ASPE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

Barriers to Attention-Deficit/Hyperactivity Disorder Diagnosis in Adults: Findings from a Qualitative Study

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by
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Office of the Assistant Secretary for Planning and Evaluation

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BARRIERS TO ATTENTION-DEFICIT/HYPERACTIVITY DISORDER DIAGNOSIS IN ADULTS: FINDINGS FROM A QUALITATIVE STUDY

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I. Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterized by one or more of the following ongoing types of symptoms: inattention, hyperactivity, and impulsivity. (National Institute of Mental Health, 2021). ADHD was long seen as a childhood disorder, and early research centered on boys because experts believed the condition was rare in girls (Hinshaw et al., 2022). Consequently, ADHD diagnostic criteria and tools focus on symptoms predominant in males, such as hyperactive physical behavior, leading to underdiagnosis in women and girls (Hinshaw et al., 2022). These historical factors, combined with a lack of U.S. guidelines for diagnosing ADHD in adults, have contributed to underdiagnosis and undertreatment of ADHD in adults.

Adults with undiagnosed ADHD experience greater psychosocial and functional impairment, such as lower education and salaries and higher rates of risky alcohol use, compared to adults who have been diagnosed (Able et al., 2007). Furthermore, adults with undiagnosed ADHD face greater disruptions in their family, work, and social lives than adults who have received a diagnosis. Notably, the American Professional Society of ADHD and Related Disorders (APSARD) announced plans to develop the first U.S. guidelines for diagnosing ADHD in adults to address a "critical need for health care providers, patients, and the public" (APSARD, 2023).

In the last two decades, diagnoses of ADHD have increased among adults in the United States. An analysis of nationally representative data on physician office visits found a 36-percent increase in adult ADHD diagnoses from 2008 to 2013 (Fairman et al., 2020). A cohort study of patient records in Northern California also found substantial increases in the prevalence and incidence of ADHD among adults from 2007 to 2016 (Chung et al., 2019). Revisions to diagnostic criteria have contributed to this increase. In 2013, the *Diagnostic and Statistical Manual of Mental Illnesses 5th Edition* (known as the DSM-5) reduced the number of required symptoms for ADHD diagnosis in adults and adolescents and increased the age of onset of symptoms to 12 years (American Psychiatric Association, 2013; Epstein & Loren, 2013).

Still, gender, racial, and ethnic disparities in the diagnosis and treatment of ADHD in adults indicate that underdiagnosis persists. White adults are more likely to be diagnosed with ADHD than adults from other racial and ethnic groups, and men are more likely to be diagnosed than women (Chung et al., 2019; Fairman et al., 2020; Kessler et al., 2006). More recently, however, the COVID-19 pandemic saw increases in treatment receipt among adults with ADHD. From 2020 to 2021, prescription stimulant use for ADHD increased substantially among adults, particularly women, suggesting to some that more adults with ADHD may have sought treatment because of reduced barriers to care, such as the expansion of telehealth (Danielson et al., 2023; Sibley et al., 2023). More research is needed, however, to understand why underdiagnosis and disparities persist in ADHD diagnosis among adults and how those barriers may be overcome.

In response to these issues, the Office of the Assistant Secretary for Planning and Evaluation commissioned a qualitative study to better understand the barriers to adult ADHD diagnosis and determine how those barriers may be overcome. The authors conducted a limited environmental scan, interviews with clinical experts, and interviews with people with lived experience (PWLE) to answer the following research questions:

1. What barriers exist to adults receiving an ADHD diagnosis?
   a. What could help reduce barriers to adults receiving an ADHD diagnosis?
2. How have adults in the United States overcome barriers to receiving an ADHD diagnosis?
   a. What role has telehealth played for patients in receiving an ADHD diagnosis?

Study highlights

- **The purpose of this study was to better understand barriers to adults receiving a diagnosis of ADHD, strategies to overcome these barriers, and the role of telehealth in ADHD diagnosis**. We conducted a limited environmental scan, eight interviews with clinical experts, and 18 interviews with people with lived experience (PWLE) who were diagnosed with ADHD as adults.
- **ADHD was long viewed as a childhood condition, and early research centered on White boys, leading to underdiagnosis of ADHD in adults and gender, racial, and ethnic disparities in diagnoses.** Clinical experts acknowledged that current ADHD diagnostic criteria and tools, guidelines, and provider training still do not adequately address adult and female manifestations of ADHD. Without proper tools and training, health care providers may lack the knowledge, comfort, and ability to diagnose ADHD in adults.
- **Before receiving an ADHD diagnosis, PWLE experienced an array of symptoms that led to personal, relationship, and professional difficulties.** Forgetfulness, problems focusing, impulsivity, and difficulty regulating emotions at times put PWLE at risk of failing to achieve important milestones, leading to anxiety, depression, and feelings of despair. Most PWLE were diagnosed with a mental health condition before receiving an ADHD diagnosis.
- **A lack of knowledge about ADHD among PWLE and providers often led to yearslong delays in diagnosis.** PWLE and their providers often failed to recognize their symptoms as ADHD because of a lack of knowledge or misconceptions about ADHD. When PWLE raised the possibility of ADHD, providers often advised them to see specialists. Healthcare access barriers, such as insurance-related issues, lengthy wait times to see specialists, and high out-of-pocket costs, further delayed diagnosis.
- **Several PWLE underwent neuropsychological testing to receive an ADHD diagnosis, yet clinical experts unanimously reported that this testing is not necessary to diagnose ADHD in adults.** Some clinical experts further underscored that lengthy wait times and a lack of insurance coverage for neuropsychological testing create barriers to ADHD diagnosis in adults.
- **Increased knowledge, supportive people, personal determination, and telehealth helped PWLE overcome barriers to receiving an ADHD diagnosis.** Increased knowledge of ADHD, supportive social circles and provider, and personal determination empowered PWLE to seek an ADHD evaluation. Telehealth offered PWLE convenience, reduced their anxiety about completing an evaluation for ADHD, and increased access to care. Clinical experts also described the benefits of telehealth, noting that it improves health equity.
- **Increasing public awareness about ADHD in adults may encourage adults with undiagnosed ADHD to seek care**. Some PWLE and clinical experts recommended raising awareness about ADHD in adults to encourage help seeking, calling for easy-to-find online resources, magazine articles, and educational efforts that inform people that ADHD is treatable.
- **Clinical experts called for increased funding for research and tool development for ADHD in adults, including research on the lived experiences of adults with ADHD.** Most clinical experts called for research to validate ADHD diagnostic criteria and tools for people of different ages, genders, races, and ethnicities, noting that research into the lived experiences of adults with ADHD is needed to inform these efforts. ◢

II. Methodology

A. Environmental scan

We conducted a search of government, peer-reviewed, and gray literature sources published in the last 20 years in the United States to identify barriers to ADHD diagnosis in adults. Our approach included scanning review articles and their bibliographies to identify potentially relevant sources for inclusion. We used findings from the environmental scan to inform the topics covered in the key informant interviews and synthesized environmental scan findings with themes from the key informant interviews.

B. Key informant interviews

We conducted 26 semistructured interviews, including 18 with PWLE and eight with clinical experts. Eligible PWLE included adults who received a diagnosis of ADHD by a health care provider at age 25 or older, which excluded people diagnosed in young adulthood or college, who may not have experienced the same barriers to diagnosis as other adults.

We developed three interview guides: one for clinical experts, one for PWLE who completed their ADHD evaluation process in person, and one for PWLE who completed all or part of their ADHD evaluations by telehealth. We coded the interview transcripts in NVivo qualitative software and reviewed the output for each code to identify common themes. We then compared and synthesized themes within and across clinical experts and PWLE. We used findings from the interviews with PWLE to develop a journey map of the common paths to ADHD diagnosis based on the lived experiences of PWLE in this study.

Exhibits II.1. and II.2. summarize the specialties of clinical experts and characteristics of PWLE who participated in this study, respectively. Clinical experts included practicing clinicians and researchers.

Exhibit II.1. Specialties of clinical experts

Specialty	Clinical experts (n = 8)
Neuropsychiatry	1
Psychiatry	4
Psychology	3

Exhibit II.2. Characteristics of people with lived experience

Characteristic	PWLE whose ADHD evaluations were in person (n = 9)	PWLE whose ADHD evaluations involved telehealth (n = 9)	All PWLE (n = 18)
Gender and age at diagnosis			
Female	7	8	15
Male	2	1	3
Median age of diagnosis	47 (range, 25–66)	38 (range, 30–60)	45.5 (range, 25–66)

C. Study limitations

The clinical experts and PWLE interviewed for this study are not a representative sample. Interview themes reflect the knowledge and experiences of the people who participated in the study. We conducted a small number of interviews and did not specifically seek racial and ethnic minority group representation in our sample. In addition, most PWLE in our sample were female. As such, the sample may have limited generalizability.

All clinical experts we interviewed for this study were experts in ADHD diagnosis who specialized in neuropsychiatry, psychiatry, and psychology. Their experiences and opinions may not reflect those of non-experts. In addition, our environmental scan featured research conducted by some of the clinical experts interviewed for this study. Therefore, it is possible that some themes from the interviews may restate findings from the literature.

The PWLE who participated in this study self-reported receiving a diagnosis of ADHD as adults. We did not require confirmation of an ADHD diagnosis for participation. In addition, we recruited PWLE for this study through the Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) research page and online community for adult ADHD as well as a Facebook group for people diagnosed with ADHD as adults. The opinions and experiences of PWLE in this study may not reflect those of people who do not engage with advocacy groups and online communities for ADHD among adults.

III. Findings

Here, we present a synthesis of the themes from interviews with clinical experts, PWLE, and the environmental scan. Themes that emerged from the interviews appear in ^*blue italicized font inside carets*.^ We use the terms "clinical experts" and "experts" to refer to the clinical experts interviewed for this study and "PWLE" to refer to people diagnosed with ADHD as adults who participated in this study.

Section A summarizes the clinical experts' perspectives on current trends in ADHD diagnosis in adults. Section B presents an overview of the path to receiving an ADHD diagnosis in adulthood based on interviews with PWLE. Sections C and D describe the barriers to and facilitators of receiving a diagnosis of ADHD in adulthood, respectively, and Section E outlines opportunities to reduce barriers to ADHD diagnosis in adults. Appendix A presents illustrative quotes corresponding to each theme.

A. Current trends in the diagnosis of ADHD in adults

1. Underdiagnosis and disparities in ADHD diagnoses

Most clinical experts interviewed for this study reported that ^*ADHD continues to be underdiagnosed in adults in the United States,*^ despite increases in adult diagnoses in recent years. Citing an ADHD prevalence rate of 2.5 to 4.5 percent among adults, one expert estimated that 75 to 80 percent of cases remain undiagnosed. Still, a few clinical experts reported that ^*underdiagnosis remains a source of debate within the larger professional community*.^ They explained that ADHD specialists and experts are "very worried" about underdiagnosis, whereas other providers, who are not familiar with the research, are unconvinced that ADHD is a valid diagnosis in adults. Nearly all clinical experts described the ^*implications of underdiagnosis of ADHD in adults as profound and far-reaching*.^ Consistent with the literature, these experts noted that adults undiagnosed or untreated for ADHD often develop secondary mental health issues (for example, depression, anxiety, eating disorders, and substance use disorders) and are at higher risk for divorce, domestic partner violence, traffic accidents, job and earnings instability, or involvement in the criminal justice system (Able et al., 2007).

> This is not just a benign little disorder. If you look at the trajectory of negative consequences for ADHD, it is traumatic and dramatic, not only to patients and families, but to society. The burden of untreated ADHD is enormous in dollars and cents.
>
> —Clinical expert

When asked about disparities in ADHD diagnoses in adults, most clinical experts stated that ^*gender disparities in ADHD diagnoses begin in childhood but appear to shift in adulthood.*^ These experts concurred with the literature, noting that males are more likely to be diagnosed and treated for ADHD as children, whereas ADHD is often missed in girls because of a lack of training and tools that capture female symptoms, as well as "symptom masking"- when a person compensates with intent to hide their symptoms(Hinshaw et al., 2022). Citing recent data on stimulant prescription fills, most experts reported that, in adulthood, women are more likely than men to seek treatment for ADHD (Danielson et al., 2003; Sibley et al., 2003). As a result, several experts suggested that diagnoses in women have "caught up" to men. A few experts offered other possible explanations for this trend. One expert suggested that ADHD is not necessarily underdiagnosed in girls, but rather the time frame of diagnosis for females might be later than for males. Another expert proposed that girls may be more likely to have the inattentive form of

ADHD, which is harder to detect in childhood but may be more likely to persist into adulthood than the more overt hyperactive form of ADHD typically seen in boys.

Most clinical experts theorized that ^*racial and ethnic disparities in ADHD diagnoses are rooted in systemic and sociocultural barriers*.^ Consistent with the literature, a few clinical experts relayed that in their view some communities, including racial and ethnic minority populations, may have varying degrees of acceptance of mental health help seeking and treatment because of stigma, instead viewing behavioral health symptoms as personality issues or problems with motivation (Waite & Tran, 2010; Conner et al., 2010). One expert also noted that language barriers may contribute to disparities, explaining that non-English speakers may be at greater risk for underdiagnosis. Some experts also cited systemic barriers—limited access to providers due to geography, a lack of "good" health insurance, and economic disadvantage—as impediments to ADHD diagnosis and treatment. In addition, a few experts mentioned that data on the extent of racial and ethnic disparities in ADHD diagnoses are lacking or mixed. One expert explained that underrepresentation of racial and ethnic minority groups in research is an issue and that the lack of validated, culturally sensitive tools for diagnosis contribute to misdiagnosis in these groups.

2. Overdiagnosis and misdiagnosis of ADHD in adults

Given increases in stimulant prescribing in 2020 and 2021, we asked clinical experts about the scope and implications of the potential overdiagnosis of ADHD, where ADHD is diagnosed but not present (Danielson et al., 2023). A few experts mentioned that ^*there are flaws in using stimulant prescription data as a measure of overdiagnosis*,^ explaining that it is not possible to determine from these data whether ADHD was diagnosed appropriately and that stimulants can be prescribed for conditions other than ADHD. However, some clinical experts acknowledged that ^*overdiagnosis occurs when people seek an ADHD diagnosis to obtain stimulants and companies prioritize profits*,^ such as implementing incentives for diagnosing and treating ADHD.

When you have venture-backed companies, and the only motive is growth, growth, growth, growth, client acquisition, client acquisition, client acquisition, you lose the magic of it … And I understand there's a huge need, and they went after a need, but when your sole motive is more, and more, and more, more people, more growth, we need hockey-stick growth so we can have an exit, there is something wrong with that…

—Clinical expert

In addition, some clinical experts explained that ADHD may be overdiagnosed inadvertently by providers who lack training to properly diagnose ADHD in adults and differentiate it from other conditions with similar symptoms. Complicating this issue is the fact that ^*ADHD occurs on a continuum, and the threshold for diagnosis and treatment are subjective*.^ For this reason, clinical experts noted that providers may view the level of impairment required for ADHD diagnosis and treatment differently.

B. Journey to ADHD diagnosis in adulthood

PWLE described their journeys to receiving an ADHD diagnosis in adulthood. Here, we describe their experiences across three stages, starting before they recognized their symptom as ADHD through the

point where they received an ADHD diagnosis. At the end of this section, Exhibit III.2 presents a journey map that illustrates the common paths to receiving an ADHD diagnosis based on the experiences of PWLE who participated in this study.

III. Living with unrecognized ADHD

Most PWLE did not recognize their symptoms as ADHD until years after first experiencing issues. ^*PWLE recalled experiencing an array of ADHD symptoms*^ in their late teens and early adult years, though symptoms sometimes became apparent in later years. Across ages, symptoms often manifested as forgetfulness and an inability to focus, issues with time management and staying organized, a lack of motivation, difficulty regulating emotions, sensitivity to rejection, trouble sleeping, impatience, and interrupting others. ^*Many PWLE developed compensatory strategies and tried other approaches to manage their symptoms.*^ For example, PWLE often created routines, sticky notes, calendar reminders, and to-do lists to help them stay organized and address forgetfulness. To improve focus and manage their emotions, some PWLE doodled, meditated, took supplements, drank coffee, and journaled. A few PWLE tried alcohol or marijuana to help them wind down but noted these substances generally were not effective.

I put a lot of systems in place. So, my morning routine, for instance, was a very dedicated routine. Everything went in the same order. My stuff was in the same place. When I came home from work, I dropped my stuff at the same place, otherwise I was losing it … even with my work, I had to set up systems to help me stay on top of things. I had Post-it notes all over my entire home.

—PWLE

^*Undiagnosed ADHD led to an array of personal, professional, and educational issues for PWLE.*^ Some PWLE reported having relationship difficulties and interpersonal challenges at work, citing issues with interrupting others, not picking up on body language, and not being able to regulate their emotions. ADHD symptoms also put some PWLE at risk of failing to achieve educational and professional milestones. For example, some PWLE reported having difficulty focusing and completing assignments in college or graduate school, and a few failed professional certifications. For one PWLE, delaying an assignment until the night before it was due led to such despair that she attempted suicide over the prospect of failing her college major. In addition, ^*two of PWLE characterized multiple life stressors as "stacking" or "piling up," resulting in an exacerbation of ADHD symptoms, anxiety, and depression*^ that left them feeling unwell and unable to cope. One PWLE later elaborated, calling ADHD, anxiety, and depression a "trifecta" of symptoms that "feed off of each other."

We had a son in April of 2017. A few months later, my mom passed away. That was devastating news. [My] anxiety was probably ramped up at this point because I had a newborn at home, and I didn't know what I was doing … Eight months later, my wife was diagnosed with breast cancer. Things started stacking and I didn't see it at the time, I just knew I didn't feel good. I was stressed out and anxious, but I didn't consider that there was a source other than the situation that could be causing that.

—PWLE

Before recognizing their symptoms as ADHD, ^*most PWLE received a mental health diagnosis that shared symptoms or was comorbid with ADHD*.^ In fact, half of PWLE reported receiving two or more mental health diagnoses before being diagnosed with ADHD. Similar to other research with adults with ADHD, PWLE in this study typically reported being diagnosed with anxiety, depression, or both, followed by post-traumatic stress disorder and bipolar disorder (Ginapp et al., 2023; Eagle & Ringland, 2023). For some PWLE, the initial diagnosis seemed right at the time, whereas others questioned the accuracy of their diagnosis, especially after medication did not alleviate their symptoms.

III. **Seeking help for ADHD**

^*PWLE often characterized the moment they recognized that their symptoms might be ADHD as pivotal*.^ Some PWLE realized they likely had ADHD after their child was diagnosed, they met colleagues or neighbors with the condition, or a friend suggested it. Others made the connection after encountering information about ADHD in adults online. For example, one PWLE felt certain that she had ADHD after watching a video on YouTube about ADHD and sensitivity to rejection, whereas a podcast revealed to another PWLE that difficulty managing emotions was associated with ADHD. After discovering that their symptoms may be ADHD, PWLE often researched the condition more online, accessing information through the CHADD website, 8ttitude magazine, medical websites, journal articles, and social media (for example, TikTok, Instagram). In addition, some PWLE joined online support communities for adults with ADHD on Facebook and Reddit to connect with peers and learn more about their experiences.

Most PWLE sought an evaluation for ADHD after realizing that it fit with their symptoms. Although a few PWLE reached out directly to providers who specialized in ADHD among adults, most raised ADHD as a potential diagnosis first with a primary care provider or therapist. Two-thirds of PWLE reported that a primary care provider, therapist, or other non-ADHD specialist referred them to a psychiatrist or neuropsychologist because of a lack of comfort or ability to diagnose ADHD. In addition, some primary care providers referred participants for robust evaluations even when the provider was confident in an ADHD diagnosis. Even after identifying the right provider, PWLE often faced logistical and financial barriers to accessing the services they needed (see Section C).

PWLE who proposed ADHD as a potential diagnosis to providers described a mix of reactions from providers. Many PWLE recounted dissatisfying interactions with providers who dismissed the possibility of ADHD or attributed their symptoms to other conditions, such as mood disorders or stress, leaving them feeling frustrated and invalidated. For example, one PWLE shared that a provider told her, "You don't come across like you have ADHD." In addition, a few PWLE reported that providers suspected them of drug seeking. Still, some PWLE reported having positive encounters with non-diagnosing providers who supported further evaluation for ADHD, as well as the providers who diagnosed them with ADHD, explaining that these providers often showed compassion and validated their concerns.

3. Completing an evaluation for ADHD

We asked PWLE about the evaluations they underwent to receive an ADHD diagnosis. As Exhibit III.1 shows, all PWLE underwent a clinical interview with a provider. In addition, most PWLE completed rating scales and questionnaires, which often assessed the symptoms of multiple conditions. Many PWLE described their clinical interviews as comprehensive, with a few noting that providers observed them over

the course of seven to eight sessions before making an ADHD diagnosis. Several PWLE reported that providers gathered input from people in their lives (for example, family members, friends) to inform the diagnostic process. In addition, several PWLE reported that they were required to undergo neuropsychological testing, which assesses cognitive abilities, including memory, attention, and problem solving.

Exhibit III.1. ADHD evaluation experiences reported by PWLE

	Clinical interview	Rating scales	Input from others	Neuropsychological testing
Number of PWLE	18	14	7	7

PWLE = people with lived experience

Navigating the path to receive an ADHD diagnosis was more challenging for some PWLE than others. However, ^*PWLE often described feeling relieved and validated after receiving an ADHD diagnosis*.^ Some PWLE further elaborated, explaining that their ADHD diagnosis helped them make sense of their lives and gave them hope about the path forward.

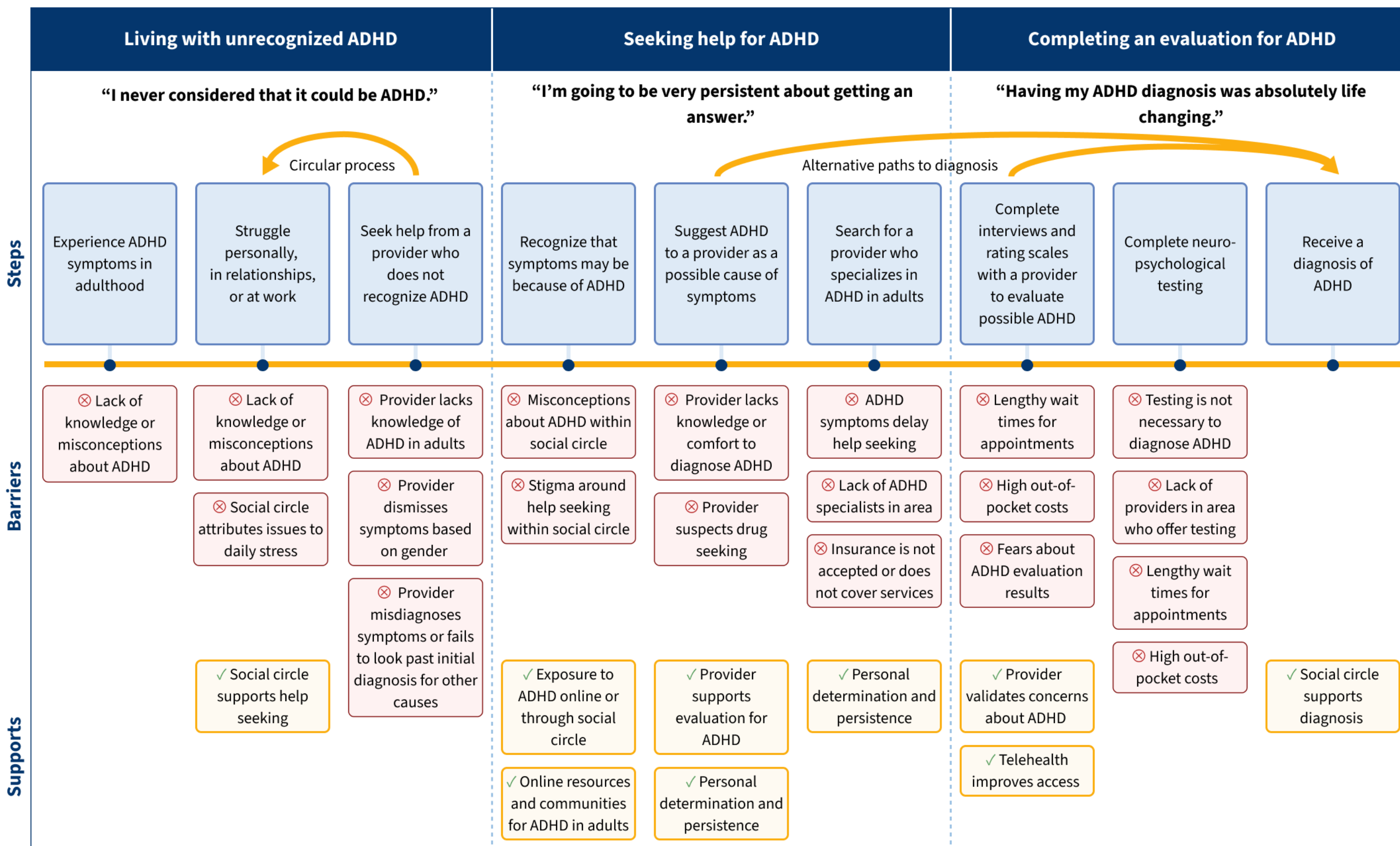
Having my ADHD diagnosis was absolutely life changing. After diagnosis, I spent a really huge amount of time understanding ADHD and how it impacted women in particular, for one thing. The more I understood, the more I was able to address these key areas in my life... So that transition to understanding myself was so incredibly, not only life changing, life improving ... I'm forgetful. It's just because of my brain. It's not because I'm broken. It's not because I'm a flawed human being.

—PWLE

4. Journey map

Exhibit III.2 is a journey map illustrating the common paths to receiving an ADHD diagnosis in adulthood. The stages at the top of the map correspond to the subsections above. The journey map shows the common path to receiving an ADHD diagnosis in adulthood, as described by PWLE. The map reflects a compilation of lived experiences: not every person experienced each step, barrier, or support. Furthermore, the journey to an ADHD diagnosis in adulthood might not always be linear, as the curved arrows indicate. The barriers to diagnosis and supports that helped facilitate diagnosis are described in greater detail in Sections C and D.

Exhibit III.2. Journey to ADHD diagnosis in adults



ADHD = attention deficit/hyperactivity disorder; PWLE = people with lived experience

C. Barriers to adults receiving an ADHD diagnosis

The PWLE and clinical experts interviewed for this study described an array of personal, provider-related, and systemic barriers to adults receiving an ADHD diagnosis. These included a lack of personal knowledge about ADHD, sociocultural factors, and fear of ADHD evaluation results; ADHD symptoms; a lack of provider knowledge and inadequate training, tools, and time to diagnose ADHD in adults; attitudes and bias among some providers; and health care access barriers and unnecessary neuropsychological testing.

1. Lack of personal knowledge, sociocultural factors, and fears about ADHD evaluation results

^*A personal lack of knowledge and misconceptions about ADHD were barriers to diagnosis*^ for many PWLE. It often took years for PWLE to recognize their symptoms as ADHD, preventing them from raising it as a possibility with providers sooner. Before learning more about ADHD, most PWLE did not understand what the condition entailed or realize that it could be a lifelong diagnosis. They believed instead that ADHD was a childhood condition, primarily involved hyperactivity and impulsivity, did not affect girls and women, or consisted of learning or developmental delays. Some PWLE were unaware that inattentive symptoms, difficulty regulating emotions, and sensitivity to rejection could be associated with ADHD.

> How do I know I have something if I'm not even aware it exists, or that it shows differently in women?
>
> —PWLE

^*Sociocultural factors sometimes made the journey to diagnosis more challenging*^ for some PWLE. Echoing the literature, some PWLE interviewed for this study avoided discussing their concerns about ADHD or desire to seek an ADHD evaluation with family or friends, whose beliefs about mental health or help seeking might leave them feeling judged (Waite & Tran, 2010). For a few participants, a spouse's denial or beliefs about ADHD served as a roadblock to diagnosis. For example, one PWLE reported that it took him six years to recognize his symptoms as ADHD because of his wife's misconceptions about ADHD.

^*Some PWLE feared what the results of an ADHD evaluation would mean for them*.^ Consistent with posts in online communities for adults with ADHD, some PWLE worried that not receiving an ADHD diagnosis would mean they were flawed, lazy, or had a weak character (Eagle & Ringland, 2023). In addition, a few PWLE delayed help seeking as the prospect of receiving a diagnosis became more real, and fears set in about how they would manage the lifelong condition.

2. ADHD symptoms

^*ADHD symptoms often made it difficult to manage the steps to seek help*,^ delaying diagnosis for some PWLE. Consistent with posts in online communities for ADHD, PWLE in our study often discussed putting off tasks, struggling to complete paperwork, and forgetting to schedule or attend appointments as barriers to diagnosis (Eagle & Ringland, 2023). A few PWLE described needing time to mentally prepare or build up the energy to make appointments, delaying diagnosis for as long as six months. For some participants, issues with impatience and

> It took me about six months to make the appointment. So, I sat with it for a really long time and had it on my to-do list for a very long time before I finally got up the energy to make the appointment.
>
> —PWLE

impulsivity made waiting months for appointments especially difficult. A few clinical experts similarly noted that people with ADHD often have difficulty keeping up with the various parts of the process to be diagnosed because of their symptoms.

3. Lack of provider knowledge and inadequate training, tools, and time to diagnose ADHD

For some PWLE, missed ADHD diagnoses by providers, coupled with their own lack of knowledge of ADHD, led to yearslong delays in receiving an ADHD diagnosis. Several PWLE lamented the fact that ^*providers often failed to suggest ADHD as a possible cause of their symptoms*^ because of a lack of knowledge about ADHD in adults. In addition, ^*some PWLE reported that providers dismissed their concerns and did not take them seriously*.^ Consistent with a study of young adults with ADHD, most PWLE were initially diagnosed with mental health conditions that share symptoms with ADHD (Ginapp et al., 2023). ^*Several PWLE saw their initial diagnoses as labels that providers failed to look past to explore other possible causes for their symptoms,*^ even when their symptoms persisted despite treatment. As a result, several PWLE considered their previous diagnoses a hindrance to receiving an ADHD diagnosis.

Clearly, it was a significant hindrance. It was clearly a red herring. Maybe that's too strong a term, but from what I've learned, I really do think that a lot of people with ADHD are diagnosed with the sort of things that were suggested to me … I bought into that. I took the antidepressants. Looking back, it does seem surprising that there was no exploration of the diagnosis.

— PWLE

Several clinical experts shared that ^*providers often lack the knowledge to diagnose ADHD in adults and make differential diagnoses because of inadequate training*.^ The experts explained that, because of its early conception as a childhood condition, primary care providers, psychiatrists who treat adults, psychologists, and social workers have historically received minimal to no training in ADHD, resulting in a lack of knowledge and confidence to diagnose ADHD in adults. This aligns with findings from a study that found only 50 percent of psychiatrists, 20 percent of primary care providers, and nine percent of nurse practitioners reported being confident in their ability to diagnose ADHD in adults (Adler et al., 2019). A few clinical experts offered that ^*family medicine providers are better positioned to diagnose ADHD in adults than some specialists*^ given their training in pediatrics and experience treating ADHD across the lifespan.

I think there's a tremendous lack of education around adult ADHD. Many clinicians my age were taught about this from a pediatric perspective. Very few of us had any formal education to even put adult ADHD on our radar screen.

— Clinical expert

Consistent with the literature, some clinical experts noted that ^*there are no guidelines in the United States for diagnosing ADHD in adults and current diagnostic criteria and tools are inadequate to diagnose ADHD in adults,*^ leading to misdiagnosis and underdiagnosis (APSARD, 2023; Adler et al., 2009). However, most experts reported being familiar with or involved in the effort by APSARD to develop these guidelines. Some experts also reiterated the literature when explaining that early research on ADHD centered on

White boys and that diagnostic tools and provider training continue to align with the expression of ADHD symptoms in boys and young men (Hinshaw et al., 2022).

A few experts believed current tools for ADHD diagnosis were sufficient but mentioned that ^*there are barriers to the widespread use of ADHD diagnostic tools*,^ including a lack of training and practice-specific applications to use these tools. Furthermore, several clinical experts mentioned that ^*primary care settings are not always conducive to diagnosing ADHD in adults,*^ which can impede diagnoses. These experts explained that primary care providers have little time to collect patient histories, assess symptoms, and administer rating scales required to properly diagnose ADHD. In addition, a few clinical experts noted that primary care providers may have limited ability to seek reimbursement for behavioral health services.

4. Marginalizing attitudes and bias among providers

^*Some PWLE attributed delays in diagnosis to marginalizing attitudes among providers about ADHD, their age, or their gender*.^ One PWLE, who was diagnosed with ADHD in her late 30s, shared that some psychiatrists do not view “late diagnosis” ADHD as legitimate. Another recalled how a primary care provider mischaracterized ADHD in a stigmatizing manner, stating that ADHD is not a medical problem. A few female PWLE believed that gender bias played a role in not being diagnosed sooner. One PWLE, whose provider attributed her symptoms to hormones during pregnancy and then later to being a new mom, questioned whether she would have been diagnosed sooner if she were a man. A few clinical experts supported this theory, noting that ^*providers may overlook ADHD in women and girls because of gender bias and assumptions about the underlying causes of their symptoms*.^

I think there's a sexist bias in mental health that contaminates accuracy of diagnosis. And to say just what I mean by that is that males, when they present with mental health issues, the focus by the clinician is on the issues that they're raising. The focus of clinicians for females when they raise issues is focused on emotionality. They more easily ascribe emotional aspects to the presenting symptoms, and that becomes the obstacle to an accurate diagnosis.

— Clinical expert

Accounts from PWLE and insights into provider attitudes from clinical experts indicated that ^*some providers have biases against people who suggest ADHD as a potential diagnosis*.^ A few PWLE reported that providers interpreted their suggestion of ADHD as a possible diagnosis as drug seeking for weight loss or based on past substance use, even though they did not request stimulant medications. A few clinical experts provided insight into these attitudes, noting that some providers do not believe ADHD is a legitimate diagnosis in adults and suspect them of faking symptoms to seek stimulants. In addition, they mentioned that some providers are hesitant to prescribe stimulant medications for patients with ADHD because of concerns over misuse and the need to see patients who take stimulants more frequently.

And when I was walking out the door, he goes, ‘Hey, you know what? You're just going to waste a lot of money. Nobody's going to give you any Adderall.’ It's like, I didn't ask for Adderall ... and I was 18 years clean and sober at that point.

—PWLE

5. Health care access barriers and unnecessary neuropsychological testing

^*Most PWLE and clinical experts described a lack of available providers and lengthy wait times for appointments*^ as impediments to receiving a diagnosis. Consistent with the literature, some PWLE had difficulty accessing care because of a lack of providers in their areas (Eagle & Ringland, 2023). In addition, several PWLE described lengthy waits for initial appointments with specialists, ranging from two to eight months. For a few PWLE, this was followed by another lengthy wait for neuropsychological testing. Several clinical experts shared that their patients experienced similar issues, noting that wait times to see a psychiatrist can range from three to six months.

Then it was a scheduling situation. It was, okay, go, meet them for the first time, which was scheduled out a couple of months, and then they schedule out a couple of months before you can start the testing. It was just a delay after delay kind of thing.

—PWLE

^*Several PWLE described insurance-related issues and high out-of-pocket costs as barriers to diagnosis.*^ They recalled frustration over their insurance plans not covering certain providers or services, including neuropsychological testing. In addition, some PWLE reported that behavioral health providers did not always accept insurance, leaving them to pay $400 to $600 out of pocket for services. Some PWLE received even higher quotes for ADHD evaluations that included neuropsychological testing, ranging from $700 to $2,000. Multiple clinical experts indicated that the cost of testing could exceed this amount (for example, one said that testing costs between $5,000 and $15,000 in their local area). High out-of-pocket costs led some participants to delay help seeking until they could afford to pay for services, obtained better insurance, or found a more affordable provider. Other PWLE accepted these expenses because they lacked alternatives or heard that the costs were typical.

At the same time, clinical experts unanimously stated that ^*neuropsychological testing is not necessary or an adequate tool for diagnosing ADHD in adults*.^ Many experts noted that ADHD diagnosis is based on behavioral symptoms, not cognitive functioning that is assessed using neuropsychological tests, . These experts emphasized that neuropsychological testing does not account for the trajectory of ADHD symptoms over time and that results cannot necessarily be generalized to everyday functioning (for example, work performance, relationships). Some suggested that providers likely refer patients to testing because of a lack of confidence in their own diagnostic skills and a lack of familiarity with the appropriate diagnostic approaches for adults with ADHD. Several clinical experts explained that neuropsychological testing is appropriate for differential diagnosis in specific circumstances, such as when a provider suspects that a patient might have an intellectual or learning disability or if the patient has experienced a traumatic brain injury, as well as to help determine education-related accommodations. Most clinical experts also emphasized that ^*neuropsychological testing creates barriers to diagnosis*,^ citing high costs, limited insurance coverage, and lengthy wait times for appointments.

Some clinicians … will use neuropsychological testing or computer-based testing of some sort as a supplement or method of diagnosis. And that's just wrong. We just know that these methods

can't rule in ADHD, they can't rule out ADHD. They're useful for all sorts of things, but not for diagnosis. And that can lead to misdiagnosis both ways, by underdiagnosis or overdiagnosis.

— Clinical expert

D. Facilitators of receiving an ADHD diagnosis

PWLE described the supports and facilitators that helped them overcome barriers to receiving an ADHD diagnosis. These included having increased personal knowledge of ADHD, supportive social circles and providers, personal determination and persistence, and telehealth. In addition, clinical experts provided their perspectives on the role of the media and telehealth in ADHD diagnosis.

1. Increased personal knowledge of ADHD

^*Increased knowledge of ADHD empowered PWLE to discuss it with providers and seek an ADHD evaluation*.^ Encountering information about ADHD in adults online and interacting with other adults with ADHD helped PWLE overcome a lack of knowledge and misconceptions about the condition. Researching ADHD among adults online and joining online communities for adults with ADHD often gave PWLE the confidence to raise it as a possible diagnosis with existing providers or seek help from providers who specialized in ADHD. Similarly, a few clinical experts mentioned that ^*media coverage and social media have increased public awareness about ADHD*,^ encouraging more adults to seek evaluations. Online communities also enabled some PWLE to seek advice from adults who had already received an ADHD diagnosis, learn about the process to be diagnosed, and determine whether their experiences seeking an evaluation for ADHD were typical.

Having that peer community. Being able to share experiences with other people and learn from others who have similar struggles and what they have used to try to address the struggles. That’s been very instrumental.

— PWLE

2. Supportive social circles and providers

^*Supportive social circles helped several PWLE overcome barriers to receiving a diagnosis*.^ Some PWLE described how people in their lives—spouses, friends, family, and coworkers—played an instrumental role in helping them overcome barriers to diagnosis. People in their social circles often encouraged PWLE to pursue ADHD evaluations, provided referrals, and supported them through the process to receive a diagnosis, which some participants called “life changing.” In addition, ^*several PWLE credited supportive providers with making their journey to receiving an ADHD diagnosis easier*.^ Some PWLE recalled non-diagnosing providers who helped them prepare for their ADHD evaluations or navigate the system to receive a diagnosis. One participant recounted a provider advocating for them to be retested for ADHD after initial results did not support a diagnosis. PWLE also expressed appreciation for the providers who diagnosed them with ADHD, noting that these providers often showed them compassion and validated their concerns.

3. Personal determination and persistence

For some PWLE, ^*personal determination and persistence were key to overcoming challenges to receiving an ADHD diagnosis*.^ PWLE sometimes credited their personal belief that they had ADHD with driving the determination to obtain a diagnosis. One PWLE recalled feeling determined to complete every diagnostic step required of them, driven by a commitment to achieving an accurate diagnosis. In addition, a few PWLE shared that being stereotyped as "drug seekers" motivated them to continue their journey to receive an ADHD evaluation. Some PWLE also took measures to ensure they did not miss a step in the process, setting multiple calendar reminders and alarms so they did not miss an appointment.

I'm used to running into brick walls. And you know what? Don't mess with me because I'll figure a way around that thing. Watch me now.

—PWLE

4. Telehealth

^*Telehealth made evaluations for ADHD more accessible, convenient, and emotionally safe*^ for several PWLE. Nearly all PWLE who completed at least part of their journey to diagnosis via telehealth described positive experiences and aspects of telehealth. Some participants praised the convenience of telehealth, explaining that it was faster and easier to attend appointments from home and that they did not have to take time off work to travel to an in-person appointment. A few PWLE reported that telehealth appointments with their providers were more readily available than in-person appointments, enabling them to receive their ADHD evaluations sooner. Furthermore, some PWLE conveyed that attending appointments via telehealth made them feel more emotionally safe and reduced their anxiety about discussing sensitive topics that they would feel less comfortable talking about in person.

It felt safer to be in my home answering vulnerable questions. For whatever reason, that just gave me a comfort level that I can do this here, whereas I think just my personal nature, I'd be kind of intimidated of a psychiatrist. Doing it virtually kind of took the edge off...

—PWLE

Some clinical experts shared that ^*telehealth can help to increase access to care, improve health equity, and reduce stigma*.^ Experts noted that telehealth improves access for people living in areas with few providers, such as rural communities. One expert also mentioned stigma is reduced with telehealth, noting that "people, especially younger generations, seem to be less afraid to digitally interact" than they might be in person. Still, several clinical experts explained that ^*providers should follow the same steps for diagnosing ADHD via telehealth as they would in person*.^ This includes using evidence-based diagnostic tools to inform an ADHD diagnosis and spending sufficient time with patients to make a proper diagnosis.

E. Opportunities to reduce barriers to ADHD diagnosis in adults

Clinical experts and PWLE offered several ideas and opportunities to reduce barriers to adults receiving an ADHD diagnosis, including raising awareness about ADHD in adults, updating and expanding clinical training and education on ADHD, and increasing funding for research on ADHD.

1. **Raise public awareness about ADHD in adults**

^*Some PWLE and clinical experts recommended raising public awareness about ADHD in adults to educate and empower people with undiagnosed ADHD to seek care*.^ Suggestions included issuing public health announcements about ADHD in adults, making it easier to find the latest information on symptoms online, publishing articles in popular magazines, and funding educational efforts. One clinical expert emphasized that educational efforts should inform people that ADHD is treatable and that treatment could have a major effect on their lives.

I think if there was more public education, whether it's via government announcements, whether it's by articles in popular magazines that are appropriate. Those are the kind of things that actually bring people to treatment. They'll say, 'oh, I read this article, and it made me think I need to be treated.

— Clinical expert

2. **Update and expand clinical training and provider education on ADHD**

^*Most clinical experts emphasized the need for updated clinical training and education to improve providers' confidence and support more consistent diagnoses*.^ They mentioned that training is needed on the adult manifestations of ADHD and differences in symptoms across genders. A few experts recommended that training and education on ADHD be provided across multiple disciplines and to diverse provider types, such as nurse practitioners and physician assistants, explaining this may expand the capacity of primary care practices to offer ADHD diagnostic services. Some clinical experts suggested that educating providers on the treatment of ADHD in adults also may improve confidence in their ability to manage patients who take stimulant medications and increase their willingness to diagnose adults.

You can improve the self-confidence of clinicians by providing them with the skills that they can execute. They can then see that the execution of those skills serves the patient well. The patient comes back and says, 'Oh my gosh. You're a genius. I'm so much better. Thank you for changing the course of my life.' That then accelerates the confidence, verifies the reality of ADHD and the fact that treatments are effective, and they continue to take on this population of patients.

—Clinical expert

3. **Increase funding for ADHD research in general and incorporate lived experiences**

^*Most clinical experts emphasized the need for increased funding for research on ADHD*.^ Some reported that ADHD research is seriously underfunded, with one expert stating that ADHD is not treated as a significant issue by some funding agencies. Nearly all experts called for research to validate ADHD diagnostic criteria and tools for adults and other groups, explaining that it is important for diagnostic criteria and tools to be sensitive to and accurately detect ADHD across different ages, genders, races, and ethnicities. One expert suggested funding population-level research for this purpose, and a few recommended funding research into the lived experience of people with ADHD. One expert mentioned that research is needed to better understand the effect of women's hormones on their ADHD symptoms across the lifespan. A few experts recommended funding for screening tools, including a universal

screening tool and a website or portal where adults can complete a screener to determine their risk for ADHD and submit the score to their provider.

The criteria for adults need to be revised... They could be made more specific to adults. They might have to address changes with age. They might have to address differences by sex and race/ethnicity. But we're not going to know that unless somebody funds a good research project to look at it...

— Clinical expert

IV. Discussion

This study contributes new insight into the lived experiences of people who received a diagnosis of ADHD in adulthood, as well as the barriers to and facilitators of diagnosis. Our findings highlight how a combination of factors—the historical underpinnings of ADHD, lack of public knowledge about ADHD in adults, stagnation in developing diagnostic criteria and tools for diagnosing ADHD in adults, failure of the medical community to embrace ADHD as a lifelong diagnosis, and insufficient government funding—have culminated in the underdiagnosis and undertreatment of a condition with serious implications for adults and society at large. As public interest in ADHD in adults rises with increased media coverage and exposure to ADHD on social media, there is a growing need to fund research and other efforts that will help reduce barriers for adults to receive what may be a lifechanging diagnosis.

- **Raising public awareness may help address a lack of knowledge and misconceptions about ADHD and encourage help seeking among adults with undiagnosed ADHD.** PWLE in this study often received a diagnosis of ADHD years after first seeking help for their symptoms. A lack of knowledge and misconceptions about ADHD prevented them from raising it with providers and seeking an ADHD evaluation sooner, leading to an array of personal, professional, and educational issues. Efforts may include developing educational resources for professionals and publishing magazine articles that feature personal stories of adults living with ADHD, the symptoms they experienced before ADHD was diagnosed, and how the diagnosis changed their lives. These efforts may inspire adults who identify with these stories and give them the confidence to discuss ADHD with their providers. Providers may also find it inspiring to know that they can make a difference in the lives of adults with undiagnosed ADHD.
- **Funding for ADHD research is needed to advance the field and address current barriers to ADHD diagnosis in adults.** Several clinical experts in this study called for more government funding for research on ADHD in adults to advance the field. They reported that current clinical training and diagnostic tools continue to focus on symptoms in children and males in alignment with early research on ADHD. Furthermore, experts emphasized that insufficient education and training has led to a lack of comfort with diagnosing ADHD in adults and bias among some providers. Therefore, it will be important for education, training, and diagnostic tools to address the symptoms of ADHD in adults and differences in symptoms across genders and diverse populations. Expanding clinical training and education to medical schools and residency programs for adult providers (for example, psychiatrists and primary care providers), and making continuing medical education readily available to providers in later stages of their careers will help to address barriers to diagnosis and care. Educating providers about evidence-based practices for diagnosing ADHD in adults is also important.
- **Research into the lived experiences of adults with ADHD is needed to improve and inform revisions to clinical training and diagnostic tools.** Clinical experts called for research to develop valid ADHD criteria and tools for adults that are sensitive to age, gender, race, and ethnicity. Funding research to understand the lived experiences of adults from diverse backgrounds, including women and non-White people, can help to inform a revised and updated knowledge base about ADHD in adults, its symptoms, and its diagnosis. This research can inform the development of tools that are validated across genders and diverse populations, provider training, and public awareness efforts and resources. Moving forward, it also will be critical to incorporate the perspectives of adults with ADHD in clinical

research and policy planning to ensure these efforts align with the needs, experiences, and priorities of the people affected.

- **Curtailing the unnecessary use of neuropsychological testing in the diagnosis of ADHD in adults can reduce barriers to care.** Clinical experts in this study unanimously stated that neuropsychological testing is not necessary or an adequate tool for diagnosing ADHD in adults and that it creates barriers to care. However, seven of the 18 PWLE in this study reported undergoing neuropsychological testing as part of their ADHD evaluations. More specifically, five of the nine PWLE who completed their ADHD evaluations during in-person appointments received neuropsychological testing, whereas two of the nine PWLE who completed at least part of their ADHD evaluations via telehealth underwent testing. Future studies may want to explore trends in the provider types, contexts, and settings that require neuropsychological testing, including whether it is a standard requirement or applied on a case-by-case basis. This research can inform the development and dissemination of standards and evidence-based approaches for diagnosing ADHD in adults and help to curtail the use of unnecessary, expensive testing that creates barriers to care for adults with undiagnosed ADHD.
- **Providing supports to better support ADHD diagnosis in primary care may help to address underdiagnosis and reduce barriers to receiving a diagnosis.** Primary care providers often serve as the front line in physical and mental health care. Funding and equipping primary care settings and providers—physicians, nurse practitioners, and physician assistants—with the skills and tools to diagnose adult ADHD may help to ease underdiagnosis, reduce misdiagnosis, and address disparities. For successful integration, funding for provider training, resources for providers and patients (for example, education, referral resources, screening tools), innovative reimbursement approaches, and other supports are encouraged.
- **Proper quality controls and oversight of telehealth can reduce barriers to ADHD diagnosis for adults.** PWLE and clinical experts in this study described telehealth as an important factor in reducing barriers to adult ADHD diagnosis. Although some clinical experts cautioned against profit-based telehealth models, they also mentioned that many telehealth providers offer thorough ADHD evaluations for adults and may offer advantages over in-person care, such as expanded reach and improved accessibility. Furthermore, PWLE who accessed services via telehealth praised its convenience, accessed telehealth services sooner than in-person care, and felt less anxious and more emotionally safe when using telehealth. With proper quality controls and oversight to ensure fidelity to evidence-based practices, telehealth may reduce barriers and facilitate earlier diagnosis of ADHD in adults.

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Appendix A. Key Themes and Illustrative Quotes

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Exhibit A.1 presents the themes that emerged from our interviews with clinical experts and people with lived experience (PWLE), the number of experts and PWLE who reported each theme, and direct quotes from clinical experts and PWLE to support each theme. In addition, we indicate in the e-scan column when a theme from the interviews reiterated a finding from the environmental scan. The themes are presented in same order in which they appear in the report. When clinical experts and PWLE reported the same theme, we included in parentheses the type of participant who said each quote.

Exhibit A.1. Themes, source, and illustrative quotes from clinical experts and PWLE

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
A. Current trends in ADHD diagnosis				
1. Underdiagnosis and disparities in ADHD diagnoses				
ADHD continues to be underdiagnosed in adults in the United States	7		Y	"It's an enormous clinical challenge and it's an enormous unmet need." "I am concerned about underdiagnosis and also overdiagnosis and correct diagnosis." "Going back into, at least, 2016 studies, that's prevalence somewhere in the region of 2.5% to 4.5% of the adult population, likely, with a diagnosis. Of that number, I remember at that time, it was, maybe, 20% actually were diagnosed or treated… a lot more of the marketing and the push, and everything, that started happening with some of these telemedicine companies during the pandemic, rates started to go up, but we were so far underwater, that to me, there was no surprise. We're still grossly under that, even just the expected prevalence of it."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
Underdiagnosis remains a source of debate	3			“I very rarely see anybody in the professional community being aware of underdiagnosis. They don't know the data, they have nothing to cite, they've never seen the research, but that's just purely their opinion. And that's why I say that bias still remains.” “[Concern about underdiagnosis] among clinical experts? Very high.”

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
Implications of underdiagnosis of ADHD in adults are profound and far-reaching	7		Y	"This is not just a benign little disorder. If you look at the trajectory of negative consequences for ADHD, it is traumatic and dramatic, not only to patients and families, but to society. The burden of untreated ADHD is enormous in dollars and cents." "So, people that are living with ADHD develop not just ADHD, but they tend to develop secondary problems with anxiety, depression, self-medication with substances, and then it has a ripple effect. And my new analogy for teaching is it metastasizes in people's lives. Untreated ADHD becomes more lethal ADHD. So, you see deaths of illnesses of despair, such as suicide, trauma, domestic partner violence, going up in patients living with ADHD that aren't getting treatment." "The issue in underdiagnosis is if the diagnosis is missed, there are substantial costs to the individual and society." "Untreated ADHD has profound implications, and it shows up in impact society-wide… It's huge rates in the prison population, the criminal justice system. You only wonder what could have happened if those people had been evaluated when they were younger. But by the time people are adults… Whatever network they're a part of is going to be impacted. They require more resources to do what other people would do without those resources, and they end up gravitating towards situations that are resourced for them. So, you end up with higher rates of divorce, higher rates of earlier having children where people aren't prepared economically and maybe maturity-wise to handle a family. You see longer and more persistent substance abuse, higher rates of any, basically, mental health condition that we identify in terms of mood and anxiety, in particular those categories."
Gender disparities in ADHD diagnoses begin in childhood but appear to shift in adulthood	5		Y	"Now, if you look at the recent CDC publication on prescriptions, you'll notice that the prescription rates in children and adolescents are higher in boys than girls. When you get into the 20s, it's actually equal. Over 35, there are more prescriptions being written for females than there are for males. We used to say that girls are terribly… underdiagnosed. Women are underdiagnosed. But the current prescription data would suggest that that's actually not correct, and that the diagnosis of ADHD in women have really caught up." "We've historically talked about the barriers to care for women, because women historically had a lower diagnosis. We now know more women are getting care than men… I think women are better about seeking health care for themselves. So, we know the prevalence of ADHD is still a little more common in men versus women. But right now, data from the CDC and other places are telling us that there's about 50% more women getting treatment than men. And so, at this point, if you look at the treatment trends, it's great that we're getting women in for treatment, but it means we're actually losing the men right now." "With respect to gender disparities, it's interesting, because we do have childhood clear diagnosis disparities for non-male individuals. But as we get into adulthood, there's a shift, and there is a higher level of diagnosis in adult women, largely because of help-seeking being increased in adult women compared to men who have the disorder. But also, you could surmise that many females being missed in childhood leads to a compression effect, where they first get diagnosed later. And so, it's not necessarily that there's overdiagnosis or underdiagnosis in women, but that the timeframe of their diagnosis is just on a staggering from male individuals." "Girls may be, in some ways, interesting, paradoxically, more likely to have a form of ADHD that does persist more over time. Boys who get diagnosed on the basis of overt overactive behaviors; those behaviors tend to go underground. The best estimates today … are that if you go to adult ADD or ADHD clinics now, they're still somewhat more men than women, but maybe 1.3 or 1.2 to one. Women are almost as likely, I'm not sure if more, but maybe the data will tell more in the next decade, to get diagnosed. Meaning that something is happening in development, which I just alluded to, that if a girl has ADHD, which may or may not be detected because it's more subtle, it's more inattentive, more disorganized, that's going to persist over time, more than the more overtly hyperactive form of ADHD that predominates in boys."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
Racial and ethnic disparities in ADHD diagnoses are rooted in systemic and sociocultural factors	3		Y	"I grew up in [a] community that is primarily a minority population … first of all, health care access is not great to begin with, and certainly not mental health care, and there's stigma about it. So, I think in those communities of color, communities of economic disadvantage, and it's not just color, it's also economic disadvantage, that we want to break down stigma and help with that access." "I do think there is stigma, culturally, in certain communities of color about whether or not you view the symptoms of ADHD as being medically related or being an aspect of your character or being an aspect of something that's personality-related, whether seeking care for ADHD is … they're less likely to have good health insurance that may give them an opportunity to get a higher level of care. I think that goes without saying. In their neighborhood, there may be less clinics that are giving specialty care for ADHD. So, there's all those systemic barriers that I think you would normally see." "The problem with underrepresented groups is they're underrepresented, and we don't have a lot of information on those groups. That's number one. There's a huge problem there. The second problem, which is probably as big a problem, has to do with cultural sensitivity and diagnosis and to what degree are diagnoses that are developed on the majority population appropriate for people of other races and ethnicities. Now, when I say appropriate, I don't mean that people of other ethnicities don't get ADHD. ADHD is a worldwide disorder. We know that. But the question is whether it's possible that the expression of symptoms is different in these groups and that, therefore, maybe they're diagnosed with another condition and not ADHD. It could also be it's a referral issue, that perhaps certain groups are less likely to self-refer for ADHD."
2. Overdiagnosis and misdiagnosis of ADHD in adults				
There are flaws in using stimulant prescription data as a measure of overdiagnosis	3			"Those are prescription fills. You remember, they're not all attached to ADHD diagnoses." "Getting a medication for ADHD does not mean that you've been diagnosed or accurately diagnosed."
Overdiagnosis occurs when people seek an ADHD diagnosis to obtain stimulants and companies prioritize profits	4			"But because of recent social media trends, we're at risk of overdiagnosis because some people know that if you get an ADHD diagnosis, you may have access to stimulant medications, and people may be gaming the system or order to get illicit substances." "Any time that you have a financial incentive built into your business model to give out as many diagnoses as possible and be as quick as possible about it, you're incentivizing a system to not take it slow, be careful and be afraid to say, 'no, you don't have ADHD.' And so I think that it's important to divorce the telehealth as a modality from a certain business model that emerged during the pandemic and, at least journalistically, was associated with problematic practices." "There seems to be some, if you will, scamming that's been done … and it needs to be stopped. No question about that. That's very bad." "When you have venture-backed companies, and the only motive is growth, growth, growth, growth, client acquisition, client acquisition, client acquisition, you lose the magic of it. All they're trying to do is... And I understand there's a huge need, and they went after a need, but when your sole motive is more, and more, and more, more people, more growth, we need hockey-stick growth so we can have an exit, there is something wrong with that...

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
ADHD occurs on a continuum, and the threshold for diagnosis and treatment are subjective	3			"Since ADHD exists on a continuum, we really have an arbitrary cut point for how severe someone's symptoms have to be in order to give a diagnosis. And our rule of thumb, based on the definition of a mental disorder that has been encoded and enshrined in the DSM for decades, is that if the person experiences impairment, then that should be the point at which we attribute their symptoms to being sufficiently severe to give the diagnosis, and therefore the treatment. But the complicating factor about that is it's gotten pretty subjective, whether someone's impaired enough or not." "So, for example, a study might say that we went and re-diagnosed everybody in a primary care clinic who had ADHD, and we found that only 70% of them met the DSM-5 criteria for ADHD. And what sometimes they don't tell you is, what do those misdiagnosed people look like? Because we have this problem of people at the threshold of diagnosis." "If you've fought your ADHD-like symptoms for a long time, and therefore it hasn't caused you any impairment, there's a clinician out there who's going to say you don't deserve a diagnosis, and there's another clinician out there who's going to say, yes, you do."
B. Journey to ADHD diagnosis in adulthood				
1. Living with unrecognized ADHD				
PWLE recalled experiencing an array of ADHD symptoms		18		"As I got into high school and college, I had more trouble as far as just trying to stay focused, get things done on time. I was late everywhere. Just a lot of inattention kind of stuff. I couldn't really pay attention to things and wouldn't remember things." "For me, I've always known that there was an emotional dysregulation thing that was happening … I had a terrible temper. My whole life, mom's like, watch your temper, watch your temper." "As I've gotten older, I've been less and less able to leave jobs on a positive note. I have a tendency to burn bridges. I work so unbelievably hard that I work myself into the ground and finally have a psychiatric mental breakdown where I've had to take months off of work just to recover from what I do to myself. But then I come home, and I can't clean the bathroom." "I first started struggling with symptoms that I did not know at all what it could be at about the age of 45 … I'm great at administrative stuff. And I had just a ton of systems and processes in place that kept me from going off the rails, and those stopped working." "I'm 30 now … leaving keys in the door overnight or leaving my keys in my car over the last few years has definitely gotten worse. It became noticeable to me when those types of things were starting to happen at work … some impulsivity. Mostly inattentive, like forgetfulness. Having just a super messy house that I just literally couldn't even… It was almost like I didn't even see it … some difficulty with interrupting conversations at work that was pointed out by co-workers as well."
Many PWLE developed compensatory strategies and tried other approaches to manage symptoms		14		"I started using caffeine … and instead of hyping me up, it helped me to focus … And then I started actually using something called Focus Aid." "Post-It notes everywhere. When I learn something new on technology, I've learned to send myself a delayed email, so I do have systems in place that I just, naturally, always have. I do that, trying to, maybe, get out clothes the night before, get a lunch ready the night before, I like to try to reduce being overwhelmed. Just naturally, putting systems like that in place." "I had started Wellbutrin years ago, which, apparently, is sometimes used for ADHD, but at the time … I didn't notice much improvement with that." "Something I can now recognize was a coping mechanism is that I am prone to doodle, and I would do that all through school, and I would get yelled at for it because it meant that I was daydreaming. But then I would pass all the tests on the subject matter … I took a class in tai chi.." "A while back, before I got officially diagnosed, my ex-husband was trying to tell me that marijuana would help but it actually made me paranoid. I tried it a couple of times… Once in a while, I would drink one or two alcoholic glasses of wine, or something along those lines, to try to calm down."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
Undiagnosed ADHD led to an array of personal, professional, and educational issues		6		"It would cause fights between me and my husband because he would think I was interrupting him, just being rude, talking over him, because I thought what I had to say was more important. Things like that. I always just thought that it was just personality traits." "I was admitted to the hospital … the reason I went there was true, but I wasn't telling the whole truth. And once I admitted that and said it out loud, 'yes, I procrastinated something so big for so long, for something so important, that I knew I was going to go home and kill myself because I couldn't be a failure. I could not fail my content area of study in university. That was not acceptable.' So, I ended up in the hospital, but I never told anyone the reason why I wanted to kill myself. And no one asked." "I had the ADHD paralysis experience. I was trying to finish my degree at that time for becoming a math teacher … you have to take a bazillion tests and do a portfolio. So, I'm working really hard on this, I'm trying my best, and then I basically failed it … I was going to do retesting and then… I tried to open my laptop. My brain is like, open the laptop, but my body wouldn't listen to me. I swear, I thought I was having a stroke or something." "Those last months before the diagnosis were some of the hardest of my life, just not feeling like I was fully functioning as myself and who I thought I was. It was discouraging. It was depressing. It was embarrassing. I would forget words in the middle of a business meeting, things like that."
A couple of PWLE characterized multiple life stressors as "stacking" or "piling up," resulting in an exacerbation of ADHD symptoms, anxiety, and depression		2		"We had a son in April of 2017. A few months later, my mom passed away. That was devastating news. [My] anxiety was probably ramped up at this point because I had a newborn at home, and I didn't know what I was doing … Eight months later, my wife was diagnosed with breast cancer. Things started stacking and I didn't see it at the time, I just knew I didn't feel good. I was stressed out and anxious, but I didn't consider that there was a source other than the situation that could be causing that." "But I would say that leading up to getting an official diagnosis, among the biggest things that touched it off were an unexpected third child when I was in the middle of getting a certification for something that I'd hoped would lead to a little more of a career, followed by, unfortunately, a terrible birth and medical care afterward, followed by the pandemic, followed by moving. It was a whole lot of stressors piling up one on top of the next. I think that that was a big part of it. I just felt like I couldn't hold it together."
Most PWLE received a mental health diagnosis that shared symptoms or was comorbid with ADHD		14	Y	"It felt right. I definitely had feelings of constantly feeling anxious and not knowing what to do with myself and that kind of thing. That felt good. It felt appropriate." "I had been diagnosed with depression and anxiety, and I constantly said I don't think that this is right, because I don't feel I have any reason to be depressed or to be anxious. It didn't make any sense to me. They had given me a medication for it. It wasn't changing anything, and so, I kept saying there's got to be more to it, which drove me to find out on my own because I wasn't getting anywhere with anyone." "Yes, generalized anxiety disorder I've been diagnosed with since I was very young. So, that's just always been in my life. And then I was treated for bipolar for a very long time. Now, major depressive disorder was a recent… The doctors said, 'No, you're not bipolar. You have major depressive disorder.'"

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
2. Seeking help for ADHD				
PWLE often characterized the moment they recognized that their symptoms may be ADHD as pivotal		12		"It's getting to know people who had the same traits that I did, and almost the same severity. Except that they were doing better than I was. The only difference was they had an ADHD diagnosis. They were on medication." "That was like a lightbulb moment with [my daughter]. I had even asked the psychiatrist, I'm like, is this genetic or hereditary or something?" "I was listening to a podcast of theirs and they were talking about specifically women and ADHD… about women being expected to be organized, especially when they're moms, and holding emotions together and all this kind of thing. And then emotional dysregulation is also a huge component of ADHD for most people … looked up at my husband and said, well, that explains a lot, and burst out sobbing, absolutely sobbing. It was really a crystallizing moment for me." "Those Facebook groups are the best. I learned so much there. And it's a place that you feel safe. I got on there and started figuring. That was when I was like, yes, this is me, this is me, this is me."
PWLE often described feeling relieved and validated after receiving an ADHD diagnosis		7		"I had the same reaction that everyone that gets diagnosed seems to have… my whole life makes sense. Everything just made sense. It was like, all the things my mom hollered at me for, things that I do around the house, difficulties I had in college." "Having my ADHD diagnosis was absolutely life changing. After diagnosis, I spent a really huge amount of time understanding ADHD and how it impacted women in particular, for one thing. The more I understood, the more I was able to address these key areas in my life… So that transition to understanding myself was so incredibly, not only life changing, life improving … okay, I'm forgetful, it's just because of my brain. It's not because I'm broken. It's not because I'm a flawed human being." "So, it felt very positive. And it also brought a lot of clarity in terms of thinking… This is very clear. There's a clear path here in terms of medication and what we're trying to tackle through other interventions."
C. Barriers to adults receiving an ADHD diagnosis				
1. Lack of personal knowledge, sociocultural factors, and fears about ADHD evaluation results				
A personal lack of knowledge and misconceptions about ADHD were barriers to diagnosis		10		"I think a lot of it came down to my own misconceptions about ADHD. I think growing up, there was this narrative pushed [that] women don't have ADHD, girls don't have ADHD. And if you have ADHD, it's something that's going to be really overt and really obvious. You're going to have behavioral issues, you're going to have issues performing academically.' And that just wasn't something that I had experienced." "I wasn't educated enough or didn't know enough. I had no idea it was attached to emotions as part of the neurology of it. Sure, I've plenty of kids, students, with ADHD that had behavior issues, but I always assumed it was that impulsivity, that hyperactivity. Oh, they're bumping into a kid in line, so, of course, the kid gets mad, then there's emotions, and they're not learning the good social skills. I always was trained that someone with ADHD, they mature at a slower rate." "I was like, well, do I have attention issues, if I could actually get projects done on time? Yes, just it being called attention deficit, even, has been an issue, to be perfectly honest, because it's not just attention." "How do I know I have something if I'm not even aware it exists, or that it shows differently in women?" "I didn't know that it was so common in girls and that it was even an option for girls. I certainly didn't know that it would still be so pertinent as an adult and that you would even need a diagnosis as an adult … I didn't think anything about women having it because I am not a classic, super-high-energy, doesn't-stop-talking stereotype."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
Sociocultural factors sometimes made the journey to diagnosis more challenging		5	Y	"I was married at the time and my wife was very opinionated about ADHD … I let her opinions influence me and dissuade me from thinking that I might have ADHD. She was one of those people that equated ADHD with having learning disabilities." "My mom is very hesitant about any behavioral health. Because she's scared that they're going to misguide me, and then I'll end up being diagnosed with something that's not real, taking meds, stuff like that. She's very hesitant about it." "I've told my sister, but I'm hesitant to say anything to friends about it because I feel like the first thing they're going to say is, really? You don't seem like you have ADHD? And I just don't care to hear that. It's not helpful. It's rude. Maybe they wouldn't, but I feel like they would."
Some PWLE feared what the results of an ADHD evaluation would mean for them		5		"I was a little bit worried that it was, I guess, a waste of my time and their time, because everybody struggles with these things sometimes, of course not to the depth that I do. I think that that also played a role, was just maybe a little bit of anxiety of what kind of response I would get." "Before I went... It's almost like a hope, yes, I think this is why I do these things, and that explains it. But if I went to a doctor and was told, 'No, that's not it,' then, what's wrong with me … a fear of, well, if it's not that, what is it, and is it just I have a poor, weak character?" "I think there was some fear there. I think if I just thought about it in my head like, yes, I probably have ADHD, and then I just stayed there with it, I could do that for a while. Because there is also fear that, hey, if I do do this and I don't have ADHD, I'm just an anxious person. Is that going to make me feel worse? So, there was some fear in actually getting the assessment because if I didn't have it, then I might just feel worse about myself than I already did. So that was probably a big reason why I dragged my feet." "With each step going through it I was like, okay, this is getting more real. What is actually going to happen if I receive this diagnosis? Because it's never going to go away … It felt like the emotions behind it, ultimately, ended up being the biggest barrier, and actually going ahead with it … do I really want to receive this diagnosis now?"
2. ADHD symptoms				
ADHD symptoms often made it difficult to manage the steps to seek help	2	14	Y	"Scheduling anything and making the appointment and being somewhere on time and providing all the paperwork that I was asked to do and completing the tasks that were assigned to me to participate in my diagnosis, that was always a challenge." (PWLE) "One of the things that I definitely, in retrospect, realized was a symptom was impatience. Just the thought of having to call and sit on the phone, and sat on hold, I really had to build myself up to it. And then, okay, now I have to go into the office, and I'm going to have to sit and wait. It's going to be a lot of sitting and waiting. Prepare yourself. It was really difficult." (PWLE) "It took me about six months to make the appointment. So, I sat with it for a really long time and had it on my to-do list for a very long time before I finally got up the energy to make the appointment." (PWLE) "Problems with time management, running late for appointments … are all core aspects of ADHD. Those definitely affect your ability to come in and see a clinician, schedule an appointment, make it there on time, remember to bring your rating forms, remember to bring your co-pay, your insurance card, making your next follow-up visit..." (Clinical expert)
3. Lack of provider knowledge and inadequate training, tools, and time to diagnose ADHD				
Providers often failed to suggest ADHD as a possible cause of their symptoms		6		"The difficulty lies in not having a professional suggest that there is the possibility that this thing is happening. I had to come to them and say, 'hey, could it be this?'" "I had a therapist … I remember even asking her during that time, I still think I might have [had] ADHD when I was a kid because I didn't fully understand how it all wove together for your whole life at that time. And she said, 'Well, you don't come across like you have ADHD' … I think she just was completely uninformed. Unfortunately, that further set back my chances of getting a diagnosis by 10 plus years, 15 years just because it was like, well, I trusted her." "Now that I know that there's so many symptoms that overlap with depression and with ADHD, I wish it would have been easier for a doctor to say, 'Well, instead of keep on trying all this stuff, what if it is ADHD?' … I wish it didn't take three years."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
Some PWLE reported that providers dismissed their concerns and did not take them seriously		5		"Doctors not taking me seriously. I don't know if it's a mindset or what. I don't know the reasoning for all that. I just wish things like that were different." "Another difficulty was in being heard for what was really going on. Yes, those are my key difficulties. How many times can you tell a person, 'here's my list of symptoms' … What's the definition of insanity? Doing the same thing and expecting something different. That's kind of how I felt." "I went to my primary care physician, raised my concerns with him, 'I'm not seeing any improvement with any of the treatment I'm getting for anxiety and depression.' I keep getting written off because I've recently had babies … I feel like after you've had kids, it's, 'oh, you're a new mom,' or, 'oh, you were just pregnant, there are so many hormones.'" "I think one of the key difficulties, particularly at the primary care level, is that I wasn't taken seriously. There was no reaction from my primary care provider which looked anything like investigation. And for all the physical symptoms that you could give that immediately provoke a process of investigation, it's striking, really, that there was just no compulsion or process for, 'oh, let's investigate that,' like you would if you had some other kind of, I don't know, biometric symptom."
Several PWLE saw their initial diagnoses as labels that providers failed to look past to explore other possible causes for their symptoms		7	Y	"I had gone to a doctor when I think I was about 23 or so, and they thought it was anxiety … Fifteen years later or so, my daughter was diagnosed with ADHD and I realized, this is so much like me. So, I had gone back to a doctor and the same thing happened. Oh, I think you're just anxious. Here's medication, and it didn't help at all. That happened quite a bit." "[My therapist] was just like, 'well, all of those symptoms are very similar to anxiety, so I don't think it's anything but anxiety.' Anxiety, anxiety, that's all she kept focusing on." "Once somebody put that stamp on me 20-odd years ago, no one stopped to consider that it might be something else." "Well, just that label of having depression. Once I had that, it seemed like everyone was happy to just… not really explore that further. 'You are depressed, you have depression, and that's it…' And yes, I guess it was difficult to move from having depression to talking about anything else." "I think, clearly, it was a significant hindrance. It was clearly a red herring. Maybe that's too strong a term, but from what I've learned, I really do think that a lot of people with ADHD are diagnosed with the sort of things that were suggested to me … I bought into that. I took the antidepressants. Looking back, it does seem surprising that there was no exploration of the diagnosis."
Providers often lack the knowledge to diagnose ADHD in adults and make differential diagnoses because of inadequate training	6		Y	"ADHD in adults has not been a focus in professional training programs. If you look at psychiatric residency, psychology programs, nurse practitioners, social workers, that's not part of their focus in their curriculum. As a result, we have clinicians out in the field over the last 20 years who've not been trained. And here it is, 2024, and if you still canvas the landscape of professional training programs, the focus on ADHD is sorely lacking. I actually believe that we're here because of the absence of education, and that's because adult psychiatry abdicated ADHD in adults. They didn't believe in it." "I think there's a tremendous lack of education around adult ADHD. Many clinicians my age were taught about this from a pediatric perspective. Very few of us had any formal education to even put adult ADHD on our radar screen."
Family medicine providers are better positioned to diagnose ADHD in adults than some specialists	2			"I think our family medicine people actually receive more training about ADHD than probably some of our adult psychiatrists do, because they're taking care of kids as well. So they do get some training, at least the childhood understandings of ADHD. And then anyone who's been in practice long enough realizes that for most of those kids, it doesn't go away. My interest in adult ADHD came out of taking care of kids." "Family medicine, and I guess just, I don't know, maybe to a lesser extent internal medicine, but certainly family medicine is well positioned here. Because they're getting lifespan training, and so they're in a good position to take what they're learning for children and bridge that to adulthood, and they also see a lot of adults. So that group has been a good group, I think, for the transitioning of expansion of ADHD care. But internal medicine doctors, who've gotten specifically adult training, my take is that they're less comfortable with it."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
There are no guidelines for diagnosing ADHD in adults in the United States, and current diagnostic criteria and tools are inadequate	4		Y	"The symptoms of ADHD were largely created for observations of middle-class boys who were entering clinics for care, mostly white boys in the 1970s essentially. We do build our symptoms around those individuals. While we have done work validating the extent to which those symptoms are helpful indicators of ADHD in groups that are minoritized or tend to be underdiagnosed, we really haven't had good work understanding the actual, most salient indicators of ADHD in people who might not have those identities." "We still get trained thinking of it as, and it's always shown as this, I would say, middle class, hyperactive, bouncing-off-the-wall White boy, is what they see. The videos we see have people... That little demonstration video things that they'll show us, always seems to be wrapped around that. If that's, now, what we're seeing and you wonder why the less overtly hyperactive girl, or woman, is not being diagnosed, is not being looked at. When we think how would they describe their symptoms, they might say I'm anxious, or I'm just overwhelmed in everything going on. But it's not... Obviously, they'll get diagnosed as anxiety." "Issue number one, maybe issues number one through 99 is, the United States has no diagnostic guidelines for diagnosing ADHD in adults. Zero... The diagnostic criteria have to do with child and teen behaviors. No one has definitive information about whether the child-related diagnostic items, symptom items, are exactly valid for adults. Therefore, no one knows whether the existing cut-offs on those child-focused diagnostic criteria for diagnosing ADHD in adults are accurate, reliable, and valid."
There are barriers to widespread use of diagnostic tools for adult ADHD diagnosis	3			"I think that we have good tools, but people have to be trained on how to use them, and they have to have enough time to use them." "There are barriers of access to some of these tools that are really necessary." "There are very effective tools for the question of, does this person meet DSM criteria? I'm pretty happy with them. What I'm not happy with is training and using those tools and the practice-specific application of those tools."
Primary care settings are not always conducive to diagnosing adult ADHD	4			"Differential diagnosis is a critical aspect of the ADHD diagnostic process in an adult who's never been identified before. There are so many reasons why an adult could be having cognitive complaints. And unfortunately, our primary care system in particular does not have a built-in pathway for reimbursement of the level of time that's needed to make a thorough ADHD adult diagnosis, especially if the person doesn't come in with the classic narrative of ADHD. So that's the number one barrier." "There are no shortcuts. You want to be able to spend your time efficiently. Do the full evaluation in individuals that are at risk, which is where I think for primary care providers, a screener can be quite helpful... They're used to screening for depression and anxiety, so they're spending more of their time where time is precious to them." "Putting it on the backs of primary care, to me, that's like putting more on the backs of teachers. We cannot just keep piling on top... I do not blame when they're like, I just don't do this, you need to go get it diagnosed elsewhere. I do not blame them one iota. I fully understand and appreciate that."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
4. Marginalizing attitudes and bias among providers				
Some PWLE attributed delays in diagnosis to marginalizing attitudes among providers about ADHD, their age, or their gender		3		"When I went back to my primary care physician, and clearly, I was pressuring her to do something, she actually said to me, 'ADHD isn't a medical problem … and maybe it should actually sit outside the medical model' … I don't know how pervasive that attitude is through the systems, but clearly, there's this kind of marginalization going on of people with ADHD and being pushed out of the mainstream, particularly adults … there is a misrepresentation of neurodiversity, or underrepresentation of that. There's underrepresentation that this is more a neurological trait which is inherited compared to a psychological challenge which might be attributed, for example, to trauma, childhood trauma, and things like that." "Stigma. Well, the stigma of being this old, because I think some people don't think you can be diagnosed this old, that you have to be diagnosed in childhood … some psychiatrists don't think late diagnosis is legit." "The biggest difficulties, honestly, were... I feel silly saying this, but discriminations. The fact of age, gender, lifestyle, to where I feel like people aren't open enough to [ADHD]... It's almost like they jump to other diagnoses first, and then you have to fight when those aren't working, to try and find something else."
Providers may overlook ADHD in women and girls because of gender bias and assumptions about the underlying causes of their symptoms	3			"I think there's a sexist bias in mental health that contaminates accuracy of diagnosis. And to say just what I mean by that is that males, when they present with mental health issues. The focus by the clinician is on the issues that they're raising. The focus of clinicians for females when they raise issues is focused on emotionality. They more easily ascribe emotional aspects to the presenting symptoms, and that becomes the obstacle to an accurate diagnosis." "I think we're storytelling about women as caregivers and dual role. And they're the ones that had more of a surge during the pandemic. Why is that? They were so burdened at home."
Some providers have biases against people who suggest ADHD as a potential diagnosis	5	3		"One in particular really accused me of just drug seeking... She had also said that she thought I wanted it because I thought it would help me lose weight. I was like, that has nothing to do with it." (PWLE) "And when I was walking out the door, he goes, 'Hey, you know what? You're just going to waste a lot of money. Nobody's going to give you any Adderall.' It's like, I didn't ask for Adderall … and I was 18 years clean and sober at that point." (PWLE) "There are some doctors who still believe that out there, ADHD is really faked in adults. It's really a kid diagnosis. It's really a boy diagnosis. And so, when a woman comes into the office, there's a lot of suspicion that she's really just depressed, or really just anxious, or she's really using other substances." (Clinical expert) "I think it's hard to divorce the assessment piece fully from the treatment piece here … Well, I think there is some data in the surveys to show that [PCPs are] hesitant to use stimulant medications because they are more cumbersome and hard to use, and there are concerns over misuse and diversion appropriately. You have to see these patients more frequently. They are harder to use. They have to be managed appropriately." (Clinical expert)

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
5. Health care access barriers and unnecessary neuropsychological testing				
Most PWLE and clinical experts described a lack of available providers and lengthy wait times for appointments	5	12	Y	"It was a scheduling situation. It was, okay, go, meet them for the first time, which was scheduled out a couple of months, and then they schedule out a couple of months before you can start the testing. It was just a delay after delay kind of thing." (PWLE) "A lot of them were private practice providers, so even finding someone who did the assessment was really difficult." (PWLE) "It took me, probably, six months to get in to see them." (PWLE) "In many communities, the waitlist to get in to see a mental health professional or a primary care that has a specialty in ADHD can be two months, six months or longer." (Clinical expert) "That's what I hear from people, is where they're waiting. They wait three to six months to see a psychiatrist, or they get into primary care, and they're told, well, we can't diagnose, you have to go to neuro-psych testing. They call, it's another three to six months, and it's thousands of dollars, and that person can't even treat them." (Clinical expert)
Several PWLE described insurance-related issues and high out-of-pocket costs were barriers to diagnosis		7		"I think the co-pay was like $600…" (PWLE) "The only thing that was an issue was, unfortunately, insurance. They don't take insurance and insurance isn't accepted in a lot of places." (PWLE) "For those who don't have insurance coverage or have low-level insurance coverage, they may not be able to access somebody who has the expertise but doesn't take your insurance." (Clinical expert)
Neuropsychological testing is not necessary or an adequate tool for diagnosing ADHD in adults	8			"We know that neuropsych testing does not make a diagnosis either. It gives you pieces of information that can be helpful. But neuropsych testing, it's a clinical diagnosis to make the diagnosis. Where I tend to find neuropsych testing of help is if I have an unusual case. If I have somebody that I think has a specific learning disability, so learning style issues beyond ADHD, dyslexia, dyscalculia, anything of that nature, I think neuropsych testing. If I have somebody who's had a complex medical history, such as CNS trauma, concussions, closed head injury, I think neuropsych testing can be very helpful there. But for the average patient, neuropsych testing is quite expensive. It's a lot of time and quite often delays the diagnosis or frustrates somebody when they're trying to get a diagnosis." "People with an IQ in the 70s range can look inattentive or even can be inattentive due to the fact that they're not comprehending what's going on in certain contexts. And achievement with learning problems as well. Even in adults, there are very specific learning problems that, again, can make people wonder if they have ADHD, because that's the diagnosis that is most known to them from information they're ingesting. So that's important. To me, and I'm very aware of the research on this, and my opinion is based on the research, there is no reason that someone should ever need to get a cognitive performance test to get an ADHD diagnosis." "Some clinicians will use neuropsychological testing or computer-based testing of some sort as a supplement or method of diagnosis. And that's just wrong. We just know that these methods can't rule in ADHD, they can't rule out ADHD. They're useful for all sorts of things, but not for diagnosis. And that can lead to misdiagnosis both ways, by underdiagnosis or overdiagnosis."
Neuropsychological testing creates barriers to diagnosis	5			"It's sometimes used as a barrier to treatment, which I think is a misuse, because it's expensive and time consuming … in clinical medicine, you would never use a test that had a 30% yield to establish a diagnosis. "That's what I hear from people, is where they're waiting … three to six months to see a psychiatrist, or they get into primary care, and they're told, 'Well, we can't diagnose. You have to go to neuropsych testing.' They call, it's another three to six months, and its thousands of dollars, and that person can't even treat them. They still have to get that report, take it back to someone, just to say, 'Okay, now I'm comfortable treating you.'" "Most insurance doesn't cover it. And so, for kids, teens, and adults with ADHD in the Bay Area, to get a full-on neuropsych workup, you're talking about $5,000 to $10,000 to $15,000."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
D. Facilitators of receiving an ADHD diagnosis				
1. Increased personal knowledge of ADHD				
Increased knowledge of adult ADHD empowered PWLE to discuss it with providers and seek an ADHD evaluation		7		"Having that peer community, being able to share experiences with other people, and learn from others who have similar struggles and what they have used to try to address the struggles. That's been very instrumental." "Like I said, at one point, I turned to Reddit to try and, basically, just see what other people recommended to try and find company names to call. Because at one point, I was just... making all day long, just trying to find anyone who would offer the testing and stuff like that, to where I feel like social media and internet, and all, has definitely helped, but not because of official sites, but more just personal experiences from people." "I sat down with my provider, and I expressed my frustration. And I said, 'For many years now, I've been diagnosed with panic attacks and depression and anxiety. I've received multiple prescriptions for antidepressants … isn't it more apparent that the root cause is ADHD, and that is where we can actually make a difference?'"
Media coverage and social media have increased public awareness about ADHD	3			"The public is starting to get it. Thank God the public media has taken an attention to this, because they have really been driving the bus and moving the field forward. Otherwise, the clinicians sit around saying, well, I don't know anything about it. I wasn't trained. I'm not writing those drugs. Go see somebody else." "The TikTok phenomenon and the rise of social media is a blessing. Especially for women with ADHD who never got diagnosed."
2. Supportive social circles and providers				
Supportive social circles helped PWLE overcome barriers to receiving a diagnosis		8		"I think a lot of it was having support of other people. I really felt like my social circle was really supportive of it, and really understood why I was going through the process." "My husband was a total believer, so that made it easy. I didn't have to convince him that it could be this. Because when the doctor had suggested it and then when my husband looked it up, he's like, that's you, you've got ADHD. So he supported me throughout this whole thing, did the driving." "I also had had a coworker that had been diagnosed with it as an adult that thought all this time she had an anxiety disorder. She was diagnosed with ADHD and she just talked about how it was life-changing when she finally was diagnosed and got on a stimulant. If she hadn't told me that, I may not have sought an assessment either."
Several PWLE credited supportive providers with making the journey to receiving an ADHD diagnosis easier		12		"Well, the fact that she was considering it in the first place and didn't just dismiss it, that was very relieving." "[My primary care physician] actually advised me that when I was calling for insurance and trying to get evaluated, I might need to avoid saying ADHD and just say that I need a behavioral health evaluation. Because if you specifically say ADHD, a lot of places won't evaluate because they don't handle ADHD." "She was very open and encouraging and easy to talk to about it. So, she wasn't... She didn't make me feel like I was making mountains out of molehills or blowing things out of proportion or anything."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
3. Personal determination and persistence				
Personal determination and persistence were key to overcoming challenges to receiving an ADHD diagnosis		5		"I feel like when I am more confident, then I'm not going to give up. I'm going to be very persistent about getting an answer..." "I make two to three calendar events reminding me when it's going to happen, and then alarms on top of alarms to make sure I don't forget when the day gets closer and that kind of thing. Just diligent about not skipping steps and not missing appointments. That kind of thing." "I'm used to running brick walls. And you know what? Don't mess with me because I'll figure a way around that thing. Watch me now." "To be persistent and just keep following up with those things. I think I was pretty determined to certainly do everything that I was asked to do, and then just keep asking, why aren't we moving forward? I think the persistence was important."
4. Telehealth				
Telehealth made evaluations for ADHD more accessible, convenient, and emotionally safe		8		"It's more convenient to get online appointments because you can take them during the day, take them during your break at work." "Maybe I would be too anxious and then they'd be like, 'you just have anxiety,' or whatever. But, no, since I was home and I could recall these things, I was just generally more comfortable with sharing stuff about my childhood. So, telehealth was definitely better." "It felt safer to be in my home answering vulnerable questions. For whatever reason, that just gave me a comfort level that I can do this here, whereas I think just my personal nature, I'd be kind of intimidated of a psychiatrist. Doing it virtually kind of took the edge off..." "To be perfectly honest, I prefer telehealth over physical. I get more anxious when I feel judged, so it's easier for me to take out the emotional part with telehealth. It lowers my anxieties, and so, I actually prefer it that way, because then it means that I have less anxiety ticking over, so to speak."
Telehealth can help to increase access to care, improve health equity, and reduce stigma	4			"I think telehealth and digital health have tried to help with health equity. It's expensive to see a psychiatrist in many communities. Psychiatrists only accept cash pay. They don't accept insurance … mental health care can be very limited in [rural] communities, but ADHD doesn't disappear. If anything, it's overrepresented in those communities. I think the role of digital health helps with health equity when used appropriately..." "Telehealth obviously increases access to people who are geographically limited in terms of specialty care. All of those things are great. And stigma is reduced with telehealth. People, especially younger generations, seem to be less afraid to digitally interact with people maybe than in-person, so."
Providers must follow the same steps for diagnosing ADHD via telehealth as they would in person	5			"I think that most of the recommended practices for diagnosis of ADHD can be done over telehealth if you have the person who's trained sufficiently and takes enough time, and they actually follow those practices." "I'm familiar with some of the platforms. I'd argue some of them, even just in their data gathering, they do a better diagnosis than the average psychiatrist in an hour eval, let alone a primary care doc in a half-an-hour." "You can do quality telehealth, but you have to have the right structures and guardrails around it."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
E. Opportunities to reduce barriers to ADHD diagnosis in adults				
1. Raise public awareness about ADHD in adults				
Some PWLE recommended raising public awareness about ADHD in adults to educate and empower people with undiagnosed ADHD to seek care	2	6		"Maybe a printed couple of pieces of paper that say ADHD for adult dummies and then it's the basic stuff that you need to understand as you go into this." (PWLE) "Having a variety of the symptoms available that are more recent. It would have been easier to Google search. Had I been able to find YouTube channels and ADHD groups earlier, it would have prompted me to realize it sooner." (PWLE) "I think if there was more public education, whether it's via government announcements, whether it's by articles in popular magazines that are appropriate, those are the kind of things that actually bring people to treatment. They'll say, oh, I read this article, and it made me think I need to be treated." (Clinical expert) "I think that public awareness campaigns are really what's needed, yes, public awareness… Not just that you may have a disorder, you may have a disorder that's relatively easy to treat and may actually make a huge change in your life. I'm sure you've talked to many providers, but more than a few patients will refer to their treatment as a miracle or life-changing or in words like that. The treatment for ADHD is much more effective, for example, than treatments for depression, if you put them on the same metric, for sure." (Clinical expert)
2. Update and expand clinical training and education on ADHD				
Most clinical experts emphasized the need for updated clinical training and education to improve providers' confidence and support more consistent diagnoses	5			"You can improve the self-confidence of clinicians by providing them with the skills that they can execute. They can then see that the execution of those skills serves the patient well. The patient comes back and says, oh my gosh, you're a genius. I'm so much better. Thank you for changing the course of my life. That then accelerates the confidence, verifies the reality of ADHD, and the fact that treatments are effective, and they continue to take on this population of patients." "The providers need to be educated about how to diagnose. If they got a good continuing education about how to diagnose ADHD, they really wouldn't need any other tools besides a list of DSM-5 questions and how to ask them, which they could be trained up to do. And it's not all that difficult to ask the questions and to understand what are the types of behaviors that reflect ADHD, answers to those questions. And also, of course, providers have to learn to ask about how the disorder impairs the patient in two or more settings, and so forth."

Theme	Experts	PWLE	E-scan	Illustrative quotes from clinical experts and PWLE
3. Increase funding for research on ADHD				
Increased funding for research into adult ADHD	4			“ADHD is more common than visual problems. We should have universal screening, and it wouldn't be that expensive. And you don't have to screen every year. You could screen several times in somebody's life, and you'd pick up the vast majority of the cases. Then it's probably going to be an initiative from HHS and CMS, where they make it a quality measure.” “I would love to have federal funding to be able to put this up on a website, make it freely accessible to patients, and protect it so that it could be... Then they can get a score, They then take it to their provider. They can then see that they screened positive and then they're off to the races.” “A lot of measurement work needs to be done, application with different communities to see if it tracks the same way. The biggest thing with the diagnostic criteria is needing an investment in population-level work, validating the right criteria for ADHD in those groups, and the differential diagnosis piece.” “One of them is just research to develop more valid criteria for adults with ADHD that are sensitive to important demographic features like age, sex, ethnicity, race … The second one, I would say, is that the criteria for adults need to be revised … They could be made more specific to adults. They might have to address changes with age. They might have to address differences by sex and race, ethnicity. But we're not going to know that unless somebody funds a good research project to look at it, because it has to be done.” “We haven't represented women in cancer and coronary artery disease and pulmonary disease, and in ADHD and autism. What we don't know about lived experience and what we don't know about symptom presentation would still fill a lot of libraries. This is a fantastic opportunity for mixed methods, qualitative and quantitative research, so that lived experience can feed into what the accurate symptom checklists are for clinicians to make a valid diagnosis.” “Going to individuals that have low access and seeing what their actual lived experience is and what the implications are for these more ivory-tower diagnostic criteria implementations. Yes, I think it's very important. How does this actually work and what are the perceived or real barriers and what are the ways around that?”

ADHD = attention deficit/hyperactivity disorder; CDC = Centers for Disease Control and Prevention; DSM = Diagnostic and Statistical Manual of Mental Illnesses 5th Edition; NASEM = National Academies of Sciences, Engineering, and Medicine; NIH = National Institutes of Health;
PWLE = people with lived experience.