This is a transcription of seminar of researchers from the EDI Caucus held online on 15 October 2024, chaired by Prof James Richards. Panel members were Dr Chiara Cocco, postdoctoral researcher; Prof Kate Sang, principal investigator of EDICa; and Beth Wedgwood, research assistant. Headings have been used to facilitate navigation in this document. The recording and the slides can be viewed here: <https://edicaucus.ac.uk/neurodiversity-menopause-at-work-seminar-recording/>

# Introduction

Chiara: Hello, I see people coming in, so yeah that's good. So just a note - Fenella, who is our wonderful Support Officer, who is usually behind the scenes, had to just leave the building at the University because there was a fire alarm and it wasn't a drill so, bear with us a little bit because I'm controlling the slides and she might be here soon. Hopefully I have James and Kate Sang but yeah I see that people got 43 people at the moment oh CRA yeah I think Kate forwarded me the link that might be the reason why yeah you should be able to change your name we've also got quite a lot of Fenella Watsons so if anybody's coming as Fenella that's not Fenella, you might want to change okay go see hopefully I won't change as both now okay see people are still coming maybe we wait another couple of minutes or so and see what Fenella also is up to nice to see quite a few people coming in and join us for today today's seminar about the experiences of perimenopause at work for neurodivergent women we are very pleased like happy to be hosting this seminar today and this week especially as it is menopause awareness day on Friday if I'm not mistaken but in general I think October is menopause awareness month so um it's quite nice to be able to sharing our research about this this issue this topic actually and actually add in the perspective of neurodivergent women.

I think I'll just maybe get a start. A few housekeeping notes; we have- I can see chat here, so is the chat enabled? I thought we were doing only Q&A but I can see a chat function here so maybe you will be able to share your comments and questions and thoughts in the chat which everybody will be able to see. We have the Q&A function, okay we have the Q&A; so yeah no, sorry I think that that's what we're doing- the Q&A and we will one of us. hopefully Fenella, but if not her one of us, James- actually Professor James Richards, is here to moderate the Q&A, so keep an eye on that and then we will be talking for about half an hour /40 minutes and then we'll have time for discussion. So as I said I'm, Chiara Cocco, and I'm a postdoctoral associate for the Equality, Diversity and Inclusion Caucus, and I've been working with Professor Kate Sang, Beth as well and James and other colleagues focusing on the study of menstrual health and perimenopause at work. Kate do you want to introduce yourself?

Kate: So hello everybody, I'll say good afternoon but I also know there's people here from North America so it might still be morning. So hello everybody my name is Kate Sang. I'm professor of gender employment studies at the Edinburgh Business School at Heriot-Watt and I will be speaking a little bit later about neurodiversity. Beth you want to introduce yourself?

Beth: Yeah, hi everyone I'm Beth Wedgwood, and I'm a research assistant for EDICa. I've been working with EDICa for about a year and recently been working on this and I'll be speaking a little bit later about the literature surrounding this project. And then finally James.

James: Good morning and good afternoon everybody or even good evening people from further around the globe of course; yeah I'm Professor James Richard -professor in employment relations. I'm involved in the EDI Caucus - more workstream 3, though. I'm the PI on the workstream 3 on organizational work, but one of the reasons why I'm involved in this is that I've done quite a lot of research over the years on neurodiversity.

Chiara: Thank you so much. Okay so, just what we're going to be talking about today we're going to be just give a very short introduction on the Caucus and the menstrual health study, then we're going to be delving into more like the core of today's topic which is perimenopause AND neurodiversity. So giving some definitions and then we're going to be talking about how we apply the social model of disability to the study of menstrual health and then as Beth mentioned she's going to be talking about the literature and the gaps, and then we are going to discuss the findings from our study, and then we end up with some suggestions and takeaways and then we look forward to your questions and comments and hopefully we'll have a nice discussion afterwards. Before starting it is important that we establish some ground rules and our code of conduct so we really are dedicated and keen to providing a harassment-free experience for everyone regardless of their sex, gender identity and expression, age, sexual orientation, disability, physical appearance, body size, race, ethnicity, religion, or lack thereof, and technology choices. So we do not tolerate harassment of event participants in any form. This is also the reason why for events with this many participants we avoid the chat functions because we also want to protect people and we want to filter any harmful messages. So this is also why we do that. So sexual language and imagery is not appropriate for any venue or online space, so event participants who violate these rules may be sanctioned and expelled from our event and the seminar in this case. So now Kate is going to be talking about the Caucus very briefly - to you Kate.

# Introducing the EDI Caucus

Kate: So for those of you that don't know, and I think quite a few of you probably do, that we're the EDI Caucus. So we're funded by UKRI - so that's the UK government's research funding stream - with support from the British Academy. And we started in 2023 and we run through to the very beginning of 2026. And the aim of the Caucus is to accelerate Equity across the research and innovation ecosystem. So that includes universities, private sector, public sector and all the areas where research is undertaken. So what we're keen to do, is to provide the evidence bases for interventions that can remove barriers experienced by marginalized groups - and that, I think, is the key aspect of what we're doing through EDICa, is creating the evidence basis for what works around Equity. Part of what we're doing with that is our own research projects of which this is one, we also have a flexible fund stream - so rounds one and two have now closed, round three is still open till the end of this month - where we're funding projects that are smaller projects looking at specific aspects of equity or inequity. And we're also, through the work that we're doing, creating communities of practice, both across the UK and internationally, of people who are committed to removing barriers to inclusion across research and innovation ecosystem. And alongside all of that, EDICa itself and all of our activities are co-designed with those lived experience of marginalization and that's a big part of what we were doing for this workstream one project which Chiara will talk about in more detail.

So I'm the overall principal investigator of the EDI Caucus and I'm also the lead researcher - or lead workstream lead - for workstream one which is looking at the career life cycle - so looking at how key life events intersect with key career outcomes across the research & innovation ecosystem. And I think that's it. Our website is now up and live which is exciting. Fenella perhaps you can put the link to the website in the chat, that's completely refurbished and all thanks has to go to Fenella for her hard work getting the website together and making it as accessible and inclusive as possible. ([www.edicaucus.ac.uk](http://www.edicaucus.ac.uk) )

# EDICa’s Menstrual Health study

Chiara: Thank you, and yeah thank you, Fenella. So just briefly, we have already hosted a seminar about the menstrual health study, back in February - if I'm not mistaken - and you can find that on the website, and I think that Fenella will post the link to the seminar because it was recorded and put online. But yeah just briefly, we drew on Kate's previous work on menstrual health in research careers which included data from over 700 people and exploring the experiences of people managing periods problematic menstruation at work. And drawing on this data we designed the study for the Caucus to specifically address not just the challenges that people face but also thinking about the next steps and how to take this data forward to design meaningful and effective solutions.

We conducted extensive interviews with 56 workers in the research and innovation ecosystem, which is a wide and broad system sector let's say and encompasses a lot of different work environments, workplaces, job settings, job roles as well, and includes non-desk-based jobs. So this is quite an important contribution of the study because the research about menstrual health at work, the existing research, is mostly centred on office-based jobs whereas we've been investigating the experience of people working in different environments such as field work, archives, labs, oil rigs, and diverse work arrangements which pose specific challenges. We have collated qualitative insights of the lived experiences of those working in this different settings while managing their periods, problematic menstruation, and perimenopause, and we learned about the multiple issues and challenges that are experienced by women in the research and innovation ecosystem. We also gauged ideas and solutions which would have supported them.

So the next step with all of this in mind was to coordinate codesign workshops with our test sites - for example universities, learned societies, companies, research centres, through a bottom-up approach to suggest interventions aimed at supporting people who menstruate and go through the perimenopause. And it has been useful to put together a wide range of people in these workshops that have different job roles and also responsibilities so for them to brainstorm to come up in the same room and to actually suggest feasible solutions that could work in their environment and for that specific test site.

So we are now at the stage of delivering some of these interventions and then we will assess the success of them. So we are also doing some site visits where research and innovation takes place and (this photo for example is from the Scottish National Galleries) and the main findings of our study just highlight the people working in the research and innovation ecosystem face specific challenges by managing menstrual health in these diverse workplaces, or is different challenges for people working in lab, others for people working in fieldwork, and we also realize that at times even like for people who do not experience problematic menstruation itself just the fact of being menstruating poses a challenge in certain work environments. We also noted that the lack of accommodations resulted often in people leaving their chosen careers and then neurodivergent people and those with long-term conditions or disability face additional barriers in managing periods at work, and this is what we're going to talk about specifically today. And then also researchers of colour and from other ethnic groups are further marginalized due to cultural bias and racism with relation to menstrual health. And we also have noticed an overall distrust in the sector to actually implement meaningful change, where just the support initiatives are seen more as tick box exercises rather than actually effecting change. And you can read more about our study here with the two reports that we have published recently. So I think Fenella will also put the links in the chat for you to just have a look. But now Kate is going to be talking about some definitions.

# Diving into perimenopause & menopause

Kate: Yeah thank you very much Chiara. I think one thing that's also important to note is that our research is predominantly with women, but it's not only women that would experience some of the challenges that we're reporting and that trans men and non-binary people also report similar kind of challenges and so our work is trans inclusive.

We've got a few slides here - one in terms of what is perimenopause and also another in terms of our conceptualization of neurodiversity. Some of this might be very familiar to you, but it's just helpful if we all know that we're on the same page in terms of the issues that we're talking about. So in terms of perimenopause, quite often people use the term menopause, they talk about menopausal symptoms, but often what they're talking about are actually the symptoms of perimenopause. And perimenopause is the period that occurs often about maybe up to 10 years before the cessation of periods entirely. And it's associated with a range of symptoms and physical changes linked to changes to levels of oestrogen and other sex hormones. So generally this happens between the ages 30s and 50s but also for many women it can happen much younger than that for example, they may have had a hysterectomy, or they may have had a chemically-induced menopause to treat conditions such as endometriosis, or they may have had cancer treatment.

This is often seen as something that affects older workers which can isolate younger women who are going through these kind of experiences. And one of the key things is that for many people they're misdiagnosed by their GP. So they might be diagnosed as having an underactive thyroid for example, or having depression or anxiety, and actually underpinning this is really the perimenopause. And increasingly there's calls for clinicians including GPs that if they are working with a woman of that kind of age that they should think perimenopause first before they diagnose a mental health condition or other condition that could have these symptoms. It's also important to note that many women find that they're facing a GP who's had very little training on menopause and women's health in general.

So a lot of the data that we have over those kind of 700 women that we've spoken to or engaged with, is that they find that they get very little support from their GP; they're dismissed, particularly if they're slightly younger, or conversely everything's written off as perimenopause when actually there might be other conditions underlying that get missed. So this can be quite serious for people.

So this is by no means an exhaustive list of the kind of things that people report. Some of them will be very familiar to you things, like hot flushes, night sweats, the psychological symptoms like anxiety, mood changes, but other things that people may not be so aware of for example, issues around continence, so increasingly more and more women are reporting issues around incontinence. But it's just not something people talk about at work. Also as well other kind of changes - so changes to hearing, hair loss, changes to skin, increasing dental problems with the loss of oestrogen, so really it's a systemic issue. It's a systemic whole-body issue; it doesn't just affect the gynaecological system but a lot of these are things that might be written off by GPs or women themselves as being due to something else- like I say mental health conditions, thyroid conditions. But what's interesting is when we've done a lot of training around this, we find that for many women at the end they say "oh God I was actually perimenopausal that whole time and I probably could have had help" whereas actually they kind of struggled through it, thought this is just normal, or were too embarrassed to go and get help or just normalized difficulties they were experiencing..

So the menopause itself is when somebody hasn't had a menstrual period for 12 months at least, and if you are in that position, and you do start to get periods again, it's really important you go and see your GP, because any kind of unexplained bleeding after menopause should always be investigated. So the average age is in the 50s, but for some people it might be much younger and for other people actually it can be older as well.

And obviously what we're talking about here is sort of the negative side of that and the symptoms that people experience, but actually it can also be very liberating for people to go through the menopause. So for example women in our research have reported that it meant the end to some debilitating periods they might have had, heavy periods, very painful periods, it often coincides with the time when women's lives are changing in many other ways, so maybe their children are leaving home, they've reached a certain stage in their career.

And what's really important to note is that quite often women lose a lot of confidence around this time, they think other people will notice reduced performance, they notice hot flushes, Etc, and actually the evidence doesn't support other people do notice that and there isn't evidence that suggest that women's performance at work decreases during this time. So a lot of it is around perceptions of aging, perceptions of the menopause, but it doesn't necessarily translate into reality at work. So that's quite an important thing for people to realize and also that the symptoms of perimenopause don't necessarily stop when the periods stop, so women can still experience things like hot flushes, psychological symptoms well into their 70s and 80s. There's a bit of a myth that suggests that these things stop at the end of menopause - they don't actually, and there can be issues with women being able to continue to access HRT for example beyond their mid-50s when actually it is supported that that can continue on much longer.

So why are these issues problematic? If half the population's experiencing them, why are they so problematic? And what we're seeing is that there's very poor understanding in Primary Care, so people being dismissed sent away or just being normalized. Employers I think increasingly want to do work in this area and there's a kind of - quite a thriving sector developing around Women's Health and delivering training to employers and lie managers. But what we're not really seeing is an evidence base as to whether or not those interventions are effective for women at work.

So quite often employees will have someone in to train all the line managers on menopause but they don't follow up to see if women's working lives and their employment outcomes have improved. And as I said quite often women just normalize these things themselves, they don't necessarily realize that there are treatment options available, and what we see is increasing number of women leaving the workforce because they feel they're not able to balance the changes that they're experiencing, the physical changes, the psychological changes, with their work.

And the kind of things that we've heard during training and workshops is women saying you know, "my life just isn't worth living", high rates of suicidal ideation around perimenopause and menopause as well, quite fluctuating, and also spending a long time going through very invasive testing for a range of other conditions (because menopause isn't a condition), when actually there was something underlying that could have been relatively easily tested and treated. And many women will be told they're just far too young to be going through this and so they're not able to access the kind of support they need.

For many people this isn't a problem, and I think that's important to acknowledge as well that actually they go through perimenopause with relatively few symptoms. But for many women it can actually be the end of their career, or they change careers or they just leave the workforce entirely because of the problems they're experiencing. So just briefly again you probably know all of this, but just to say where we're coming from.

# The Social Model of Disability

EDICa is rooted in the social model of disability, which I'll talk about a bit more in the next slide, and for us we understand neurodiversity being the idea that quote unquote conditions or differences such as autism, attention deficit hyperactivity conditions (what use to be called ADHD), dyslexia, dyspraxia, are just normal or natural variations amongst humans. But neurodiversity - neurodivergence, sorry - is more reflective of people who perhaps have a cognitive profile consistent with autistic traits. And you'll note that we don't use person-first language in the Caucus; we use identity-first language for neurodiversity which is the preferred term of most autistic people in the UK. And we don't use person-first language with disability either.

And then on the other side, we have the term neurotypical that's often used, and it's a term that is sometimes used to describe people who are not neurodivergent. So there's obviously people have their own language and own ways they prefer to be described. What we do here is we go with the preferred term of the majority, but we fully respect that some people may not use this kind of language to describe themselves. But key for us is that being Autistic or having ADHC etc is not in itself a disability.

Many autistic people don't consider autism to be a disability, for example. But we would argue that neurodivergent people are disabled by neurotypical working environments. And that is underpinned by the social model of disability which is that disability is a form of oppression that arises when a person with an impairment interacts with the environments that is designed by and for non-disabled people (so people without impairments). And this is contrary to the medical model of disability which locates disability within the individual; it's a problem to be fixed within the individual; and that's where you'd see person-first language - so "person with a disability". But we would say "disabled person" or to indicate that person is disabled by the environment that they are working in - for us, that's employment.

It's really important as well to know that disability and gender can intersect, and that's the main thing that we're looking at today. Neurodivergent women have been neglected from much of the research generally on neurodiversity and on menstrual health not exclusively, but for the most part, and in terms of employment, there's very little understanding of the experiences neurodivergent women at work. It's really important for us that we recognise disability is a form of social oppression. We're not saying that if somebody's autistic they are inherently disabled but that they may be disabled by neurotypical working environments and in the case of this study disabled by neurotypical masculine working environments. And I think that's where I hand over to Beth.

# Reviewing existing literature

Beth: Hello yes so, with the literature for this research, I was trying to gain some insight into the interactions between menstrual health and menopause with neurodivergent conditions and the literature was -- and if there was any impact on that of work -- and the literature was limited, but it certainly did provide insight into the experience- the challenges that neurodivergent individuals may face at these life stages. And there's a few interesting pieces of literature that can be seen on the slide here and the rest can be found in our report that Chiara mentioned earlier that should be linked in the chat.

Regarding autism, the literature explored the experiences of autistic women and suggest that they face unique and heightened and often overlook challenges related to menstruation and menopause. This can be due to heightened sensory sensitivities difficulties, with emotional regulation and communication barriers. And these experiences can then lead to increased anxiety, pain, social isolation, and impaired functioning. And the research has also indicated that autistic individuals experience more pronounced physical symptoms, such as painful periods, irregular cycles, and conditions like PCOS.

As well the menopause can intensify sensory issues and psychological distress and it was suggested that perimenopause can be particularly challenging for autistic women as hormonal changes can worsen sensory overload and emotional regulation and make daily functioning more difficult. And this increase in autistic traits during perimenopause is believed to be leading to more autism diagnoses in women in later life, as the menopause intensifies these traits that may have been possible to mask in earlier life stages, but with the symptoms of the menopause are no longer able.

In terms of ADHC or ADHD, the literature exploring the interactions between ADHD and menstrual health and menopause suggests that hormonal fluctuations can significantly affect ADHD symptoms in women. It suggested that rising oestrogen levels can actually improve focus, mood, and motivation by boosting dopamine and serotonin but increased progesterone levels in luteal phase often worsen symptoms like irritability, forgetfulness, and emotional disregulation.

So it's suggested that women with ADHD are likely to experience exacerbated symptoms in the premenstrual phase, and this can be made worse if they have -- often many women of ADHD experience, coexisting conditions such as depression or anxiety and during perimenopause oestrogen loss reduces dopamine, which may worsen symptoms such as brain fog, memory laps and fatigue, which are already common symptoms in ADHD. And this has been suggested to severely impact daily functioning and also may reveal previously undiagnosed ADHD for many women. And it's also been suggested that hormonal shifts affect the effectiveness of ADHD medications, and the research indicates that dosages should be adjusted in the premenstrual phase, or during menopause should be combined with HRT in order to balance out the symptoms.

Whilst there's not really any specific focus on the workplace in the existing literature, some of the literature does suggest that perimenopause and PMS (premenstrual symptoms) may cause career challenges for some women due to struggles with lack of focus and motivation and memory loss, and causing some people to fear for their jobs. And others reference that the oestrogen changes can increase symptoms such as ADHD symptoms such as impulsivity and this has led to some women to make rash decisions such as quitting their jobs only to regret them later when their emotions stabilize.

The available literature does primarily focus on autism and ADHD or ADHC, but some studies have suggested that other neurodivergent conditions may be impacted by the menstrual cycle or perimenopause and menopause.

For women with dyslexia, it's been suggested that hormonal shifts may impact cognitive function. Some studies have found that those with Tourette's syndrome often notice an increase in ticks before their period, and that those with Tourette's syndrome, that oestrogen may influence the severity of ticks. Women with auditory processing disorder may face notable difficulties during low oestrogen phases. One study found that lower oestrogen in postmenopausal women can lead to difficulties with auditory processing, even when their hearing is normal.

It's also possible that hormonal shifts can make challenges such as motor coordination in dyspraxia, numerical processing in dyscalculia, and visual sensitivity with Irlen syndrome more pronounced. So this literature is really interesting and it shows some of the interactions between neurodivergence and menstrual health and perimenopause and menopause. But despite this evidence that menstruation and perimenopause may be particularly difficult for neurodivergent women, there is a lack of evidence about how neurodivergent women experience and manage their menstrual health and perimenopause symptoms at work. But also a lack of insight into how employers can support and improve the experiences for these women. And also our data reports some differences to some of the existing literature at times, and that's what Chiara is going to continue to talk about so, I'll hand back over to her.

# Our findings on menopause & neurodiversity

Chiara: Thank you Beth. Yeah, so as I say before, we have conducted in-depth interviews and we have 56 people in total, and 27 of them reported a long-term condition or disability. Some of them actually did not report it a recruitment -- in the recruitment stage when we kind of survey them -- but actually disclosed it during the interview. And some of them it's interesting to note how they considered menstrual health itself and perimenopause and menopause to be a disability. And 16 of them disclosed they were neurodivergent. So out of the 16 neurodivergent participants, 12 of them reported to have a long-term condition or experience of disability. So this data substantially adds further nuances to their experiences of menstrual health management at work -- in the work environment.

So in many cases, as you see here, we noted that there is an interaction between periods, perimenopause, and menopause, with the existing conditions and especially a neurodiversity, which is what I'm going to address in the last part of the presentation. And I'm aware of the time, so I'm going to try and speed up as much as I can. So as Beth discussed earlier, from the current literature and our study on the management of menstrual health in the workplace, we know that there are interactions between neurodiversity and menstrual health and perimenopause. And we also know that with neurodiversity sometimes the medication used to manage certain symptoms can affect how people experience the symptoms of, for example, hormonal fluctuation - which is particularly relevant for the menopause transition - and if we consider the management of neurodiversity and menstrual health in the workplace from the social model of disability as Kate explained, we note that there is a lack of human resource policy on neurodiversity, as well as a stark lack of awareness on the interaction between neurodiversity and menstrual health by employers -- and often by neurodivergent individuals themselves.

Such unsupportive work environments can negatively impact those managing problematic menstrual health and perimenopause. In our study it was confirmed what has been explored in previous research so that there are problematic effects of hormones on neurodivergent traits, and it does appear that neurodivergent individuals face greater challenges in managing the perimenopause and menopause as I mentioned. And because of this, for many neurodivergent women, period suppression also might not be an option because of the interaction between hormones and their ADHD, for example, or the medication for neurodivergency as well.

There is also some things that need to be considered in terms of treatment. Perimenopause can be particularly challenging for neurodivergent individuals. So our data is slightly different here from some of the existing literature, because the existing literature suggests that particularly for autistic women, they find their periods -- so the menstruation -- to be difficult to manage in terms of like hyper sensitivity and like a challenge in managing the menstrual blood and finding that quite problematic. But actually in our data the participants missed -- quite a lot of the participants missed -- having their period when they reached perimenopause and the menopause itself, because menstruation was in a sense a point of regularity in their life. And this is especially obviously the case for those that had regular periods because it was a sort of like structure that helped organize their life and what we noted from our participants is the issue lay mostly on the cognitive and mental health side of the menstrual cycle, particularly before the onset of menstruation.

Many neurodivergent women shared that because of the hormonal fluctuation during the menopausal transition or perimenopause, they were unable to mask their neurodivergence trait. This is particularly important because masking refers to people being able to perform neurotypical behaviours and particularly in the workplace setting. It seems that, and unsurprisingly, women are more likely to be performing masking and it's also, as I think Kate mentioned that before, that the study - the research on neurodiversity- particularly autism -- comes from work that is done on men - and associates in a sense autism with masculinity. So autistic girls and women are greatly neglected from a lot of the studies around neurodiversity. And this is a trend that we really want to shift with our research.

Another interesting aspect that we found in our study is that for many of these women, workplace policies on menopause are not particularly accessible for example, like the menopause cafes (maybe you might have heard of those), the menopause cafes are talking sessions organised in different settings such as the workplace and it's like for people - so for women - actually it's they're open to everybody, but it's mostly for women going through perimenopause and menopause to come together and share their experience. But some of our neurodivergent participants told us that they just didn't feel that those were safe environments for them. And they didn't feel they were represented, that they were - in their words - able to be stereotypically female, and then they didn't find the spaces particularly useful.

And finally another point is that from our data we found an overall unsatisfaction towards clinicians, the medical environment -- because I think that there is also something that Kate mentioned already that the diagnosis for neurodivergency, autism might take very long and neurodivergent people are dismissed and also they reported a lack of knowledge about menstrual health and its interaction with neurodiversity. So neurodivergent women find that they are often unsupported both in the workplace and then from their GPs.

One takeaway message from here is that there is really not one size that fits all in terms of how someone might manage menstrual health at work. And in the case of neurodivergent people, their experiences are often neglected in the existing literature and the current study and in the policies that employers put together. So there is a real need to try and bring together policies around neurodiversities with other policies on menstrual health to ensure that we take into account the different experiences. So I'm again conscious of time, so I'll move on to some of the insights from our participants, which, I think, say more than I could ever really explain. So from their words.

This is like an example from from one of our interviews that really explained the interaction between neurodivergency and perimenopause.

"As a neurodivergent person, when you go through perimenopause, your symptoms, your neurodivergent attributes and struggles heighten. Perimenopause hormonal stage impacts what the body is already dealing with."

Again we can see this interaction between the two conditions. Also the PMS and I think that Beth mentioned that the premenstrual syndrome - so before the onset of menstruation - that's another thing that our neurodivergent participant really highlighted.

"I've got this crossover of mental health, ADHD, and being a woman, PMS. My PMS is quite a strong one. She's really got the reigns during that time of the month and so, I'm quite regular in terms of actual menstruating, the actual bleeding, but the mood swings are hefty... I'm sure there is some kind of co-morbidity with the ADHD there."

So again, the interaction and here we can really see how actually the menstruation itself is not the issue but the whole hormonal fluctuation before the onset is what causes the most challenges. And then again masking, I've got two examples of the masking, as I mentioned before, so:

"I am diagnosed with dyslexia and possibly I have some ADHD symptoms, which feel a lot worse when my hormones are not doing very well. And so, kind of feel that my organization becomes more chaotic... I've always been able to mask my ADHD to the point where nobody would know, and probably that's still true. But I feel out of control if my hormones aren't under control."

So this in terms of like something that is established in terms of the ADHD, so the ability to mask in order to conform to the neurotypical workplace, but then that goes away when the hormones are perceived as irregular or fluctuating. So in terms of like perimenopause for example or PMS and finally another example from a lecturer at a university.

"I'm autistic, so I'm very familiar with masking. And that does help me to function in society, because certainly with teaching, that is a mask I enjoy wearing. It is where I can sort of put on the professional face."

And this person is really enjoys her work in terms of like teaching at the University, but because of like the interaction between her autism and the struggle that she faced throughout perimenopause and the fact that she wasn't supported, actually led her to not progress in her career. So now what can help? What are the suggestions that we can discuss and what can we do about it?

As Beth mentioned, you know, there are studies about this, we've done some research, we are understanding the challenges, but what can we actually do to support people going through menstrual health and neurodiversity? First of all, include diversity of voices when planning to introduce interventions. Employers should really ensure that menstrual health policies are accessible to all. Ensuring multiple modes of engagement, which can create comfortable and safe spaces for neurodivergent women. Also it is important to avoid assumptions on the experiences of Womanhood and Menstrual health. Heavy bleeding is not the only challenge, there are also other challenges such as the mental side of the menstrual cycle. Then policies and managers must be aware of the debilitating emotional and psychological challenges that some neurodivergent women report. Then some women do not identify with normative gender socialized behaviours. And as such, all-women events might not be suitable.

We also recommend absolutely the use of inclusive language, so recognizing that not all of those who go through perimenopause are first of all, older women, and some might be transmen or non-binary people. It is important to create workplaces where employees can be their true selves without the need to mask who they are and abide by neurotypical and accessible structures. And also be aware that there may be interactions between neurodiversity and menstrual health - so the effect of hormones. And also we encourage employers to design any policies and practices in relation to menstrual health - not just ***on*** the people that are affected but ***with*** them. So embedding, really, the lived experience of a diverse range of people who menstruate, go through perimenopause, the menopause - and that will ensure that your policies and practices address a diverse range of needs. So this is me and this is us. Do get in touch and I think we can open the floor to questions, comments and look forward to the discussion.

# Q&A

James: Thanks Kate, Beth and Chiara for that. I appreciate time is running away with us quite quickly. We've got about 10 to 15 minutes but I think we can probably almost certainly cram a lot into there. We've already got a range of questions - some of which have already been answered by text. So if you've got any questions please get them in now and hopefully we can answer them now. If not, I'm sure we could follow up at another point as well. And just to be clear as well, even if your name is on there or there's some personal information in there we won't be sharing that in this particular forum so, just want people be to sure about that as well, this is a space. So the first question that we've got is somebody who's asking whether long shifts or even night shifts featured in any way in which the participants who were in the study, whether that was a feature of the study itself. I don't know who wants to take that maybe Chiara - Chiara is probably the lead on this project and maybe wants to start with that one.

Chiara: James could you repeat the last part, I didn't quite get it.

James: Yeah someone's asking whether um the people who took part in the study whether there's anybody in the study who is noted for working long shifts, particularly night shifts, given that could be a kind of, you know, affects everybody in some kind of way, but relating it to this particular - the key issues of this project.

Chiara: Yeah sure, in terms of - well actually yeah I do remember one particular person who disclosed her neurodivergency and worked in an oil rig, and she particularly worked at night-time, so she did always the shift at night. So we did - because of the nature of the research and innovation ecosystem, which is quite broad, we could actually explore so many different work arrangement, work roles, so we did look at also irregular work pattern. And that also had an impact. Although this particular person actually chose to be working at the night shift. So for some people that actually is more suitable, but in terms of like what can be done for them, to support them, for example, one of the main recommendations overall is to have some sort of flexibility at work and that is not always possible because of the way work is organized, because some people working in labs might need to be working in person, might need to have quite physical jobs. So that's why it is very important to think about the individualized experiences to be able to support each individual person. I don't know if Kate wants add anything on this.

Kate: No I mean the question is also specifically about health care, so it's you know EDICa is focusing on the research and innovation ecosystem. So one of the areas we haven't really looked at is healthcare unless people are working as clinical academics. It's certainly something that is of interest to us in terms of future projects, but the note of caution is that obviously work shifts and the Circadian rhythm work together and they can have a big impact on people's health overall. And you we're not health researchers. And I can see a lot of the questions here are quite specific questions around sort of treatment options and specific sort of questions around menopause and advice, and we can't give that kind of advice. But it's an area that needs more research. There is quite a strong body of literature on health and shift work in particular and in terms of health care we know anecdotally that actually women working in hospitals find it very hard to access secondary and even primary healthcare in terms of gynaecological health, because of shift working and difficulty accessing the NHS. So we have anecdotal data, but I'd be hesitant to go into more depth about it than that but it's certainly an area that we're interested in pursuing further.

James: Thanks for that, yeah, I think there are a couple of questions here and this one touches on as well. It appears more of a statement more than anything else, about the difficulties of getting a health practitioner, a GP, to recognize the symptoms and ultimately to take some particular action, of which they appear to have achieved that. Is there anything from the report that could be useful perhaps, people could use in interactions with health professionals? I suppose that might be a question that we could potentially go down, but I imagine that's quite a big question in itself.

Kate: Well I think there's nothing wrong with taking a report with you. You know, not necessarily our report, but there's quite a lot of literature out there. I think it's very careful to not - you have to be careful not to get dragged down the route of people who are not - don't have expertise in this area. But in terms of speaking to, certainly primary care, who are the gatekeepers to secondary health care, it's important to be as empowered as possible. And one of the things, certainly I've seen in my data, is that women themselves often don't realize they're going through perimenopause and they write it off as other things as well. So I would say don't be afraid to say something to your GP and insist and take some research with you, is always quite helpful.

James: The next question, I really nevertheless - clearly this is beyond the boundaries of what you can answer then obviously just need to say that. And I'll read this one out verbatim. "Are incontinence issues specifically linked to perimenopause or is there just an association with the ageing and/or having given birth.

Kate: So yeah I mean, again, none of us are urologists or gynaecologists. What I would say is there's nothing "just" about incontinence. And it's a bit of a kind of myth about women's health that incontinence is inevitable after child birth or aging or perimenopause, and it's not. There's a lot of treatment available for incontinence for urinary continence issues, so it's not something to just accept as a natural part of aging. There are a number of options. It doesn't have to be what somebody's experiencing.

James: Thank you Kate. I suspect that there will be a similar answer in terms of "best to speak to a clinically trained person" for answering this particular question, but any thoughts might be helpful to get things started. Just to say that "the average age of menopause is 51. Do you know what the average is when surgically- or medically-induced menopause is discounted?"

Kate: I think that is the average age when surgically or medically induced are removed, but that's -- you know I think what's key for EDICa is we're looking at how work changes can be made to the workplace, and that's our focus, is on workplace changes. And it's natural in these kind of sessions that people have lots of questions and it's probably illustrative of the difficulty accessing a professional to ask some of these questions to. So yeah in terms of that, my understanding is that the sort of mid-50s are the kind of average age if you take out the surgical medically induced menopause.

James: Sure. The next question is perhaps closer to home, something I suspect we'll be able to come on in some particular way. "What are we doing to include persons of colour?" A question obviously at the very least on intersectionality. Almost all representation of menopausal women are white. Also those who are hashtag Au ADHD there's a huge overlap.

So do we want to comment on the profile of the demographics of the study and what further steps may be taken to include things that have been mentioned in this particular comment from now onwards?

Chiara: Yeah no, I can take that. Sure, that's an important question, we have actually in the reports properly explained our methodology. And one of the things that we have ensured, is that every sort of advertisement and material for recruitment was intersectional in every way, in terms of actually wanting to hear from experiences of marginalization. That could be from like an ethnicity point of view, religious point of view, disability, neurodiversity, and sexual orientation and gender identification. And what we have done is actually also to provide different interviewers, so different researchers, and share our own profile and our own experiences of marginalization, and we did have a black interviewer. And this actually allowed -- and a couple of neurodivergent interviewers -- and this has allowed people -participants - to actually choose the people that they would identify themselves more with and to be more comfortable in the interview stage. So with that, we have attracted quite a diverse range of participants including people of colour, black people, different religion, and sexual orientation, a few non-binary. We didn't actually hear from trans people - we have interviewed a trans woman - and we always are very keen to include all the different experiences. And we are also keen to hear on how we can do better on this.

James: Thanks for that. A following question - I think we're going back into the medical territory to a certain extent. "Is work being done to join up research about peri/menopause with the impact of hormones more generally" (and there's a word coming up that I don't know, I'm not familiar with so - Kate's grinning, maybe you could pronounce it for me and I can finish the sentence off)

Kate: "Menarche"

James: "...menarche" (Might have got that wrong) "during pregnancy and miscarriage." I don't know if you want to take that Kate, now that you've obviously know the words.

Kate: So in terms of -- we're particularly interested in the workplace and there are people now researching particularly miscarriage in work so Illaria Boncori, at I think she's at Essex, is researching this. It's not something that falls under the banner of what we've done in this study. My previous big study did look at issues of miscarriage, including miscarriage at work. We quite -- I have to say some really quite distressing material included. I think it's -- for us, we're not looking at the impact of hormones on work, we're not looking at the impact actually of even perimenopause on work. We're looking at the impact of being perimenopausal and how work creates a barrier for people. But, I referred earlier, in terms of -- there is a study by a Grady et al. called the three M's - so that's menstruation, maternity, and menopause - and that's a systematic literature review looking at the impact of the kind of issues that you're talking about. And it has, obviously, a variety of findings. What it generally shows is that the impact of hormones is overemphasized. And I did sort of refer to this earlier and I said that you know women often think that actually they might be experiencing cognitive decline and it's noticed by other people, or it's some hot flashes and it's noticed by other people. And actually it's not.

And people don't necessarily have the decline in performance that they feel that they're having - a lot of it is linked to a lack of confidence. So that's not - we're not - researching hormones per se, but there is a body of literature out there, and that study by Grady et al "The 3 M's" is probably a good place to start if you want to see an overall view of the literature.

James: Okay looks like we're running out of time, but I'm sure we can just shoehorn in one last question; we can answer it as quickly as possible. But I think what the question here is based on somebody's personal experiences and looking to see whether this is something that may have come up in the research or it's something that may not have got reported in the research but it did come up in the interviews that didn't quite make it to the report. This person is saying "do you think there is a link or a common misdiagnosis of chronic illnesses like ME or fibromyalgia for people with ADHD going through the Menapause" and this person is saying this is something that has happened to them in particular. Is that something that's come up at all?

Kate: So yes is the answer to that question. I think the literature is sort of quite clear on this and also around thyroid disorders as well. But the point I wanted to make is actually these things may not be separate and certain underlying conditions can become worsened by perimenopause or triggered by perimenopause. And I think I did say earlier, there's a real danger of things just being dismissed as perimenopause and that's it just slap some HRT on it and everything will get better. And it won't. But equally, other conditions might not get better until the perimenopause is addressed. The other kind of underlying thing is, that a lot of these conditions like thyroid disorders, fibromyalgia, chronic fatigue syndrome, etc, don't exclusively affect women, but they are predominantly diagnosed in women. And so there's similar experiences in trying to navigate a Health Care system that is not designed for, or by, the needs of women. So they have kind of underlying/underpinning sociological similarities as well. But yes certainly in our data - or my data over the last kind of eight years or so - and also more widely, we know that people find themselves either being misdiagnosed as perimenopausal or misdiagnosed as something else and going through lots and lots of testing, when actually that wasn't the underlying issue. But what's also important is that both of those things could be true at the same time and neither condition is being addressed appropriately because of this point.

James: Any than any further comments at all while we bring this session to an end? Unfortunately we've run out of time and there's two or three good questions in the chat function. I'm sure that's something that we can come back to, and if people have left their names we can perhaps respond to people individually. We'll be keeping a transcript of this. So I'd just like to thank everybody, in particular Chiara, Beth and Kate for doing the presentation today. And thanks to everybody who's come along to hear what we have to say and has contributed to the conversation which is really helpful and it's good to know so many people are interested in this. And clearly it's something that more work needs to be done on this and I'd like to hear more about what the research is being done out there if anybody is doing that and sharing your anecdotes as well because you know sometimes research like this inevitably will miss just these little bits which could be something that means something to other people. So I'll bring this to an end, thank everybody, and just to be sure, I think, this is being recorded so you will be able to access a copy from our EDICa website hopefully in the next few days. Thank you very much. Goodbye.

Thank you. Thanks