ThinkDivergent Patient Insight Report:

Co-Designing Digital ADHD Assessment Platform with Neurodivergent Adults

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Executive Summary

This report synthesises the lived experiences of neurodivergent adults and carers navigating ADHD assessment pathways across the UK. Drawing on in-depth narrative interviews and focus groups, we employed trauma-informed, participant-led methodologies to surface systemic challenges and identify priorities for digital service redesign. Five key themes emerged: (1) *traumatising diagnostic journeys*, (2) *post-diagnosis voids*, (3) *gendered/cultural misunderstandings*, (4) *distrust in services*, and (5) *workplace/educational exclusion*. Participants reported emotional distress, misdiagnosis (especially among women), and unmet needs for holistic support. These insights directly informed the co-design of the ThinkDivergent platform; a trauma-informed, neuro-affirming digital assessment tool designed to reduce harm, restore agency, and address equity gaps.

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1. Introduction

Attention-Deficit/Hyperactivity Disorder (ADHD) is a neurodevelopmental condition often misunderstood within healthcare systems, particularly for adults and marginalised groups. Late identification of ADHD in adults is increasingly recognised as a public health issue, yet pathways to assessment and support remain complex, inconsistent, and often retraumatising. Neurodivergent individuals frequently encounter systemic barriers shaped by stigma, misunderstanding, and inflexible clinical processes. Existing digital tools tend to replicate biomedical paradigms that fail to account for neurodivergent experiences of identity, culture, and trauma. Existing literature has documented diagnostic delays and systemic exclusion, but few studies centre patient-led innovation to redesign care pathways. In response, ThinkDivergent developed a digital ADHD platform co-designed with neurodivergent individuals to assess, affirm, and empower. This report presents the participatory insights underpinning the platform's creation.

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2. Methodology

2.1 User-research Design

We adopted a participatory, narrative-driven qualitative approach rooted in trauma-informed and neuro-inclusive principles, with a strong emphasis on participant autonomy and emotional safety. The user-research integrated individual interviews and focus group methodologies to capture breadth and depth of lived experience.

2.2 Participants

Participants included:

- **76** neurodivergent adults and/or parents/carers engaged in narrative interviews
- **11** individuals participated in focus group discussions

- Participants were diverse in terms of age, gender, ethnicity, and socioeconomic background
- Included individuals who accessed both NHS and private assessment pathways

2.3 Data Collection

- Participant-led, narrative interviews (30 minutes to 2 hours)
- Focus group discussion exploring shared experiences (2 hours)
- All discussions conducted using neuro-affirmative and trauma-informed facilitation techniques and took place between January to March 2024

2.4 Data Analysis

Data were analysed thematically using reflexive thematic analysis. Narrative threads were also preserved to honour individual voices and complexity. Themes were iteratively developed and cross-validated with the design team to inform platform development.

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3. Findings

Five core themes emerged, each directly shaping the ThinkDivergent platform design:

3.1 **Prolonged and Traumatic Diagnostic Journeys**

“You’re queuing in complete darkness.” (P86, Focus group)

"I had to educate my GP to even get a referral" (P71, Interview)

“I needed to pause, come back, and know I hadn’t failed.” (P3, Interview)

Participants described complex, lengthy journeys; often marked by disbelief, confusion, and bureaucratic stasis, which they found dehumanising and emotionally distressing. For some, diagnosis took over six years, and many described having to educate their own GPs to even initiate referral. The NHS pathway was often described as a “maze with no map,” leaving people to turn to private pathways out of desperation only to be met by new barriers (e.g. shared care refusals from NHS GPs and/or ADHD diagnosis dismissed due to ‘quality concerns’). They also reported that pre-assessment forms to be inaccessible, language alienating, and the system unkind to anyone struggling with executive dysfunction. Stories of depression, addiction, self-harm, and suicidal ideation were also strikingly common.

Design Implications:
Clear onboarding with progress tracking, save-and-return forms, supportive prompts, plain language, trauma-sensitive content, neuro-inclusive, and sensory-friendly interface.

3.2 **Post-Diagnosis Void and Emotional Cliff-Edge**

“They handed me a leaflet about meds and called it ‘support.’” (P1, Interview)

“I got a PDF with my diagnosis and that was it. I felt I was left to fall off a cliff” (P5, Interview)

"Post-diagnosis grief hit me like a truck and nobody warned me." (P87, Focus group)

"No support plan. Just... nothing." (P82, Focus group)

Diagnosis was a turning point but often followed by an emotional cliff edge. Most received generic leaflets or a vacuum of guidance after diagnosis. Many had to "research everything themselves" and were left to "figure it out alone." Grief, confusion, and shame were common. Many described feeling stranded and turned to informal communities, often lacking safe guidance. There was frustration with one-size-fits-all advice and little recognition of evolving needs. Participants needed support with identity integration and daily life strategies, not just a diagnosis. There was a strong demand for non-pharmaceutical strategies, with a lack of NHS guidance on lifestyle-based interventions noted.

Design Implications:
Personalised AI-generated reports, emotional validation content, holistic lifestyle integration, and strengths-based framing of ADHD with diagnosis as a starting point, not an endpoint.

3.3 **Intersectional Misrecognition**

"My South Asian family called ADHD a white people problem." (P2, Interview)
"I was misdiagnosed with bipolar, but it was undiagnosed ADHD." (P67, Interview)

"In my culture, ADHD doesn't exist. It's just being lazy." (P85, Focus group)

"Doctors said I was 'just anxious.' Turns out I'm autistic and ADHD." (P77, Focus group)

Gendered and cultural biases shaped both formal diagnoses and interpersonal validation. Women, non-binary individuals, and racialised participants reported misdiagnoses with mood or personality disorders along with family invalidation. Some also reported skepticism from clinicians based on cultural or gendered expectations. Intersectional stigma led to concealment, delayed help-seeking, and identity dissonance.

Design Implications:
Culture- and gender-sensitive questions, inclusive assessment items, and clinician-facing tooltips addressing diagnostic bias.

3.4 **Distrust and Adversarial Clinical Encounters**

"I felt like I was constantly on trial during assessment." (P4, Interview)

"I needed to be believed, not managed." (P50, Interview)

"It felt like I had to prove I wasn't making it up." (P78, Focus group)

"It felt adversarial, like you were proving you were broken enough." (P81, Focus group)

"I felt like a suspect, not a patient." (P82, Focus group)

Participants described assessment processes as judgmental, adversarial, invalidating, or triggering. Experiences of trauma were exacerbated by the inflexibility of clinical interactions, and follow-up care was perceived as arbitrary or absent. Participants highlighted a need for trust, transparency, and collaborative care.

Design Implications:
Self-guided portal with transparent process steps, agency-preserving navigation, trauma-informed design principles, and transparent clinician interfaces grounded in shared decision-making and patient voice.

3.5 **Lack of Environmental Modifications**

“Open-plan offices destroyed my productivity, but HR said ‘just try harder.’” (P6, Interview)
“College nearly booted out my autistic/ADHD child—there was no plan.” (P48, Interview)

“It wasn’t that I couldn’t work, it’s that no one ever asked how the workplace worked for me.” (P79, Focus group)

Participants reported lack of environmental modifications in education, workplaces, and also at home. Masking, burnout, and attrition from education or employment were common. Fear of disclosure were common threads with some participants sharing that disclosure often resulted in discrimination and misunderstanding, not adaptation.

Design Implications:
Contextual environmental adjustment recommendations for work, home and study settings, guidance on disclosure, and signposting to support schemes (e.g., Access to Work, Disability Student Allowance).

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4. Cross-Cutting Design Principles

Principle	Platform Design
Trauma-Informed	Opt-in sensitive topics, non-linear forms, emotionally safe language
Neuro-Inclusive	Flexible navigation, skip/revisit features, attention-friendly design
Strengths-Oriented	Emphasis on lived context, growth framing, identity affirmation
Cultural / Gender Inclusivity	Inclusive language, diagnostic variability acknowledgment, tooltips for clinicians on bias mitigation
Autonomy-Respecting	Transparent steps, user control, collaborative tone

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5. Discussion

This user-research has been invaluable in embedding lived experience into digital health innovation. Participants' narratives revealed not only systemic failures, but also opportunities for more humane, inclusive, and responsive digital infrastructure. By treating diagnosis as a relational and identity-based journey—rather than a checklist—we developed a platform that affirms neurodivergent users rather than pathologising them.

These findings align with emerging critiques of standardised assessment protocols and contribute to calls for equity-oriented digital mental health design. Notably, our approach centred co-production not as tokenistic consultation but as foundational methodology.

6. Conclusion

Neurodivergent users are not passive recipients of diagnosis; they are knowledge holders. Co-designing with neurodivergent adults revealed deep systemic shortcomings in ADHD assessment pathways but also clear blueprints for improvement. The ThinkDivergent platform demonstrates how trauma-informed, culturally sensitive, and autonomy-respecting design can transform digital health tools from gatekeeping mechanisms into empowering interventions. Lived experience is not an optional perspective, it is essential to ethical and effective design.

By centering lived experience, the ThinkDivergent platform offers a blueprint for equitable, empowering care that bridges diagnostic and post-diagnostic gaps.

7. Acknowledgements

We thank all participants for their generosity, vulnerability, and insight. This work would not exist without their trust and candour.