Appendix 2

NHS
Kent and Medway

Adult Attention Deficit Hyperactivity Disorder (ADHD) Review

November 2024 – February 2025

Summary

This winter, NHS Kent and Medway asked people for their views on how they think adult ADHD services might be improved.

Over the past few years, demand for ADHD assessments in England has risen at such speed that services are unable to keep up.

In the past two years, Kent and Medway has seen a rapid 600 per cent increase in demand for adult ADHD services. This is a national issue and waiting lists for a specialist assessment with the adult ADHD service can take several years.

We recognise that change is needed.

So, we have worked in partnership with providers and people with lived experience to understand the sort of support most effective for people living with diagnosed, undiagnosed or suspected ADHD, including family, friends or carers of someone living with diagnosed or suspected ADHD. We also welcomed feedback from representatives supporting Voluntary, Community and Social Enterprise (VCSE) sector or other organisations.

1,157 people took part in the survey and we also held events, two in-person and two online discussions, which 42 people attended.

What we have heard highlights significant challenges in accessing assessments and treatment, as well as support pre and post diagnosis. People said they would like tailored support, such as coaching, therapy, crisis services, financial and employment guidance. Other suggestions to help improve services include awareness and training for healthcare staff and GPs, better communication during the process, self-referral options, crisis escalation pathways, and a central directory for ADHD-friendly services. We also heard practical solutions, such as introducing a post-diagnosis welcome pack, text or WhatsApp reminders, and a visible NHS waiting list system.

We will now use this feedback to inform our plans as we look to commission extended support for people with ADHD.

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What we heard

There is a high demand and long waiting times with many respondents waiting several years for an assessment. This has led to additional impacts for some, who have then experienced issues with their mental health or had to rely on private diagnosis due to NHS delays.

More than half of the participants across both the survey and events are on a waiting list and not accessing support. Those who have accessed support have used a variety of tools, including an app (COGS AI) which was reported by many to be difficult to use, or online coaching which is said to be helpful but can be difficult to access due to timescales.

Further experiences include fearing judgment and feeling shame due to significant challenges around systemic barriers and a lack of centralised support for managing daily tasks, such as cleaning, paperwork, meal preparation, and the need for hands-on support. There were also many reports of finding it difficult to navigate services. People also shared ADHD-related struggles in accessing systems and facing penalties, increased risk of self-harm, and feeling a burden to carers or family.

We heard there are challenges with many health professionals lacking training, confusion around shared care for ADHD medication or referring patients for assessments. People also reported poor communication with the referral system with many feeling they were ‘forgotten’, ‘lost’ or ‘abandoned’ in the process. Some struggled with transition from child to adult services, requiring reassessments that create unnecessary delays. Many participants said that there is a need for pre and post diagnosis support, including more in-person support for ADHD, help with completing forms, follow-up care, medication management, parenting, peer groups, employment and financial guidance, therapy and coaching.

It was also suggested that communication is improved and that people on the waiting list are provided regular updates on their estimated waiting times. People would like better communication to patients around medication shortages. There were also calls for services to be more accessible, with self-referral options and in-person neurodivergent support and crisis support. This includes having accessible formats in ADHD friendly information e.g. short videos and written bullet points instead of wordy booklets.

People shared possible solutions. These included
- having a central place and directory for ADHD-friendly services
- care navigators
- dedicated crisis support
- therapy
- tailored mental health help
- support for carers and families
- a buddy system to provide emotional and practical support
- employment and workplace support.

Other suggestions include having a visible NHS waiting list system, multi-format communication methods (written, video, social media), a crisis escalation pathway and consideration of a partially funded diagnostic route to reduce wait times. One suggestion included introducing a welcome pack post-diagnosis with practical tips, local groups, tracking tools and self-care guidance. Many people said that their preferred method of contact was via text or WhatsApp and that they would like reminders via this route.

Some suggested that improvements could be around clearer triaging criteria and prioritising urgent cases.

Overall, most participants still seek a formal diagnosis due to its impact on treatment access, employment, and personal validation. There is also a clear demand for including increased resources, GP training, dedicated crisis and tailored support, and better awareness of and communication in ADHD services.

What happens next

We would like to thank each person who got involved and shared their views, experiences and ideas.

These findings will be presented to the Learning Disability and Autism Delivery Partnership Board, as well as being shared with Medway Council and Kent County Council’s Health and social care scrutiny committees.

We will then consider all feedback from this engagement, advice from subject matter experts and those with lived experience, as well as relevant national policy, to help inform decisions on how we can improve adult ADHD services. The results of which, will be shared in due course.

Background

Prior to starting this engagement, NHS Kent and Medway commissioners and the Communications and Engagement Team worked with the Adult ADHD Patient Reference Group (PRG) to develop a proposed model with the view to inform a procurement for ADHD assessment and support. While going through this engagement process, updated legislation meant that ADHD assessments would become a right to choose service and no procurement was needed for that aspect. Therefore, although we began by looking at a model it became apparent that the model wouldn't change significantly. We therefore focused our engagement on where patient experience would have the most impact, around the commissioning of support.

Methodology

Our approach to engagement was to gather insight into people's views, firstly through an online survey (Appendix A) that was shared widely across Kent and Medway.

We asked people about:

- What experience they have for an assessment, medication review or support
- What type of support they have accessed
- Whether the person is waiting for a dual diagnosis for autism and ADHD
- How could we make the experience of using adult ADHD services better
- What kind of support matters most for a person with ADHD/undiagnosed ADHD
- For those that do not have a diagnosis – what their preferences would be to access support
- If the person had support needed to live well, would they still want to seek/receive a diagnosis
- Whether they are seeking specific mental health support as well as an ADHD diagnosis
- Their thoughts about the proposed pathway and if there is any specific support to consider.

  Read the full survey in appendix one.

The survey was shared widely with the following community organisations who had experience of working directly with adults with ADHD who we wanted to hear from.

ADHD Aware
ADHD Sheppey
ADHD Sheppey Parent, Carer, adult Support Group
ADHD support for women and girls
Advocacy for All
AG Counselling
Ambitious about Autism
Arts without Boundaries
ASD Ashford
Bemix
Carers First Medway
Downs Syndrome Association
East Kent Autism & ADHD social
East Kent SNAAP (children SEN)
For Us Too
Imago
Insighful minds
Kent Autistic Trust
Kent PACT (although SEN 0 - 25)
Kent Parents and Carers Together
Medway MAGIC
Medway PACT
Medway Puzzles (adults with autism or LD)
Medway SEND Information, Advice, Support
Megan CIC
Mixmatched
Neurodivergent Friends in Thanet
neurodiversity social group
PCAS
Practical Wisdom
Shepway Autism Support Group

Shepway Spectrum Arts
The Education People
The ND Harbour Kent
The Omnibus Project
Together 21
We Got You
You Me and ADHD

Text messages were also shared with 4,000 people who had been waiting the longest for an ADHD assessment.

We also ran a social media campaign across Facebook, Nextdoor and Instagram to encourage people to complete the survey. Graphics for the social media campaigns are included in Appendix C.

A news story was published on NHS Kent and Medway's website with people directed to the Have Your Say website to complete the survey. The news story was also highlighted in our publications including:

- News for you (a community bulletin to 8000 people across Kent and Medway)
- GP bulletin (shared with 2000 people who work in GP practices)
- Stakeholder bulletin – 800 people who work in health and care partner organisations across Kent and medway

The survey was open 9 October 2024 and closed on 4 December, 1,157 people took part.

The second approach was to hold discussion events. A news story was published on NHS Kent and Medway's website which directed people to an Eventbrite page to book a free place. The events were promoted via Facebook, LinkedIn, Instagram and TikTok.

Medway Council, Ashford Borough Council and Kent Community Health NHS Foundation Trust shared the posts on their own Facebook pages.

A poster (Appendix D) was also displayed at:

- Chatham Waterfront Bus Station as well as The White House
- The Pentagon Shopping Centre (Bus info display)
- Medway Maritime Hospital Bus Stop
- Chatham Library & Community Hub

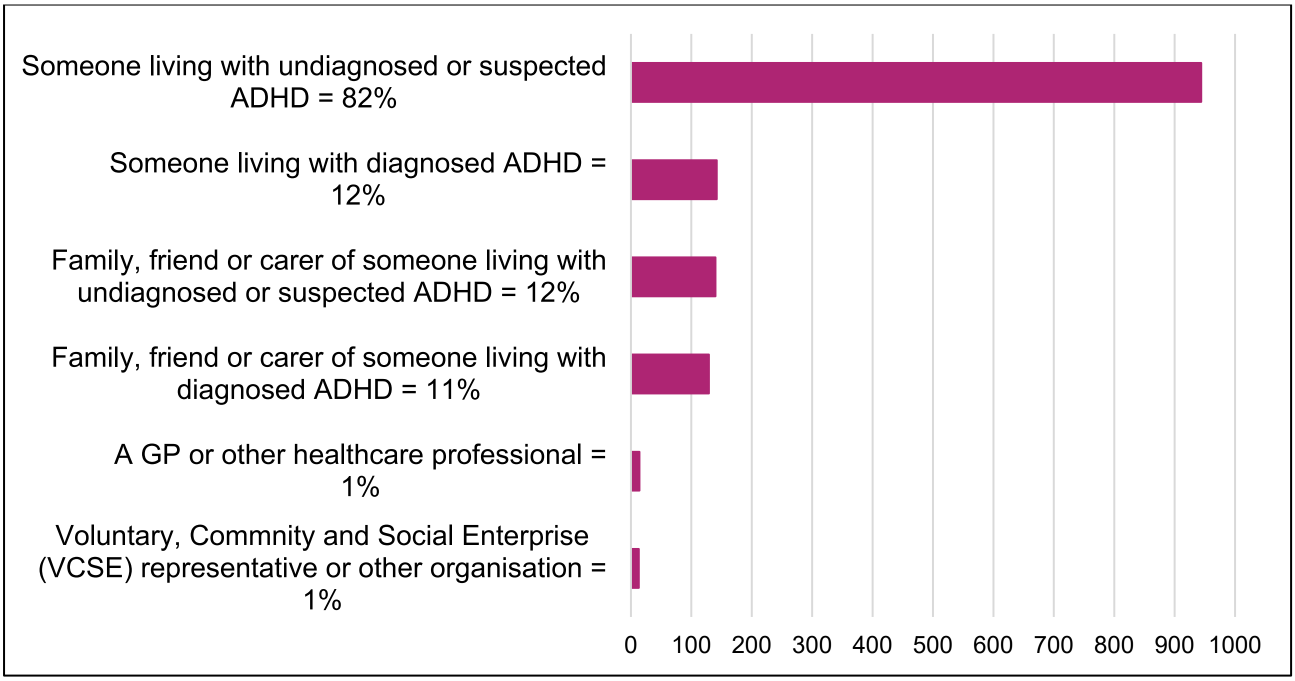
Two events were held in-person and two were held online. A presentation (Appendix B) was shared, followed by a question-and-answer session and then a detailed discussion where we asked:

- What type of support do you need?
- How do you want to access support?
- How can we provide the greatest amount of support to the greatest number of people?

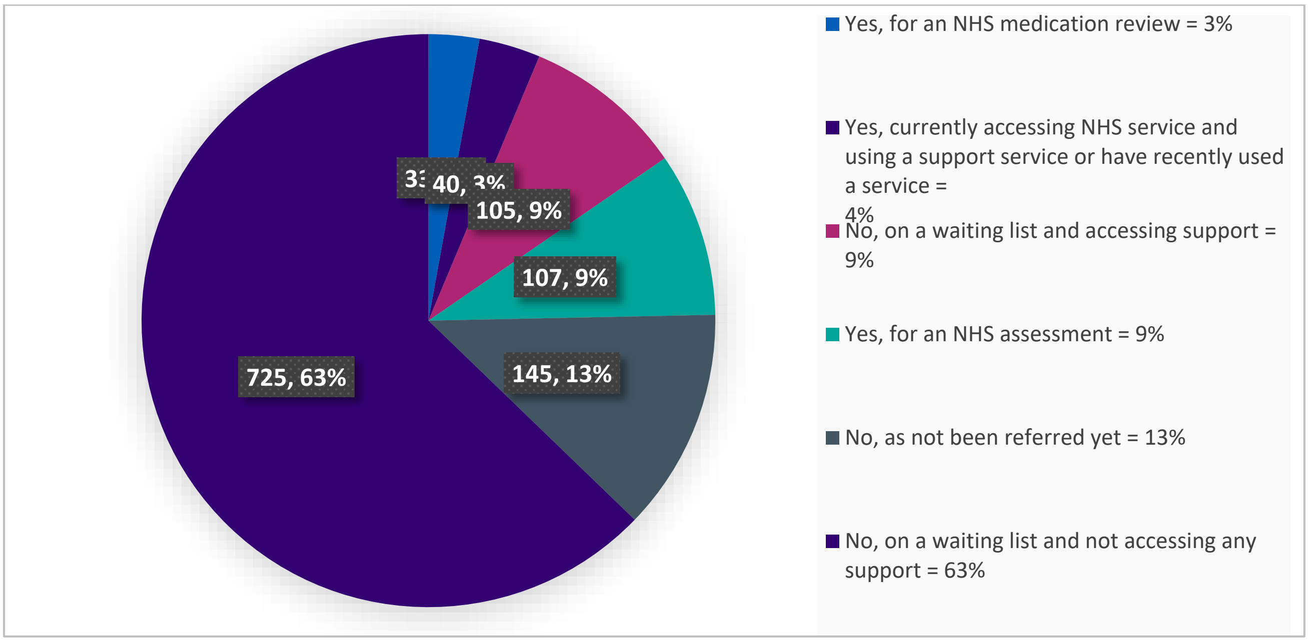
Both the survey and events were co-created with a patient reference group of people with lived experience and we thank them for their time, thoughtfulness and insights which improved both methods.

People’s experience with ADHD - survey responses

Question one: How would you describe yourself? Multiple options were allowed.



Question two: Do you (or the person that you know with ADHD/undiagnosed ADHD) have experience of using the adult ADHD service either for an assessment, medication review or to access support, e.g. app-based support or online workshops or group coaching?



Question three: Please tell us what type of support you are accessing e.g. app-based support, online workshop, group coaching etc.

This was a free text answer. 145 participants responded, the key themes are:

App support - COGS AI

The highest response was from 64 participants who said they use the COGs AI app. Some found the app challenging and difficult to use or not helpful. It was suggested that app-based services need to be more tailored and that support requires active engagement, which can be challenging for those with ADHD symptoms.

"An app called COGs which I personally find is more directed towards children with Autism. I haven't found it useful at all."

"I got sent a link to get the Cogs App. But for me it's not great as I have to actively remember to use it which never happens. And it was only free for 6months so not the best when I could be on a waiting list for years."

Coaching or online workshops - Practical Wisdom support

13 people said they access online workshops or coaching, however the name of the organisation providing the workshops or coaching was not provided.

16 participants said they access Practical Wisdom coaching or workshops which had some positive feedback about being supportive and helpful, but issues were raised with accessibility and being flexible with timing.

"I have had online coaching with Practical Wisdom which has been illuminating and really helpful."

"I have joined the practical wisdom coaching sessions; however, they are difficult to access live as they are during work hours. I do have the replay links but it's remembering to watch them! Saying that, they are useful."

Therapy and counselling - Many said they have accessed private tailored support (that includes assessment), medication and therapy. Feedback confirmed that counselling sessions, CBT and coaching are beneficial but difficult to access.

Not accessing support - Several said they were not accessing any support at all. Challenges include lack of understanding and accessing tailored support. One extreme example was a person who said they were: "Using alcohol, sometimes crack."

Paying for private support - Several participants said they relied on private diagnosis and medication due to NHS delays, incurring significant costs. Some want easier transition from private to NHS for medication purposes.

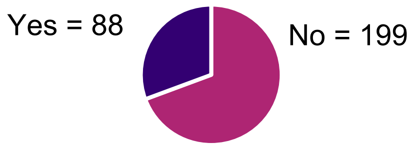
Respondents mentioned numerous types of support or services they use including:

- Access to Work
- Advocacy for All
- CBT
- COGs AI
- Counselling

- CPN
- Family and friends
- Finch AP
- Forward Trust (supporting people affected by drug or alcohol issues)
- Fraught to Focus
- GP
- Managing Emotions course
- Mindfulness
- Mum group
- Music
- Neurodiversity at work
- Peer support at school
- Research
- SEAS social activities
- Shared care with 360

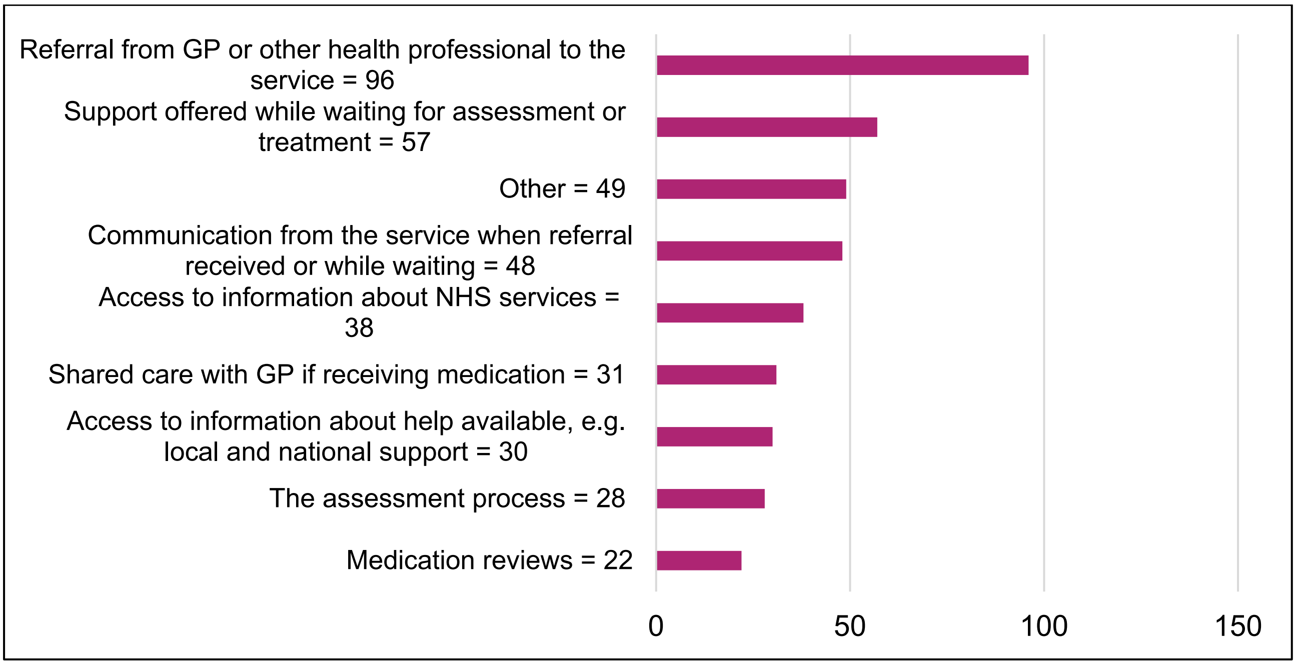
Question four: Are you waiting for a dual diagnosis for autism and ADHD?

287 people responded



Question five: What worked well in your (or the person that you know with ADHD/undiagnosed ADHD) experience of using the adult ADHD service (please tick all that apply)?

242 people responded.



The options less chosen, in order with least chosen at the bottom were:

- communication from the service when referral received or while waiting
- access to information about NHS services
- shared care with GP if receiving medication
- accessing information about help available
- the assessment process
- medication reviews.

Responses under ‘other’ (21 responses):

Right to Choose -Two participants mentioned the Right to Choose initiative, with one accessing private therapy.

> *“The right to choose initiative that meant I could get my diagnosis so much quicker. “Right to choose - if it wasn’t for the right to choose and paying for private therapy I would be struggling.”*
>
> *“The only thing that worked well for me was the part of the process that the NHS commissioned to a private provider. The rest of it has been poorly run, without information, and the waiting lists...................”*

Non-medication support - A participant mentioned the only thing that sounded positive is opting for non-medication support.

Specific concerns raised include:

- Being misdiagnosed with depression
- Dependence on private providers and issues with Psychiatry UK
- Existing services being inaccessible including moving from private to NHS
- Feeling unsupported
- Issues with GPs
- Waiting for two years and in the meantime buys street drugs
- Prolonged waiting times for diagnosis, titration and medication
- Receiving conflicting information and communication.

"It was all an uphill struggle. Diagnosis was a spectacular and unacceptable wait and was required for RA at an education setting. As such we were left with no option other than seeking a private diagnosis. The transfer to NHS for titration and medication was a further unacceptable wait. When eventually this was achieved after some issues, the method with Psychiatry UK was obscenely inaccessible for someone with ADHD. Having been discharged due to classic ADHD characteristics around exec functioning and forgetting passwords. It was a battle to get back on titration and then there was a shortage of drugs just when exams were being sat. You couldn't come up with a more ADHD unfriendly system if you tried."

Question six: *How we could make the experience of using adult ADHD services better?*

This was a free text answer.

981 people suggested improvements with the key themes being:

- Waiting times and diagnosis
- Communication
- Support pre and post diagnosis
- Information and awareness
- GP training and resource

Waiting times and diagnosis

More than a third (325) of respondents reported that services would be better if waiting times are improved. Many said they have been waiting several years for an assessment. The delays were said to impact existing conditions and mental health, work and relationships.

"Make appointments available. I still have not seen a hospital assessment face to face aside from filling in a questionnaire. I have cancer and should be prioritised for this clinical assessment now."

"7 year wait too long. I have given up. The same goes for Autism assessment where I had to pay for my own costing £2500, which then confirmed the diagnosis. I think I also have ADHD, but I can't face another assessment in 7 years, if it happens at all. You commission from a provider that outsources assessments to private companies, this disadvantages people who mask when assessments are online only (e.g. Psychiatry UK). The mental health trust (KMPT) doesn't have expertise in neurodiversity, so aren't neuro-affirming."

“Shorten the waiting list! Educate GPs more. There is still such a stigma to ADHD, especially adult ADHD. When I asked for my referral, the GP said, ' it can just be anxiety you know, it doesn't have to be ADHD.”

“I think by saying 'not everyone will need a diagnosis' in the narrative for this survey is not a fair assumption. If you had a suspected broken leg but the dr said 'it's ok, you don't need a diagnosis we're just going to try a few things before we bother with an xray as there's a long wait for one of those', that wouldn't be acceptable, would it? Without a diagnosis people cannot make an informed choice about the path they then take. Medication may be the thing they need to improve their quality of life and sense of purpose and achievement. I assume you need a diagnosis to be prescribed medication. Denying anyone this, or any other potential care and treatment pathway is inhumane.”

“Quicker diagnosis. I am in my 60’s and ADHD is worst it’s ever been. Feeling suicidal a lot these days.”

Communication from and between services

126 people said they want improved communication overall with regular updates on referral status, estimated wait times and available support options. Some concerns were raised about having no communication at all since being referred and the impact this can make. With little or no communication, many people saying they felt “lost”, “abandoned” and “forgotten”. It was further suggested that position on the waiting list is trackable.

There were also suggestions that less paperwork would be helpful as it can be overwhelming. Feedback included that the process could be simplified with easier to understand communication, more local services and support, help with forms and the consideration of a helpline

“I’ve been on the waitlist for months with no communication. I understand that services are overstretched, but having regular communication about anticipated timelines and next steps would make it easier. At present, I’ve heard nothing and am concerned I’ve been forgotten.”

“It would be nice to get acknowledgment of receipt of the referral and every six months, perhaps, a letter or text saying he's still on the list. He was referred by the GP several years ago, but I have no idea if the referral means he's on the list or dropped off it. But as he has other disabilities, this would be helpful, because it might mitigate his other problems.”

“There is a total lack of communication, you go from one place to another, getting in touch in one place would be ideal not “go to the doctors, for this medical review elsewhere, checkups somewhere else, access to services all online’ its completely draining and puts you off, then you miss one appointment due to all the constant mix ups and you have to restart - a one place for all this would be ideal.”

“Give some indication of your position on the waiting list and dynamic updates of current wait time. It's so frustrating to be left on a waiting list that is currently measured in years with no updates. I feel abandoned and that my mental health doesn't matter.”

*“Help with forms, easier to understand. A couple of suggestions included having a helpline
Easy to access. Many older people with undiagnosed ADHD treat it as a stigma, something that they just have to get on with and will often not really accept it which makes it really hard for those of us who are married to them. Too many obstacles to overcome to access help (once they admit that they need it) will just put them off.”*

"Less and more simple writing. There is an information overload all in written form. I can't process words that I read, so I have to read it over and over again before any of the information sticks in my mind. This means I avoid reading majorly. It causes me stress (because I might be judged as being lazy for struggling to read as people might think I don't want support) and frustration with myself for not being able to do it."

Support pre and post diagnosis

69 people said they had little support and that the digital app was unhelpful or patronising. It was suggested that more accessible support is provided pre and post diagnosis in the form of peer support groups, coaching, therapy, help with mental health and coping strategies. There were also a couple of suggestions on having a service that checks in with people waiting.

"Providing supportive services over the course of the waiting period as opposed to a 6-month trial of an app when the wait time is 7 years. Some form of counselling/mentoring/therapy would be useful and more signposts to support groups."

"Support after diagnosis, particularly for those who do not wish to take medication. There was confusion about my referral to the provider's own counselling service, after which GP could only offer me a generic counselling service renewal. Not sure what aftercare for ADHD looks like but doesn't appear to be much in place."

"I got offered the use of COGs and Practical Wisdom which has been life changing for me. It would of been helpful to have links or signposting to decent ADHD support on social media or where to find out more, I've done it on my own and have found some good groups after trial and error and am in a good place now."

Information and awareness

65 people want to have more information and guidance about getting a diagnosis, or a dual diagnosis and what support is available. One person said they wanted information about why they have been refused an assessment.

People would like more awareness of what support is available, symptoms of ADHD including symptoms with co-existing conditions and information to break the stigma.

"Create an awareness of what support could be available. Following my diagnosis which was done on the NHS I was told if I didn't accept stimulant medication I would just be discharged because there was no other support available. For personal and health reasons I did not want to take this medication and felt very let down that other options and interventions were not made available to me. I have spent many years coping alone with no support and been told there is no support just medication if I am referred back in. This is really challenging."

"More awareness for symptoms of ADHD to appear postpartum."

"Better information given at first point of contact, better explanation of different avenues for getting a diagnosis (right to choose, etc.), in general GPs should be better informed on how to progress an ADHD referral."

"More information on both ADHD and autism. Having bring diagnosed with both within the same year I haven't had any support or guidance. All I know about either is from Google or TikTok."

Healthcare professional training and workforce resource

75 comments were made about skilling the workforce and improving resource across the system. There were many comments suggesting additional training for general practice staff about ADHD, so patients feel ADHD is taken seriously, and general practice can offer support in signposting and referring. There was also a suggestion to give more authority for general practice to diagnose, prescribe and to make changes to medication. Some people were dropped from services without available support options, some had to travel or pay for private prescriptions, and it was suggested that patients should be able to self-refer.

People suggested more funding, more skilled and qualified professionals, allowing more providers to conduct assessments, and to address increase in demand with more resource.

“Better knowledge - I spoke to my GP about my potential ADHD diagnosis and was told "if you had ADHD, you wouldn't be able to have a conversation with me right now, you would be stepping into traffic without looking first as you can’t focus". because of this I had to do NHS right to choose, to choose the only place I found on Google searches for help (private) am on a waiting list and have no idea of NHS services to support me.”

“I have not had any help; I have been on a waiting list for years. I decided to get a private assessment and over 2 years after my diagnosis have changed GP surgery and found a lovely surgery that has accepted Shared Care. So, after more than a year of paying for private prescriptions, I have just had my 1st NHS prescription. Being on ADHD medication has changed my life for the better. So, I would say just about everything needs to change, especially the attitude towards ADHD from a lot of GPs. I think some up-to-date training on ADHD would be a good idea.”

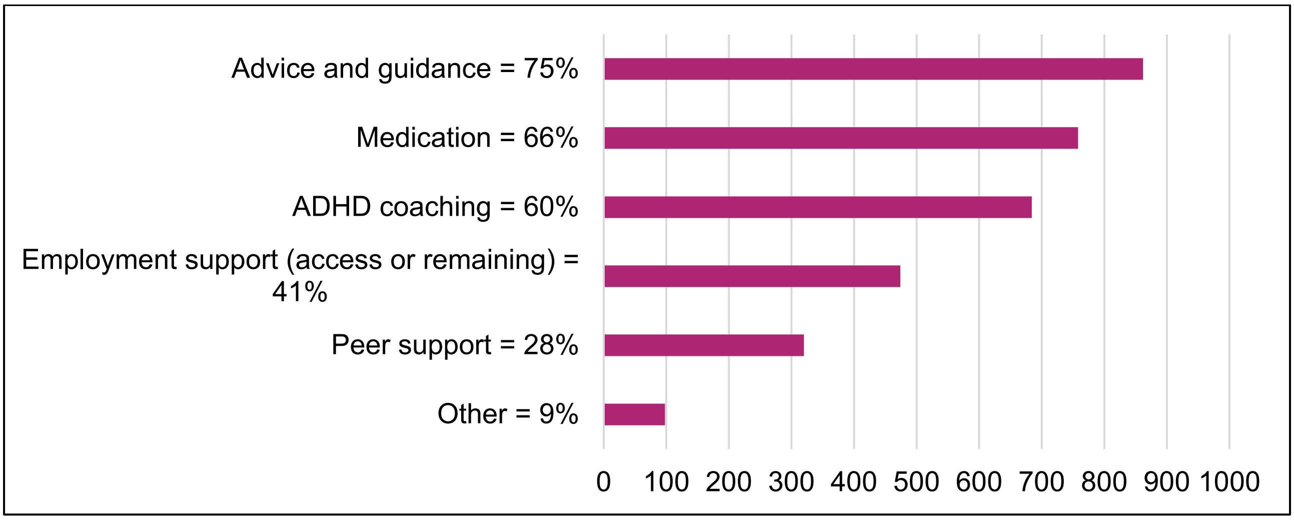
“I mean easier said than done but bring the waiting list down as soon as possible. And GPs need to be less resistant to shared care agreements. I’m worried about going down the private diagnosis route and then being stuck paying for the medication because of the many stories I’ve heard of GPs refusing to accept shared care agreement. I can save up for the private assessment and titration possibly, but ongoing medication is unaffordable to stay private. Going years without a diagnosis feels like I’m getting even more behind all my peers, and I can’t catch up - it affects my ability to work and focus. And I can’t even access disability support without a formal diagnosis.”

“To address the increase in demand, you should hire more staff to effectively manage the situation and reduce waiting lists. Additionally, you could consider involving community mental health teams in the diagnosis and prescription of ADHD medication, which will further help decrease waiting times. It’s also important to provide better support for KMPT colleagues who are currently on the waiting list for assessments.”

“More funding into the service to lower wait time and GP taking all requests seriously and not playing them down or disregarding our concerns from a simple look.”

Question seven: ***What kind of support matters most***? Six options were provided.

1,149 people took part and were able to choose multiple options.



The least chosen option was for ‘other’ information and there were 53 open responses themed around:

Getting a diagnosis - most responses were around the importance of getting a diagnosis (so people can understand themselves better, access accommodation and also get support at work).

Support pre and post diagnosis -
Participants also shared a need for support pre and post diagnosis, including support for:

- 1:1 unlimited coaching session rather than a group
- awareness
- CBT with medication (currently not offered)
- coaching from a lived experience coach
- completing forms
- complex needs
- day to day life and coping strategies
- training education, work and health care professionals including acceptance
- financial and housing support
- medication
- mindfulness and managing symptoms
- parents, families and carers – managing relationships
- understanding both autism and ADHD
- waiting times

A sample of quotes include:

“Access to groups and classes which could be beneficial in managing symptoms such as yoga, mindfulness, psych ed classes.”

“CBT is recommended alongside medication for the best possible outcomes but isn’t offered for children or adults.”

“People giving coaching or training must be people who are themselves autistic or with ADHD and never a person who is neuro typical. You need to have a foundation based on reality not false pretence which a neuro typical person will never understand the world we live in and never will so

this is critically important as it takes time building a relationship with people and the approach must always be focused by being person centred as we are all different."

"Coping strategies."

"Educational support and being able to make adjustments for university."

"Training for employers to allow them to better support staff with ADHD."

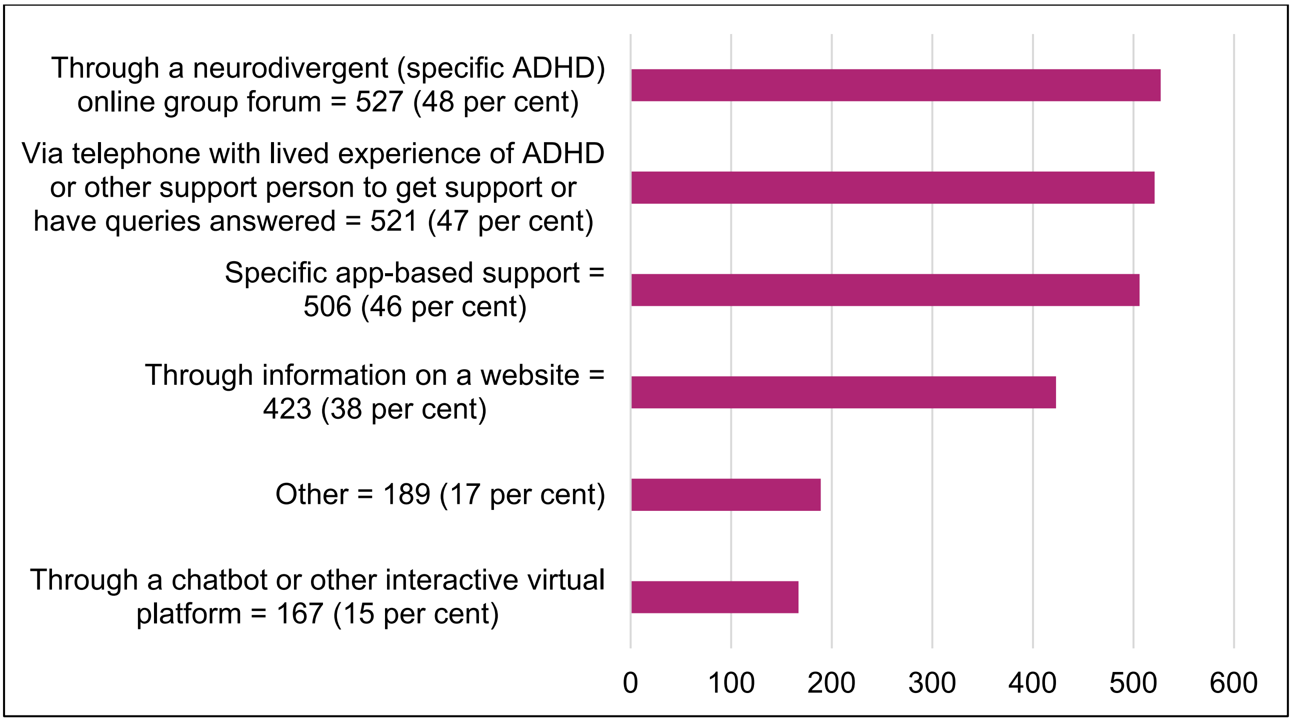
"Support/ helpline for carers/parents."

"Relationships - how to maintain relationships with partners, children and friends."

"Just help with our day-to-day life."

Question eight: How could we support people better who do not have a diagnosis and if they were able to access support without a diagnosis, how would they prefer to do this.

1,102 people responded and chose multiple answers from six preference options.



106 included open responses that have been placed into themes below:

Face-to-face, in-person and coaching support
28 people said they would prefer face to face, in-person support (e.g. therapy, CBT) and coaching support. A couple said they would prefer this with a specialist. This is important for people who find online resources frustrating. Some said they want tailored support with trained professionals.

"Coffee mornings, support groups face to face as I hate using tech and get frustrated easily."

“There needs to in-person support and not just all available online. ADHD can be really lonely and it's only when you meet others with ADHD do you feel less alone.”

“I would still wish and like to be seen by a professional that understands ADHD, I feel hiding behind technology you don’t and won’t get the full extent to how my undiagnosed ADHD has affected my life in every aspect. More face-to-face support groups are needed.”

Diagnosis delays
Nine (eight per cent) others said they need a diagnosis which have long waiting times and hinders access to support, with one in particular who wanted a diagnosis to share with their work and another who said they cannot get help without a diagnosis. One person said they were misdiagnosed.

“The whole point of me seeking a diagnosis is for documentation to present to my work.”

“There is no help without a diagnosis.”

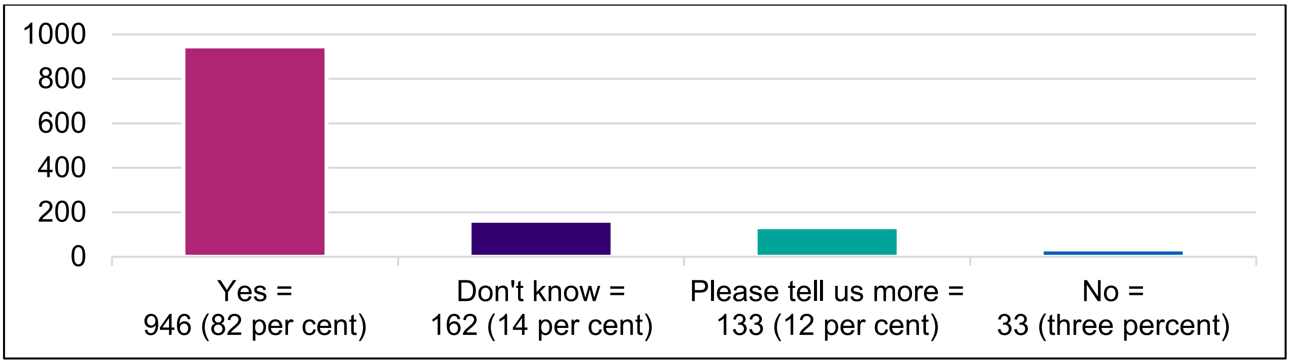
“By making waiting list status more accessible - updates on how long to wait by having been on the waiting list more recognised within workplaces and uni, otherwise adjustments are not made in adequate time - perhaps having coordinator to facilitate these discussion Mental health support from suitably trained and experienced mental health professionals. Employment and education support.”

Lack of validation and respect
Participants shared experiences of feeling dismissed with lack of compassion from healthcare staff, who would benefit from training.

“Initially, it would be important for professionals to show respect towards what you are going through, to not feel like a number and to actually feel like you're being heard. Validating experiences is really important. It is hard to say what would help after as, in my experience, I struggle to keep up with certain things, keep track and up-to-date information, I also struggle to recollect my day. This being said, it would be useful to have a forum of like-minded people as currently I'm just finding things on social media which can be great, but it can also be destructive.”

Question nine: *If you had support you needed to live well, would you still want to seek/receive a diagnosis?*

1,151 people responded



69 people provided open responses themed as follows:

Importance of diagnosis
Most comments (29) were about needing a diagnosis for own validation and in order to access treatment and get support around struggles with day-to-day life and feeling misunderstood.

Misconceptions around neurodivergence can make an impact so access to support and treatment is paramount for undiagnosed individuals, especially for families and in work and education settings.

“The difference a diagnosis makes to the person is immense. It proves to us - especially us older people - that we were never mad or bad - just different - and our ADHD was NEVER our fault.”

“I would NEVER have got a diagnosis if it wasn't necessary I hate having to label myself just to get the support I need to live normally, diagnosis are becoming more prevalent because this support isn't being provide elsewhere in society such as in universities and the work place, people need to be educated and put in place systems that support neurodivergence because living in society has become simply incompatible with it.”

“Yes, probably because professional services do not accept that you may have an issue without GP evidence. Everyone is affected differently and has different support needs but without a diagnosis your needs from other organisations are dismissed and your sometimes penalised.”

“I need a diagnosis to get help in the workplace and through the rest of my life. Services change from place to place, but a diagnosis will carry through to all areas of my life. It is evidence of disability and protects me from discrimination. It will help me access support and treatment options in all areas and stages of life.”

“I think without a diagnosis, you are only treating the symptoms (like applying a band aid but never treating the underlying cause). A diagnosis could help you understand where the symptoms are coming from, help you put in place measures to better cope with this and have medication or treatment specifically for that. It’s like you saying your leg hurts and the doctor saying well as it hurts just ice it and take painkillers as that will treat the symptom of pain, but without an x-ray to diagnose it how do you know if it might be broken or need surgery. Treating only the symptom doesn’t resolve the issue and why should mental disorders be treated differently to physical?”

“Yes, because it's as much about the support as it is about the validation of the diagnosis. When you've gone your whole life feeling/being treated differently and struggling but not knowing why or not being believed we need that diagnosis for our own mental health but also to protect us in regard to discrimination in education or employment etc.”

“I have lived 27 years not diagnosed and handling it myself and it has been tough, but it gets to a point where you need the help, especially when thinking of having kids. They'll need me so I need to have ADHD under control for them.”

“Yes, because it helps understand why I’m the way I am and hopefully get better support and more specialist support happens with diagnosis (hopefully).”

“I would like to understand the way I am thinking and feeling about certain things, I have been informed that many of my symptoms may be Neurodiverse rather than anxiety and depression which it has been diagnosed as.”

Medication

Nine people commented about medication, including needing it to get by and being reliant on a diagnosis to access medication.

“Unlike autism, there is medication that can help with ADHD - and this is inaccessible without a diagnosis.”

Question 10: *Are you seeking specific mental health support as well as an ADHD diagnosis?*

426 were already accessing mental health support
459 were not seeking mental health support
267 people were seeking support and were asked to clarify what they were seeking.

143 participants added comments around the primary themes of:

- anxiety and depression
- therapies and counselling
- challenges around sleep
- access and waiting times for services and lack of awareness or barriers and impact on day-to-day life and support needs.

Anxiety and/or depression

39 people said they are seeking anxiety and depression support. Many have been prescribed antidepressants or anti-anxiety medication, but it is not tailored to ADHD needs. Impact on daily life and wellbeing are mentioned e.g. sleep (insomnia) and difficulties accessing better ADHD specific mental health support add to anxiety and depression.

“I'm hoping that if I can treat my ADHD symptoms, I will no longer need repeated (and not always successful) treatment for anxiety and depression. I think there is a chance that my mental health will improve with the correct medication or access to strategies.”

Therapy and counselling

23 people said they are accessing a type of therapy including talking therapy, CBT, private therapy, one mention of private psychotherapy and three mentioning seeing a psychiatrist. Whereas 11 people said they were accessing counselling, with one person requesting help or suggestions around ‘EDMR’. Five other people said they are seeking mental health support.

“I’ve done CBT and a lot of counselling. All of it says my ADHD makes it worse. But because I can’t get any diagnosis or treatment, I’m stuck in this loop of life being miserable.”
“I've had CBT, DBT, and counselling, and still qualify for further counselling; the problem is getting hold of GPs and mental health services for help.”

Sleep

13 people mentioned seeking support for trouble sleeping.

“Everything listed above I find it hard to sleep I feel like I can't shut off I'm always worried about what people think of me because I tell people how it is.”

Autism

11 people are seeking support for autism.

“I have autism, and depression and anxiety associated with that and the suspected ADHD. I've tried to seek support from MH services via my GP, and through other charities and services. I've been basically told by the different places that either I'm not in a bad enough state for them to help because I'm just about coping and can work etc (mostly by MH teams), or told that I'm too bad for them to really deal with (mostly by GPs and MH nurses), that because I have autism I need to go to an autism support charity (by MH teams), but I should go to a MH health team because charities can't deal with associated MH conditions. So basically, I end up getting passed from pillar to post.”

Question 11 asked participants for their views on a proposed pathway and if there was any specific support to consider.

This was a free text question. 835 people provided open responses themed as follows:

Challenges with healthcare professionals' knowledge and understanding
Many respondents feel that GPs lack sufficient training and information to recognise ADHD and will be a barrier, potentially leading to misdiagnoses or refusals to refer patients, making it harder for individuals to access specialist assessments. One person asked how someone could appeal. People also mentioned that they needed support pre and post diagnosis.

"GPs don't have the knowledge or training to recognise someone with ADHD even mental health psychiatrists don't have the training to recognise it instead branding many adults with common mental health conditions when they don't have the condition."

"I do not think that most GPs have the expertise or understanding to judge whether a person needs a diagnosis or not. This pathway puts all the onus on the individual to convince the GP that they are worthy of a specialist assessment. It is a way of rationing diagnoses which could be transformative for people living with undiagnosed/untreated ADHD. Many employers will not put reasonable adjustments in place without an official diagnosis and people with ADHD cannot know the difference that medication could make to their lives without having the opportunity to try it."

"The process looks ok, but is there an opportunity to appeal the outcome if denied an assessment or you disagree with the diagnosis?"

The proposed pathway does not seem different
There were many comments around the proposed pathway not seeming significantly different from the current system, leading to scepticism about its effectiveness to reduce waiting lists.
Some respondents feel it creates additional bureaucratic hurdles rather than simplifying access to diagnosis and treatment. Many feel that clearer triaging criteria should be introduced to prioritise urgent cases.

This pathway seems no different to what currently happens. I went to the GP and was referred on, that does not make the waiting time for a full assessment any quicker. There needs to be a triage with specialist who can prioritise assessments for those who are in more immediate need (in crisis, cannot access work or unable to manage day to day life due to the overwhelm of their symptoms) to be seen sooner. Some people's traits are more apparent than others so should be able to be diagnosed quicker than those who maybe need more evidence.

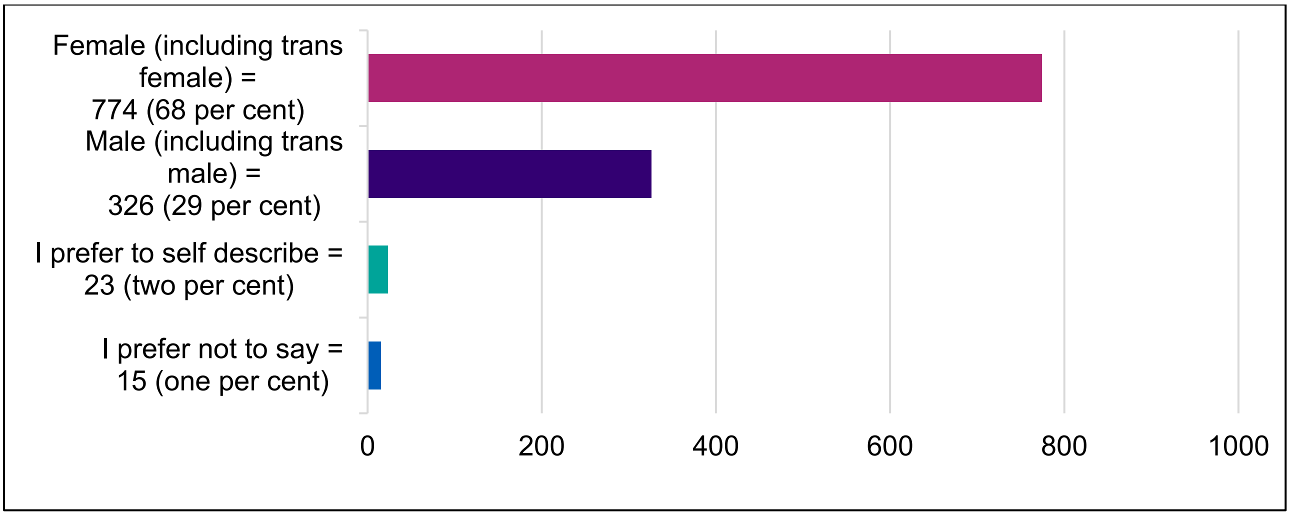
Suggestions for improvement

"This is helpful. However, it does not include information about the Right to Choose pathway. This should be included. There are very limited free or low-cost ADHD services for adults. There is no free coaching. Will it be signposting to all private support? You should include the fact that the person is likely to end up on a waiting list for years, rather than being "offered an appt"."

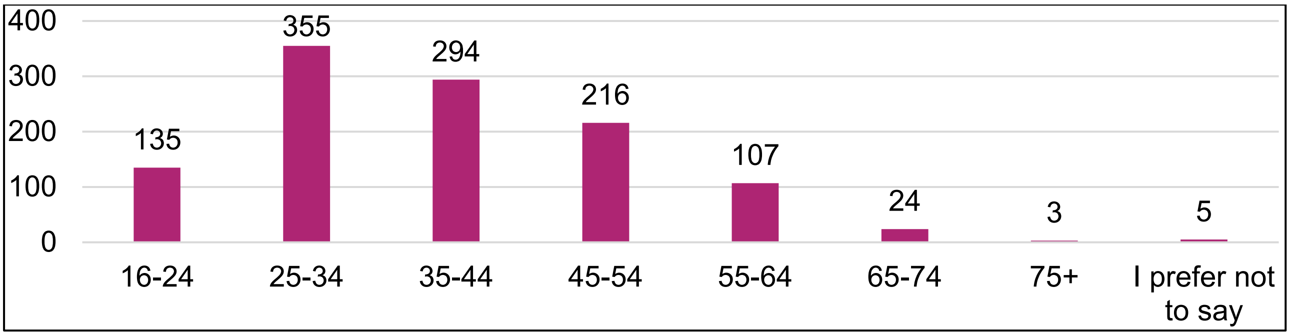
"The pathway seems fine, however the times between the pathway outcome and assessment is hard."

Survey demographic breakdown

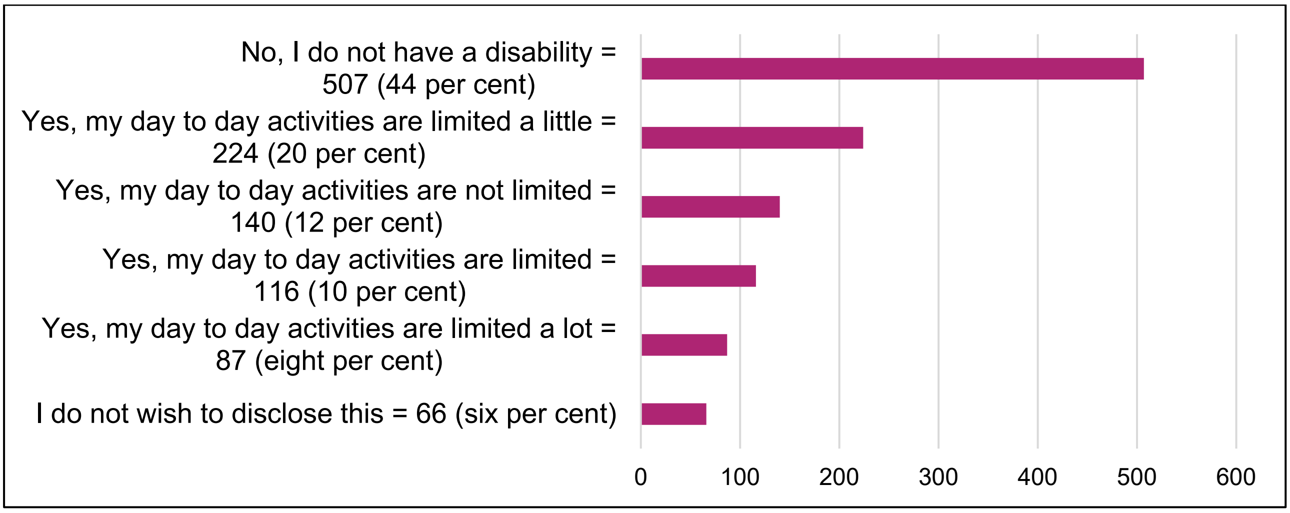
Gender: 1,138 people provided a response



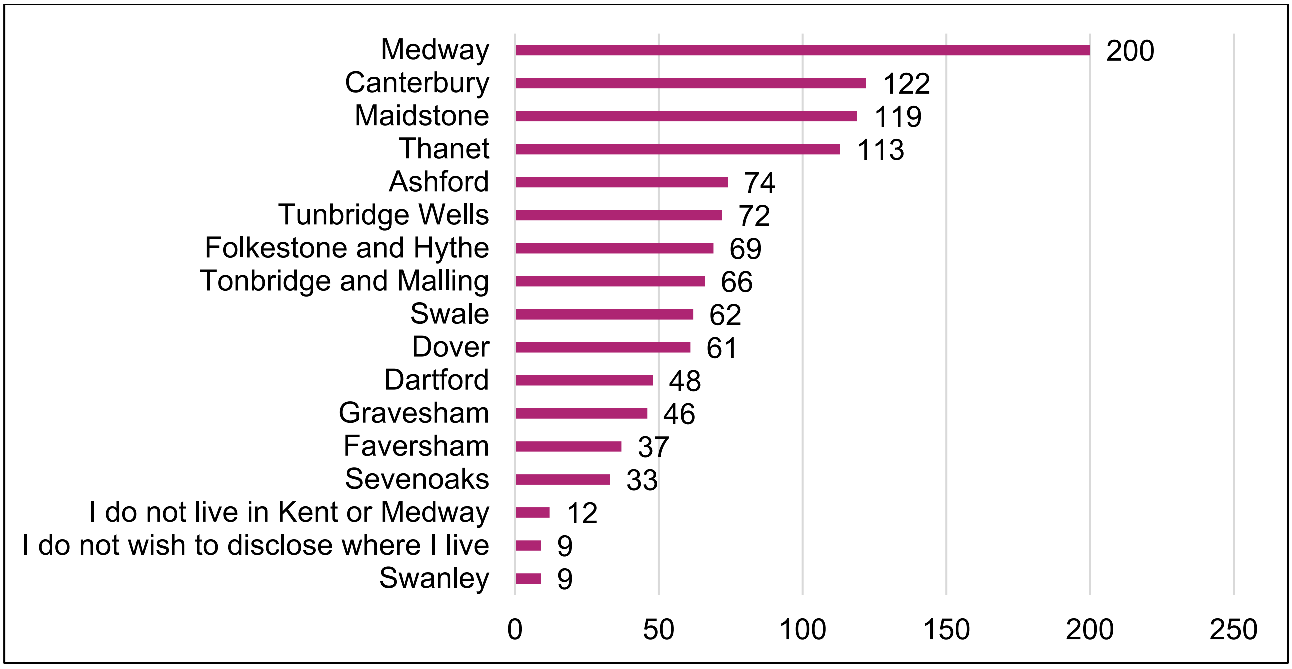
Age: 1,139 people told us their age



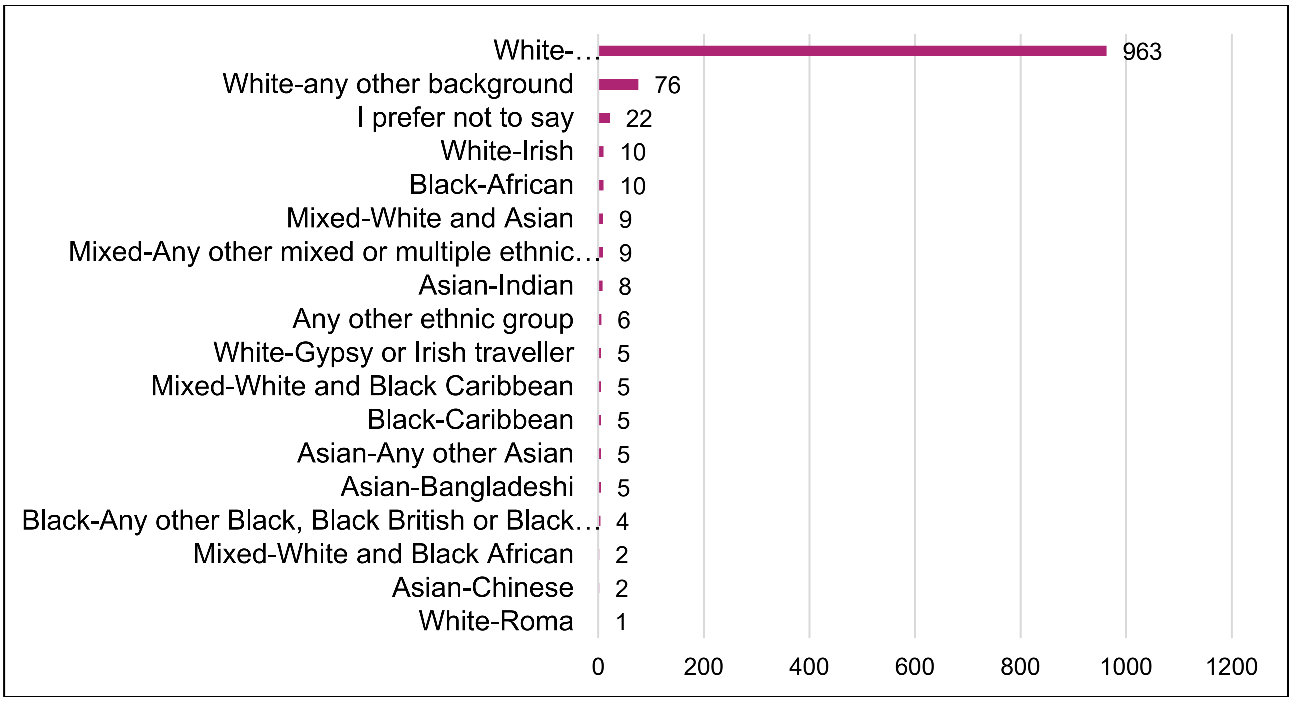
Disability: 1,140 people answered this question



Resident areas: 1,152 people told us the town or area they live



Ethnicity: 1,147 people provided a response to describe their ethnicity.



Events

Four events consisting of in-person discussions in Medway and Ashford and two online discussions, open to any participants across Kent and Medway were held in February 2025. We planned the events to be as ADHD-friendly as possible, thanks to helpful advice and guidance from the patient reference group. We ensured these were offered at different times of the day and that the in-person discussions were held in a safe space, with consideration of accessibility, natural light, the environment and having a separate quiet room. We also shared public transport and driving details with photos of the building, car park and provided a What3Words address, to participants.

In total, 42 people took part, with many sharing common experiences:

Access to support
We heard how many experiencing long waiting lists, and how transition gaps from child to adult services make it difficult for individuals to receive care. Struggles with navigating systems, often missing deadlines and facing penalties, were also raised.

GP shared care and prescribing
Several participants said GPs are opting out of shared care, and it was felt they lack expertise in ADHD, medication reviews and treatment. Further concerns were around transitioning from private assessments to NHS and feeling abandoned after diagnosis with a lack to meaningful support.

Treatment
In some cases, there are barriers around medication shortages, and confusion over shared care agreements. This includes limited options for ADHD-specific therapy or ineffective treatments such as CBT instead of DBT in some cases.

Impact on ADHD patients
Participants shared their experiences about the impact ADHD has had on them, including increased risk of self-harm, struggles with daily tasks and finances, and lack of structured support after diagnosis. Shame, frustration and forgetfulness cause difficulties in organisation, paperwork, and basic tasks. There is also a fear of judgment or feeling a burden to families or carers that prevents many from seeking help. Some raised the importance of ADHD symptoms often being misinterpreted, especially if masking many factors, leading to misdiagnosis and inappropriate support. Other challenges include securing and maintaining employment with difficulties navigating and adapting to reasonable adjustments.

Ideas for solutions

Participants shared their ideas about possible solutions to help improve services as follows:

- **Support systems**: A centralised directory for ADHD-friendly services, alternative prescribing hubs, stimming aids and practical tools, structured aftercare and peer mentoring programs. Introduce a welcome pack with practical tips, local groups, tools and self-care guidance.

- **Employment and workplace support:** Job coaching, ADHD peer supporters in workplaces, and clearer guidance on reasonable adjustments.

- **Communication improvements**: More transparent waiting list systems, proactive outreach and follow-up, better GP awareness and neurodivergence-friendly communications and services. Keep people up to date about medication shortage.

- **Accessibility**: Send SMS/WhatsApp reminders for appointments, ADHD-friendly online resources, and AI-driven support tools.

- **Community support**: Face-to-face meetups, parenting support, online coaching, wellbeing checks, and ADHD-friendly home assistance (cleaning, organisation help).

- **Neurodivergence-aware crisis and therapy**: Dedicated crisis support tailored and compassionate to ADHD needs including mental health services, CBT/DBT access, and care navigators to assist individuals in finding help. Provide training and awareness to all healthcare staff including GPs.

Some participants shared their thoughts about what they found most useful about taking part in the discussion:

“Meeting peers.”
“How people genuinely listened and wanted to help.”
“Seeing there’s listings and possible actions to be taken.”
“The staff and organisers were welcoming and warm. It was good to engage with fellow ADHDers and not feel so alone.”
“Hopefully helping shape support in Kent and Medway. Personally great to meet other ADHD people and hear experiences. Instructions EXCELLENT (although I almost missed email) I’m not sure what more could have been done, a reminder call/text?”

This includes what they found was *not* so useful:

“Struggling with having faith that things will improve.”
“Sometimes the layout of info made me lose focus. I found the interactive activities (discussions) most engaging.”

Conclusion

We would like to thank each person who shared their views and experience.

What we have heard highlights significant challenges in accessing ADHD assessments and support services, with long waiting times. Participants raised the importance of support pre and post diagnosis that is tailored to the person's needs such as therapy, crisis services, financial and employment support. Current resources, such as the COGs app has been reported as difficult to use or unsuitable, and the online coaching, though beneficial, can be improved.

Participants reported systemic barriers, including judgment, shame, and difficulty managing daily tasks without hands-on support. Responses to the proposed pathway included concerns around ADHD-related struggles navigating services and facing penalties and getting access to medication. A lack of training for health professionals, triage criteria, and poor communication within the referral process further exacerbate these issues, which currently leave many feeling "forgotten" in the process.

Suggestions to help improve services include offering more tailored and accessible support, training for health professionals, and better communication overall including multi-format ADHD information). This includes offering self-referral options, crisis escalation pathways, and a central directory for ADHD-friendly services. We also heard practical solutions such as introducing a post-diagnosis welcome pack, text/WhatsApp reminders, and a visible NHS waiting list system.

Overall, we heard the need for better communication, awareness, training, and getting the right support pre and post diagnosis. And for many, we heard that they feel a formal diagnosis is still necessary to be able to access support as well as treatment.

"Thank you for organising this and making me feel like something might actually happen to help this group of vulnerable people."

NHS
Kent and Medway

Appendix A – full survey

NHS Kent and Medway is reviewing the adult ADHD (attention deficit hyperactivity disorder) service, and we want people's views on how they think the service might be improved.

Over the last few years, demand for ADHD assessments in England has risen at such speed that services are unable to keep up.

In the past two years, the Kent and Medway area has seen a rapid 600 per cent increase in demand for adult ADHD services. This is a national issue and waiting lists for a specialist assessment with the adult ADHD service can take several years.

We recognise that change is needed. Getting a diagnosis is not the only route to support and many people will not need an assessment if they can access appropriate support at the right time for example: app-based support from COGS-AI, web-based support, national websites, and online group coaching via Practical Wisdom. So, we have worked in partnership with providers and people with lived experience to develop a proposed model and new pathway (detailed in this survey) that we would also like your views on.

This survey is for people living with diagnosed, undiagnosed or suspected ADHD, including family, friends or carers of someone living with diagnosed or suspected ADHD. We also welcome feedback from representatives in supporting Voluntary, Community and Social Enterprise (VCSE) sector or other organisations.

There is also a demographic section (to capture age, gender, disability etc.) that will help us measure fairness and bias around the system. The information you supply will not be used for any other purpose. Your data will not be shared with any third party. Details of how we handle your data can be found on our website.

All feedback will be analysed, and we will publish a report about your views and how we will be improving services as a result of the information you've shared.

Please note that this survey will take 10 minutes to complete and is open from 9 October 2024 and will close on 4 December 2024.

1. How would you describe yourself?

○ Someone living with **diagnosed** ADHD
○ Someone living with **undiagnosed or suspected** ADHD
○ Family, friend or carer of someone living with **diagnosed** ADHD
○ Family, friend or carer of someone living with **undiagnosed or suspected** ADHD
○ Voluntary, Community and Social Enterprise (VCSE) representative or other organisation (please specify below)

2. Do you (or the person that you know with ADHD/undiagnosed ADHD) have experience of using the **NHS** adult ADHD service (please tick all that apply)?

   - ○ Yes, for an NHS assessment
   - ○ Yes, for an NHS medication review
   - ○ Yes, currently accessing NHS service and using a support service or have recently used service
   - ○ No, as not been referred yet
   - ○ No, on a waiting list and not accessing support
   - ○ No, on a waiting list and accessing support

3. Please tell us what type of support you are accessing e.g. app-based support, online workshop or group coaching etc.

4. Are you waiting for a dual diagnosis for autism and ADHD?

   - ○ Yes
   - ○ No

5. What has worked well in your (or the person that you know with ADHD/undiagnosed ADHD) experience of using the adult ADHD service (please tick all that apply)?

   - ○ Access to information about NHS service
   - ○ Access to information about help available, e.g. local and national support
   - ○ Referral from GP or other health professional to the service
   - ○ Communication from the service when referral received or while waiting
   - ○ Support offered while waiting for assessment or treatment
   - ○ The assessment process
   - ○ Medication reviews
   - ○ Shared care with GP if receiving medication
   - ○ Other (please specify below)

6. How could we make the experience of using adult ADHD services better?

7. Please tell us what kind of support matters most for a person with ADHD/undiagnosed ADHD?

   - ○ ADHD coaching
   - ○ Peer support
   - ○ Employment support (access or remaining)
   - ○ Medication
   - ○ Advice and guidance
   - ○ Other (please specify below)

8. We would like to support people better who do not have a diagnosis. If you were able to access support without a diagnosis, how would you prefer to do this? Please select all of your preferences below.

   ○ Through information on a website
   ○ Specific app-based support
   ○ Via telephone with a person with lived experience of ADHD or other support person to get support or have queries answered
   ○ Through a neurodivergent (specific ADHD) online group forum
   ○ Through a chatbot or other interactive virtual platform
   ○ Other (please specify below)

9. If you had the support you needed to live well, would you still want to seek/receive a diagnosis?

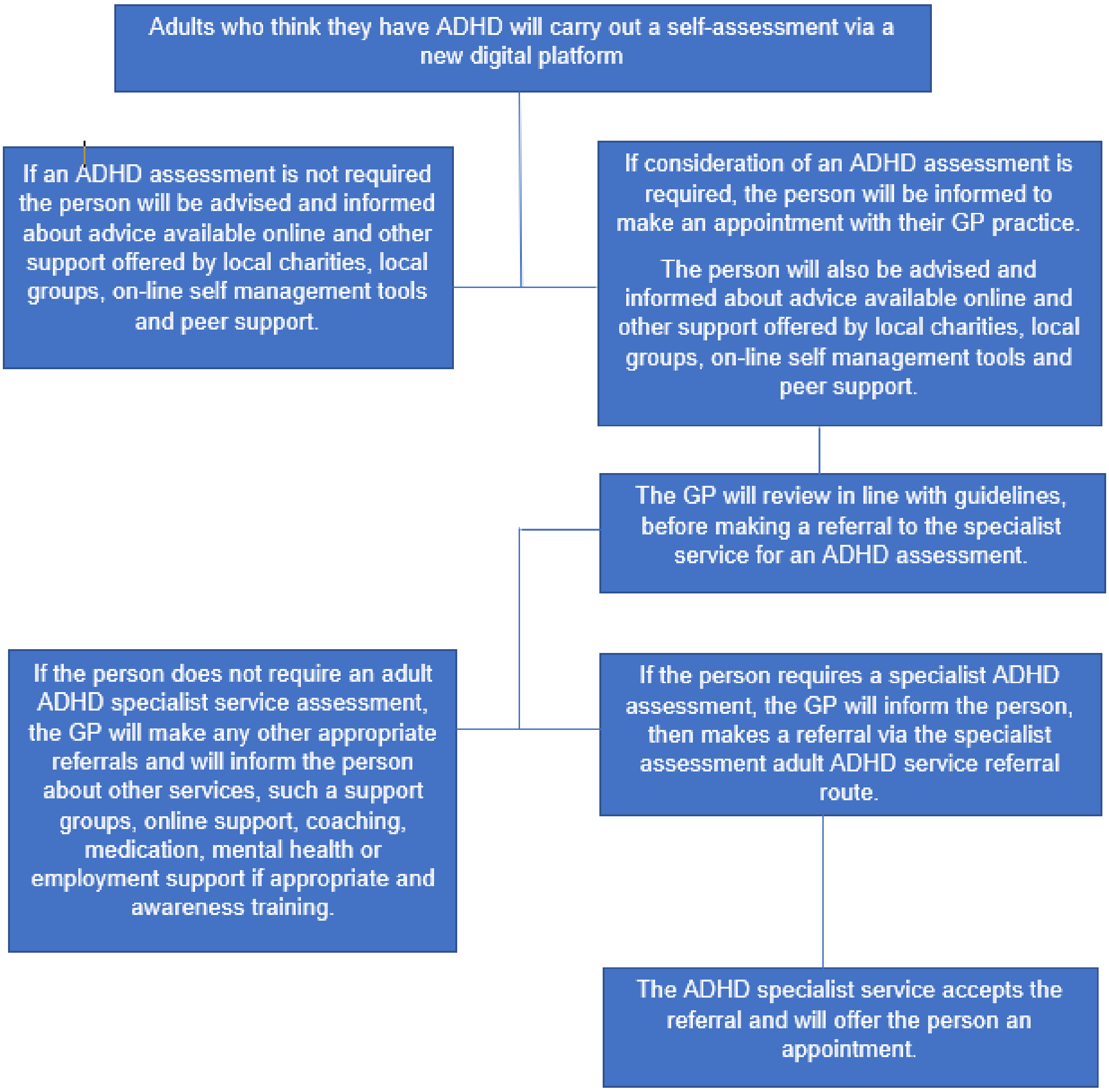
   ○ Yes
   ○ No
   ○ Don't know

   Please tell us more:

10. ADHD can occur alongside other conditions e.g. anxiety, depression, sleep issues etc. Are you seeking specific mental health support as well as an ADHD diagnosis?

   ○ Already receiving mental health support
   ○ No
   ○ Yes (please tell us what specific support you are seeking)

This table shows a proposed pathway for adult ADHD services. It is aimed at improving access to support people without a diagnosis:



Adults who think they have ADHD will carry out a self-assessment via a new digital platform

If an ADHD assessment is not required the person will be advised and informed about advice available online and other support offered by local charities, local groups, on-line self management tools and peer support.

If consideration of an ADHD assessment is required, the person will be informed to make an appointment with their GP practice.

The person will also be advised and informed about advice available online and other support offered by local charities, local groups, on-line self management tools and peer support.

The GP will review in line with guidelines, before making a referral to the specialist service for an ADHD assessment.

If the person does not require an adult ADHD specialist service assessment, the GP will make any other appropriate referrals and will inform the person about other services, such a support groups, online support, coaching, medication, mental health or employment support if appropriate and awareness training.

If the person requires a specialist ADHD assessment, the GP will inform the person, then makes a referral via the specialist assessment adult ADHD service referral route.

The ADHD specialist service accepts the referral and will offer the person an appointment.

11. We are aware of the current issues and are trying to address these, which will take time. Please share your (or the person that you know with ADHD/undiagnosed ADHD) thoughts about this proposed pathway and if there is any specific support to consider:

About you

Thanks for your responses. So that we can be sure that we are reaching a range of people, can we please ask for some details about you?

The information you supply is purely to help improve services and will not be used for any other purpose. Your data will not be stored with any third party. Details of how we handle your data can be found on the [NHS Kent and Medway site.](#)

Please tell us what age you are:

○ 16-24 years

○ 25-34 years
○ 35-44 years
○ 45-54 years
○ 55-64 years
○ 65-74 years
○ 75+ years
○ I prefer not to say

What is your gender?

○ Female (including trans-female)
○ Male (including trans-male)
○ I prefer not to say
○ I prefer to self-describe (please comment below)

Please tell us the town or area you live in:

○ Ashford
○ Canterbury
○ Dartford
○ Dover
○ Faversham
○ Folkestone and Hythe
○ Gravesham
○ Maidstone
○ Medway
○ Sevenoaks
○ Swale
○ Swanley
○ Thanet
○ Tonbridge and Malling
○ Tunbridge Wells

○ I do not live in Kent or Medway
○ I do not wish to disclose where I live

Do you consider yourself to have a disability?

○ No, I do not have a disability
○ Yes, however my day-to-day activities are not limited
○ Yes, my day-to-day activities are limited a little
○ Yes, my day-to-day activities are limited
○ Yes, my day-to-day activities are limited a lot
○ I do not wish to disclose this

How would you describe your ethnicity?

○ Arab
○ Asian-Indian
○ Asian-Bangladeshi
○ Asian-Chinese
○ Asian-Any other Asian
○ Black-Caribbean
○ Black-African
○ Black-Any other Black, Black British or Black Caribbean
○ Mixed-White and Black Caribbean
○ Mixed-White and Black African
○ Mixed-Any other mixed or multiple ethnic background Mixed-White and Asian
○ White-British/English/Welsh/Scottish/Northern Irish
○ White-Irish
○ White Gypsy or Irish traveller
○ White Roma
○ White-any other background
○ I prefer not to say
○ Any other ethnic group (please specify):

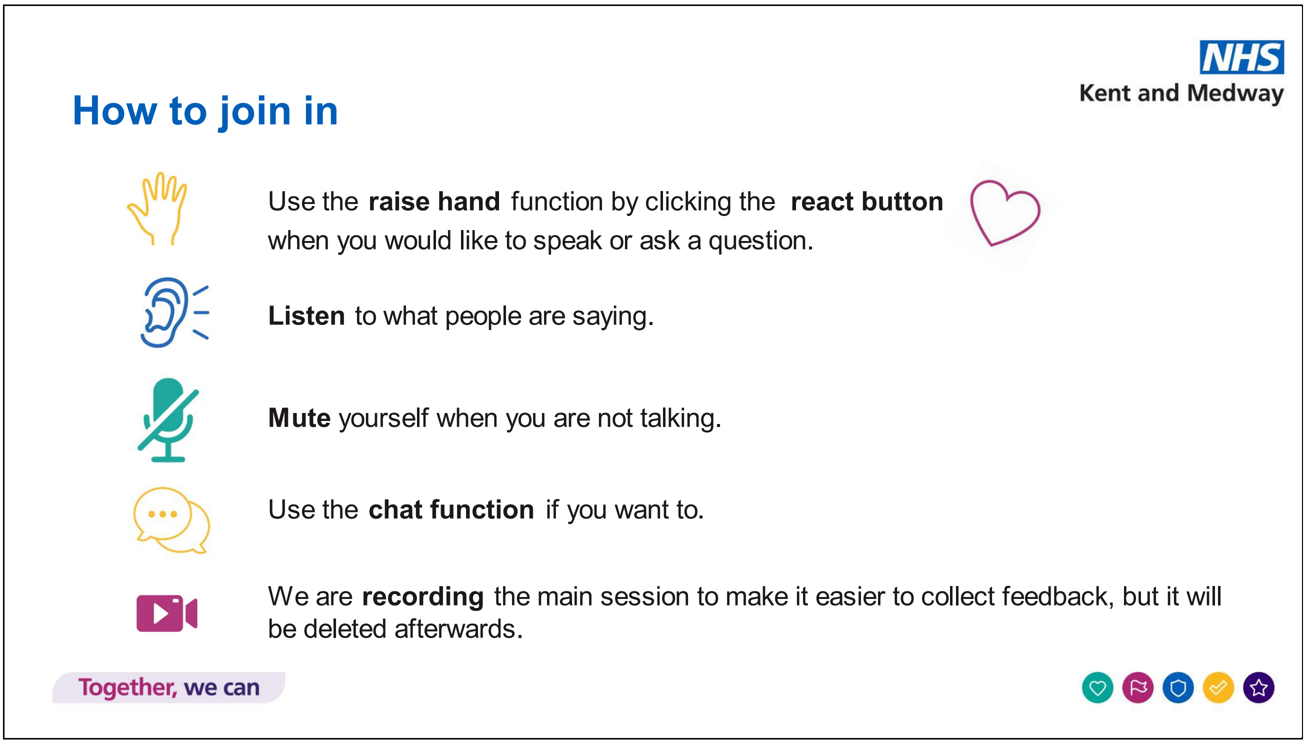
Thank you for taking the time to complete this survey!

Appendix B – Presentation given at events

NHS Kent and Medway

Review of Adult ADHD Services Discussion event

Together, we can



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How to join in

Use the **raise hand** function by clicking the **react button** when you would like to speak or ask a question.

Listen to what people are saying.

Mute yourself when you are not talking.

Use the **chat function** if you want to.

We are **recording** the main session to make it easier to collect feedback, but it will be deleted afterwards.

Together, we can

Event agenda

NHS
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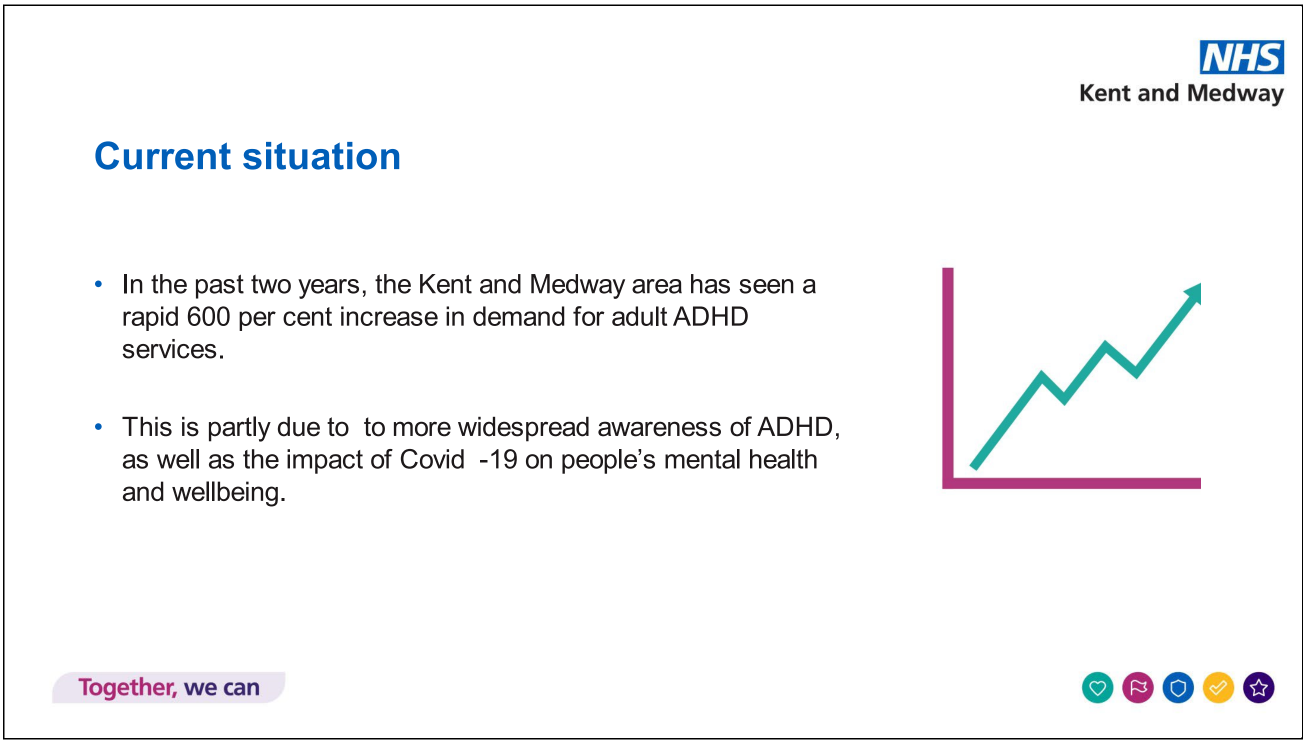
Introduction – the current situation
What have we heard so far?
Questions and answers
BREAK
Discussion groups – what type of support do you need and how do you want to access that support?
Feedback and next steps
Close

Together, we can



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Kent and Medway

Current situation

- In the past two years, the Kent and Medway area has seen a rapid 600 per cent increase in demand for adult ADHD services.
- This is partly due to to more widespread awareness of ADHD, as well as the impact of Covid -19 on people's mental health and wellbeing.

Together, we can

NHS
Kent and Medway

Current situation

- There are more than 13,000 adults waiting for an ADHD assessment. Waits for medication reviews are up to two years.
- As with all services, the NHS has a finite amount of money to support neurodivergent people. There are not enough providers of assessments to carry out the number that is now needed.
- As a health service, we must prioritise those people with the greatest clinical need for assessments.

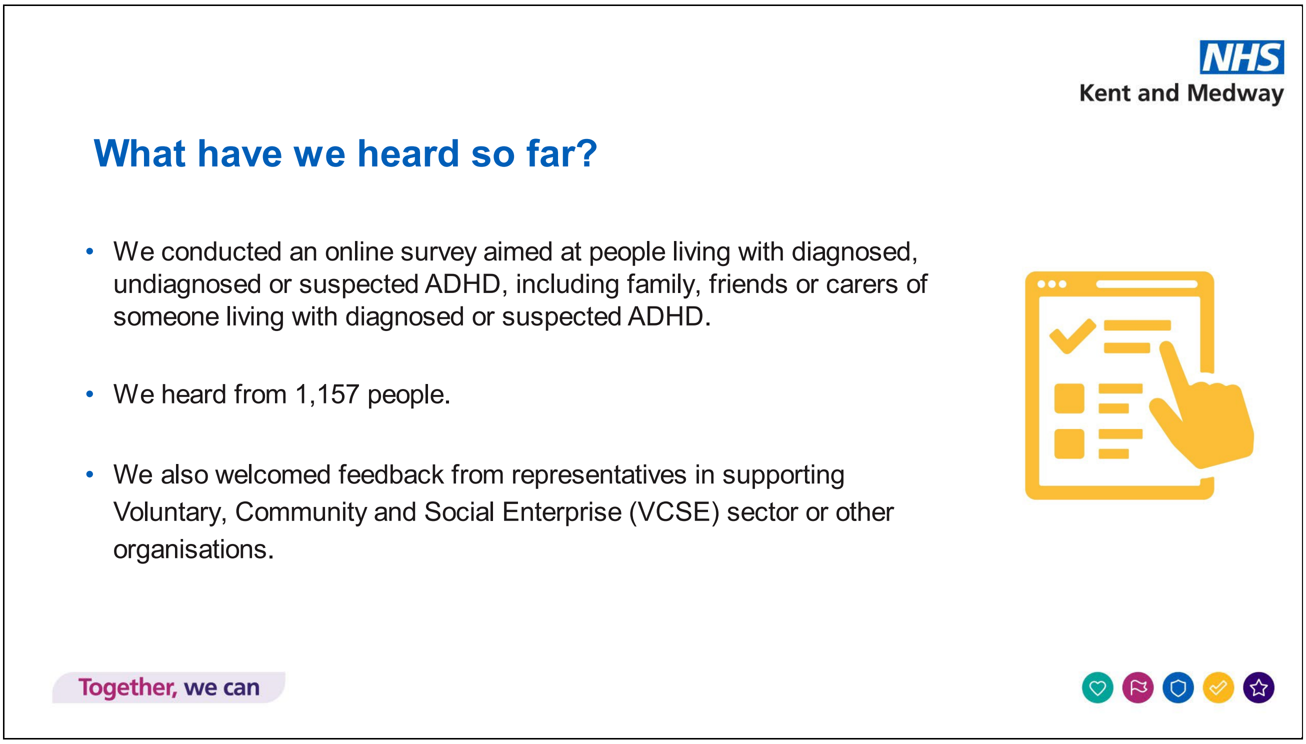
Together, we can

NHS
Kent and Medway

Current situation

- We recognise that change is needed.
- Getting a diagnosis is not the only route to support and some people will not need an assessment if they can access appropriate support at the right time.
- We have worked in partnership with providers and people with lived experience to make changes to the way we support people.

Together, we can



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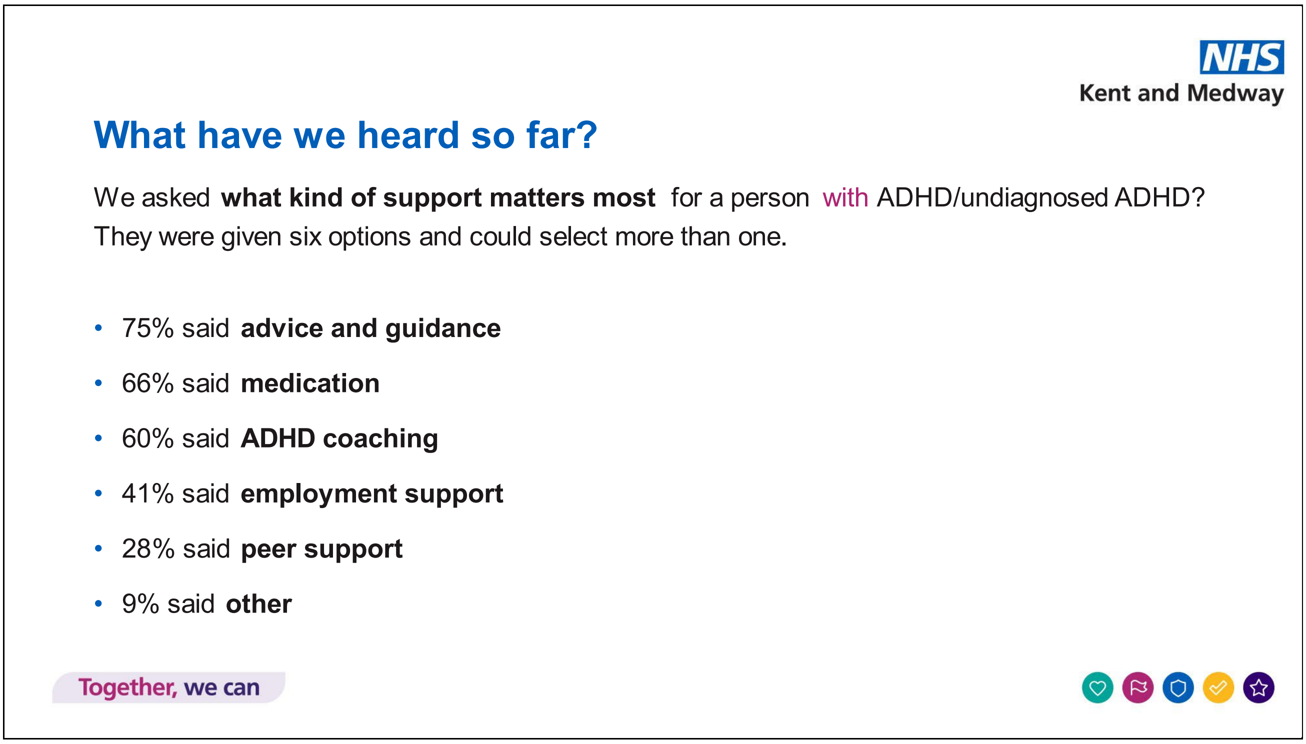
What have we heard so far?

- We conducted an online survey aimed at people living with diagnosed, undiagnosed or suspected ADHD, including family, friends or carers of someone living with diagnosed or suspected ADHD.
- We heard from 1,157 people.
- We also welcomed feedback from representatives in supporting Voluntary, Community and Social Enterprise (VCSE) sector or other organisations.

Together, we can



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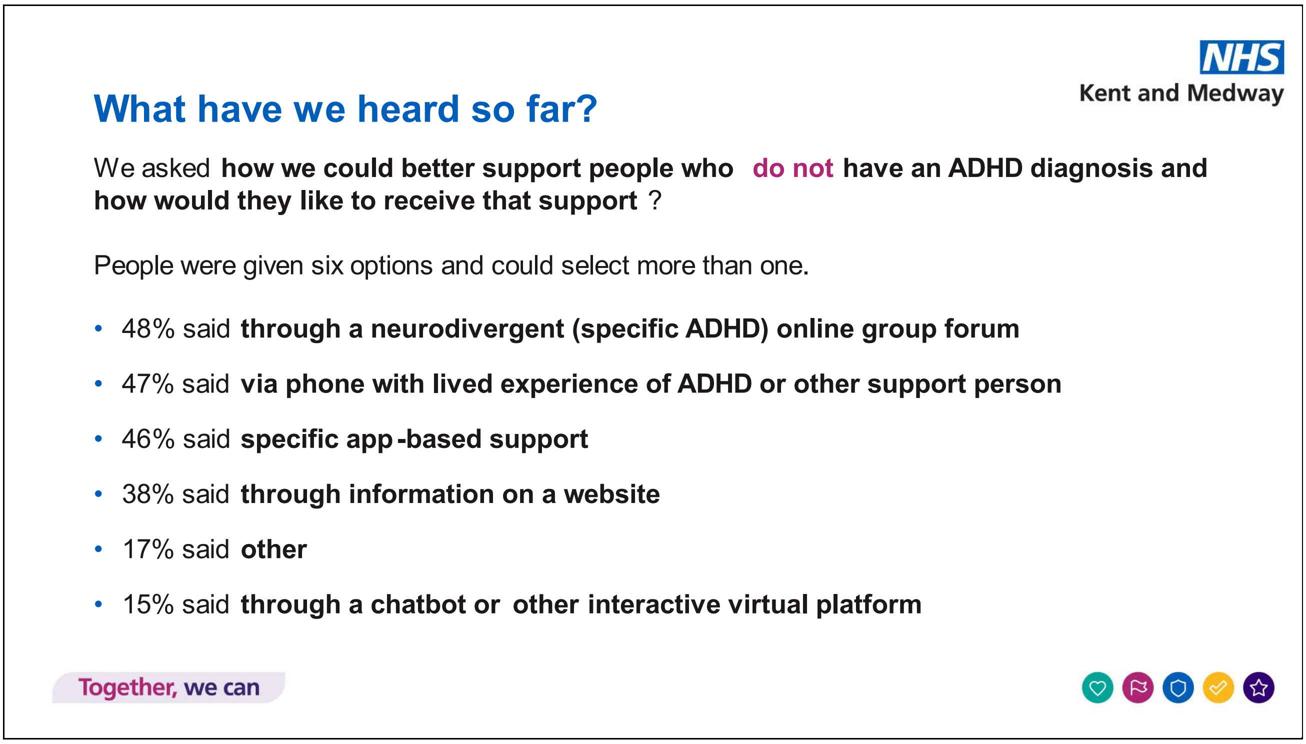
What have we heard so far?

We asked **what kind of support matters most** for a person with ADHD/undiagnosed ADHD? They were given six options and could select more than one.

- 75% said **advice and guidance**
- 66% said **medication**
- 60% said **ADHD coaching**
- 41% said **employment support**
- 28% said **peer support**
- 9% said **other**

Together, we can



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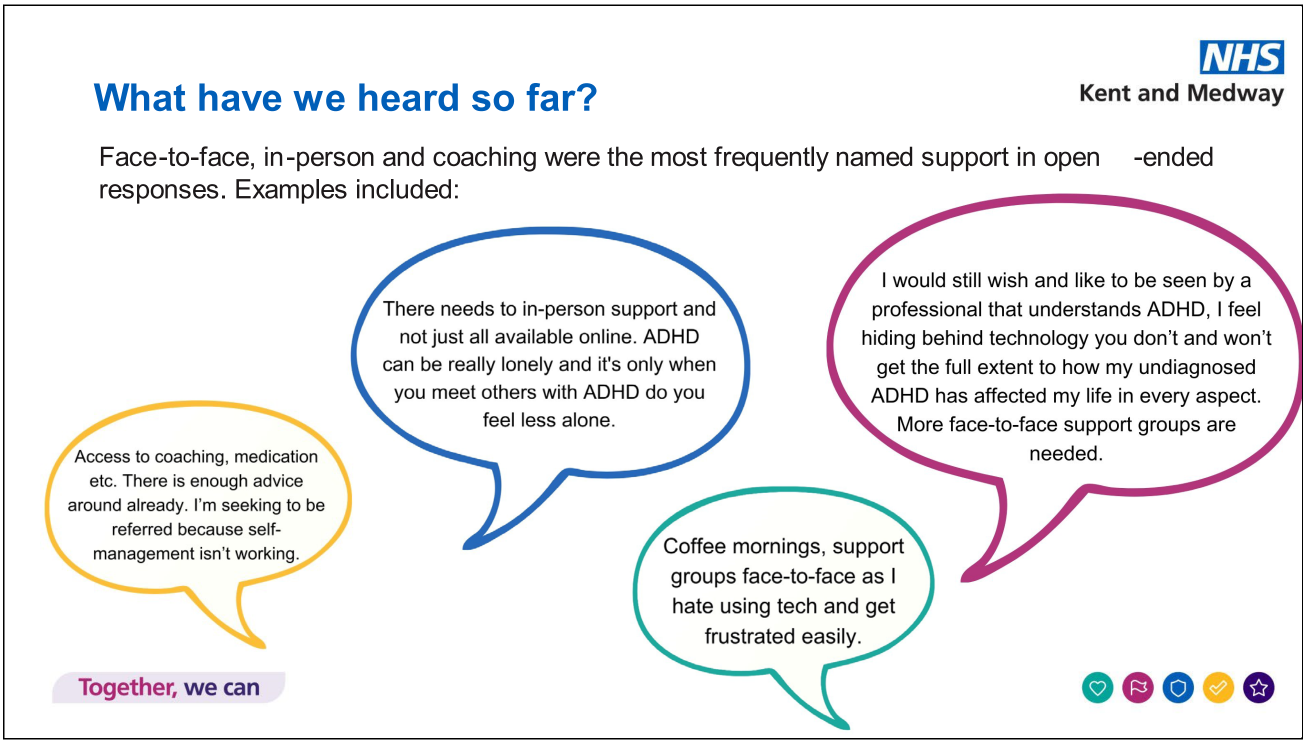
What have we heard so far?

We asked **how we could better support people who do not have an ADHD diagnosis and how would they like to receive that support** ?

People were given six options and could select more than one.

- 48% said **through a neurodivergent (specific ADHD) online group forum**
- 47% said **via phone with lived experience of ADHD or other support person**
- 46% said **specific app-based support**
- 38% said **through information on a website**
- 17% said **other**
- 15% said **through a chatbot or other interactive virtual platform**

Together, we can



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What have we heard so far?

Face-to-face, in-person and coaching were the most frequently named support in open-ended responses. Examples included:

There needs to in-person support and not just all available online. ADHD can be really lonely and it's only when you meet others with ADHD do you feel less alone.

I would still wish and like to be seen by a professional that understands ADHD, I feel hiding behind technology you don't and won't get the full extent to how my undiagnosed ADHD has affected my life in every aspect. More face-to-face support groups are needed.

Access to coaching, medication etc. There is enough advice around already. I'm seeking to be referred because self-management isn't working.

Coffee mornings, support groups face-to-face as I hate using tech and get frustrated easily.

Together, we can

NHS Kent and Medway

Your voice matters

- We know some offers of support aren’t working as well as they should.
- Following the results of the survey, we have already made changes to the support we are commissioning.

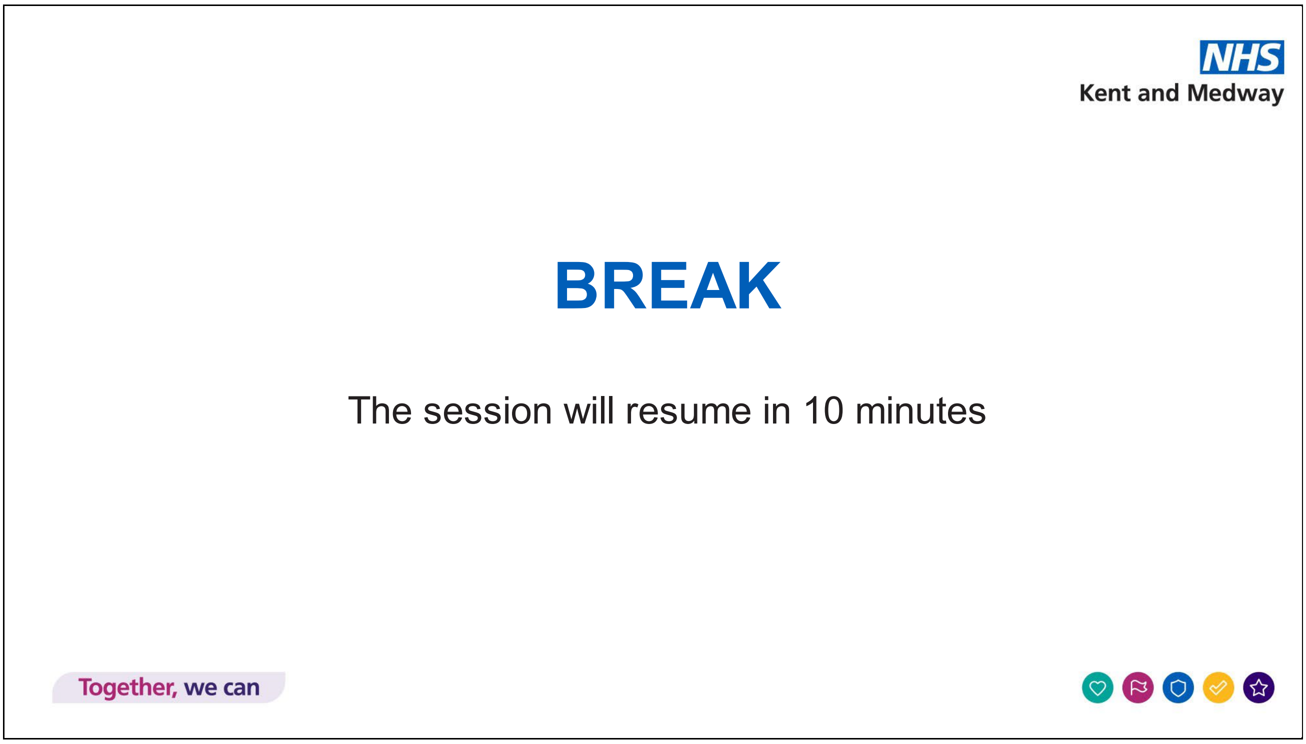
Together, we can

NHS Kent and Medway

Any questions?

- Before we take a short break, please take this opportunity to ask any questions you have about current ADHD services.
- When we return, we will be having discussions in smaller groups about what we can do to improve the support provided for people with ADHD.

Together, we can



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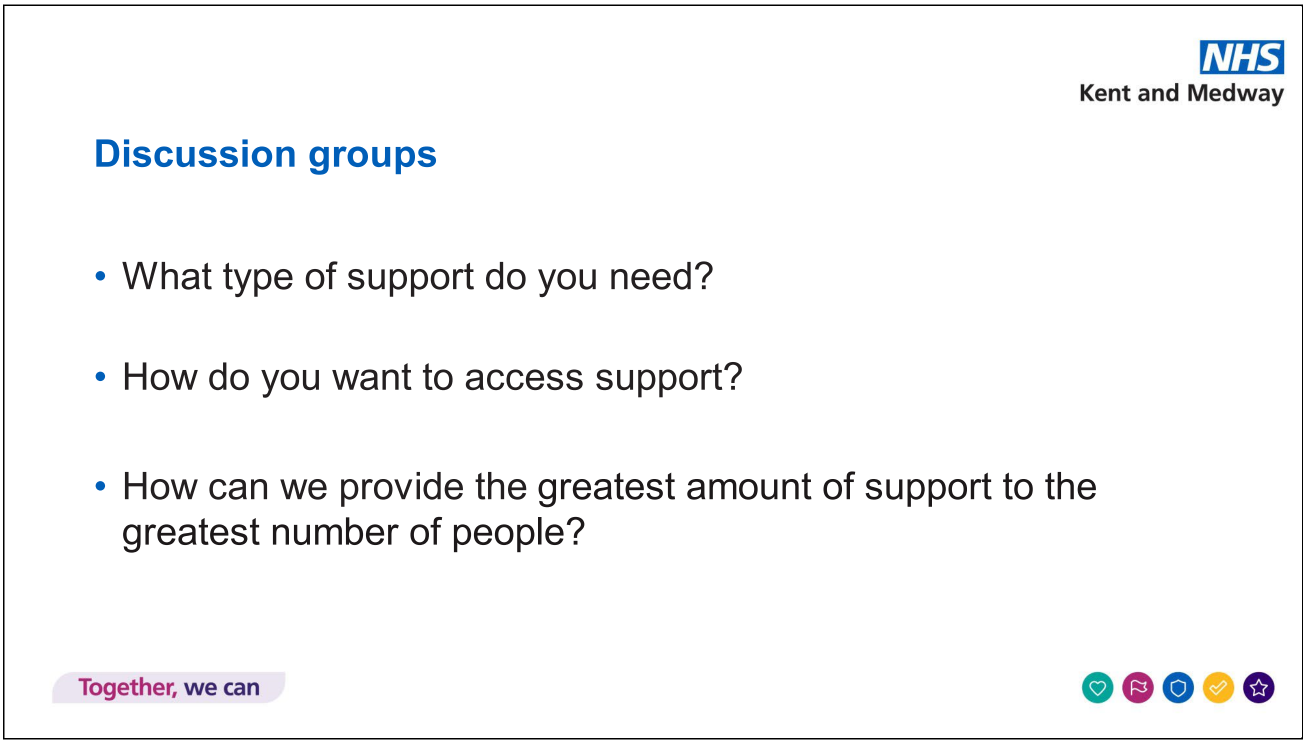
BREAK

The session will resume in 10 minutes

Together, we can



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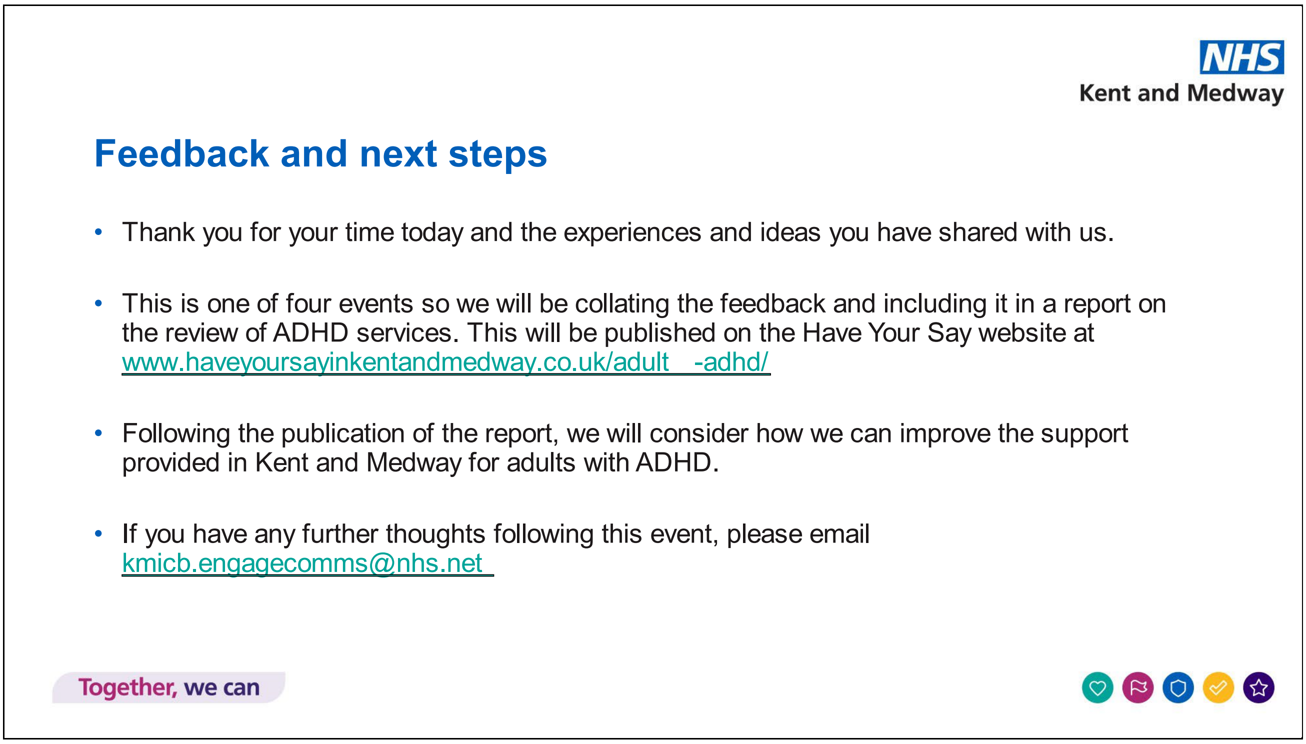
Discussion groups

- What type of support do you need?
- How do you want to access support?
- How can we provide the greatest amount of support to the greatest number of people?

Together, we can



NHS
Kent and Medway

Feedback and next steps

- Thank you for your time today and the experiences and ideas you have shared with us.
- This is one of four events so we will be collating the feedback and including it in a report on the review of ADHD services. This will be published on the Have Your Say website at www.haveyoursayinkentandmedway.co.uk/adult -adhd/
- Following the publication of the report, we will consider how we can improve the support provided in Kent and Medway for adults with ADHD.
- If you have any further thoughts following this event, please email kmicb.engagecomms@nhs.net

Together, we can

Appendix C – Examples of social media graphics

Visit **haveyoursayinkentandmedway.co.uk** to get involved.

Join NHS Kent and Medway to discuss how adult ADHD services can be improved.

Events are taking place online and in-person in Medway and Ashford.

Join NHS Kent and Medway to discuss how adult ADHD services can be improved.

Tuesday, 4 February
2 – 4pm
Canterbury Christ Church University, Medway Campus

Appendix D – Poster to advertise Medway event

ADHD support

NHS
Kent and Medway

Have Your Say

Join NHS Kent and Medway to discuss how adult ADHD (attention deficit hyperactivity disorder) services can be improved.

Tuesday, 4 February
2 – 4pm
Canterbury Christ Church University,
Medway Campus

Places must be booked via the link below.

For more information on this event and alternatives, visit **www.haveyoursayinkentandmedway.co.uk/adult-adhd** or scan the QR code above.