waiting rooms, meeting rooms etc.) with awareness of lighting, sound, etc. Identify places where people could be offered a quiet, low sensory waiting option, such as in SABP’s newer buildings.
2. Train reception staff to recognise when people are uncomfortable in the waiting room environment, how to support and offer appropriate reasonable adjustments, and increase awareness and sensitivity of people’s needs.
3. Explain the purpose of Multi-Disciplinary Team (MDT) meetings as standard (when people have capacity and/or explain to their carer), including when the outcome of the meeting would be discussed with the individual. Support anyone who wishes to provide more information about themselves to produce a written statement which could be read out on their behalf.
4. At the end of an appointment, summarise key discussion points and actions with the client with the opportunity to add or correct details. Allow the client to receive a copy of these action points and takeaways should they wish to.
5. Using the existing learning disability care passport by Surrey County Council (SCC) as a starting point, develop a general care passport for physical and mental health clients including reasonable adjustments, support system, history, medication etc. Signpost people to this before their appointment to support them to access the care they need.
6. Offer appointments in person, online or on the telephone so the individual can choose the option that best suits their needs. Online appointments may be less stressful and anxiety provoking for autistic people than travelling to attend in person or coping with a phone call and allow the use of closed captions for people who prefer visual communication or have hearing loss but may be inaccessible to people without the necessary skills, confidence or technology.
7. Assess the accessibility of Safe Havens/Harbours and other CMHTP supported services, including actively making sure spaces are neurodivergent friendly and considering public transport routes during commissioning and planning.
8. Review services to ensure each has a clear pathway for communication with the service, offering a variety of methods (text, email, phone) with clear expectations about time frames when services will respond. Include clear contact processes for amending inaccurate notes and appointment changes/cancellations.
9. Map the existing offer of mental health and wellbeing services outside of conventional working hours (Monday to Friday, 9am-5pm) and highlight absent provision in each geographical area or clinical type.
10. For neurodivergent individuals, the GPimhs/MHICS standard offer of 4-6 weekly appointments may be too brief. Longer-term support with sessions every fortnight or month and extended appointment lengths are recommended to allow for additional time to process information and ask questions to clarify understanding.
11. Offer neurodivergent individuals short follow up appointments or individual emails for addressing questions that come up after they have had time to process their appointment.
12. Ensure up-to-date information is available about post-suicide attempt support pathways so that relevant information can signposted to and shared with individuals at that time.
13. Where possible, endeavour to match clinicians with patients based on their shared experiences to provide more effective care as shared experiences can help people understand each other better and build trust quicker, i.e. clinicians from minority ethnic cultures or neurodivergent.

## Carers support

1. Distinguish between mental health carers, neurodivergent carers, and physical health carers when commissioning services as each carer type has different support needs and experiences.
2. Carers assessments need to be undertaken consistently by professionals once a carer is identified. Assessments must be clear and concise with the outcomes followed through and monitored by a named professional, service, or organisation.
3. Carers assessments must be carried out by professionals with thorough training in showing empathy and understanding for the context of each individual’s situation to avoid making assumptions, as each carer’s approach will be different depending on their loved ones needs and challenges.
4. Assign a named organisation responsible for guiding carers through the support process to help reduce carers bouncing around the system unable to find the help they need. This organisation is to be mandatory signposted to when a carer is made known to the system.
5. Carers require more support and increased communication with professionals while respecting patient confidentiality. Carers should be included in pathways, and a consistent named contact professional should assess both the client and their carer/family members. Promotion of Home Treatment Teams and Recovery College is also important.
6. Commission psychoeducation for Older Adult carers and carers of Older Adults to build an understanding about ‘why we care’ and the ongoing capacity and resilience of carers, with focus on adaptability to help avoid people getting locked into co-dependency.
7. A review of opportunities for carer respite in each district and borough should be undertaken, as there is currently no consistent respite offer for carer breaks. Instead, carers are reliant upon charity organisations with long waiting lists.
8. Review long term carer support and the resources available when a carer cannot continue their caring responsibilities. Increase awareness of resources available for care planning for when carers are unable to care for their person.
9. Provide individualised and empathetic support for carers, recognising this may require flexibility, consistency and perseverance in encouraging them to accept it, as keeping carers healthy supports the work of health and mental health services.

## GPimhs/MHICS

1. Review which external roles could triage people for GPimhs/MHICS service other than GPs and allow Community Connector organisations and GPimhs/MHICS Lived Experience Practitioners to directly communicate with the GP when they identify someone in need of the GPimhs/MHICS service to improve integrated working and help reduce bounce when accessing GP appointments.
2. Residents lack clarity on what the GPimhs/MHICS services offer. Clearer communication is required about its purpose, the referral pathway, waiting time, type of mental health support provided, and its non-crisis nature.

## Minoritised ethnicities

1. Professionals from minority backgrounds should be supported and encouraged into working in mental health services – especially in clinical roles such as therapists or counsellors so people can choose to speak with someone who understands their cultural environment without having to explain the ‘why’ each time.
2. Develop a strategy to reach out to specific communities through mental health ambassadors attending community venues and events to promote services and support, and signpost to organisations.
3. Residents would like more opportunities for Mental Health First Aiders to be trained within minority ethnic communities to spread awareness of mental health, support and signpost people and break down stigma.
4. Ensure professionals record service users’ ethnicity, as this data can be used to understand need and access within minority ethnic communities.

## Unmet need

1. In the event of appropriate support not being available, professionals are to record ‘needs not met’ to flag the system and feed this information back into the wider system for learning and creating future commissioning plans.
2. Allow people to opt in to be contacted after discharge if their needs were not met and a suitable new service becomes available. Review any cases in which needs were not met after 6 months.
3. Link people to Community Connections newsletters, such as Mary Frances Trust, Action for Carers and Catalyst, as standard. Practitioners should explain what the newsletter is for and support clients to sign up within the appointment time to help streamline the process. These newsletters include information about existing support groups and keep people informed about new offers in their area.

## Training

1. Work with GPs to identify how to support their understanding of mental health and codesign additional bitesize training regarding psychiatric needs and medication, information around the local offer and partnership working across Primary Care and Secondary Care.
2. Partner with LGBTQ+ charities (e.g. Blossom LGBT CIC) to build knowledge and commission mandatory training for workforce to improve inclusivity and understanding.
3. Commission specialist training for mental health practitioners in primary and secondary care in the mental health needs of autistic and neurodivergent people, co-designed and co-delivered by neurodivergent people, to go beyond the basics covered by the Oliver McGowan training, covering:
   * The spectrum of neurodivergent conditions,
   * Considering neurodivergent presentation during mental health assessments, including understanding of masking, stimming, body language and communication differences,
   * The use of augmentative and alternative communication (AAC) for neurodivergent and mental health conditions and consequential communication challenges, including stress induced mutism,
   * Comorbid and cooccurring conditions and diagnostic overshadowing,
   * Recognising burnout, and how this can be exacerbated by conventional treatments for depression if it is misdiagnosed.

## Other

1. Identify a dedicated named lead within the mental health system to build and maintain working relationships with higher education institutions in Surrey and North East Hampshire, including University of Surrey; Royal Holloway, University of London; Merrist Wood College; Nescot College, Farnborough College of Technology and more. Direct working with universities and colleges will increase communication about support and services available to their students in the local community.
2. Establish peer-support groups or forums aimed at the Older Adult demographic (65+), which could also present opportunities to share lived experience to develop services and training. Current commissioned services for this demographic tend to focus solely on Dementia and loneliness, leaving other mental health needs of people in this age group unmet. Collaborating with knowledgeable local community support organisations like Age Concern Epsom & Ewell, Age UK, and faith centres is recommended.
3. Ensure CAMHS leavers are signposted to GPimhs/MHICS with clear instructions on how to access it, to support young adults to find the services they need in a holistic and timely way.

# Glossary and Acronyms

**Bounce** - When a person (and their carers/family): has difficulty getting into services, is passed between services, or is ‘dropped’ by services, has their view as an expert in their own lives disregarded in a way which results in that person’s needs not being met and an accompanying feeling of rejection and/or invalidation or trauma. (Definition from Surrey MHIP)

**CAB** - Citizens Advice Bureau

**CAMHS** - Children and Adolescent Mental Health Services

**Carers** - When this project refers to carers, this is someone who cares for a friend or family member who cannot cope without their support.

**CMHTP** - Community Mental Health Transformation Programme

**Cognitive behavioural therapy (CBT)** - A talking therapy that can help you manage your problems by changing the way you think and behave. It's most commonly used to treat anxiety and depression but can be useful for other mental and physical health problems. (definition from NHS)

**Community Connectors** - Specialist voluntary sector partners who work within the integrated mental health services. They work with their clients to access the local support they need. This can include drug and alcohol support groups; debt and housing support via organisations such as Citizen’s Advice; social networks to combat loneliness and isolation; volunteering opportunities; activities to enhance your wellbeing; employment support from Individual Placement and Support (IPS).

**Deductive coding** - Creating codes before doing data analysis and applying them to the data.

**Demographics** - Refer to the specific characteristics within a population and include things as age, income level and geographic location.

**GPimhs** - GP integrated mental health service in Surrey Heartlands ICS

**Holistic** - In the NHS the term “holistic care” refers to a method of providing healthcare that considers the entire individual, including their emotional, social, and psychological well-being in addition to their physical health.

**ICB** - Integrated Care Board

**ICS** - Integrated Care System

**Inductive approach to coding** - Generating themes from qualitative data/textual datasets.

**IMHN** - Independent Mental Health Network (Surrey and North East Hampshire). Network of people (aged 18 years+) living in Surrey and North East Hampshire that have lived experience of mental ill health or care for somebody with mental ill health.

**MHICS** - Mental Health Integrated Community Service in Frimley Health and Care ICS

**Qualitative data** - Non-numerical data that is collected and analysed, such as words, images, or observations.

**Quantitative data** - Numerical data that can be measured or counted. Often used in research and typically collected through methods such as surveys, experiments, and statistical analysis.

**Reflexive thematic analysis** - Continuous and reflective analysis, identifying, analysing, and interpreting patterns in qualitative data.

**SABP** - Surrey and Borders Partnership NHS Foundation Trust

**South Frimley Health and Care** - The Southern part of the Integrated Care System that covers East Berkshire, Surrey Heath, Farnham, and North East Hampshire.

**Space2BU** - Psychoeducation and skills training for carers of people with mental health needs (pilot service).

**Surrey Heartlands** - The Integrated Care System that is split in four place-based partnerships or Alliances: Guildford and Waverley; East Surrey; North West Surrey; and Surrey Downs.

**VCSE** - Voluntary, Community, Social Enterprise

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| Logo, company name  Description automatically generated | IMHN cropped.jpg |
| Independent Mental Health Network Surrey and North East Hampshire  Surrey Coalition of Disabled People (The Coalition)  Astolat  Coniers Way  Burpham  Guildford  Surrey  GU4 7HL | |
| [surreycoalition.org.uk](https://surreycoalition.org.uk) | [surreycoalition.org.uk/IMHN](https://surreycoalition.org.uk/imhn/) |