

# Volume Two: Appendix

EXPLORING MINDFULNESS IN A HEALTHCARE DESIGN RESEARCH CONTEXT WITH ADHD WOMEN

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# Introduction

# How to use this volume.

Volume Two serves as an accompaniment to the main thesis. Each appendix pertains to different components of the fieldwork design process. The main volume notes where the appendix is applicable.

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# Appendix: A

Communication design and development of recruitment, ethics & consent

# Appendix A: Communication Design

## A.1 Visual Communication

Reviewing visual tone for female mental health:

"Adults expressed a dislike for the use of cartoons and illustrations as ADHD is perceived as a kid's condition"

The Experience of Receiving a Diagnosis and Treatment of ADHD in Adulthood Susan Young et al. 2008



IMAGE 1 - SCREENSHOT OF MIRO MOODBOARD EXPLORING FEMALE VISUAL IMAGERY, SOURCE: AUTHOR

Findings from the design inquiry showed a predominance for women's mental health, apps and self-care tips to use illustrations. I discovered that graphic design legend Paula Scher identifies as ADHD. Her bold colours and typography style inspired my initial explorations in creating an identity for the study.

The visual identity used the capitalised D to explore themes of deficit, and design's capacity to create a wealth of female data. This motif has been brought to the thesis itself to symbolise deficit and the creation of data. The

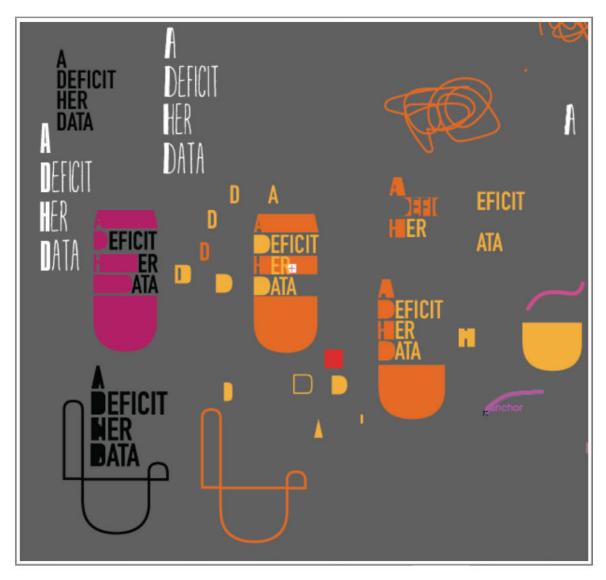


IMAGE 2 - SCREENSHOT OF IDENTITY DEVELOPMENT IN ILLUSTRATOR DOCUMENT SOURCE: AUTHOR

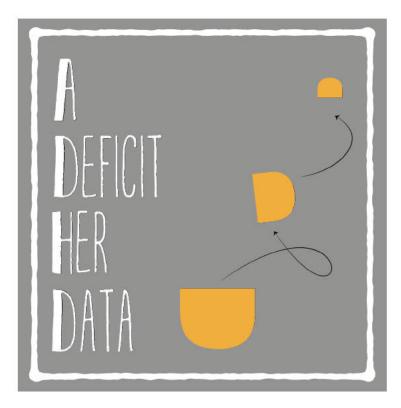


IMAGE 3 - A DEFICIT HER DATA IDENTITY SOURCE: AUTHOR



IMAGE 4 - AI GENERATED 1960'S ADHD SCHOOL GIRL SOURCE: <u>LETSENHANCE.IO</u> TEXT PROMPT: 1960'S SCHOOLGIRL WITH ADHD

# Stage One: Scoping Recruitment Design

# A2. PARTICIPANT INFORMATION SHEET

An invitation to participate was posted on two Scottish ADHD peer support Facebook groups, participants could directly message me on Facebook, send an email or go onto the link provided for the project website. This sought to address personal preferences for interaction.

Clinicians were contacted directly to participate.

# DIGITAL HEALTH & INNOVATION

11 May 2021

Donna Jamieson

MRes GSA School of Innovation

AN INVITATION TO TAKE PART IN PROJECT SCOPING CONVERSATIONS

working title:

# Capturing the Dynamic Data Self:

Adult AD/HD Diagnosis, The Female Experience.

### **Project Intentions:**

The aim of this project, is to explore the experiences of Women receiving an AD/HD diagnosis in adulthood. And in doing so, begin to define design requirements for future digital healthcare services seeking to provide support. Mindfulness will underpin methods of inquiry and will be offered to support participation during the course of research.

#### WHY AM I BEING ASKED TO TAKE PART?

You have been identified as someone with an important perspective on the diagnosis of adult AD/HD in Women. You may be a healthcare professional / someone seeking diagnosis / have a family member who has been diagnosed/or have an AD/HD yourself.

#### WHAT IS A PROJECT SCOPING?

Here at Glasgow School of Art, our approach to Digital Healthcare Innovation is a participatory one. Before design research begins, it can be useful to explore different viewpoints and experiences. Capturing these views during a scoping phase can help define project goals and set limits i.e. what is out of scope for this project I It can also help direct research fieldwork in phase 2.

#### DO I HAVE TO TAKE PART?

Your involvement is strictly voluntary! Please review this information sheet and decide if you would like to be involved. You are free to offer as much information as you feel comfortable sharing, and you are free to withdraw whenever you choose. Your personal details will be deleted at this point.

#### WHAT IS MINDFUL INQUIRY?

Mindful Inquiry is a qualitative research approach. It uses mindfulness meditation and Buddhist philosophy as foundational principles. Mindfulness exercises will be offered to support participation, aiming to increase focus and attention as required. As an inquiry method, it is used to explore individual 'lived experience'.

4

IMAGE 5 - PARTICIPANT INFORMATION SHEET 1. PAGE 1. SOURCE: AUTHOR

#### WHAT CAN I EXPECT?

Our conversation will be unstructured & informal, lasting between 45-60 min.

Before we begin, you may like to jot down a few 'need to knows' - key points about AD/HD & diagnosis that you wish to cover during our conversation. This is not a medical research project, but an exploration of the human stories behind diagnosis. You may like to discuss themes of timescales, stress points, self understanding, or whatever is important for you right now.

I can offer a short mindfulness practice - to settle awareness and focus - if you have a sense this may be helpful before starting our session.

Conversations will take place via zoom or telephone - at a pre-arranged time to suit you. You are invited to only share that which feels comfortable. As a voluntary participant you are free to withdraw from the conversation at any time

After our initial conversation you may be invited to contribute to a participant group resource page - Padlet or Miro - to upload information and visual resources that have supported your understanding of an AD/HD diagnosis.

# WHAT WILL HAPPEN TO MY INFORMATION?

Your personal details, contact information and consent form will be retained for the duration of the project - 2 years. If however, you decide to withdraw from research at any time your details will be securely destroyed.

Conversation notes and recordings will only be made with your prior consent. Any quotes taken from our conversation will not be used in research reports or public displays without seeking your consent.

Your name will be anonymised to protect your identity, no images or recordings will be publicly used. Recordings will be transcribed and held securely at GSA for the duration of the project and assessment period. After which the recordings will be securely destroyed.

#### **ETHICS**

The Ethical approaches of this project have been approved by The Glasgow School of Art Research Committee.

If you would like more information or wish to discuss the research further, please contact:

Research Student: Donna Jamieson

If you have any concerns about this research or wish to make a complaint, please contact:

Project Supervisor: Sneha Raman

NOTE: Please retain this information sheet for future reference

# A3. STAGE ONE - ADULT CONSENT FORM

Research Project Title: A Deficit/He Sufficiency	er <b>D</b> ata: Mi	indful Inquiry Towards Data		
Lead Researcher: Donna Jamieson	1			
Contact Details:			Please init	
I confirm that:  1. I have read and understood the participant information sheet /website information. I understand the nature of the study.				
_	D/HD; this ss to the in	was less than 5 years ago; was ternet and smartphone/compute	er.	
I have had an opportunity to have had these answered sa		the information, ask questions ar 7.	ıd	
4. I have agreed to take part in two workshops. On zoom and in-person. I agree to these activities being recorded for the purposes of analysis by the researcher. Recordings will not be shared, and only be made available to academic supervisory staff upon request.				
<ol> <li>I agree to these recordings being transcribed and excerpts/quotes being used in the final published research thesis – I understand that this data will be anonymised to prevent identification.</li> </ol>				
<ol> <li>I am happy to be contacted r agree that my personal cont purpose, in accordance with</li> </ol>	act details	can be retained solely for this		
Name of participant	Date	Signature	_	
Name of person taking consent (if different from researcher)	Date	Signature	_	
		Signature		

IMAGE 7 - STAGE ONE ADULT CONSENT FORM, SOURCE: AUTHOR

# A.4. WEBSITE

Project information, option to download the participant information sheet and contact me directly.





www.adeficitherdata.uk

IMAGES 8 & 9 - SCREENSHOT PARTICIPANT INFORMATION WEBSITE, SOURCE: AUTHOR

# Stage Two: Recruitment Design

# A.5.WORKSHOP PARTICIPANT INFORMATION SHEET

An invitation to participate was posted on two Scottish ADHD peer support Facebook groups, participants could directly message me in Facebook, send an email or go onto the link provided for the project website. This sought to address personal preferences for interaction.

#### PARTICIPANT INFORMATION SHEET

In designing the look, feel and tone of the invitation to participate, I focused on encouraging action and participation in "good design" - doing something positive for your Health Community. Although, stating the female position as biased within healthcare, it set out to strike an empowered tone. Evidence-based mindfulness was aligned as a recommended component of the larger self-management strategy.

# DIGITAL HEALTH & INNOVATION

RESEARCHER: Donna Jamieson

GSA SCHOOL: MRes @ The School of Innovation

WEBSITE: www.adeficitherdata.uk

16 FEB 2022

AN INVITATION TO TAKE PART IN A PARTICIPATORY DESIGN PROJECT

# A Deficit/Her Data: Mindful Inquiry Towards Data Sufficiencies

## Research project goals:

- To partner with AD/HD Women to design **empowering** digital healthcare 'interventions'.
- To create an inclusive, mindful and empathetic collaborative design environment
- To identify female data sufficiencies

# **GOOD** Together!



Good design isn't just about the way something looks, it's also about it's **intention**, **purpose and utility**.

By sharing the wisdom of your experiences, your concerns and ideas. We can set out to do good by designing digital 'interventions' that are relevant to **women** navigating diagnostic assessment in adulthood.

Good digital design embodies empathy and creates advocacy for those it is designed for.

Let's take action!

## Why MINDFULNESS?

Traditional Mindful practices can help develop attention and compassion towards ourselves, others and the world at large. Research has shown mindfulness to be effective in improving attentional focus and memory for those with AD/HD. This study aims to embody these components of mindfulness, so that we may create a an inclusive design environment.

#### **DURING THE STUDY WE WILL EXPLORE:**

- · Your diagnostic journey.
- Sharing Circles (deep listening skills)
- Digital Innovation
- Taking Compassionate Action

#### WE WILL AIM TO ANSWER:

How can mindfulness practices support engagement in participatory design activities?



The researcher is a certified and insured **mindfulness coach** with a daily meditation practice of 20+ years.

## Why a **FEMALE** focus?

In recent years, we have come to understand that diagnostic traits of **Neurodevelopmental** conditions such as AD/HD, may be influenced by your sex. Consequently, Women are now more aware that their 'long-standing' **mental health issues** may have a developmental origin. As such, they are reported to be the **fastest growing AD/HD demographic.** 



#### WOMEN ON THE HEALTHCARE SYSTEM:

- services may be 'out of step' with current Female diagnostic criteria.
- "fighing" for assessment may disadvantage women with mental health issues.
- assessment forms often seem weighted towards male symptomatic traits

#### AIMS TO ANSWER:

How can digital innovation improve the experience for women seeking an AD?HD diagnosis in adulthood?

#### An invitation to volunteer

Research is student-led, as such it seeks to specifically address the question of mindfulness in a collaborative design context. It aims to work intimately with a small group to create design insights for further future research.

Your experience of pursuing a diagnosis for AD/HD is invaluable! Your role is voluntary, this means that you are free to withdraw from the study at any time!

### What can I expect?

Research will take the form of a case study, as a model of how mindfulness may support design methods. There will be three sessions, \*dates tbc\* with a total **time commitment** of approx **4hrs**.

#### **ONLINE** Workshop 1, 90mins

Exploring the 'What Is' of our experience. Working as a group we will mindfully explore our individual diagnosis and collective experience.

**Mindful practice**, followed by mapping exercises, and group sharing practices.

# **ONLINE** Workshop 2, 90mins

Exploring the "What could be" of diagnosis. Working individually from home we will explore how digital may innovate the diagnostic. We will upload our design insights and feedback to the group remotely.

A guided meditation practice will support the design activities.

# ONLINE 'Mindful Morning' 1hr

The 'Mindful Morning' will be an **unstructured group chat** where we will reflect on our insights from the workshops and **celebrate** our achievements. The session will begin and end with opportunities to participate in **mindfulness practices**. You may be offered an **individual feedback** session if you choose not to attend.

Inclusion & Risks

Donna Jamieson

Sneha Raman

PERSON CENTRED: Each participant will be asked to complete a **consent form.** This indicates that you meet the inclusion criteria for the study. Additionally, you will be asked to reflect on your individual support needs and make the researcher aware of them during the **participant interview**.

TECHNOLOGY: You will need a stable internet connection with access to Zoom and Padlet software (all FREE to download)

WELL-BEING: Mindfulness in this context will be orientated simply towards paying attention to your present moment experience. You will not be guided toward deep meditative states. That said, for your safety during this study, I must make you aware that on rare occasions mindfulness can retrigger PSTD and episodic mental illness in those with a history of these conditions. If you identify as 'at-risk', it would be be advisable not to participate in the study at this time. If you do participate and find that you are 'triggered', please contact your GP or Mental Health charities SAMH www.samh.org.uk or Mind www.mind.org.uk to find out how you can access support.

DATA: Your personal details i.e. contact information will be retained by the researcher. As will audio recordings of the workshops, for the purposes of transcription and analysis by the researcher. Excerpts or quotes may be used in the published thesis. Any personal details that may enable identification will be anonymised to protect your privacy. All research data will be stored by the researcher - on a password protected laptop - for a maximum of 10 years, and disposed of securely, in line with GSA Data protection policies. The researcher and academic supervisory staff will have access to this data.

ETHICS: The ethical approaches of this project have been approved by The Glasgow School of Art Research Committee. If you would like more information or wish to discuss the research further, please contact:

please contact:

Research Student:

Tara French

If you have any concerns about this study or wish to make a complaint, please contact:

IMAGE 13 - STAGE TWO, PARTICIPANT INFORMATION PAGE 4, SOURCE: AUTHOR

# A.6. STAGE TWO, ADULT CONSENT FORM

Research Consent Form Phase 1 - Scoping Conversations		GS	A		
Research Project (Working) Title :	Capturing	the Dynamic Self			
Lead Researcher: Donna Jamieson					
Contact Details:			Please initio		
<ol> <li>I confirm that I have read and understood the participant information sheet for the above study;</li> </ol>					
<ol> <li>I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily;</li> </ol>					
<ol> <li>I agree to being our conversation being recorded on Zoom as part of the 'Scoping Phase' of the above research study and understand that these will be kept private (not published or displayed publicly.)</li> </ol>					
<ol> <li>I agree to the aforementioned recorded Zoom Interview Recordings being transcribed and excerpts/quotes being used in the final published research thesis – I understand that these excerpts /quotes will be anonymised to prevent identification. I understand that I can choose to use a pseudonym to further aid anonymity.</li> <li>I agree to take part in Scoping Phase 1 of the above study.</li> </ol>					
Name of participant	Date	Signature			
Name of person taking consent (if different from researcher)	Date	Signature			
Researcher	Date	Signature			

IMAGE 14 - STAGE TWO, ADULT CONSENT FORM, SOURCE: AUTHOR

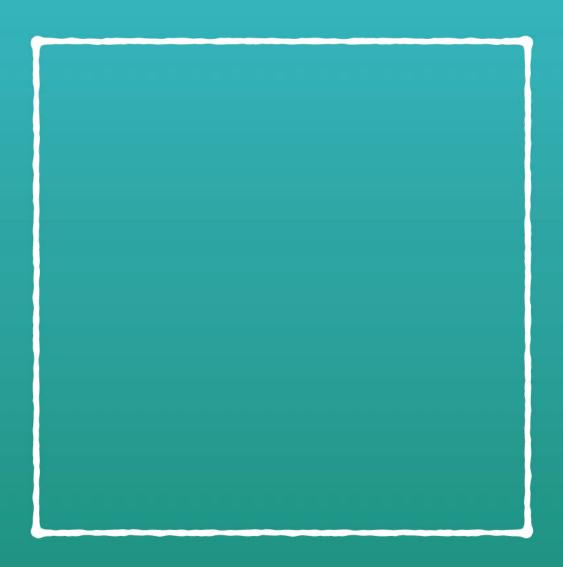
# A.7 SHARED DIGITAL RESOURCES

A Padlet board was designed to provide visually organised space for project resources, this also allowed for both live and asynchronous participation. Participatory flexibility was felt necessary, as an empathetic response to challenges around social engagement, timekeeping and scheduling. A recording of a mindful praxis was uploaded for the asynchronous cohort.

Padlet: https://padlet.com/djamieson12/a-deficit-her-data\_mindful-workshops-wrmsudhr90gy8qox



IMAGE 15 - SCREENSHOT, PADLET RESOURCE BOARD, SOURCE: AUTHOR



# Appendix: B

Design of Data Capture, worksheets, collaborative boards

# Appendix B: Data Capture Design

# **B.1. WORKSHEETS**

Workshop #1 worksheet: this was designed to capture somatic and cognitive responses to the word diagnosis, and receiving a sense of care during praxis.

This asked -

Where am I holding diagnosis?
What words accompanied this felt sense?
Did a diagnostic situation come to mind?
How did I respond to a sense of care?

The timeline was designed to enable participants to pinpoint where the diagnostic event occurred.

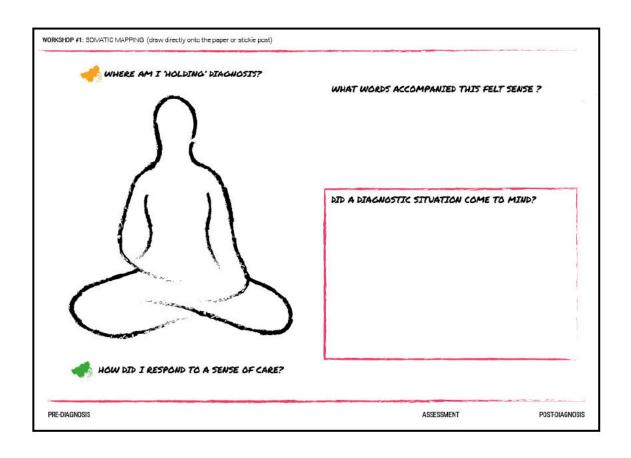


IMAGE 16 - SOMATIC PARTICIPANT WORKSHEET SOURCE: AUTHOR

Workshop #2 worksheet: Prior to praxis participants were asked to bring to mind relationships and interactions from their diagnostic experience. Negative value below the line, positive value above the line and neutral on the line. They were asked to choose a caring, neutral and difficult memory. After praxis they were asked to map any changes that occurred to the value and memory perception.

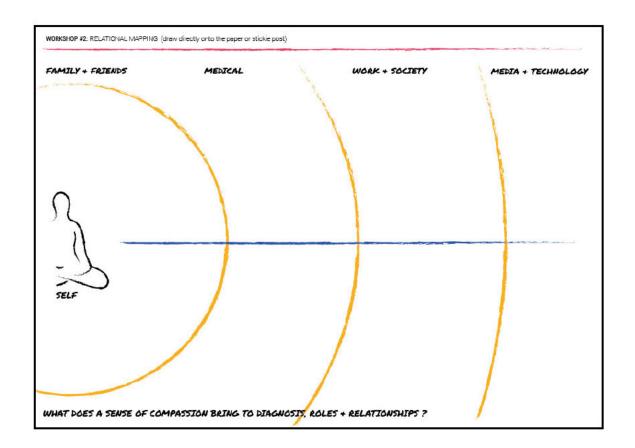


IMAGE 17 - RELATIONAL PARTICIPANT WORKSHEET SOURCE: AUTHOR

# B. 2. MINDFUL POSTAL PACKS

Mindful Design Packs were created to be posted out to participants, so that a sense of shared experience may be created despite working remotely. Elements included A3 worksheets to map phenomenological experience, pens and coloured pencils, a journal, a candle and herbal tea bags.



IMAGE 18 - PHOTO MINDFUL POSTAL PACK, SOURCE: AUTHOR

# **B.3. DIGITAL DATA MAPPING**

Digital collaborative workspaces were designed to capture worksheet data.

Participants were encouraged to engage by providing comments on one another's narratives, the workshop itself and themes to take forward to the next workshop.

Miro board link > <a href="https://miro.com/app/board/uXjVMPHFhMl=/?">https://miro.com/app/board/uXjVMPHFhMl=/?</a> share link id=289775146659

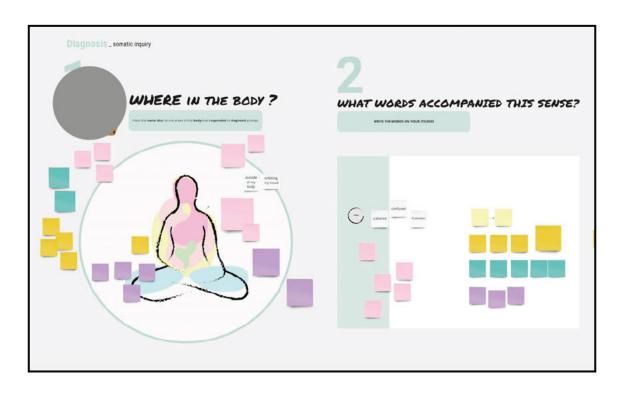


IMAGE 19 - DIGITAL MIRO BOARD, SOMATIC MAPPING COLLABORATIVE WORKSPACE,, SOURCE AUTHOR.

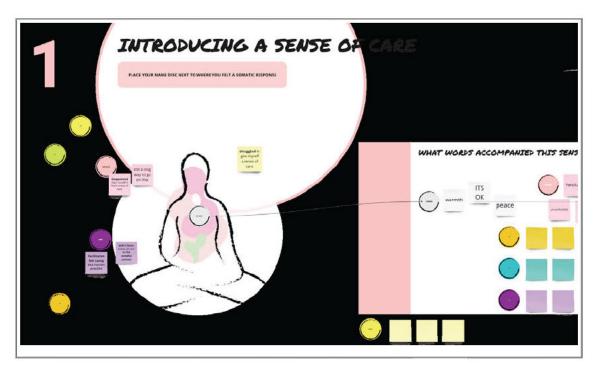


IMAGE 20 - DIGITAL MIRO BOARD WORKSHOP #1, CAPTURING A SENSE OF CARE, SOURCE AUTHOR

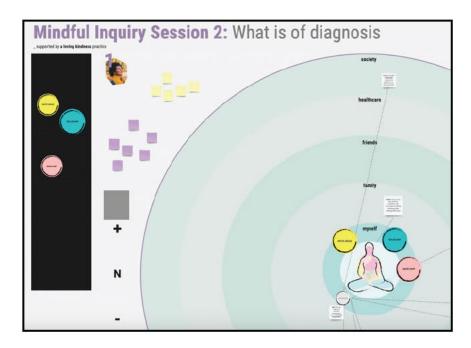


IMAGE 21 - RELATIONAL WORKSHOP, MIRO BOARD, SOURCE: AUTHOR

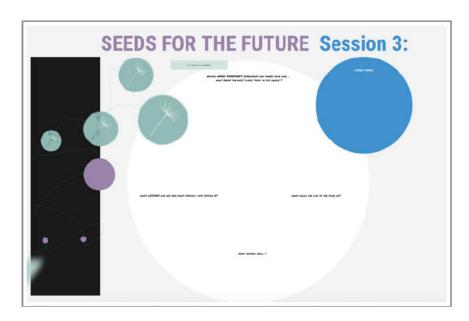
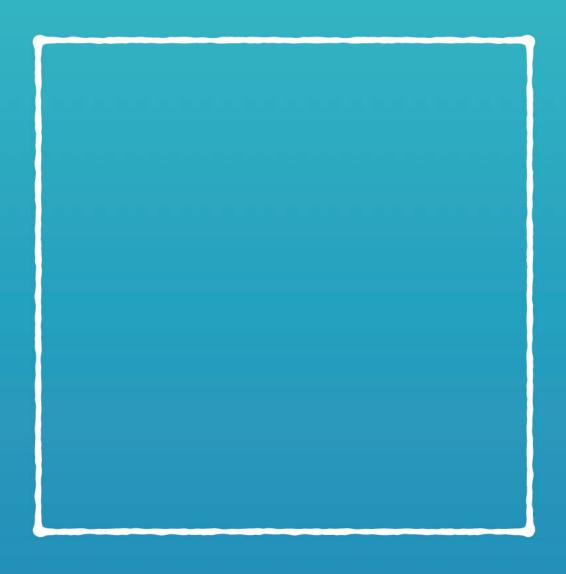


IMAGE 22 - WORKSHOP #2 - MIRO BOARD TO CAPTURE FEEDBACK FOR FUTURE WORKSHOPS, SOURCE: AUTHOR



# Appendix: C

Mindfulness Design, scripts and supporting praxes

# Appendix C: Mindful Workshop Design

# C.1 STRUCTURE AND TIMING

The approach to the design of the workshop was to find synergistic areas between participatory design and mindfulness praxis. I had been leading both practices online during lockdown with a good degree of success, so felt that this would be achievable.

The workshops were structured to fit a tight schedule, to heighten attention and focus within the group.

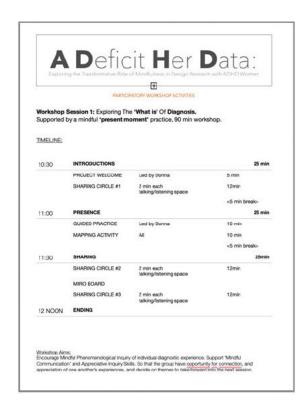




IMAGE 23 & 24 - WORKSHOP ITINERARY, SOURCE: AUTHOR

# C.2 SCRIPTS

Traditional Mindfulness Praxes were selected for fieldwork experiments, these were foundational praxes of 'present moment awareness' and the 'cultivation of kindness.' Both were then adapted to suit aspects of design inquiry, using the body as a site for investigation and relationships as a potential site for transformation.

# C. 2.1 SOMATIC INQUIRY

## Introduction to practice

In this next exercise, we are going to bring our attentional focus to our present moment experience, just as we find ourselves. I will take you through a 'grounding in the body' exercise, then we will tune in to our feeling tone, and lastly drop in our diagnostic experience.

The purpose of this exercise is to create some space around the thinking mind, by tuning in to our other senses, we can perhaps gain a fresh perspective outside of our usual narratives. This is invitational practice, please feel free to take whatever you need from it, and if need be take time to rest.

#### **Anchoring Attention In The Body**

Please find a comfortable position on your chair or cushion. If you are feeling sleepy then it may be useful to keep your eyes open, looking down with a soft focus to a spot two feet in front of you on the floor.

We could begin by taking **3 settling breaths**. Moving our **attentional focus** into the feet, sensing into our points of contact with the floor, grounded, stable and supported. Perhaps drawing a sense of stillness from the ground up through the feet.

Moving our **attentional focus upward**, through the base of the body, toward our **legs**, our **thighs**, sensing into the **hips**, to find a position of balance, neither tripping too far forwards or back.

Moving our **attentional focus** into the tailbone and spine, and with a sense of lifting and lengthening we can move our awareness up through each vertebra in the **lower back**, and upwards to the **neck**.

Rolling our shoulders back we can allow the **shoulder blades** to slide down the back, arms heavy by our sides and hands resting on our lap.

Moving our focus back to the neck, we can perhaps draw up through the neck to the crown of the head as if being pulled by an invisible thread upwards to the sky. From this place of being supported, we can release any sense of effort, trusting that the body knows how to support itself, we can let go of any sense of striving. Resting in the natural support available in our body. Releasing our focus from here ...

### **Bringing Awareness To The Senses**

We can move our attention to the **ears**, and the landscape of **sound**, noticing ... are we chasing after the sounds? Can we allow them to land within our sense experience? Just noticing!

Bringing our attentional focus to the **eyes**, and although they may be closed we perhaps have a sense of **light levels** in the room, and **colours** playing on the lids. Again, just noticing!

We can rest our tongue on the roof of the mouth, tuck our chin in .... as we expand our attentional focus to this **present moment experience**. With these sounds, these light levels, these thoughts, felt sensations in this moment, then this, then this.

#### **Bringing Awareness To The Breath**

Welcoming everything in on the **in-breath**, releasing and letting go on the **out-breath**. Whole body breathing in, whole body breathing out. Following the journey of air, as it becomes breath, nourishes the cells of our body, then releases, as breath becomes air

once more. Whole body breathing in, whole body breathing out, following the rhythm of our breathing body.

#### **Bringing Awareness To The Feeling Tone**

**Releasing our attention** from the breath, we can perhaps sense our **feeling tone** in the body. A sense of excitement, perhaps in the belly, tightness in the throat, heaviness in the chest? Or perhaps nothing, just noticing our felt sense of the body!

#### Dropping In Research Probe - Diagnosis

We can drop in the word **diagnosis** ... **ADHD diagnosis**. With a **listening presence**, just noticing how our body responds, any changes, a tightening, a movement of energy, or perhaps just the same? Just noticing whatever is there. Perhaps a feeling or thought arises in response, a word, a memory... just noticing ... "How am I holding the experience of **diagnosis?**"

#### **Dropping In Research Probe - Caring Touch**

See if it's possible to meet this 'holding' with a sense of **care**, we could perhaps place our hand on our chest, belly or both ... as we meet this 'holding' with care, seeing if it's possible to receive this sense of care. ... noticing any response, feelings, words, memories emerging ... just noticing ...

#### Closing Practice, Awareness Of Our Body In Our Environment

Releasing our attentional focus **from our feeling tone**, we can invite 3 nourishing breaths. Welcoming the in-breath and releasing and letting go on the out-breath. Expanding our awareness out to our body, our points of contact with the floor, we can bring this practice to a close as we invite a sense of movement, and when we are ready, we can open our eyes, and perhaps stretch.

# C. 2.2 SOMATIC MAPPING

The worksheet design took inspiration from body maps used in healthcare design, to denote sites of pain and thoughts and feelings surrounding the sensations. It sought to link the body and memory perceptions to provide a new lens on diagnostic experience.

## **Questions To Encourage Mapping:**

1. Where are you holding diagnosis?

What did this feel like, for example, tension, heaviness, butterflies or energy?

2. What words arose in response to this?

Relief or confusion, use full sentences if you like.

3. Did memory, thought or image of an event accompany this?

Describe the event and place it on the diagnostic timeline.

4. How did it feel to receive a sense of care?

# C.3 RELATIONAL INQUIRY

### Introduction to practice

The Loving Kindness practice is described as the second wing of mindfulness training. So the first wing is training your attention, and through that, you gain wisdom or insight into the bigger perspective of your reality. The second wing is compassion, the intention is to cultivate the heart qualities of allowing acceptance, equanimity, and empathy. The traditional practice invites us to open-heartedly extend phrases of loving kindness to everyone equally. And it's a practice of Eastern origin. And it said that here in the West, we often find offering ourselves kindness, the most challenging stage. Additionally, I would say that the emotional energy of ADHD may also see us fixating and ruminating on negative interactions with people, which leaves little room in our awareness or memory for the more positive ones.

In today's practice, we will offer loving kindness towards ourselves, a friend, a neutral person, someone who we're having difficulty with.

#### Introduction to Mapping

On your worksheet, I'd like you to map your diagnostic relationships, diagnostic relationships. Above the blue line, note positive experiences, the blue line is neutral., and below the line note down negative experiences.

Tuning into a sense of 'aliveness', which of these relationships feels pertinent for you to work with today in a loving and kindly way? Select an interaction that felt caring, one that felt neutral and one that felt a little difficult and not completely triggering. Try to stay away from the story and stick with the feelings instead.

**PRAXIS** 

Grounding

We could begin by finding a position of comfort. Either closing our eyes or keeping a soft

gaze a couple of feet in front of us on the floor. We could take three settling breaths,

whole body breathing in, whole body breathing out, in out.

Settling our attentional focus inwards, towards our heart centre, we can perhaps get a

sense of how we are in this moment. We could place one hand on our heart, and one on

our belly, offering ourselves warmth, comfort, kindness and perhaps encouraging a sense

of gratitude for simply showing up here today.

**Ourselves** 

Let's now explore the practice of kindness. We can repeat the words of loving kindness

silently to ourselves

May I be well

May I be happy

May I live with ease

Resting our attentional focus on our heart centre, "how does it feel to offer myself these words of

loving kindness?" ... noticing how the body responds ... energetically, tensions, a thought, or an

image emerges ...

May I be well, in mind and body.

May I be happy, joyful and grateful.

May I live with ease, stillness and contentment

Caring

Moving our attentional focus, we can bring to mind our caring interaction, perhaps

someone or thing that supported us during our diagnosis ... again, just noticing how our

body responds as we bring this care into our mind's eye ... offer our words of loving kindness ...

May you be well, x 2

Neutral

As we move this sense of care to one side, we can bring to mind our neutral, someone or thing that perhaps had little input was simply just here, and as we bring our neutral to mind, just notice how our heart centre responds ... as we offer them our words of loving kindness ... we can ask ourselves "how does it feel to offer this neutral person our words of loving kindness?"

May **you** be well, x 2

Difficult

As we move neutral to one side, we can bring to difficulty, as we do so, just noticing how the body responds ... and tightening, tension, unexpected joy ... just noticing whatever arises ... we can perhaps recognise that this person brings their own experience, intentions and knowledge to situations ... as we offer our words of loving kindness ...

May **you** be well, x 2

Widening Circle

We can widen the circle of our attention to include ourselves, our caring, neutral person, difficulties to all of us who are participating today, those we've encountered on ADHD social groups, and those we may never meet babies, parents, school children, teachers, healthcare workers and all those living in relation to ADHD.

May **they** all be well, x 2

How does it feel to offer these words of loving kindness to ourselves, all beings.

May all be well, in mind and body.

May all be happy, joyful and grateful.

May all live with ease, stillness and contentment.

Returning your attentional focus to your heart centre, finding a place of rest. We can take a deep nourishing breath, letting go of this practice. We can tune in to our surroundings, the sounds, the light, feelings of warmth and cool.

When you are ready, we can invite movement, perhaps stretching ... as we bring this practice to a close.

# C.3.1 RELATIONAL MAPPING

The worksheet design took inspiration from actor maps used in design, to denote healthcare relationships and interactions. This sought to create an interconnected lens of diagnosis, as something that doesn't simply happen to an individual.

### **Questions To Encourage Mapping:**

- 1. Did you observe any changes in relational value, caring, neutral etc?
- 2. Did you notice any changes in tensions or sensations in the body?
- 3. Any differences in your thoughts or memory perceptions?

# C.4 MINDFUL COMMUNICATION

### **Sharing Circle Praxis**

Mindful communication principles

Sharing from 'Aliveness'

Attention on the speaker and how their words land

Presence

Communication as relationship

# **Facilitator Notes On Sharing**

Each of us will have **two minutes** to **check in** and **share**, we can share as much or as little and **we can choose to pass**. You are invited to share from a place that **feels alive** in you, try not to rehearse what you will say.

When others are speaking, we can offer them **50% of our attention**, and offer ourselves **50% of our attention**. We can listen in and notice how the words of the speaker land, and our energetic response. If it feels supportive we can place a hand on the heart, stay present, and remind ourselves that listening is to be in relationship with what is heard.

## Workshop #1 Soma

- 1. Share what you can see, hear, taste, touch, smell etc 'alive'
- 2. Praxes Feedback
- 3. Session Feedback

## Workshop #2 Relational

- 1. Share your senses, what is 'alive' re 'loving kindness'?
- 2. Praxis Feedback
- 3. Session Feedback

#### C.5 MENTAL HEALTH FIRST AID

## **Square Breathing**

#### How to do square breathing

- Begin by slowly exhaling all of your air out.
- Then, gently inhale through your nose to a slow count of 4.
- Hold at the top of the breath for a count of 4.
- Then gently exhale through your mouth for a count of 4.
- At the bottom of the breath, pause and hold for the count of 4.

Definition from zencare.co

#### 5,4,3,2,1

#### Q: What is the 54321 method?

The 54321 (or 5, 4, 3, 2, 1) method is a grounding exercise designed to manage acute stress. It involves identifying 5 things you can see, 4 things you can touch, 3

things you can hear, 2 things you can smell, and 1 thing you can taste. By doing so, it helps shift your focus from anxiety-provoking thoughts to the present moment.

Definition from calm.com

## C.6 Facilitator Praxes To Support Research Activities

Mindfulness like creativity, is perhaps seen as a somewhat intangible human quality, that sits outside our ability to communicate or appropriately define. It is hoped that I can set out to demystify this process here. As the project began during lockdown, like many other people, boundaries were blurred between home, work, and spiritual practices. Everything moved online, including my mindfulness teaching, Zen practice and retreats. I therefore had to create an alternative framework for my praxes, as achieving time on my own could often be challenging. Praxes took the form of -

#### Daily Walking Meditation - 20 minutes

This practice entails bringing awareness to your feet touching the ground, and the full body experience of walking and breathing. Noticing when the mind wanders and setting your intention to return to the anchor of the breath in the body and your feet on the ground. In zen tradition, you observe a brisk walk, in a circular path, with the hands placed at the heart centre, one hand clenched in a fist and the other hand placed over the top.

#### Writing, journaling

Stream of consciousness writing, being in the moment, daily 4 sides of A4.

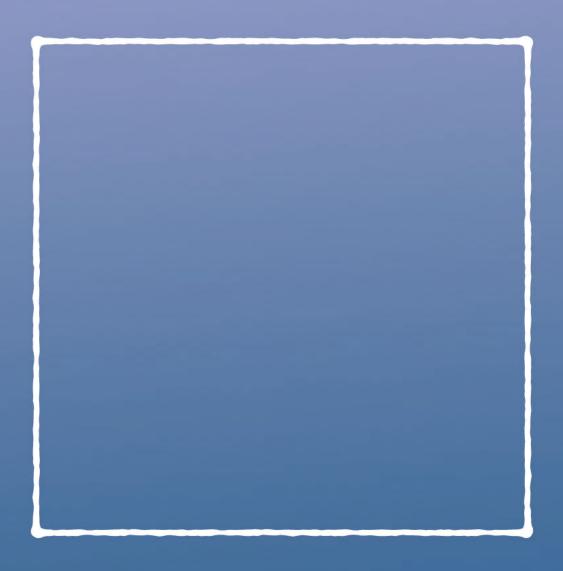
#### **Online Group Praxis**

Twice weekly, 90 min zen practice. Three rounds of 25-minute sitting praxes with 5 minute walking practice in between.

## **Supervisor Meetings**

Supervisor sessions began with a 3-minute sitting, to arrive. Then a check-in of what feels 'alive' in the moment. After this project themes were discussed with regards to teaching points, facilitation and goals. Meeting were every two months then one prior to workshop then one after.

The 54321 (or 5, 4, 3, 2, 1) method is a grounding exercise designed to manage acute stress. It involves identifying 5 things you can see, 4 things you can touch, 3 things you can hear, 2



# Appendix: D

Fieldwork Data And Analysis

## Appendix D: Fieldwork Data

# D.1. Workshop #1 Design, Participant Analysis GROUP FEEDBACK

Miro Boards were designed to include participant feedback on the workshops, this used an appreciative model through its framing of the questions. The findings then informed the iteration of the following workshop.

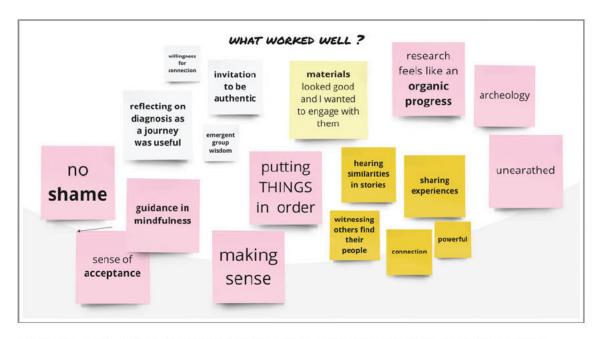


IMAGE 25 - WORKSHOP #1 PARTICIPANT FEEDBACK, WHAT WORKED WELL, SOURCE: AUTHOR

#### Top Down Themes:

**Facilitation:** Scarlet Crane and White Grass expressed that they appreciated the inclusive welcoming tone and sense of care in facilitation. Tensions arose as a facilitator from a 'goalless' workshop, and a desire to progress from phenomenological inquiry into a collaborative digital design space.

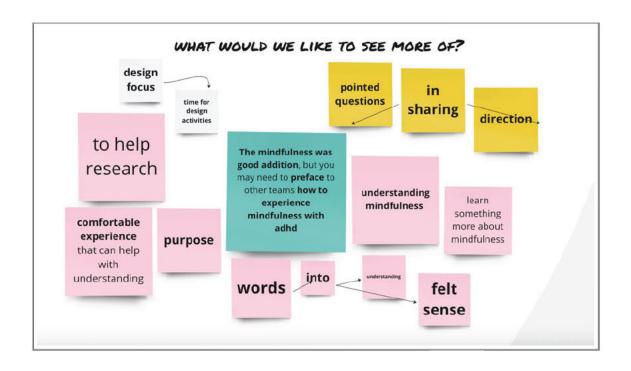


IMAGE 26 - workshop #1 participant feedback, see more of?, Source: Author

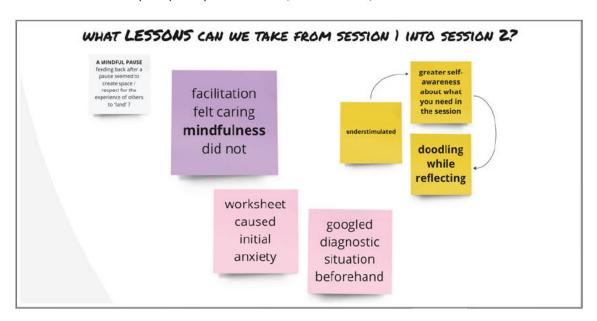


IMAGE 27 - WORKSHOP #1 PARTICIPANT FEEDBACK, LESSONS?, SOURCE: AUTHOR

**Materials:** Mindful packs were positively received by White Grass who said that they were inviting and made her "want to engage." Snow Harp on receiving the Mindful Pack via post, began to Google terms such as diagnostic experience. Engagement with the paper-based design activities did not prove to be an issue, some doodled on their notebooks and worksheets during introductions. Only Scarlett Crane

expressed a sense of overwhelm when using digital collaborative tools at work. There was little indication that Padlet resources had been engaged with, requests for comments, feedback and

journalling pages was not forthcoming. Further research would be necessary to validate the effectiveness of digital tools.

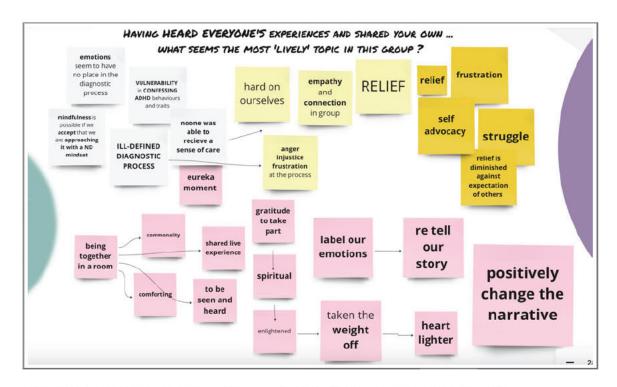


IMAGE 28 - WORKSHOP #1 PARTICIPANT FEEDBACK, LIVELY TOPIC?, SOURCE: AUTHOR

**Inquiry Methods:** Mindful inquiry praxis appeared to be well received, although perceived as a struggle participants appreciated the valuable insights that were revealed. Snow Harp likens the process to an archaeological dig, and values being able to put things in order.

## **Emergent Themes:**

**Emotional Integration:** This theme came up for one or two participants across both workshops. This is encouraging and shows a desire to continue with praxis. This is a consideration for the design of future workshops that aim to include people who struggle with emotional dysregulation.

**Connection:** The most powerful theme for the group was the ability to share experiences, and hear aspects of their own narratives reflected back.

## D.2. Workshop #2 Design, Analysis



IMAGE 29 - WORKSHOP #2 PARTICIPANT FEEDBACK, TAKE AWAY, SOURCE: AUTHOR

## D.3. Asynchronous reflection

This mode of engagement was originally designed for those with social anxiety and/or timekeeping issues, so they could contribute in their own time at their own pace. In the field, participants who were offered this option did not fit into this category. They were keen contributors to the group workshops and simply couldn't make the date or time due to other commitments. They disengaged from correspondence, there are no further findings or insights.

# Appendix DD: Participant Data

The workshop transcripts, worksheets and digital boards were analysed using IPA for UX. This employed top-down, bottom-up thematic analysis, conceptual understanding and UX artefact generation.

Group Generalisable Data

Individual Participant Data

A. UX artefacts

B. Workshop #1 IPA Analysis

B.1 Conceptual Understanding

B.2 Top Down Themes

B.3 Bottom Up Themes

**B.4 Complete Transcript** 

B. Workshop #2 IPA Analysis

B.1 Conceptual Understanding

B.2 Top Down Themes

B.3 Bottom Up Themes

DD.1.0 Snow Harp

Research Inquiry: The Diagnostic Experience

DD.1.1 UX ARTEFACT: VIGNETTE

DD.1.2 IPA: CONCEPTUAL UNDERSTANDING OF DIAGNOSIS

Three points of contact view: Scoping, Somatic, Relational Inquiry

The developing picture is one of a woman who has experienced life as chaotic, this can be influenced by her home life or events in the world, that she can feel compelled to respond to e.g. refugee crisis. During our time together she was offered an opportunity to reflect and make sense

of her life experience in a novel way.

Mindful Inquiry: Digital Design Learning Summary

SH actively participates in the world, UX can offer an engaged and interactive experience

• Somatic inquiry - reflection and processing of emotional journey

• Relational inquiry - positive emotions and behavioural insights, desire to make change.

· Seeking diagnosis was viewed as an act of self-care, and a desire for self-understanding

• Unmedicated in workshop 2, heightened emotions and more talkative

**Somatic** 

The praxis and mapping exercise allowed SH to tap into the positive emotion of hope in her heart,

and reflect on her experience as a previously unseen positive emotional journey. She was grateful

for this insight.

Relational

Prior to praxis SH touched on difficulties in her environment due to refurbishing her home. This

created a desire to focus primarily on her partner in the praxis. This exercise allowed her to view

her diagnostic experience as being compassionately supported by her partner. She was afforded

insights into her behaviour towards him that contributed to their difficulties.

Scoping Conversation: Digital Design Learning Summary

• Developmental issues, dysgraphia, dyscalculia and memory created anxiety about the

administrative process.

• Reminders to hand in forms were required

SH spoke little of her clinical assessment, it had been validating and supportive. She spoke more

about her life experiences - from feeling different as a child, being intelligent and her struggles

labelled as lazy or daydreaming. The story was delivered chronologically, and accounts of her low

points and high points in life were given. I was made aware that our previous meeting had been

cancelled as her daughter had made an attempt on her life, and her Father was dying. She spoke

of how much her medication was helping her through this time.

Workshop #1 Somatic Inquiry, 4minute Sharing

DD.1.3 IPA: UNIQUE PERSPECTIVE - SOMATIC Words And

Descriptions Used

The mindful exercise is described as "interesting"

Mindfulness made the "Roomba-like" mind worse.

Mindfulness has "opened up to me" my expectations of diagnosis

Feelings "bounced around"

Was "hesitant and uncomfortable" with receiving a sense of care.

"Connected the dots" over the years (suspecting she had ADHD)

"Coming to grips with" emergent emotions in the exercise.

"Taken me on a wee journey" (pre to post-diagnosis)

"A big step forward" (having new awareness)

"Really, really surprised" at what's just happened in "our wee situation".

DD1.4 IPA: TOP-DOWN - SOMATIC Thematic Analysis

**MINDFULNESS:** Had been experienced as interesting.

SH came to the 'experiment' with misgivings about mindfulness, which she hadn't

expressed in our initial interview, she had declined the mindful exercise at this time saying

that she felt relaxed enough in her garden. Although I had clarified that relaxation was not

the goal of mindfulness, she hadn't

processed this information into a new understanding at this time. Mindfulness had

previously been suggested to her as a tool to calm the mind, during periods of trauma.

There may still have been an association with mindfulness as a salve, and that her ADHD

brain wouldn't do it properly. Her intention for today was to bring her curiosity which she

did.

**MAPPING:** Had been experienced as a journey

Through engaging in the mindful and mapping praxes she was able to open up her

awareness to the wealth of different emotions that she was experiencing in relation to her

diagnosis, label them and plot them on a timeline. This proved to be an analytical tool for

her conflicting emotions. She was able to visualise the emotional journey she had been on

from a place of confusion and self-criticism to self-compassion and strategic planning. She

was able to see the previously unacknowledged positive emotional transformation inherent

in her diagnosis.

TRANSFORMATIONAL INSIGHTS:

• Negative Self-Talk: Became aware of a lot of negative self-talk during mindfulness,

overwhelm, incl. the feeling of still underachieving TI

• Big Step Forward: SH feels that it has been a big step forward for her to now have

awareness of all of her feelings surrounding her diagnosis. TI

• Surprised: SH expresses surprise that she has gotten anything from mindfulness in such

as short space of time. TI

• Care: SH had hoped that she had moved forward with her ability to receive care however

this was not her experience today TI

• Hope: Hope was the "biggest" emotion felt. TI

DD1.5 IPA: BOTTOM-UP - SOMATIC - Thematic Analysis

• **Gratitude:** is expressed for taking part and having the insights.

• Self-Care: As a nurse, she expresses care and compassion for others daily, however, in the

exercise she was disappointed to note that she was unable to receive this sense of care from

herself at this time. Although she has expressed a desire to "move forward" with this, it

perhaps shows that there are still emotional barriers to accepting her life history and existing

unique behaviours and ADHD traits. She did say that a private diagnosis had been a birthday

present to herself, this was perhaps an externalised act of self-care. This may be important for

those with ADHD regarding "object permanence", or "out of sight, out of mind" the inability to

remember something that isn't objectively in front of you, internal emotions may be

downplayed or remain unseen as they are overshadowed with whatever is happening in the

moment. I am caring if I tend to others, I am performing care.

• Future-Focused Language: Hope, big step forward, much of SH language speaks to

making progress emotionally, and her expectations of diagnosis which hadn't been met. This

perhaps speaks to the issue of self-acceptance, just as we are with our many faults. And also

speaks to a desire to run into an imagined future, rather than accept the present which is a

theme for Mindfulness.

DD1.6 IPA: RAW TEXT - SOMATIC

**SUMMARY OF THEMES:** 

• Struggling with mindfulness

• Future Focus - expectations, feelings, awareness, step forward

• Inviting Care, I hoped I'd moved forward with that

• Where are you holding the diagnosis? Heart, hope.

• Emotional Journey, chaos and confusion to self-compassion and problem solving

• Positive Result, surprised and grateful for praxis.

**FULL RAW TEXT:** 

**Theme:** Struggling with mindfulness

That was that was really interesting. I think.I, I have experienced what I probably was kind

of expecting because I am actually very, I struggled with mindfulness massively, which

is why I was so interested in this. I've always struggled with it. It's been I have my brain is

like a Roomba. of thought and mindfulness almost made that worse for me. Often,

especially when I've been through times of trauma, and it's been a suggestion for

sort of kind of grounding and things. And then now is it is a fairly stable time or kind of

as much as it can be. And it used to and it's something I really want to get to grips

with whether that will happen or not, I don't know.

Theme: Focus on Diagnosis - expectations, feelings, awareness, step forward

But when in this instance, where we have actually just had a few moments to focus

specifically on diagnosis and the feelings surrounding that. And it's really opened up

to me how I felt about what I expected from my diagnosis and where I am now. And

the feelings I have bouncing around. Are maybe partly disappointing, but partly, I'm

actually aware of them, which is probably a big step forward for me, which is

something that I probably didn't have before.

My diagnosis is fairly recent three years. It was my 40th birthday present to myself. And it's

something I've always suspected of as an ex-neonatal nurse. And it was a discussion we

often had with our parents, and I was very premature baby myself. So it was lots of

connecting the dots and over the over the years. And this actually has brought that out so

from

Theme: Inviting Care

how did I respond to a sense of care was a big thing for me with our focus there,

because actually, I was hesitant. I'm uncomfortable with it. And I'd hoped that I

maybe would have moved forward with that. Em the words that accompanied the

sensations that I was coming to grips with were overwhelm searching. Still

underachieving. So lots of negative self-talk has come out of the mindfulness.

**Theme:** Where are you holding diagnosis? Heart, hope.

However, when we looked at the where am I holding diagnosis I've got in my heart,

hope, I think, was probably one of the the biggest things that I felt while, we were

just quiet and going through the different parts of the body.

**Theme:** Emotional Journey

And I think I have had like them the words here on our on our piece of paper, pre diagnosis, assessment and post-diagnosis has actually taken me on a wee journey. If I look at the words I've written down to pre-diagnosis, anxiety, confusion, chaos, feeling juggling, assessment itself, curiosity, determination, and post-diagnosis, relief, self-compassion, problem-solving, and identifying strategies.

Theme: Positive Result, surprised and grateful

So it's actually when I've gone when I've gone down, identified negativity, the end of it actually there is when I look at pre and post, I think there has been something positive, come out of that. And I've, I've unwittingly got something out of a mindfulness situation that I've never actually got before, potentially, if that makes sense. And that's been in a very, very, very short space of time. So I'm, I'm really surprised. I don't know. Yeah, I think surprised. I'm really, I'm really surprised at what just happened in our little situation. So thank you. Thank you very much, Donna, and thank you, as well ladies for being about and giving this a go, I suppose really, is what this is.

Workshop #2 Relational Inquiry, 10 minute Sharing

DD1.7 IPA: RAW TEXT - RELATIONAL

SUMMARY OF THEMES:

• Difficult to stay on task, decision-making

• Equanimity, going through story with compassionate heart

• Neutral Partner Primary Person For Support, Relabelled Compassionate

• Navigating Other People's Reactions, Supported by Partner

• Self-reflection and Behaviour Change Towards Partner

• Media And Tech, rabbit Hole, Supportive And Toxic

• Insight - get a balance with tech

Theme: Difficult to stay on task

Yeah, this has definitely has grown like was difficult for me to stay on task. Because for

every person in relationship I could identify a positive neutral or negative experience with

there are so many others that and especially for each because that in my head, I was

trying to identify something in each area as well. So I'm trying so I've brought it down to

two things that actually meant the most to me over from diagnosis and the people that

were around at diagnosis to, to now, just just to make it briefer, because like I have written

down stuff down sort of for other bits as well.

**Theme:** Equanimity

But I think probably the most important thing to stand out to me. And this our mindfulness

session there has done exactly what I think it was designed to do, because I know you

explained what equanimity was. But it surprised me what it meant. And when I looked at

it, I have achieved equanimity, from sitting with my emotions, and feeling compassion for

the areas that I've been doing, like going through the negatives.

Theme: Partner Primary Person

For a number one person around to me and my partner, my partner, and I met just literally,

just as I was actively seeking out private diagnosis, and on our first date, and he

confessed to me that he had ADHD. And I was like, wow, actually, I think I do too. And I'm

actually actively seeking diagnosis. And it was something that we had in common, and we

hit it off straight away. And he was there throughout me getting assessed and over the,

you know, kind of period of assessment, then diagnosis, then trying medication, which all

coincided with lockdown and the pandemic, and he by far has been the closest and most

understanding and supportive. But I think that's because he's he knows himself, he

understands and having that support from someone who has exactly the same struggles

and more has been,

Theme: Navigating Other People's Reactions

I think, invaluable, especially when having to navigate the the stress of other people's reactions, for example, my family, people around me work, because they had, you know, various positive and negative experiences at work.

Theme: Partner Is Assigned Neutral, Then Grateful

But I think my biggest issue were around my relationship with my partner, X, we've been on and off in that that whole period of time, but we are now very much on is the neutral part of of my feeling regards diagnosis, in particular in relation to our relationship together is we've got so much so many similar problems. But we've also got such different needs and challenges, which almost can actually add almost a little bit, I think, to some of the challenge, like challenges. And I think the phrase that you're using, I hope you are well. And I hope you're basically I hope, I hope you will live at ease. And it's just like, all you can think about is the one thing that ADHD people have is it's not easy, Nothing's easy. But how how can I make that easier and I don't think I make life easy for X at all, because that is the closest person to me. He gets it in the neck from me the most grumpiness irritability, the anxiety, the stress, the constant overwhelm. And it's something that I've been really battling this past few months. But this little exercise of mindfulness has actually allowed me to sit and examine my positive, the positive around having him in my life and having someone that like being grateful that I've got him around understanding everything that I'm going through and having someone to bounce off and feeling privileged to have someone so close to me that understand so well what what it's like because I know so many people so many of us simply don't have that we aren't necessarily in a relationship with another neurodivergent person and you know, that comes with its own issues.

Theme: Self-reflection

But yeah, look examining the negativities that I'm feeling about myself towards him is the fact that I feel like I'm always grumpy, irritable, when is he getting the benefit, especially recently of the happy me that the what brought us together in the first place, this shared experience and the understanding each other and being able to laugh and joke about the same things and in that exercise I feel more compassion for my partner and coping with me I feel an easing like a real easing of the the negative emotions I have, about myself the guilt, you know, the, the guilt and the shame actually have not been the nicest, kindest

person around him because he makes me feel safe. So I need to understand that a lot of my behaviour towards him is because I feel safe to do so I know he isn't, it isn't not demonstrated a desire to leave yet. So I need to make sure that that doesn't happen. And why does he make me feel safe, because I love him and trust him.

Theme: Insight - Behaviour Change

And actually, I need to start treating him like love and trust him, which is all about. It's given me just give me another perspective as to why I feel the way I do at the moment. And what I can do about that to actually stop and make sure that I don't slide into continuous negative stressy, anxiety, anxious behaviour, because it will end up driving him away. But these, like, feelings have all come about the chaos that we're living in at the moment.

Theme: Media And Tech, rabbit Hole, Supportive And Toxic

But it brings me to the role for media and technology. Because it's kind of connected, because we're both quite chaotic, messy, trying very hard to stay on top of that we're clean people, it's just we've got so much stuff. And because everything's been getting decorated and things, we've been living in complete chaos for about four months now. But it's, it's getting better now. But from the media and technology side from diagnosis, I discovered all these shared platforms, like all the social media apps, I've got some sort of community that you can join Facebook groups, Instagram, there's something on everything, it's a rabbit hole, which is great for being supportive, and finding people in the same situation as you. And it was wonderful to experience when I find when I was starting to join groups around the time of diagnosis, and including the ones the like ADHD Direct one. And things there's just this massive relief, and an awe of all these people who have the same experiences the same thought processes, watching people's description of themselves and having a good laugh about the fact that they're describing me and common words that that the all use to describe our challenges, but also how deeply toxic these platforms media, social media platforms can be as well for negativity trolling, and abuse. Which, you know, when when you have ADHD and and you know, you're too good at hyper focusing on something and getting lost down the rabbit hole of, of negative talk, it will only contribute to that.

Theme: Insight - Behaviour Change In Relation To Tech

So it's it's understanding, you need a balance in this this from technology side is understanding how to limit yourself so that it's not deeply unhealthy. And that's actually quite difficult. But also understanding that these groups these apps, and and, and thinks they're all communication platforms, the means to communication. So trying to use that kind of got more and more neutral attitude towards it to try not to think too much about it or to help to help you be able to take a step back. And the but the one the one thing that one of the biggest things I got out of the media and technology side was I don't know if any of you guys have heard of neurodivergent cleaning crew. It's an incredible, it's an amazing, amazing group on Facebook for neurodivergent ND people that really do struggle with with self care. And sorry.

## DD.1.8 Snow Harp

Scoping Conversation Analysis

## DD1.8.1 UX ARTEFACT: PERSONA

Snow Harp is a 42-year-old Neonatal Nurse with a good understanding of the impacts of premature birth on Neurodevelopment. Her diagnosis was achieved privately, with a prior shared care agreement in place from her GP. Her ADHD medication has been life-changing, she describes it as "the best anti-anxiety drug" she has ever had, it is currently supporting her through challenging life circumstances.

After a lifetime of "chaos", and ADHD symptoms being attributed to trauma, COVID provided SH with the space she needed to reflect and act on her instincts that she had ADHD. When her divorce settlement came in, she described "treating herself" to a private diagnosis after a period of researching reputable companies. Overall her experience was very supportive, validating and a relief, the forms presented a minor challenge for her dysgraphia and dyscalculia.

Digitally supporting women like Snow Harp through diagnosis would mean providing a professionally mediated safe space for peer group discussions, that provided well-researched and

good-quality information. It would also recognise SH biggest challenge, self-compassion and the release of shameful feelings about her past, perhaps allowing opportunities for positive reflection.

## DD1.8.2 UX ARTEFACT: BARRIERS AND OPPORTUNITIES

## Diagnostic Well-Being Support Needs

PRE DIAGNOSIS - 7 years	ASSESSMENT - 3 weeks	POST DIAGNOSIS - Ongoing
Barriers: Dismissive attitude to ADHD Symptoms labelled as trauma Life too choatic to pursue diagnosis.	Barriers: Dysgraphia and dyscalculia Executive Function and Memory Concern that she has internal	Issues: Shame around life experience Ongoing family difficulties
Opportunities: Others suggest she is ADHD Divorce settlement payment GP offers shared care	Opportunities: Researches reputable company	Opportunities: Works with healthcare team to get her medication right. Working with psychiatrist.

## DD1.8.3 UX ARTEFACT: **DIAGNOSTIC JOURNEY**

## Snow Harp - Questionnaire and Remote Assessment

DAWNING					
EVENT	THINKS	FEELS	ACTS		
Awareness: Psychology student becomes aware of ADHD  Caseworker, is identified as ADHD  Nurse understands	I have ADHD	"I felt comfortable with my ADHD"	Sees Psychiatrist for "trauma"		
CATALYST: HELP SEEKING					
EVENT	THINKS	FEELS	ACTS		

COVID allowed time for reflection on the more negative aspects of ADHD and life felt more settled.  The divorce settlement allowed her to take the Private diagnostic route.	"Not having all these demands to me was suddenly quite liberating."  "I thought to myself, I'll treat myself to myself here. And I'm and I said right. This is what I've always	Calm	Joined Facebook groups  Researched a reputable organisation.		
CLINICAL ASSESSMENT: PRIVATE					
EVENT	THINKS	FEELS	ACTS		
Administration	"Oh my god, all these tick boxes, and having to keep a straight line and make sure that I'm selecting the right,	Motivated to complete administrative tasks and get diagnosis.  Anxious about tick	Returns forms		
RESULT: COMBINED ADHD					
EVENT	THINKS	FEELS	ACTS		
	"I was very conscious that I may have internal bias ticking boxes that I was	Relief  Validation and trust that her instincts had been correct.	Calls her Mum to tell her. Mum is also relieved.		

## DD1.8.4 IPA: Conceptual Understanding

Themes

## Reflections:

When asked to tell her diagnostic story, SH begins by saying that she always felt "different." She describes herself as bright at school, disengaged and mislabelled lazy and a dreamer. These comments align with the literature findings. When we met over zoom, she felt herself to be mindful and relaxed sitting in the garden, I offer an alternative view of mindfulness and choose not to push the point. For the most part, SH talks about the chaos of her life, her darkest moments and high points of exceptional achievements and bravery awards. Her diagnosis is prevented initially by her own misgivings about ADHD, being mislabelled as trauam, she then feels comfortable with it, and

during lockdown, she reflects on all of the impacts on her life. Until this point, her life has been too demanding and chaotic to pursue a diagnosis. Her divorce settlement allows her the opportunity to pay for and find a reputable private company. She has a mix of feelings of relief, grief and validation when she receives her diagnosis. On telling her Mother of her diagnosis she is shocked by her remark that she also was relieved as it meant that she hadn't been a bad parent. I had the sense that self-compassion is the biggest hurdle for SH, forgiving herself for her alcoholism, her nervous breakdown, suicide attempt and parenting. She was successfully navigating an extremely difficult period in her life when we met, and was thankful for the

medication that was supporting her at this time. The conversation felt like an "off-road safari" into a bumpy an unknown terrain of someone's life.

Our conversation was conducted via zoom and took an unstructured form, to order to create a sense of conversational "collective inquiry".

## Clinical Assessment And Privilege:

The assessment itself was not discussed in detail. She had researched "reputable" private organisations and opted for ADHD Direct. She spoke of the difficulty with form filling, and that the team had to remind her twice to complete her forms and that she was highly motivated to complete the administrative tasks to achieve her diagnosis. A recurring theme for SH was her sense of privilege a) she could afford the private assessment b) her GP had agreed to shared care c) she was well educated and could communicate well, and understand what was asked of her. On undertaking an online ADHD education course she once again observed the white, middle-class experts and participants. She felt passionate about representing diverse voices and experiences.

## Mindfulness As A Relaxed State Of Mind:

SH did not take the opportunity to engage in a mindfulness practice as she currently felt relaxed in her garden. We discussed the merits of mindfulness practice, she felt that she had a "natural" practice, knowing when to "just sit" in her garden and "listen to the birds" as a form of relaxation. I offered the reflection that Mindfulness was not only about relaxation, that you may be "sitting with your anger". We left the conversation there and to begin our inquiry.

## Chaos, Balance And Timing:

SH described herself as "a riot" and her life as "chaotic". Much of the conversation was focused on a life "out of control". Within all this she had married, raised children, completed a degree and held down demanding work as a Nurse. She shared her insights of the need for balance or lack of turbulence when requesting a diagnosis. It was deemed neccessary to ensure that medication was taken and its impacts assessed.

## Medication:

Her medication had created a transformation in her. "A light had gone on" she had the ability to organise and see things as never before. She worked with her team to get the medication right. She could now see her life issues for the difficult experiences that they were, and no longer had the tendency to self blame.

## Transformed Sense Of Self:

She feels confident now post-diagnosis to describe herself as intelligent. That she is kinder to herself and tries to accept her mistakes and past experiences. She is curious about what her AD/ HD brings to the table. With psychological support, she has developed the capacity to engage with psychological tools to help with dissociation and hyperfocus that arise from her difficult life circumstances. She describes herself and her life as a "riot". She spoke of herself as a sensitive child who avidly read but didn't respond to academic subjects that didn't engage her passion or creativity.

## Digital Opportunities:

We spoke a little about digital tools. For her, they seemed to be about facilitating research to understand and manage ADHD. She spoke of the credibility of information, and advice available on forums and placed her trust in peer-reviewed medical reports. She also spoke of the internet as both an overwhelming and useful tool.

## DD1.8.5 IPA: Top Down Thematic Analysis

Themes

## **WOMEN AND ADHD**

Having a medical background, she was aware of gender bias in research and medicine Women may be dismissed "I know it's incredibly difficult process to go through that people are very often

dismissed. And all too often, I think, especially women."

Women's mental health is quickly labelled when in fact it's a trauma response

"pathologising of women's mental health, and I think we're very quick to label

women as having a personality disorder or bipolar when actually, it's reactions

to trauma, plus or minus ... an element of undiagnosed ADHD"

#### Medical Mysogny

"I do believe ... studies have been done on boys ...therefore the criteria have

been created with boys presentation, when women present with their sort of

inattentiveness and things like that ...there's I think a lot of medical misogyny

is involved... this hysterical woman not coping with, you know, the duties of

wife mother working with or whatever...being able to put it down to anxiety,

women's issues, hormones, whatever."

"although my hyperactivity isn't like, you know, traditional boys like bouncing

off the wall sort of thing. It's my brain. It's my chatterbox... it's up here"

(points to head)

## CLINICAL ASSESSMENT

Private diagnosis appeared straightforward.

"Took around 3 weeks and involved questionnaires"

Cost: SH appreciated and her acknowledged her privileged position.

"I'm very aware of my privilege of that I was also very lucky that my GP practice was more than happy to engage in and shared care which I know

a lot of GPS won't do that. So lucky stars because I couldn't have afforded

a private prescription for these medications"

"I was privileged enough to be able to afford a diagnosis."

Emotions: Impact of the diagnosis.

Patient response: relief

A feeling of **relief** whilst conscious of the fact that she wanted a positive diagnosis.

"You know, those kinds of things and the relief, I felt the absolute massive relief, because I'm very conscious of the fact that very many, many of us who

seek these diagnosis there maybe an element of internal bias because we are

looking for things when we are ticking the boxes that it may be that we're wanting to tick those boxes, but it was confirmation for me."

## Parental response: relief

"her first reaction was, you know what? I got such relief hearing that because I feel like less of a failure. Thanks. Oh, wow, mom. "

Administration: Forms had proved to be slightly troubling with her dysgraphia and dyscalculia.

"Because like, like you see, like, even when I got the forms, and I was

looking at the forums, and I was like, Oh my god, all these tick boxes. and

having to keep a straight line and make sure that I'm selecting the right, the

right number."

"I may have dysgraphia and dyscalculia, but I have no problems reading. So I am privileged in that I can I've been able to seek out all this

information about ADHD and read it and process"

"... my assessment paperwork came in a few days, and they had to send me a couple of reminders to send it in. I was motivated to complete it because I knew that there was, there was a purpose and this was going to benefit me up up here. So you know, that was my motivation."

## DIGITAL OPPORTUNITIES

Responsible, moderated and peer-reviewed information.

## Responsible Information:

"The women's ADHD group, which is moderated by actual professionals, which is

really useful because they're constantly posting, you know, peer-reviewed responsible

information and things like that. But I think obviously, by the very nature of ADHD, we

easily jump down rabbit holes. And I think the internet can be both a useful and

overwhelming space."

## Education:

**Education** opportunity for **professionals**.

"it'd be nice to have something that actually educates health professionals"

## DD1.8.6 IPA: Bottom Up Thematic Analysis

- Starting point: "I always felt a little bit different"
- ADHD Language: "ping pong brain", disappearing down "rabbit holes", "chaos", "a riot" and "laser focus".
- Passion: creating motivation and impulsive actions to improve situations.
- Biology: Premature birth increases the likelihood of Neurodevelopmental dysfunction.
- Negative Childhood Labels: impacts on sense of self "intelligent" but "lazy", daydreamer.
- Timing: Finding the right time for diagnosis, when life is stable enough to allow medications to be routinely taken, and their efficacy to be measured.
- Psychiatric Opinion: The Pyschiatrist had difficulty in differentiating a "pathology" from a 'natural' trauma response, given everything she had been through.
- ADHD Geek: Interested in "the brain" and drawn to other people with ADHD.
- Being Recognised by Others As ADHD: Children with ADHD had identified her as having the condition.

Own Opinions And Beliefs: she had been "dismissive" of ADHD when she was younger, then she felt comfortable with the idea and didn't seek help, then in a period of self-reflection

recognised the life impacts.

Kindness and self-acceptance: medication and psychological "tools" are a pathway

towards self-management and self-care. "My diagnosis has helped me be less critical of

myself, whilst also not using it as an excuse"

DD.2.0 White Grass

Research Inquiry: The Diagnostic Experience

DD.2.1 UX ARTEFACT: VIGNETTE

DD.2.2 IPA: CONCEPTUAL UNDERSTANDING

Three points of contact view: Scoping, Somatic, Relational Inquiry

The developing picture is one of a woman who experiences life as overwhelming or "on fire", particularly the long hours and stress involved in achieving her work goals. She is extremely proactive and engaged in problem-solving. Connection with others is a big theme for WG, during our time together she was offered an opportunity to reflect on her relationships and the support

received during her diagnosis.

What can digital design learn from this?

WG actively participates in the world, UX can offer an engaged and interactive experience

• RSD requires scaffolding, as the diagnosis can be experienced as traumatic

• Other diagnoses such as MS require careful consideration

• The ability to adequately prepare for clinical assessment could be a feature.

• Sharing life experiences may be labelled as "shame"

• Positive affirmations allowed the ability to thank others safely

White Grass found her clinical assessment extremely difficult, the workshops took place one year after our initial conversation, and much of her hurt and anger from her experience still remained. I found her hugely proactive in our initial conversation, having met very challenging circumstances with energetic solutions. What came through strongly for me was her need to feel a connection with others, which she had found online and through a fertility app, by seeing others who are going through the same as her. She responded really well to the relational inquiry and felt emotional at all the kindness and support she had received, she appreciated the ability to thank people. And she wanted to do the practice all over again!

#### **RELATIONAL INQUIRY**

Through the loving-kindness praxis, WG felt positive emotions such as gratitude. Although the themes of her story remained largely the same, there was a much kinder view of events.

#### New Details:

- A best friend who offered "unflinching support"
- Her Dad's support despite his misgivings about ADHD
- Her Psychiatrist is seen as "more human", a woman carefully going about her business.
- Peer support was seen as an "outpouring" of kindness that made her want to reciprocate.

#### SOMATIC INQUIRY

Somatic inquiry revealed that the diagnosis had been experienced as "horrible", she described feeling "frozen in the horror of it all" across her shoulders. The mapping exercise was found to be useful in seeing the journey of diagnosis. The story of diagnosis remained largely the same.

#### New details:

- the peak "eureka moment" of discovering she has ADHD
- "Deep dive" into research.
- A sense of belonging is found online.
- Disappointment that medication hadn't fixed everything
- Anger at not being heard.

#### **SCOPING CONVERSATION**

WG's scoping conversation began with her feeling "different" as a child, her high IQ and her lack of school success. She had originally been given an MS diagnosis for her memory issues, and had been seeking a better fit when she alighted on ADHD. Despite having this answer, she delayed assessment feeling that she had challenges of work to deal with. The catalyst for assessment came when she had to turn down a "top job" and felt that she had a small window of opportunity before menopause would be blamed for her ongoing cognitive difficulties. Clinical diagnosis was upsetting:

- School reports were not sufficient, so a request was made to speak with her Dad. This makes her feel "unheard" and triggers childhood issues.
- Peer support is found online, she downloads forms and watches videos to prepare her Dad.
- Her medical reports contain errors, such as the misspelling of her name and factual inaccuracies, and she requests amendments.
- She feels that she spent a lot of money on a clinician and felt "betrayed by her".
- She spoke of her understanding of the challenges facing women and diagnosis.
- She spoke of her concerns about data sharing, and disclosing a disability.

## Workshop #1 Somatic Inquiry, 4 minute Sharing

# DD.2.3 IPA: **UNIQUE PERSPECTIVE - Somatic** Words and Descriptions Used

thinking about diagnosis "being in the stages"

"picture of the journey"

"Eureka moment" first became aware of ADHD

in "true ADHD fashion" does a deep dive into research.

"massive hunger to read everything" about ADHD

diagnostic process was "horrible"

wanted to speak to 85-year-old Dad as "validation"

angry that "I wasn't being heard"

"prepped him" for the call

"felt I had to beg to go on medication" because of recreational past use

"she couldn't even spell my name right" inaccuracies in reporting

"Joy" at finally getting the diagnosis

girls have to "leap through so many hoops"

#### "Having a tribe and belonging"

disappointment that meds would "fix everything" but haven't

## DD.2.4 IPA: TOP-DOWN THEMATIC ANALYSIS

#### **Mindfulness**

White Grass responded to the exercise by describing a visceral sense of horror, and discomfort that reflecting on her diagnostic experience had created.

#### **Mapping**

SH resonated more with the design activity which allowed her to perhaps return to the safety of her story. Her narrative illustrates her as extremely proactive in her diagnosis. Each obstacle is met with an action that progresses her path towards her end goal.

## DD.2.5 IPA: BOTTOM-UP THEMATIC ANALYSIS

#### Design Activities, Mapping the Phenomenological Journey onto the Worksheet

- WG seeing the stages, picture of the journey
- WG tells the narrative through the lens of emotion
- Feeling: Eureka moment when WG found out about ADHD
- Action: WG took a deep dive into researching the condition
- Feeling: This is me recognition in the research materials.
- Feeling: "Maybe it's not all my fault" (an antidote to self-criticism)
- Event: GP dismissive due to her academic achievements.
- Action: Seeks Private diagnosis
- Event: the psych asked for her Dad's input
- Feeling: Anger, invalidated, "he was never there", doesn't believe.
- Action: Preps Dad for interview using DIVA form
- Event: Dad was interviewed, he changes his opinion.
- Feeling: JOY, relief at getting diagnosis
- Event: Psych sends letter to GP "3-page dossier" listing inaccuracies and every "mistake I've ever done".
- Feeling: SHAME
- Action: raises a complaint asking for amendments to the dossier.

DD.2.6 RAW: FULL TEXT: 4 Minute Sharing

Theme: Seeing the stages

I agree with what SH actually said ....(inaudible) like and seeing it written down thinking

about it as, and being in the stages ... maybe not the same, right? (inaudible) picture of

the journey. And so pre diagnosis, shame, frustration, self hate, underachieving

(inaudible) yourself, and others low self-esteem, uncomfortable. And then I think there was

a kind of Eureka moment when I first became aware of what ADHD was. And then I kind

of thought, maybe it's not maybe, maybe not on all my fault. And, and then, and kind of

true ADHD fashion, like deep dive into research and everything like a massive hunger, to

read everything to learn more and more and more. I felt it was definitely me and

Theme: Diagnostic Process Horrible

then the diagnosis process was horrible. I am nerves was a massive (inaudible) , I got

totally stressed. I got a degree that I didn't really have ADHD because I've managed to

achieve something that my school reports weren't bad enough for me to have ADHD.

Theme: Involving Dad

And then the person needed to speak to my 85 year old as validation who was always at

work and was never there. And I'm angry that in and angry that I wasn't being heard, and I

needed validation from my dad. Who doesn't even know what it ADHD was. But he

agreed to do the call. And I had prepped him. And then he agreed to do the call. Because

he knew it was important to me, but he doesn't really believe it. And he didn't really agree

with it. But actually then when she started to ask him all the questions about what I was

like, being little, he kind of changed over the course of the call and started remembering

things that I had no memory of I have very little memories of being quite young i found

quite hard.

Theme: Disclosing Drug Use, Shame

So I told my psychiatrist, everything I didn't leave any of my (inaudible) out or recreational

drug use or anything like that, I told her everything I want to cover for the diagnosis. And

then she wrote a report from a GP and she included everything, absolutely everything in it.

And she was like inaccurate so my GP got three pages dossier on every bad mistake I've

made every time that we were in . And I felt so angry and such shame (tears). And so I felt

like I that I had to beg go on medication because it had the recreational drugs had been

noted.

Theme: Complains About Inaccuracies

And I wrote a letter to the psychiatrist to complain about the inaccuracies, she couldn't

even spell my name right, and I feel my GP to say I feel this is inaccurate. I've asked her to

write a new letter which she did and (inaudible)

Theme: Joy And Finding A Tribe

and then JOY at finally getting a diagnosis Anger at how hard it is. I think especially for girls

who are inattentive, about like having to leap through so many hoops and relief self-

kindness. Biggest thing is (inaudible) compassionate (inaudible) and having a tribe em

then belonging, a bit of disappointment that meds would fix everything but that they

haven't fixed everything.

Workshop #2 Relational Inquiry

DD.2.7 IPA: **UNIQUE PERSPECTIVE** Words and

**Descriptions Used** 

thinking about diagnostic relationships "made me aware of my gratitude"

"Unflinching support" and "incredible listening skills"

"Connecting with a community"

"Outpouring of kindness", "actual tangible and practical help"

"The kindness of women all over the world who I'd never met"

"I have a desire to give back"

"He thinks **everybody can be late and lose things** ... if everybody just paid more attention, dah dah dah"

"it was difficult to establish rapport with me those words are still singed in my head"

"It helped me to **see her as more human**", "going about her business trying to make sure she doesn't give dangerous drugs to someone",

"She was definitely very robust"

## DD.2.8 IPA: TOP-DOWN THEMATIC ANALYSIS

#### **Mindfulness Praxis**

#### **Transformative Perspectives**

Humanises People, Despite Prior Negative Interactions

More Can see the negative person as more "human", going about her business, and being robust in a difficult diagnosis.

Dad Supporting In His Own Way Despite His Misgivings

Grateful to Dad, who is a nonbeliever. Says that everyone loses things and is late etc.

Despite his opinions, he agreed to be part of the diagnostic process.

## DD.2.9 IPA: BOTTOM-UP THEMATIC ANALYSIS

#### Tech Facilitating Connection And Support, Received As Kindness

Grateful to Media and Tech first and foremost. Wants to give back. "Amazing" women from all over the world going through the same process, connecting and helping.

Ability To Thank People, Feel Gratitude, Which You Perhaps Can't IRL Felt useful to say thank you to everyone.

COMPASSION RAW TEXT: 7 minute Sahring

Theme: Best Friend, listening skills and kindness

I'm sorry. So strangely, so I had amazing support from my best friend. And the practice

definitely made me aware of my gratitude for her unflinching support, and her incredible

listening skills and her kindness.

Theme: Grateful for Media And Tech

And that actually, I think, the, where I found what I found the most, what I found the most

grateful for. In the process of my diagnosis came from media and technology. And it was

connecting with the community of other people that were going through the same process

from all over the world. So I had my first meeting with a psychiatrist. And she told me that

there wasn't enough evidence and, and that she would need to speak to my Dad. And I

came out of that meeting, like crying. And I walked to my local park and I went on to an

ADHD Women Facebook group wasn't the Scottish one, I think it was the international

one. And I wrote a big post about how it had gone. And, like, literally, there was like, 100

people responded, in about 20 minutes. And the outpouring of kindness from all of those

other people an actual tangible, practical help, like, okay, she wants to speak to your Dad.

Look at the Diva questionnaire go through the questions. We're sorry that this has

happened to you, like, I actually feel quite emotional thinking about it. But definitely, one of

the biggest things that helped me in my diagnosis was the kindness of like, women all over

the world that I had never met before. And I, I'm aware of that, and I have a desire to give

back to that. So like, I still scan those Facebook groups. And when I see you know,

anybody saying oh, they need to, you know, it needs we need proof of, of it as a child. So

we need to corroborative evidence or somebody. Then I try to share my experience and

anything I can do to help.

**Theme:** Grateful For Dad The "Non Believer" Agreeing To Conversation

And so yeah, I feel very grateful for that. And my neutral person is actually my Dad,

because he doesn't, he's not really I think at the start, he would describe himself as an

unbeliever, a nonbeliever in ADHD because he thinks everybody can be late and

everybody can lose things. And if everybody just paid more attention, then dah dah dah dah dah. And but I'm very I wouldn't have my diagnosis if it wasn't for him agreeing to have the conversation with a psychiatrist. And, and I'm grateful for him agreeing to do that. Because he wanted to help. He knew it was important to me. So I'm very I'm very grateful to him. For that, I guess it's slightly complicated and that he's never mentioned it ever, ever after it. He's never asked me how my medication is working out. He's never really referenced it again. And to be completely honest, I think he's totally forgotten all about it.

Theme: Useful to Say Thankyou To Everyone

But it was useful to me to say thank you to B my best friend and thank you to all of those amazing women that took time out their day. Thank you to my Dad because I wouldn't have my diagnosis without him. Well, although that still makes me a bit angry. And then my so I've done the positive the neutral and

**Theme:** Sees Negative Person as "more human"

it will not come as a surprise that my negative is this psychatrist that diagnosed me so she said on her first meeting, that it was difficult to establish a rapport with me. And like those words are like singed still in my head. Hm because I was really trying. Em ... but I think the practice I think I'll try to do again. I think it's one of those things that maybe through repetition, you get better at em. I guess it maybe helped me see her more as a human. She has now stopped doing private practice because she said her NHS work is so intense that she doesn't have the time to commit to private practice. So I no longer have to see her again. I've got a new psychiatrist I've not met but I think I'm actually very glad that I think I can be kinder to her now knowing that I don't have to to meet with her again. And but I think this practice did help me em helped me try to view her more as just a woman going about her business trying to make sure that she doesn't give like dangerous drugs to someone that you ... like she was definitely very robust in her diagnosis like she was she it like it was not an easy diagnosis I think that's all I've got to say I don't I don't know if I've I don't know if I've done that right sorry.

DD2.10 White Grass

Scoping Conversation Analysis

DD2.11 UX ARTEFACT: PERSONA

White Grass is 44 years old and has recently been diagnosed with ADHD, despite recognising

herself as ADHD 10 years earlier. She had been looking for a better explanation for her memory

issues, lateness and losing things, which had originally been diagnosed as intermittent MS. She

didn't accept this diagnosis. As her symptoms are persistent, she wonders if she has both.

Her private clinician did not identify which type of ADHD she has, and she found the diagnostic

experience to be traumatic. She expressed that she had paid a lot of money to get specialist help

and support. Instead she obtained an "opinion" which seemed coloured by character judgements.

She is well aware of the struggles of achieving a diagnosis, particularly for women. She subscribes

to a more "American outlook" of positively

working to your strengths. When we talked in June 2021 she was about to start on medication.

Her diagnosis still appeared emotionally raw and brought her to tears.

For digital to support women like White Grass, it would create a safe space to make

recommendations and advice, ensure data privacy to ensure there's no risk of disclosing disability.

It would provide a transparent process and reporting system which could be reviewed by the

patient. It would also employ a family-centred approach to help mange relationships and reporting.

DD2.12 UX ARTEFACT: BARRIERS AND OPPORTUNITIES

Diagnostic Well-Being Support Needs WG

Barriers: Life felt too busy too pursue diagnosis MS diagnosis	Barriers: Patient Account & School Reports not viewed as sufficient information	Issues: Reporting Inaccuracies
	Elderly Dad "who was never there"	
Opportunities: Menopause creates deadline Career opportunity creates motivation	Opportunities: Researches adoption specialist Peer group support Is given reminders	Opportunities: Asks for amendments and change of clinician

## DD2.13 UX ARTEFACT: **DIAGNOSTIC JOURNEY**

## WG- Tele-Conference x 2

DAWNING			
EVENT	THINKS	FEELS	ACTS
Decade prior to diagnosis.  "Came across ADHD" Whilst looking for explanations for memory and forgetfulness.	"I wasn't really wanting to seek a diagnosis my early 30syou still got like a lot of things going on challenges with work and everything."	Still a lot to achieve in life wants an answer.	Online researching, reading books on ADHD and joining peer groups.  "I began to read up on it and the more I read, the more I became <b>convinced</b> that it was something that I had"
		Ambitique	nad
	CATALYST: H	ELP SEEKING	
EVENT	THINKS	FEELS	ACTS
<ul> <li>turned down a top job.</li> <li>Neurologist suggested symptoms were "MS Brain Fog" however intermittent MS comes and goes which didn't fit WG's experience.</li> <li>Hormonal window</li> </ul>	"I didn't feel like I could take on the prioritization of those 26 people"  "Going to see my neurologist galvanised my wanting to get a diagnosis."	WG had been reassessing her life during COVID  "I felt I had a very short window to get a diagnosis before people started telling me it was peri-menopausal brain fog"	Speaks to GP  "I spoke to my GP"  They advise there is a Long waiting list.  "So I decided that I was going to, I was going to go private, and I just to get it done"
		Reflective, time-	Decisive, wanted

CLINICAL ASSESSMENT: PRIVATE			
EVENT	THINKS	FEELS	ACTS
INTERVIEW	"I was completely honest I wanted to be able to access medication on the NHS and not have to pay for it."	"Unburdened" of everything she has "been carrying"	Emotionally Upset.
	Speaks in confidence, and talks honestly about her past and how her symptoms		
PARENTAL REQUEST Clinician: "I can't just believe you, I need to have corroborative	"My Dad always worked late and my Mum was my primary carer"	"I feel that you are a 44-year-old woman, but we still need to speak to your Dad. Made me feel really unheard."	Posts online for advice. Downloads DIVA Forms and "sits down with Dad" to prepare, watches videos to educate
TELE-INTERVIEW  PARENTAL INPUT Conversation with Psychiatrist  "Dad didn't believe in ADHD, he didn't want his daughter to have access to stimulant drugs."	Hearing what Dad had been through with me as a child made me realise how difficult it must have been for my parents.	"I think it wasreally positive for my dad to consider that some of my in more irritating tiresome, annoying. troubling, worrying tendencies, were down to that" (ADHD)	
RESULT: ADHD			
EVENT	THINKS	FEELS	ACTS

		20.0	PAGE 100 10 100 100 100 100 100 100 100 100
REPORTS	"when I got that letter	Unhappy	Calls to ask for
O AD/IID	through I was in		amendments
Confirms AD/HD	tears, and I was		
doesn't specify which kind	unhappy."		
	"I'm utterly	Shocked & betrayed	
Contains	blindsided by this		
inaccuracies -	and I'm actually very	WG feels betrayed	
name spelt wrong,	upset. And I feel like	by the person she	
date of stopping	there are very	had turned to for	
taking "recreational	important	"help and	
drugs" last year	inaccuracies that I	guidance."	
instead of 10 years	want you to correct"		
ago etc.			
Characters and		Misrepresented	
Traits presented as	"Focus seemed on		
someone who is	the more scandalous		
difficult to connect	aspects of ADHD		
with and emotionally	traits"		
volotilo Thio io	CALABARETC:		

## DD2.14 IPA: Conceptual Understanding

**Themes** 

#### Reflections:

When asked to tell her diagnostic story, WG begins by saying that she always felt "different" and recounts her difficulties from school onwards. She found her diagnosis particularly upsetting as she had taken time to find an adoption specialist, feeling that they would be empathetic to her needs. She is further upset by the report which shows inaccuracies incl. a misspelt name, and incorrect factual information. Her recounts of the clinician appear to show disregard for her feelings, while the inclusion of her Dad causes additional emotional difficulty due to his age and his view of his daughter as "lazy." She is extremely proactive, asking for help from peer groups, doing her own research and preparation and asking for changes in her report. She is careful around issues of personal data, and disclosing disabilities. Through her years of research, she has found a "rich seam" of information that has a positive approach to ADHD. She is also very aware of narratives surrounding female disadvantage in the diagnostic context and can provide her own examples from friends' stories.

#### Reflections:

WG did not engage in the mindfulness session offered as she was taking a break from work - at 7pm - and returning to it after we had finished, so she was mindful of time. Equally, I did not benefit from a mindfulness session, so perhaps felt the conversation started with a little less ease.

## Diagnosis and Clinical Report:

The main theme that we returned to was that of the clinical report and the practitioner who had diagnosed WG. As a psychotherapist she had simply interviewed Wg for 2 hrs and hadn't provided any forms or questionnaires. During this time WG had "unburdened herself" of all that she felt she had been carrying. She felt emotionally vulnerable.

When she read the clinical report sent to her GP she felt betrayed. The details on the report were wrong, including the misspelling of a name. She felt that the more "salacious" themes had been given more focus and some information was factually incorrect. She had to ask that the document be amended as she felt that she wanted her medical records to be accurate. She did not appreciate the way that she was depicted as "not making eye contact", difficult to connect to and being "prone to tears".

## Family input

Having to corroborate the evidence with her Dad raised feelings of not being "heard". That her accounts as a 44 year old adult was not to be trusted. She asked Facebook for advice where someone advised that she go through the DIVA form with her Dad. This was good as a prompt for memory which she was concerned about as he is 84. When she heard her Dad recount stories of her as a child with difficult behaviours it made her feel sad, she had no idea that she had caused her parents so much "stress." Luckily her Dad got on board with her having AD/HD and began to understand that it had shaped her forgetful behaviours and traits.

## Diagnostic Tone:

By assessing the negative aspects of ADHD it had set a negative tone for WG. She felt that there was too much focus on dysfunction. This had perhaps acted as an emotional trigger for low self-esteem and feelings of "failure".

### Digital Opportunties:

WG has only recently started to use project management tools. She is distrustful of data sharing and privacy issues. But sees that there may be scope in community building and sharing of knowledge and information. With a ADHD positive outlook.

#### General:

During WG accounts of her diagnosis she was upset, she looked away from the camera as she was clearly reliving the raw emotion of her difficult diagnostic experience. I was unsure of where the conversation would go. I shared a lot more personal information than before, and ideas about the project theme specifically about Women. It is here that we seemed to gel. By the end of the session, I felt more comfortable with WG, she seemed enthusiastic about the project theme and excited to see where it would go. I felt that we were on the same page and would work well together in a workshop setting.

## DD2.15 IPA: Top Down Thematic Analysis

#### ADHD WOMEN:

#### Themes

White Grass clearly made a distinction when she spoke of medical practitioners as being male or female, inferencing a bias. Her own assessor was female. Gender was of concern to her, from her extensive research she had evidenced many who had cited gender as a diagnostic barrier.

## Hyperactivity:

- "....my friend ... waited three months on the NHS, got her appointment, went to see
- the specialist ... it was a locum. And he said, "Tell me about your hyperactivity"...she
- said "I don't have hyperactivity, of any kind."... he said, "that doesn't exist you have to
- have both of them."... she said, "can you tell me how many women you've in you've
- diagnosed as only inattentive" and he said "zero! Because it doesn't exist!"
  ....I do
- really feel like it's so hard... I would like it not to be for, for a for all the people..."

- "the undiagnosed generation of in females who weren't the ones running around
- classroom bashing stuff up, but they were just looking out the window and their
- coping strategies and how they kind of overcompensate. And I guess that will have
- gender and expectations are amongst women of and why it was so largely undiagnosed and how there's like this. Like, I believe there's a massive amount of
- undiagnosed women around about by my age."

## Comparative Male experience:

- " a male friend went his doctor got asked to fill in the ... self questionnaire, got an
- appointment on the NHS, they gave him another appointment, they gave him the
- same questionnaire. And they said, "Only one way to find out we'll start your
- medication. If it works, you've got it. If you don't then, you know ... that was his
- experience, a half an hour, one appointment... I have yet to find a girl who has had an
- experience like, extremely interesting."

## High Level of Education:

- "the friend that I mentioned earlier, the first time she went to the GP, her GP said or her
- male GP said, You've got a first you can't have ADHD." (First Class Degree)

## Shame And Struggle:

- "I don't want young girls to have the same shame and the same struggle and the
- same not being believed and like, yeah, I hope that it gets better. And I think the
- research that like you're doing on others like is really important."

#### **CLINICAL ASSESSMENT**

#### Themes:

#### Cost:

Private diagnosis was described as **costly**, additional tests were offered that also had a cost attached to them too.

"the person I paid 800 pounds to, and turned to for help and guidance. Really, in some ways, like almost did more harm than good."

"800 pounds is a considerable amount of money to me"

## Reporting:

The letter sent to her GP, it contained inaccuracies and WG felt that her confidence had been betrayed.

"I felt betrayed, I had spoken in confidence"

"I was imagining that the letter would be ... we've undertaken an assessment, and we confirm that there was ..... but basically it was a really inaccurate transcription of every single thing that I had told her. It said, WG, stopped using recreational drugs last year, when it was over 10 years ago. I run my own business. I've run my own business since 2011. I'm quite successful in my field."

"The focus of the report seemed on the more scandalous aspects of ADHD"

"The diagnostic letter reduced me to a failure"

#### Administration:

There had been **no forms to fill out**, this had been carried out via an inperson interview. A peer had alerted her to the DIVA form which she went through to prepare for the interview with her Father. **WG had to email three school reports as evidence, this was not deemed sufficient.** 

"There were no forms, it was all based on her subjective opinion"

"Dad didn't believe in ADHD, he didn't want his daughter to have access to stimulant drugs. Thankfully there was an American woman of the Facebook group who suggested doing the DIVA form together"

"I feel that you are a 44 year old woman, but we still need to speak to your Dad. Made me feel really unheard. There was no guidance as to what she was speaking to my Dad about."

## Emotions: Impact of the diagnosis.

- "I was so overjoyed when I got my diagnosis .... on my way home I lost my bank card
- and ordinarily I would have been absolutely raging that it fell out of my pocket and
- would have been beating myself up about it. But my Dad was like, "well I guess I
- can't give you a row for that now" I'm going through a lot of changes in myself .... to
- see it all written down ... It's all really upsetting "

#### MINDFULNESS:

Mindfulness is perhaps seen as a positive alternative support.

"I paid a lot of money to a private clinic to get a diagnosis and the prize was to be able

to access medication. At no point was there any mention of mental health or

mindfulness."

## **DIGITAL OPPORTUNITIES**

Themes:

## Data Sharing:

WG concerns around data sharing, disclosing personal information on apps.

- "I don't use anything currently, I would maybe be slightly concerned about how that
- data is being used and identifying myself as having ADHD and that could count
- against me in a job. I've not disclosed this to any employers ... when I first got my MS
- diagnosis, I would go incognito to look up things because Ididn't want to be getting
- targeted ads about MS ... I didn't want that in my life ... I was trying to manage my
- MS without taking any medicine and through diet and exercise ... I also had like a
- mental thing ... I don't want to ... a victim ... I don't want to identify as, as being
- disabled and have things I can't do ... I'm going to try my hardest not to let that
- happen ... With ADHD, if there was something developed, that was beneficial, and I

## Sense Of Community:

- "...if you are looking at an app where ...people can pose questions ... communicate,
- ...having that sense of community, if there's something that could embed some
- executive function type, reminding ... possibly with like something like, human and
- kindness ... that is generous, and shares, links to external that maybe people can vote
- on what they found useful on a topic, that could be like a really useful outcome."

#### GlowApp

"... it told you that 67% of women who's cycle you are in sync with also are experiencing pain, mood swings. It gave me a sense of community. Support network"

## G.B.4 IPA: Bottom Thematic Analysis

Themes:

- Story Starting point: childhood, "I had always been aware of feeling slight different, I felt different."
- Delays Diagnosis: Didn't pursue a diagnosis immediately as life was busy and felt she still
  had a lot to do achieve.
- Alternative Diagnosis: Intermittent MS in 2019, unsure if this is a misdiagnosis of ADHD or an additional condition. As her congitive, brain-related symptoms are always present so don't fit the intermittent picture.
- Waiting lists, and COVID: GP advises that she use a Private company due to waiting
  times. GP agrees to shared care. Covid had presented an opportunity to reflect on the life
  impacts of ADHD particularly the negative aspects.

#### Clinical Assessment

#### Themes:

- Care: describes her diagnostic assessment as a "dereliction of care" no questionnaires, misrepresenting information in report and no useful links or support offered as after-care.
- Parental Input: WG's Mum had passed away and her Dad needed "prompts" to
  remember events, as he had not been the primary caregiver. Asking parents to "corroborate"
  her evidence made her feel like she wasn't being heard. Hearing how difficult her behaviour
  had been as a child was hard, her Dad could see that ADHD was the cause rather than her
  will.
- Biological Family: Her family biology/history had not been taken into consideration i.e. that
  she had spent six months in care and was adopted (ADHD is more prominent in this group),
  and that her biological Mum had a history of impulsive and risky behaviour.
- Advice: A male friend advises that she is honest about her 'historic' recreational drug use.

  However, this information is shared in the report to her GP. It is inaccurate and misrepresents her as someone who may currently be at risk of abusing medication.

#### Personal Attributes

#### Themes:

- Proactive approach: Researched topic thoroughly for 10 years. Asked questions on Facebook, downloaded the DIVA form, showed her Dad videos so that he could understand ADHD better and why she wanted a diagnosis.
- **Positive:** Takes an "American approach" to ADHD in that she views it positively and wishes to work with her brain rather than against it. Hire people to support your gaps i.e accountant and cleaner.
- Motivation: offered a high paying role with a lot of responsibility that she felt she had to
  decline. Also that she felt she had a small 'window of opportunity" before her symptoms
  were misattributed to perimenopause.

Seeking Advice: This had mixed results.

DD.3.0 Scarlet Crane

Research Inquiry: The Diagnostic Experience

F.B.1 IPA: CONCEPTUAL UNDERSTANDING

One point of contact view: Somatic Inquiry

The brief picture observed is one of a woman who is struggling to process her diagnosis, beyond

the task of seeking workplace accommodations. She is a working Mother, her home is sensorially

distracting and organisationally chaotic. During our time together she became emotional, and her

recount of diagnosis was scathing.

What can design learn from this?

• SC actively participates in the world, UX can offer an engaged and interactive experience

• Understanding the diagnostic process and trusting the outcome may be key to integrating and

reframing a healthy sense of self.

• UX may have to explore how sensory deregulation impacts digital experience

F.A.1 UX ARTEFACT: VIGNETTE

Workshop #1 Somatic Inquiry

F.B.2 IPA: UNIQUE PERSPECTIVE Words and Descriptions Used

"I don't feel a sense of care in mindfulness, I'm sorry"

"Pain becomes really apparent all over my body"

"I continue to put myself in **these situations**" determination

"I feel like someone has turned up the volume"

"I wasn't quite aware, hadn't named properly" insight of complex emotions

"So mindfulness works, I suppose" (reluctantly)

Like most of us, the whole diagnostic experience has been "pretty shit"

"No reassurance about any of it"

"The whole thing was really quite horrific"

"shit at being human"

"You lay out all these things, so vulnerable"

"Unfinished projects and negative coping strategies"

"Okay, tick, you've got ADHD bye" brush off

"left me with such a **sense of all my deficiency**, and just, yeah, just deficit, huge deficit"

"There's no space to discuss feelings, because they don't fit into the little boxes"

"trying to talk about the feelings of it. There's just no space ever for it."

## F.B.5 RAW: TRANSCRIPT 4-minute sharing

#### **SUMMARY:**

Theme: Impacted by emotion from the previous story

Theme: Struggle With Mindfulness

Theme: Awareness Of Feelings

Theme: Diagnostic Process As Struggle, Horrific

Theme: Gold Standard NHS

**Theme:** Disclosing Vulnerable Information

Theme: Left With Feelings Of Deficiency

Theme: Where are you holding diagnosis? Gut churning

Theme: No Room For Emotions In Tick Boxes

Theme: Impacted by emotion from the previous story

Hello, sorry, I'm actually just feeling really, really emotional hearing your story. WG didn't know why, like I hear people's shitty experiences that shouldn't have happened so often.

But like, yeah, I didn't know maybe it's just after the mindfulness exercise. I'm really sorry.

That's a horrific thing to happen to you. And this should never have happened anyway.

Theme: Struggle With Mindfulness

Excuse me, sorry. I really struggle with mindfulness. So really, really? So? Yeah, and

unfortunately so like. Yeah. How did I respond to a sense care? I don't, I don't feel a sense

of caring mindfulness. I'm really sorry. I just feel it absolutely exacerbates all the symptoms

I find really difficult I my mind races. It's like, you know, someone's turned the volume up

on everything. My skin itches all the bits of my body, that ache, joints, pain becomes really

apparent all over my body. So it's really difficult. And I like I can't remember who it was

that something was you, SH, I really want to get better at mindfulness. So I still continue to

put myself in these situations, but the outcome is generally the same.

**Theme:** Awareness Of Feelings

But saying all that it did. Like you're SH like lots of things that perhaps I wasn't quite

aware, and hadn't quite named properly about diagnostic experience and how I actually

genuinely feel about it did become apparent through doing that. So mindfulness works I

suppose.

Theme: Diagnostic Process As Struggle, Horrific

Yeah, like, I'm sure most of us the whole diagnostic journey has been pretty shit. So much,

so many words on this piece of paper, like anxiety and fear and uncertainty and self-

loathing. And then just so much frustration, it's like the diagnostic processes designed to

make like people with ADHD really struggle. So no information, how long will it be no idea,

no support throughout the whole thing? Am I doing the right thing? What my spirit? What

are the expectations, no reassurance about any of it. And then suddenly a letter and come

to this thing? I don't know if I'm supposed to bring anyone bring any information. I don't

know what's going to happen at that meeting how long it's going to be. So like, the whole

thing was really quite horrific.

Theme: Gold Standard NHS, Invalidates Her Experience

And then all for like a 50 minutes, what's supposed to be a gold standard NHS diagnosis.

So you kn So you know, whoopee and the winner of a magic NHS diagnosis, not one of

those awful private diagnosis that we're all being told to meaningless at the moment. But I

don't feel it is, you know, it was so short and so insufficient, that I still continue to question

whether it was valid, which is really difficult, I think, sorry, I'm feeling really emotional.

**Theme:** Disclosing Vulnerable Information

So I think just the vulnerability of like, you've just talked about WG, like laying out all the

things because you feel like unless I lay out all the things, they're gonna send me away

with a label that is not ADHD, just shit at being human. So you lay out all the things but the

stuff so vulnerable, all the mistakes, you've made, all the unfinished projects and bad

decisions, and you don't drug use and smoking and all the you know, negative coping

strategies, and you lay it all out. And then you get a "Okay, tick, you've got ADHD bye".

**Theme:** Left With Feelings Of Deficiency

And so it left me with such a sense of all my deficiency, and just, yeah, just deficit, huge

deficit, which is one of the appeals actually, of this, you know, you're talking about data

deficit, but I feel like the whole process has resulted in me only seeing deficit and deficiency.

**Theme:** Where are you holding diagnosis?

So yeah, I think I hold my diagnosis, there's like a jaggy stone in my gut that still kind of

churns a lot. And I also did a lot of stuff on here about your head, because it all seems to

be head stuff and very little about, you know, any feelings.

**Theme:** No Room For Fmotions In Tick Boxes

There's no space to discuss feelings, because they don't fit into the little boxes. And once

you've got diagnosis, everyone goes, Oh, that's brilliant, really happy for you. And what does

it mean and reasonable adjustments and it's all head stuff. But trying to talk about the feelings

of it. There's just no space ever for it. So anyway, I've talked too you long that's me. I'm sorry.

I'm really feeling emotional.

DD. 4.0 Indigo Nature

Research Inquiry: The Diagnostic Experience

F.B.1 IPA: CONCEPTUAL UNDERSTANDING

One point of contact view: Somatic Inquiry

The brief picture observed is one of a woman who has been emotionally transformed by her recognition of herself as ADHD. Consequently, the diagnostic process is described as "very annoying". She has a good capacity to engage in positive self-talk to "talk herself off a cliff". Still struggles with her day-to-day tasks, during our time together she was able to identify and express the visceral sensation of self-diagnosis, as a release of unseen tension.

What can design learn from this?

• IN actively participates in positive self-talk and reframing, UX may offer this feature

• IN positively uses the label "brain disorder" to give herself empathy and grace

• UX can seek to understand how extreme negative emotions may impact digital design

• UX can seek to understand sensory under stimulation may impact digital design

Workshop #1 Somatic Inquiry

F.B.2 IPA: UNIQUE PERSPECTIVE Words and Descriptions Used

"quiet time was like punishment"

"I was full-up of negative feelings"

"You don't realise how much it is aching"

"I am not just horrific at basic existence, it's a brain disorder."

"I know that lots of people reject the label of disability, I have no qualms with that because I already rejected my own self-existence"

"I always knew something was wrong"

"I would ask myself, am I stupid or unambitious ?... well ... no ... but I don't

have a better answer, so it must be that"

"That was the theme of **filling in the blanks** because I didn't have a better option."

"I just immediately clung to it. It made sense."

"There's a little bit of **imposter syndrome**, am I just making this up for attention?" "for the first year and a half when I didn't seek out a diagnosis just to make sure this wasn't just **some like little thing that I was obsessed with** for a few weeks that I would then forget about"

"it has really just been a second lease on life for me"

"I still have bad days ... do stupid things ...I still get upset with myself ... but before that spiral (of self-loathing) would just end up ... suicidal ideation or ... self-hatred, because I couldn't figure out what the problem was ... now, when those moments happen, eventually, at some point, **I bring myself back** and I'm like, but no it's not because I'm inconsiderate and careless... it's because my brain really struggles with this sort of thing.

"I'm able to have such **space and compassion and grace and empathy** for myself. Whereas before I had none, I mean, not even the littlest bit"

"I guess, the grounding of it for me, where I can talk myself off of a ledge of like losing my mind"

"my actual diagnostic experience was very annoying. But passable, I suppose."

## F.B.5 RAW: TRANSCRIPT 6-minute sharing

#### **SUMMARY OF THEMES:**

Struggle With Mindfulness

Few Negative Feelings Since Self-Diagnosis

Poetic Metaphor

Accepts Disability Label

Imposter Syndrome & Waiting

Second Lease Of Life, From Self-Loathing To Self-Compassion And Grace

Describes Beating Myself Up

Gratitude For Diagnosis

Theme: Struggle With Mindfulness

I feel like my experience while my experience with mindfulness is very similar what SC said it is. I wouldn't say overall, I struggled from intense under stimulation. But as soon as I'm in a place where I tried to do that, like everything

me is like, you touch your hair, you have a drink, like just it's just such a funny thing. So just in general, it's never really been ... like a guiet time was like punishment when they were like, Let's just be quiet for a minute and I was like, Oh, I don't want to um,

**Theme:** Few Negative Feelings Since Self-Diagnosis

diagnostic wise, I feel like what I'm gonna say is a little bit different than everybody says big Because I did get diagnosed in like the very ... December 30 ... very end of 2021. And I had sort of self diagnosed myself about a year and a half earlier. And I have had very few negative feelings since then. Because I had them all from my earliest conscious memories until the day that I read something and was like, that's just like me. And so I guess I was full up of so. So basically, upon reading this and discovering, I think I have ADHD, it was like,

**Theme:** Poetic Metaphor

the way I liken it to is like in the winter when you're always cold. So you're like very like you keep yourself in to kind of just stay warm. And then the first summer's day, we were like, Oh, my God, like that was a it was you don't realise how much it's aching. And that is the visceral reaction of how I can describe it of like, having been like this for so long, to finally being like, ah, ah,

Theme: Accepts Disability Label

I as SC said, like, I am not just horrific at basic existence. It's a brain disorder. Okay, thank God, because I know a lot of people sort of reject the label or if it's a disability, I have no qualms with any of that, because I already rejected my own self existence. And so I also always knew, though, that something was wrong. And I would ask myself all the time, like, why am I like this, which is the reason of the Show, just funny. And I would go through and be like, Well, is it because I'm this like, is it because I'm, like, stupid and unambitious? And I would think, well, no, I really not that, but then I don't have a better answer. So it must be that. And so that was just this theme of like, filling in the blanks and in the back of my head, knowing that that was wrong, but not having a better option. So when I had the better option, it was like, I just immediately clung to it. It made sense. There was a

little bit of and there still is sometimes

**Theme:** Imposter Syndrome & Waiting

imposter syndrome of like, am I just making this up for attention? And then I will do something or say something? And I'm like, No, there's something wrong with me like this. I'm not making it up. There is definitely something going on there. And I definitely had that in the beginning, that for the first year and a half when I didn't seek out diagnosis just to make sure this wasn't just some like little thing that I was obsessed with for a few weeks that I would then forget about which

you know, and so post all of this, for the most part,

Theme: Second Lease Of Life, From Self-Loathing To Self-Compassion And Grace

it has really just been a second lease on life for me. Not necessarily like I mean, obviously, I have bad days, and I still do stupid things. And I still really get upset with myself and all those things. But I come back to always like that spiral of self loathing of being like you did you know, you miss this appointment again, for the 17th time, you're so stupid bla bla bla bla totally. And before that spiral would just end up like, really like suicidal ideation or just just truly just self hatred, because I couldn't figure out what the problem was. But now, when those moments happen, eventually, at some point, I bring myself back and I'm like, but no it's not because I'm inconsiderate, and careless, and or whatever it is. It's because my brain really struggles with this sort of thing. And now I know that and so I can kind of start to compartmentalise and it really has just made the small things in my life easier. I mean, still not really. Like, for example, I'm here on a visa, my visa expires in six days, I only put my application in two days ago, okay, so we're not doing that great. It's fine, but it's not like it's life is you know, but I'm able to have such space and compassion and grace and empathy for myself.

**Theme:** Describes Beating Myself Up

Whereas before I had none, I mean, not even the littlest bit, I just, I almost relished

the opportunity where I would really like fuck up, because then I can be like, see,

look how horrific or whatever. Like, I almost looked forward to it. So I could beat

myself up again. And I don't look forward to it at all. And I can have that almost

like that conversation with myself or being upset with myself. And then at some

point, being like, no, no, this is not because you're whatever this is because you

have this. This is that symptom. And really, that is I guess, the grounding of it for

me, where I can talk myself off of a ledge of like losing my mind and saying,

No, you weren't late because of this, you really because of this. So overall, my dia,

my actual diagnostic experience was very annoying but passable, I

suppose.

**Theme:** Gratitude For Diagnosis

But my own personal experience with my life has been incrementally

better for sure. And even though when it goes back down, it always kind of

comes back up. And I'm very grateful.

DD 5.0 Sea Bloom

Research Inquiry: The Diagnostic Experience

F.A.1 UX ARTEFACT: VIGNETTE

F.B.1 IPA: CONCEPTUAL UNDERSTANDING

Two points of contact view: Somatic And Relational Inquiry

A picture emerged of a highly capable woman who can strongly advocate for herself and wishes to

support others through her skill. Although her diagnosis experience was extremely supportive she

struggles with processing strong emotions. During our time together she was able to identify her

emotions, experience them somatically and positively integrate them into a sense of 'healing'.

What can design learn from this?

- SB actively participated in her diagnosis and wishes to help others
- SB underplays her emotions due to having them invalidated from a young age
- SB used "positive affirmations" to transform her emotions
- Digital can learn from her positive diagnostic experience, being talked through the process, being listened to and her experiences believed

### Workshop #1 Somatic Inquiry

# F.B.2 IPA: **UNIQUE PERSPECTIVE** Words and Descriptions Used

- "I do not have the expectation of mindfulness that probably **neurotypical people** would have"
- "I am in the centre while everything else is happening around me."
- "in my brain at any given time, about 50 lanes of traffic"
- "I underplay the situation because for years I have been doubted and ridiculed"
- "it's all in your head, you're just a bit dramatic"
- "the shame and the kind of rejection sensitivity I'm pretty sure most of us have was unparalleled at times"
- "I gotta describe this sense of clicking everything into place"
- "I found this woman on Tik Tok in Bristol, 32 years old talking about ADHD and I was like, fucking hell. This is me."
- "What a relief that my lived experience is valid. It's is there it's real. It's my reality."
- "I had a positive diagnostic experience primarily because when I want to advocate for myself, I do not take prisoners I would not, I would not just let go."
- "I am hearing all these **horror stories** of people being **horribly invalidated** and other media are on to us and try to **attack** us our very existence, it pisses me off to no fucking end"
- "I will continue to move my body will do this, and my mind will have all these things. How can I do that in this reality, in this reality, because **this is my reality. and I own it**."
- "I am disappointed at the lack of support there is for people."
- "I allow myself to be the way I am just as a kind of a wee affirmation type thing."

F.B.5 RAW: TRANSCRIPT 7-minute sharing

THEMATIC SUMMARY:

Gratitude For Everyone In The Group Sharing

Acceptance Of Current Emotions

**Neurodivergent Mindful Expectations** 

**Underplays Situations** 

Suicide. Self-harm, spirals of Self-loathing

Tik Tok, Recognising ADHD

Diagnosis Poetic Metaphor

Positive Diagnosis

Theme: Gratitude For Everyone In The Group Sharing

First of all, can I just say from the bottom of my heart, thanks, everybody for sharing these

things.

**Theme:** Acceptance Of Current Emotions

And I'll keep crying. If you don't mind. I started crying, (laughs) I might as well continue.

**Theme:** Neurodivergent Mindful Expectations

And so mindfulness for me, I do not have the expectation of mindfulness that

probably neurotypical people would have. And the way I visualise it every time

because I'm I'm trying mindfulness in the way that I know, I get to a core of myself. And

the way I visualise it, is that I am in the centre while everything else is happening

around me. That's how I visualise it because as, as most people mentioned, I have in

my brain at any given time, about 50 lanes of traffic, making different noises and

stuff. And like always remember to do this ... lah lah lah lah. So for me, it's not about

trying to silence any of this. It's just finding a centre in

that and just let the floor will be. And I think the biggest change for me has been trying to

shape mindfulness into what a neurotypical mind would be able to do. And that

visualisation always really helps.

Theme: Underplays Situations

One of the second things I wanted to say is, as I was filling in the exercise at the back of

the mindfulness exercise, I wrote down I always underplay the situation. And I underplay

for the situation because for years I have been doubted and ridiculed. And all it's all in your

head, you're just a bit dramatic.

Theme: Suicide. Self-harm, spirals of Self-loathing

You're just this that on the other thing, and I am going to talk s, pre-diagnosis for me

suicidal ideation, self-harm, and feelings of failure, the shame and the kind of rejection

sensitivity I'm pretty sure most of us have was unparalleled at times and the kind of the

spiral the IN spoke about was always there. (emotional)

Theme: Tik Tok

And okay, I gotta describe this sense of clicking everything into place when I found this

woman on Tik Tok in Bristol, 32 years old talking about ADHD and I was like, fucking hell.

This is me. And when we were doing the exercise when the,

**Theme:** Diagnosis Poetic Metaphor

the idea of diagnosis, I just immediately saw fireworks in my mind, fireworks

popping in every which directions in multitude of colours because? Because, for

me, the diagnosis was, and what words accompanied. I'm not crazy. It all makes

sense. And, like, what a relief. What a relief that my lived experience is valid. It's is there

it's real. It's my reality.

Theme: Positive Diagnosis

And and then I had a positive diagnostic experience primarily because when I want to

advocate for myself, I do not take prisoners I would not, I would not just let go. I spoke to

my GP and I was like, Really listen, these are this symptoms, I have three pages left of

symptoms. I've also got autistic traits, you can three pages of symptoms. And so these

are the symptoms, you need to refer me to psychiatry likes that. And nobody says that,

but didn't say that. But like, I was like, You need to refer me psychiatrist. And I was

diagnosed two years ago.

Theme: Diagnosis Timeframe, 12 weeks acknowledges unique

And for me, the diagnostic experience has been, because end to end from referral to

diagnosis, I, it was 12 weeks, so people have had to wait years. And the things that I've

put injustice in inside the hearts in my paper, because I am hearing all these horror stories

of people being horribly invalidated and other media are on to us and try to attack us our

very existence, I pisses me off to no fucking end.

Theme: Post Diagnosis, Accepting Reality

And post diagnosis for me is how do I adjust what my expectation of my life is to versus to

make it manageable into my reality. And things that have changed radically is an or just to,

to, to, to add to it that I have been in therapy for years is is the fact that I will feed it, I will

continue to move my body will do this, and my mind will have all these things. How can I

do that in this reality, in this reality, because this is my reality. And I own it. And I'm just

Yeah.

**Theme:** Gratitude to the group

So so first of all, it's such a privilege to meet all of you because I feel I feel like wow. So

thank you, everybody. From the bottom of my heart. This has been this has been fantastic.

So yeah, but one of the things I put on the post it note is post diagnosis,

**Theme:** Lack of Support For People

I am disappointed at the lack of support there is for people. And I, I had felt

unsupported anyway, but I've put in acceptance and in a bracket that I allow myself to

be the way I am just as a kind of a wee affirmation type thing. Yeah, so

Workshop #2 Relational Inquiry

F.B.2 IPA: **UNIQUE PERSPECTIVE** Words and Descriptions

Used

F.B.5 RAW: TRANSCRIPT 6-minute sharing

Theme: Affirmation, May You Live With Ease

Yeah, of course. First of all, the strongest kind of affirmation that will that was

that was very powerful in sensation of all of them across all kind of positive,

neutral and negative aspects is, may you live with ease. And I think it's kind of

it's kind of what SH said about, you know, people with ADHD not living with

ease necessarily. Just the caveat for me to say that, you know,

Theme: Not Medicated ATM

I am not medicated at the moment I, I have not medication has had is is really

impactful for me. And at the same token, it's, it's challenging, obviously, to try

and live with ADHD without getting some medication support. In terms of my

positive,

Theme: Positive, Seen And Heard By Psychiatrist

I had a really positive experience with my diagnosis, my psychiatrist was very

helpful. And I felt seen and heard, and was explained kind of the process in

detail. And it was timely. And in terms of friends and family, I spoke to a lot of

people, but I was kind of on my own with navigating diagnosis.

Theme: Neutral, Friends With A Curious Mind Rather Than Dismissive

Having said that, I feel like some people some of my friends kind of took what I said with more more of a curious kind of mind versus others, who kind of dismissed it a bit. And that was kind of the **neutral** aspect of me, some people did not seek to to ask more questions or do not seek to understand better.

Theme: Negative, Comment By Senior Leader "We are All A Bit ADHD"

And in terms of kind of **negative**, I had an interaction at my work, and I it was not necessarily the person I think maybe more the attitude of that person where we had this and it was kind of a senior leader as well within my organisation. That was a bit Oh, **we all are a bit ADHD** and I was like Excuse you me No, no, we're not. Which kind of pointed me in the direction of advocating and in terms of general societal

Theme: Mindful Exercise, As Healing And Connection

sensations of my the mindfulness exercise, I did feel a very strong kind of healing sensation, a strong like connectedness and I felt intense kind of gratitude I've written down here I feel a lot of love surrounding me I feel the power within me growing. I feel like I'm bringing love to other people's life I am valid I feel connected.

**Theme:** Meeting everyone Where They Are, As Equanimity

And kind of and one of the things that I've really highlighted **meeting everyone**where they are which is my interpretation of maybe equanimity and, and I

think what I am feeling very grateful of is connecting my

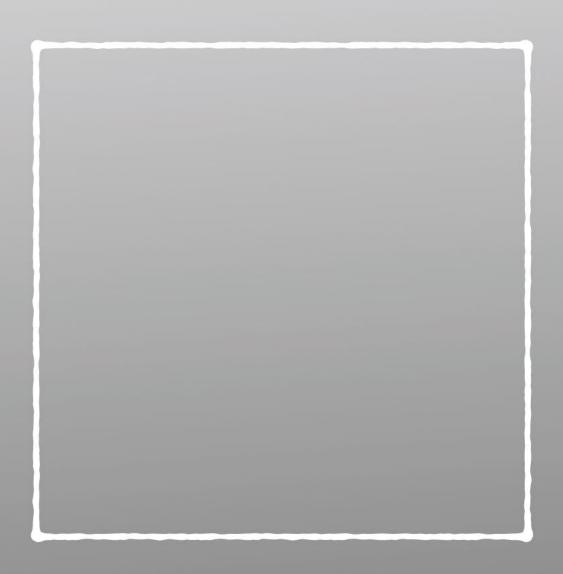
Theme: Authenticity, Acceptance, Managing Expectations

connecting with people by myself **being authentic being genuine** being but one of one of the things I did note down is this is for me, this is much more beyond the diagnosis is much more ah, and acceptance into an acceptance of,

of an acceptance on and maybe managing my expectations. I don't know how to describe it like this very solid feeling of this is it. And I, I embrace it, embrace it, so so to speak.

Theme: Workplace Support

Yeah. And I want you to, to highlight as well that I have written one in terms of positives that I have in terms of my immediate colleagues and management of work, that I have had incredible support and safety. And I'm so, so grateful, because I wouldn't be able to continue with work overall, and in that specific environment, where it's whereby it's a bit away from my kind of values as a as a person without having that level of really good support. So yeah, so that's, that's kind of, I've made a lot of notes. But if I felt really, and just one things, one thing I've jotted down, kind of in the middle of everything is diagnosis, compassion, compassion for us. Compassion for our lived experience. Yeah, so that's me.



# Appendix: $\mathbb{E}$

**UX Artefacts** 

# Appendix E E 1.0 Fieldwork

## E1.1 Fieldwork Somatic Workshop

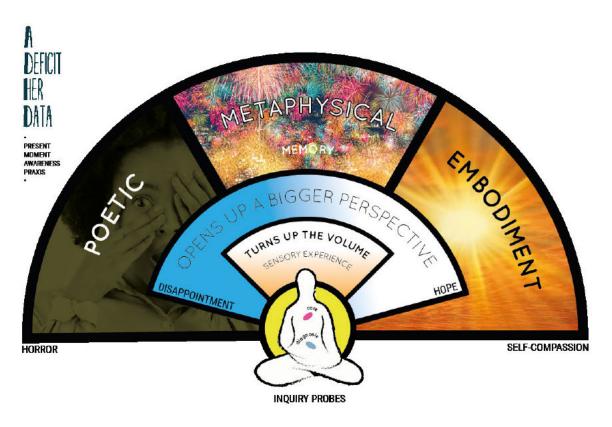


IMAGE 30 - WORKSHOP #1 PHENOMENOLOGICAL EXPERIENCE OF PRAXES, SOURCE: AUTHOR

#### **Key Themes from Somatic Inquiry**

This illustration was used to synthesise the key findings onto a spectrum of responses -

- O Sensory turning up the volume
- O Widening of emotional awareness
- Poetic visual metaphors to describe somatic sensations, frozen in horror, sunshine and ease, an explosion of fireworks

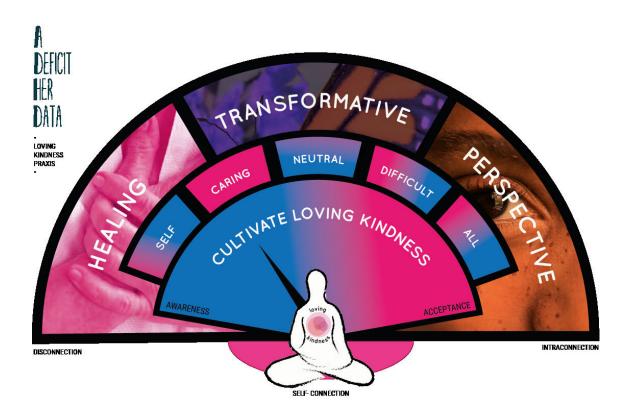


IMAGE 31 - WORKSHOP #2 PHENOMENOLOGICAL EXPERIENCE OF PRAXES, SOURCE: AUTHOR

## E1.2 Fieldwork Relational Workshop

#### Key Themes from Relational Inquiry

This illustration was used to synthesise the key findings onto a spectrum of responses -

- O An increase in positivity promoted cognitive relabelling e.g. neutral to caring
- Somatic sense of 'releasing' and 'healing'
- O Insights into own behaviour and actions self-understanding

## E1.3 Development of **Healthcare Vignettes**

Each participant's pseudonym is shown, next to their age and occupation. It was important for me to show an occupation, to give participants a real-world context. To highlight that we may be encountering people with ADHD daily. Nurses, Psychiatrists, or Teachers etc, and we may never know the extent of their struggles due to their capacity to 'mask' and use coping strategies to perform their daily activities.

Catalyst for diagnosis, female concern, and process

- somatic inquiry quotes
- relational inquiry quotes
- peak experience emotions
- What we can learn from each participant's experience
- How digital can support women like them



#### **EVENTS PLANNER, WHITE GRASS**

PRIVATE DIAGNOSIS: NEGATIVE Experience



"I knew I had a small window before menopause was going to be blamed for everything"

"the Psychiatrist report contained **innaccuracies** ... they even spelled my name wrong"



#### SOMATIC INQUIRY

where am I 'holding' diagnosis?

"tension in my neck and shoulders it was uncomfortable to think about"

"it was helpful to zoom out and see it as a process"

"I struggled to give myself a sense of care"



#### WHAT DOES A SENSE OF KINDESS BRING?

"I feel gratitude for the kindness of my best friend ... and my Dad who was a non-believer"

"During the practice I saw the psychiatrist as a woman going about her business ... robust in her process of what was a difficult diagnosis ... I'm still angry though"

"I feel emotional just thinking about it .... the community of people from all over the world going through the same thing as me ... the outpouring of kindness and tangible help"



IMAGE 32 - WHITE GRASS VIGNETTE SOURCE: AUTHOR

## E 2.0 Scoping Phase

## E2.1 Scoping DAWNING TO DIAGNOSIS model

Thematic Analysis of Conversations:

#### STAGES OF THE DIAGNOSTIC JOURNEY:

- aggregate themes from participant & clinician perspectives (looking for patterns,

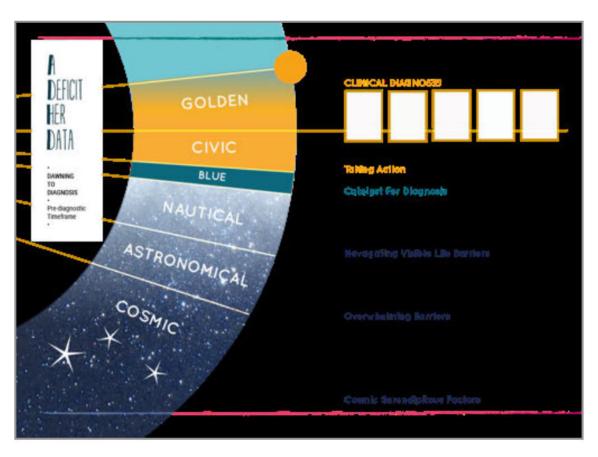


IMAGE 33 - DAWNING TO DIAGNOSIS, SOURCE: AUTHOR

In attempting to analyse the Anatomy of diagnostic experience, I first looked at the timescales involved. From first recognising the symptoms, making a request for diagnosis, investigation, assessment process, and receiving the diagnostic result. During the contextual immersion phase, I observed the frustration of Facebook group members, as Scottish regions followed different protocols, and individual assessors appeared to not adhere to the recommended framework. Whilst the patient's experience seemed to follow a more prescriptive path.

To aid sense-making, I mapped their experience onto a poetic visual metaphor of the stages of the rising sun - Dawning to Diagnosis.

Day - full sun

Golden Hour - coloured by imminence daylight and clarity

Civic twilight - has enough light to take action

Blue Hour - coloured by doubt

Nautical Twilight - has enough light to see the horizon, pathway ahead

**Astronomical Twilight** - has enough light see the constellation of symptoms

**Dark Night** - no light

#### Golden Hour

Self-diagnosis, self-compassion and self-understanding. Propelled into this space by understanding that you have ADHD. Although the steps towards getting a diagnosis may drop you farther back down the process.

#### The Blue Phase into Civic Twilight - action/procrastination

In this phase, there is typically a catalyst something that sparks motivation to take action. This can be future-focused, as concern mounts about maintaining a career, or the potential impact of menopause that may serve to worsen symptoms. Diagnostic inquiry and action is taken at this time.

#### Nautical Twilight - reflection / rumination

You have the first sight of a horizon, and perhaps a strong sense of seeking new understanding to move ahead. This may be cognitively trying to find medical explanation or a reflective process of reframing your life experience with a sense of regret.

#### Astronomical Twilight - overwhelm / shut down

This phase occurs by chance rather than by design, a small amount of light has been shed on the apparent source of issues. Maybe it's ADHD, a faint outline, some doubts as it perhaps doesn't seem to explain the overwhelming enormity of the previous phase.

#### **Dark Night**

The dark phase, sees women stuck in behavioural patterns that they, their families and society can't understand. In this phase, women may be experiencing addiction, alcoholism, hospitalisation, nervous breakdown, eating disorders, self-harming and suicidal ideation.

	Serendipity	Response:	Catalyst
WHITE GRASS	ACTION: Healthcare research  Neurologist had diagnosed intermittent MS, patient had persistent symptoms so it didn't seem a good fit.  NEED: a better reason for poor memory.	ACTION:  Cognitive: "Deep dive into medical research"  ACTION: Joined online communities  FEELS: Found my tribe  10 years	FUTURE FOCUS:  "I had to turn down a top job"  Prospect of menopause making things worse.
SNOW HARP	ACTION: Healthcare education, interested in the human brain. Takes psychology course age 19.  Neonatal nurse, working with preterm babies.  Working with ADHD children in care.	ACTION:  Did a lot of reading around the subject, saw similarities in others stories  ACTION: online communities  FEELS: not always a supportive space	Received money 'treated herself'  SELF UNDERSTANDING:  "After my nervous breakdown, I wanted to know why I was so impulsive"
SPARROW TWIST	ACTION: Joins Online Work Support Group  Finds recommendations for supporting ND Women in Academia  NEED:	ACTION: Research  Took an online course on ADHD to learn how it directly impacts women.  Months	SELF Understanding after nervous breakdown.

PAVILLION CORAL	ACTION: Follows Social Media Fashion Influencer  "I am embarrassed to say"  NEED: Style tips, likes to imagine she may be that elegant one day.	ACTION: Research lock-down, not working provided the time necessary to thoroughly investigate. Months	PAST: ruminating on personal history SELF Understanding, wanting to know why
CLOUD MUSIC	ACTION: Son is diagnosed and suggests that she has it.  "My son was diagnosed with ADHD, they were very much family traits. It became clear mainly to him that I had ADHD."	ACTION: Research on and Off Feels: emotionally processing, reframing 'eccentric family traits as ADHD"  18 months	Self Understanding  Son is encouraging her. "What difference will it make at my age?"
ACORN RAIN	ACTION: Takes on an ADHD flatmate, who identifies her as ADHD.  Complex mental health picture, hospitalisation.	ACTION: Research to a high degree of expertise. Feels: unsure, personal circumstances so difficult it doesn't seem like a fit.	About to leave her profession  Wanted to find answers to extreme mental health instabilities, difficult health history and responses to medication.

## E2.3 Scoping Persona Development

Personas were developed for the participant group to move onto the workshop stage of mindful innovation. After scoping activities, I decided to return to the participant's perceptions of the diagnosis to further investigate the impacts of mindfulness as part of the design research inquiry. The patient's experiences as retold in the scoping conversations had not been significantly impacted by mindfulness.



IMAGE 34 - SCOPING PERSONA, SOURCE: AUTHOR