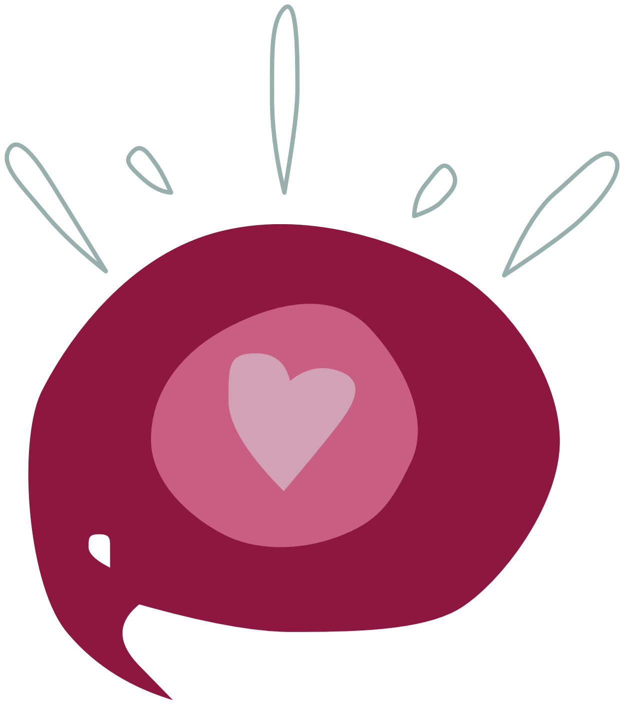


See *me*, Hear *me*, K*now me*

DIGITAL DESIGN FOR HEALTH STORYTELLING

Marissa Cummings
Masters of Research (MRes)
The Innovation School
The Glasgow School of Art

APPENDIX

Contents

List of Figures

1 *Tools*

1.1 Project Information Sheet

The project information sheet was made available to potential participants online (https://futurehealthandwellbeing.org/see-me-hear-me-know-me) during the recruitment process. After joining the project, they were also sent a paper copy of the project information in the mail.

Over the following three pages:

Figure 1: Project information sheet. Images. Source: author's own.

see me
hear me
know me

See me, hear me, know me:

Digital interfaces for health storytelling

My name is Marissa Cummings, and I am a Master of Research student at The Glasgow School of Art. Thank you for considering taking part in my project!

This information sheet will explain more about what this involves, so that you can decide whether to participate.

Please feel free to discuss this with others if you wish, and if you need any further information, please ask.

What is this project about?

People living with long-term conditions are asked to constantly share information about their health conditions in order to access support, a process which can be complex and emotionally challenging. These stories are vital to help professionals better understand the person's challenges and goals, and yet they are not currently part of our health records. My project looks at how a piece of software could be designed for recording and sharing health stories. I've asked patients living with more than one health condition to take part, to understand how these more complex health stories can be recorded.

How is this project being funded?

My Master of Research training is funded by the Digital Health & Care Institute (DHI), which is a Scottish Funding Council initiative between the Glasgow School of Art, The University of Strathclyde, and NHS 24. The DHI aims to bring together health, care and third sector professionals, academics, industry partners, and citizens to work together to develop innovative ideas to overcome health and social care challenges.

see me
hear me
know me

What does the project involve?

If you decide to participate, we will do three 1-to-1 sessions together remotely online. Each session will last from 1 to 1.5 hours.

1. In the first session, I will ask you to tell me about your health story. The amount of detail you choose to provide is up to you – you will never be asked to share information that you don't want to.
2. In the second session, we will create a visual representation of your health story using digital tools I will prepare in advance. After this session, I will use the ideas that we created together to design a prototype for a new digital tool to support people to make and share their health story.
3. In the third session, we will look at the prototype together. You will have the opportunity to try out the prototype and tell me your thoughts.

Anything that we design during our sessions together will be kept by myself for the purposes of my research. However, if you would like a digital copy of the output for your own use, I would be happy to provide one.

What tools will be used?

Our online sessions will be carried out using the video conferencing software Zoom (https://zoom.us/), using a secure Pro account. Video recordings of each session will be recorded and stored securely by myself.

For our collaborative work, we will be using an online tool called Miro (https://miro.com/). This tool creates an virtual whiteboard where we can both work together. The board will be kept secure and only shared with the two of us for the course of the work. After we have finished work I will further restrict sharing to only myself, to make sure your information is kept safe.

Do I have to take part?

No. Taking part is your decision and it is entirely voluntary. You can also withdraw at any time, without giving a reason. If you would like to be involved, you will be asked to give verbal consent confirming that you understand what is going to happen and are happy to participate.

Will my taking part be kept confidential?

Yes, your participation will be kept entirely confidential.

What will not happen:

- No identifiable images of you will be used in the research output (e.g. my thesis paper).
- Your name and personal details will not be disclosed. You will have the opportunity to select a pseudonym (fake name) by which you will be identified.

What will happen:

- Images of the health story we create will be used in the research output. These will be edited to obscure any personal or identifying details. You will have the opportunity to review these and indicate anything you wish to keep confidential.
- If you agree, a video recording will be made of our sessions. You may also choose to have only audio recorded of you, with no video. The recording will only be used by myself and my supervisors, and will not be made public. If still images are used from this recording, I will blur any faces and personal details to ensure they remain anonymous.
- Selected quotations from the transcript of our sessions may be used anonymously in the research ouput.

Any items which contain personal information (such as your consent form) will be kept securely on The Glasgow School of Art Campus.

What will happen to the results?

Any information collected during the research will be anonymised and identified using a pseudonym (fake name). This will be altered to remove and/or obscure any personal or identifying data.

If you change your mind about anything you have shared, you can ask me to omit that from the final output. You will also have an opportunity to review the final output and give consent before it goes into the published version.

Your anonymised information will be used in publications (e.g. my thesis). It may also be used in an anonymised form on The Glasgow School of Art or DHI's websites, conference papers, journal articles, lectures, and broadcasts as part of future research and teaching.

What will happen to my information?

Your personal information (such as your name and contact details) will be kept securely on The Glasgow School of Art campus, and will be destroyed 3 months after the completion of the project.

Any data produced during the project (such as recordings of you) will also be securely kept as part of the research data. Following The Glasgow School of Art's research guidelines, it will be kept for up to 1 year after the completion of my course.

What if I want to withdraw?

You can choose to withdraw from the project at any time, simply by notifying me that you wish to do so. If you decide to withdraw, any information regarding yourself and your participation will be securely destroyed, and your research data will not be used in any output.

see me
hear me
know me

Contact

For more information about this project, please contact:

Marissa Cummings
M.Cummings1@student.gsa.ac.uk

What if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact GSA using the details below for further advice and information:

Dr. Jay Bradley
j.bradley@gsa.ac.uk

The Innovation School
The Glasgow School of Art Blairs Farm Steading
Altyre Estate Forres, IV36 2SH

Thank you!

Thank you for reading this information sheet and for considering taking part in my research. Please keep this sheet for future reference

INNOVATION
SCHOOL
THE GLASGOW
SCHOOL OF ART

DIGITAL
HEALTH & CARE
INSTITUTE

1.2 Participant Consent Form

The consent form was originally developed for use in-person. After the start of COVID-19 lockdown, I used the form to obtain oral consent which I recorded during our first workshop. Participants were also sent a paper copy of the form in advance for their reference.

On the following page:

Figure 2: Participant consent form. Images. Source: author's own.

Participant Consent Form

Research Project Title: See Me, Hear Me, Know Me: Digital interfaces for health storytelling
Lead Researcher: Marissa Cummings (M.Cummings1@student.gsa.ac.uk)

Stage 1 Consent
Please read each question carefully, circle yes or no and write your initials in the final column.

	Circle	Initial
I am 18 years or over.	*Yes No*	
I have read and understood the project information sheet and have had the opportunity to ask questions.	*Yes No*	
I agree to be a participant for the purposes of the above research project.	*Yes No*	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. Any information I have given will be used with my permission or may be withdrawn from the research.	*Yes No*	
I agree to being audio recorded during the remote workshops. I understand that these recordings will only be used for purposes of the research and will not be shared or made public.	*Yes No*	
I agree to the screen being video recorded during the remote workshops. I understand that these recordings will only be used for purposes of the research and will not be shared or made public.	*Yes No*	
I understand that I can turn off my video camera if I do not wish my face to be recorded in the video.	*Yes No*	
I understand that any research data made publicly available in the final output, such as quotes or still images from the recording, will be altered to obscure any identifiable details about myself, and that I will be identified using a pseudonym.	*Yes No*	
Do you wish to add any other instructions or restrictions in relation to your contribution? (Please specify in the section below.)	*Yes No*	

If **yes,** please give details:

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Stage 2 Consent (to be completed after the second workshop)
Please read each question carefully, circle yes or no and write your initials in the final column.

	Circle	Initial
I have reviewed my health story visual from our workshop, and have removed anything that may publicly identify me.	*Yes No*	
I give permission for images of this visual to be made publicly available on the project website (futurehealthandwellbeing.org) and in publications, presentations, reports or examinable format (dissertation or thesis) for the purposes of research and teaching.	*Yes No*	

Complaints about the conduct of this research should be raised with: Dr Jay Bradley (j.bradley@gsa.ac.uk)

Signed:		**Date:**	
Name (block caps)			
Address			
Telephone number			
Email			
Researcher signed:		**Date:**	

Complaints about the conduct of this research should be raised with: Dr Jay Bradley (j.bradley@gsa.ac.uk)

1.3 Workshop 1 Interview Questions

For the first workshop, I developed a series of questions based on the health storytelling prompts developed by Marini (2019).

About you

Tell me a bit about yourself.

- What pseudonym would you like to use?
- How old are you?
- Tell me about what conditions you are currently managing.
- What object did you decide to bring to the session? How does it represent your health story to you?

Before the illness

What was your life like before your current health conditions started?

Then something happened to me

Can you tell me a bit about when you first found out that you might have *condition(s)*?

- Do you remember the first sign that you might have condition(s)?
- How were you feeling physically and emotionally?
- What was your life like at the time that you were diagnosed?

After that, things/some things were not like before

What happened after you were diagnosed?

- Who did you talk to about your diagnosis? (both healthcare professionals and family/friends)
- How did people react to your diagnosis?
- How did that make you feel?

Now

What is your health like currently?

- How are you managing your condition(s)?

- Have (or haven't) people around you helped you with your condition(s)?
- How has your life changed since you were first diagnosed?

Tomorrow

When you think about the future, where do you see yourself?

My story

How did it feel to tell me your health story?

1.4 Research Journal Prompts

I used the following prompts, adapted from the field notes template used for Warner et al. (2012), to record entries in a research journal following each workshop.

What do you see?

- Where is this person located? (Also, as the participants have selected the location, why might they have selected it?)
- Note initial impressions on their appearance, attitudes, and behaviour during the interview.

What happened?

- What were the particular moments of note?
- What (if any) events occurred outside of the engagement format, e.g. interruptions, technical problems?
- Note any emerging analytic insights.

Reflecting on myself

- How do I feel about this person?
- What emotions/reactions did I have?
- How do I think this person feels about me/the research? How may I have influenced them?
- Is there anything I think I did badly that I want to improve on?

Reflecting on the research

- Was there anything about the structure of the engagement that worked well or didn't work? Is there anything I could improve for next time?
- Is there anything I want to follow up on in my next session with them?

1.5 Workshop 1 Analysis Prompts

To analyse the health stories from Workshop 1, I developed a series of prompts for myself using the narrative elements identified by Rita Charon (2006).

Frame

Describe the storyteller’s surroundings.

Form

- Identify the genre of the story using categories from Hunsaker Hawkins (1999) and Frank (2013) (shown in Figure 3).
- What metaphors does the storyteller use?
- Does the storyteller allude to any other events or topics?
- What is the storyteller’s presentation throughout (speaking style, emotional affect, facial expressions)?

Time

- What order is the story told in?
- What time period does it cover?
- What is its pacing?

Plot

Identify and describe the main categories (themes) in the story’s plot – link to relevant overarching categories, if any.

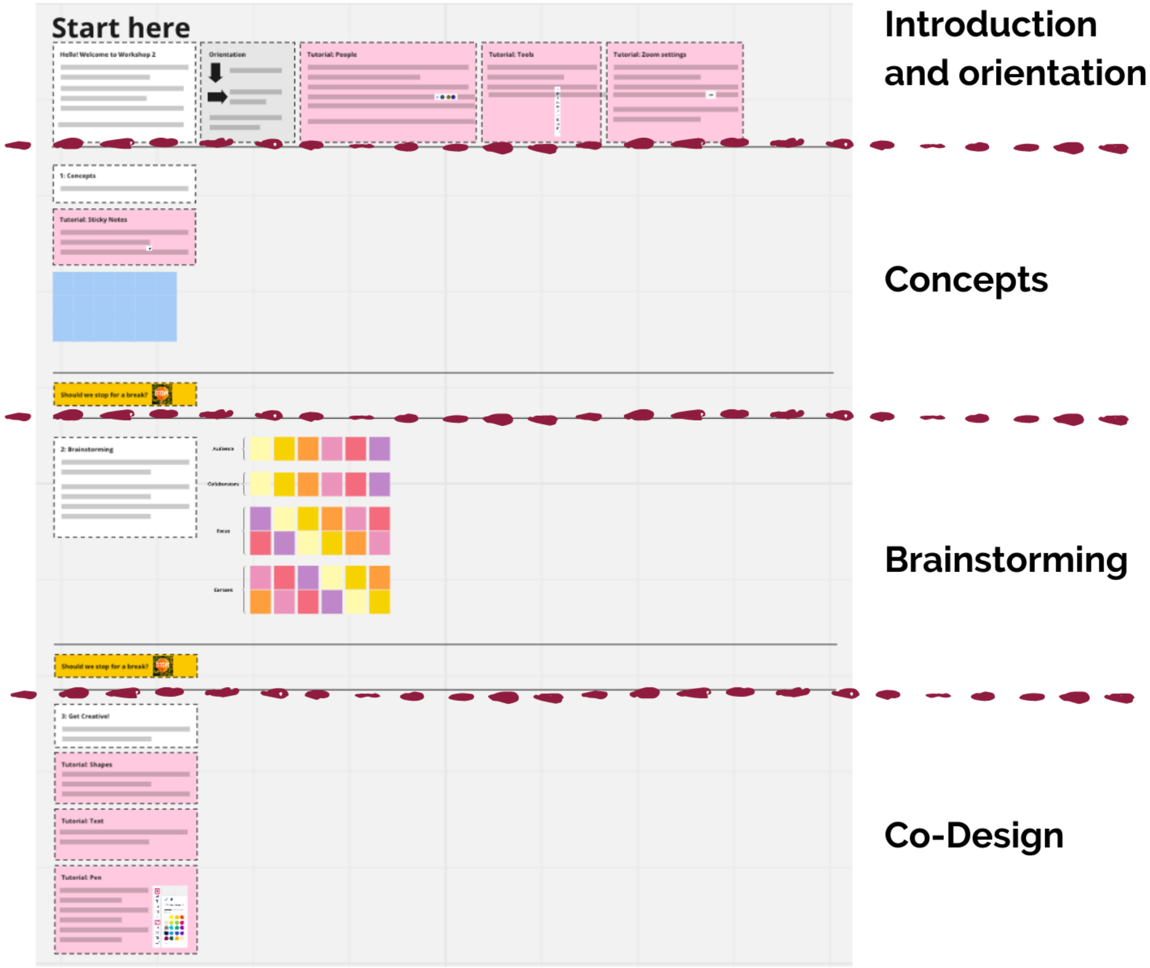
Desire

What do I feel that the storyteller wants me to understand by telling me this story? Why do I think they participated in this project?

Hunsaker Hawkins (1999)	**Healthy-minded** Espouses a form of treatment	**Battle** Illness as a battle **Journey** Illness as a journey, usually framed in mythic tones **Rebirth** Person is transformed by the illness	
Frank (2013)	**Restitution** Ends in triumphant cure	**Quest** "Illness is the occasion of a journey that becomes a quest" (p. 113)	**Life-as-normal** Person prefers to ignore their illness and live as normal **Chaos** Person is overwhelmed by disjointed nature of the illness, the "anti-narrative" (p.98)

Figure 3: Narrative genres from Hunsaker Hawkins (1999) and Frank (2013). Diagram. Source: author's own.

1.6 Workshop 2 Miro Board



Introduction and orientation

Concepts

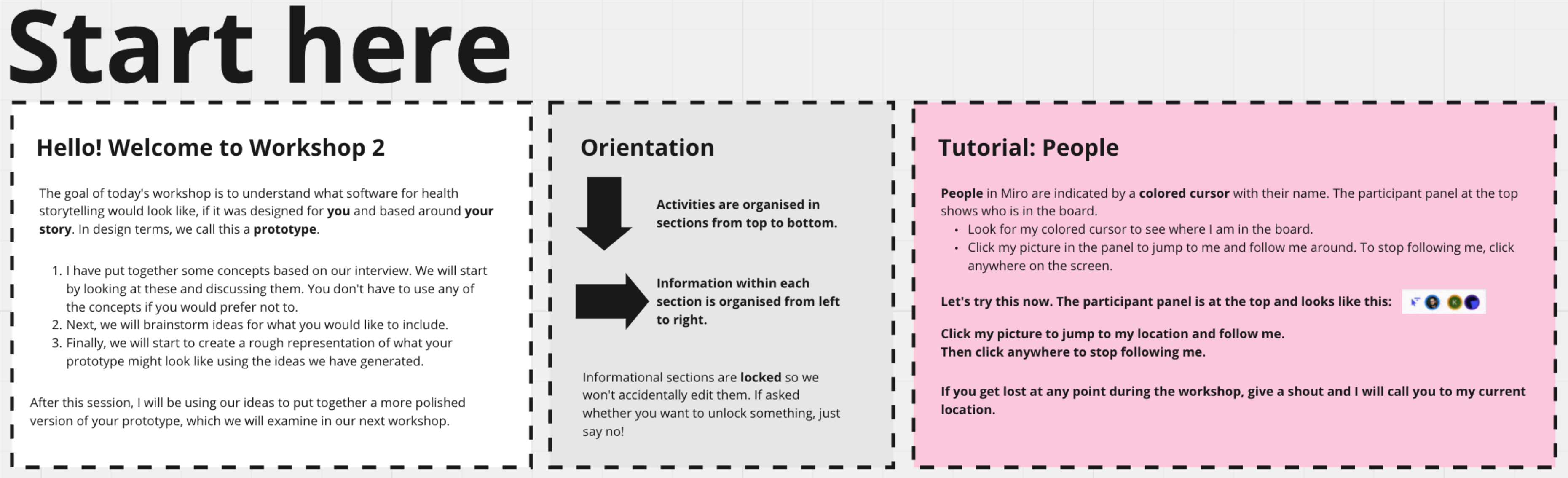
Brainstorming

Co-Design

Figure 4: Screenshot of Miro layout for Workshop 2. Image. Source: author's own.

1.6.1 Introduction and Orientation

Upon entering the session in Miro (https://miro.com/), I first greeted the participant and walked through a quick series of exercises to orient them to the tool and allow them to practice using the controls (Figures 5 and 6).



Start here

Hello! Welcome to Workshop 2

The goal of today's workshop is to understand what software for health storytelling would look like, if it was designed for **you** and based around **your story**. In design terms, we call this a **prototype**.

1. I have put together some concepts based on our interview. We will start by looking at these and discussing them. You don't have to use any of the concepts if you would prefer not to.
2. Next, we will brainstorm ideas for what you would like to include.
3. Finally, we will start to create a rough representation of what your prototype might look like using the ideas we have generated.

After this session, I will be using our ideas to put together a more polished version of your prototype, which we will examine in our next workshop.

Orientation

Activities are organised in sections from top to bottom.

Information within each section is organised from left to right.

Informational sections are **locked** so we won't accidentally edit them. If asked whether you want to unlock something, just say no!

Tutorial: People

People in Miro are indicated by a **colored cursor** with their name. The participant panel at the top shows who is in the board.

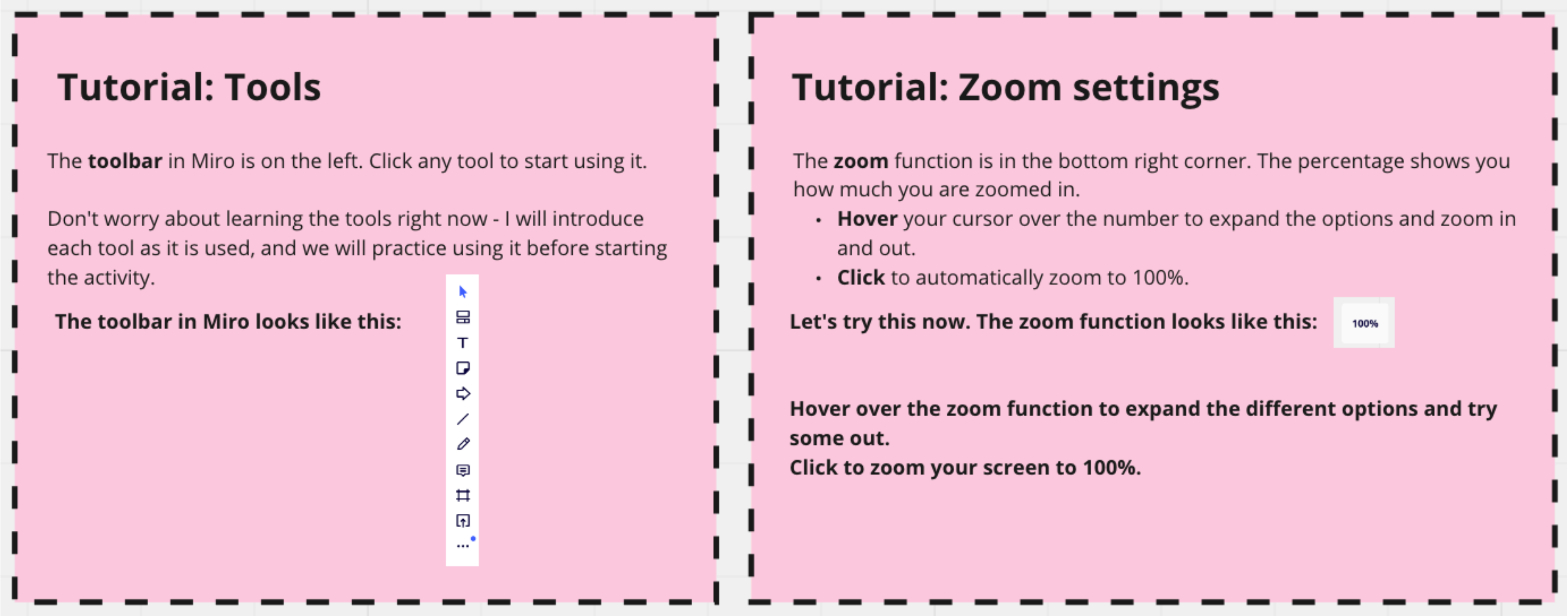
- Look for my colored cursor to see where I am in the board.
- Click my picture in the panel to jump to me and follow me around. To stop following me, click anywhere on the screen.

Let's try this now. The participant panel is at the top and looks like this:

Click my picture to jump to my location and follow me.
Then click anywhere to stop following me.

If you get lost at any point during the workshop, give a shout and I will call you to my current location.

Figure 5: Screenshot of Miro board, Orientation pt.1. Image. Source: author's own.



Tutorial: Tools

The **toolbar** in Miro is on the left. Click any tool to start using it.

Don't worry about learning the tools right now - I will introduce each tool as it is used, and we will practice using it before starting the activity.

The toolbar in Miro looks like this:

Tutorial: Zoom settings

The **zoom** function is in the bottom right corner. The percentage shows you how much you are zoomed in.

- **Hover** your cursor over the number to expand the options and zoom in and out.
- **Click** to automatically zoom to 100%.

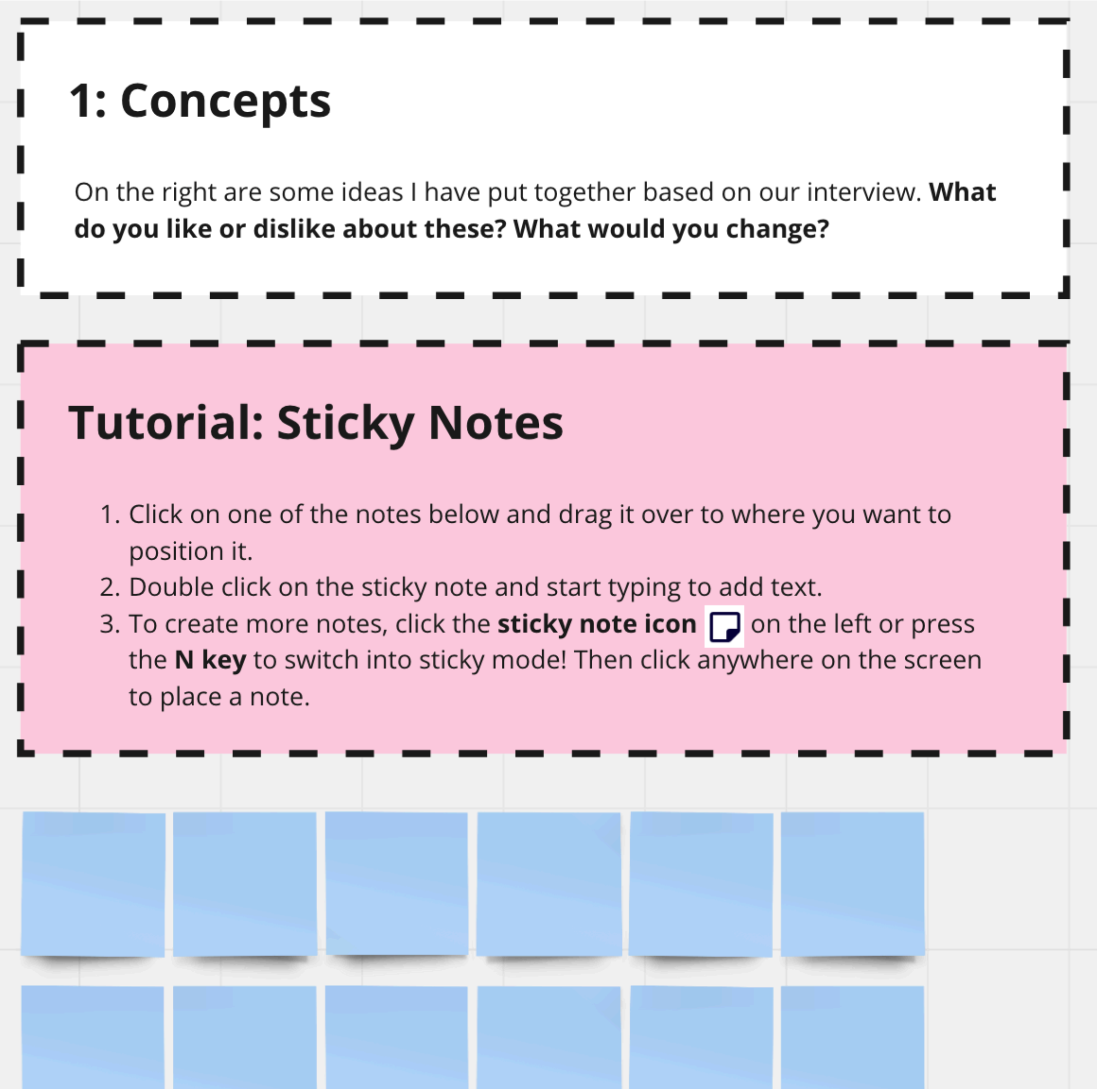
Let's try this now. The zoom function looks like this:

Hover over the zoom function to expand the different options and try some out.
Click to zoom your screen to 100%.

Figure 6: Screenshot of Miro board, Orientation pt.2. Image. Source: author's own.

1.6.2 Concepts

Participants were then shown visual concepts that I had created. I deliberately kept these rough in style, implying a work in progress, so that participants would feel comfortable criticising them (Pernice, 2016). I also included some notes on ideas that I thought the participant might be interested in building off of, as well as images I had used to create the concepts to give additional inspiration. Participants were given a brief tutorial of Miro's sticky note function and invited to use these to comment further on the concepts (Figure 7). Screenshots of the concepts for each participant can be found in Chapter 5 of the thesis.



1: Concepts

On the right are some ideas I have put together based on our interview. **What do you like or dislike about these? What would you change?**

Tutorial: Sticky Notes

1. Click on one of the notes below and drag it over to where you want to position it.
2. Double click on the sticky note and start typing to add text.
3. To create more notes, click the **sticky note icon** on the left or press the **N key** to switch into sticky mode! Then click anywhere on the screen to place a note.

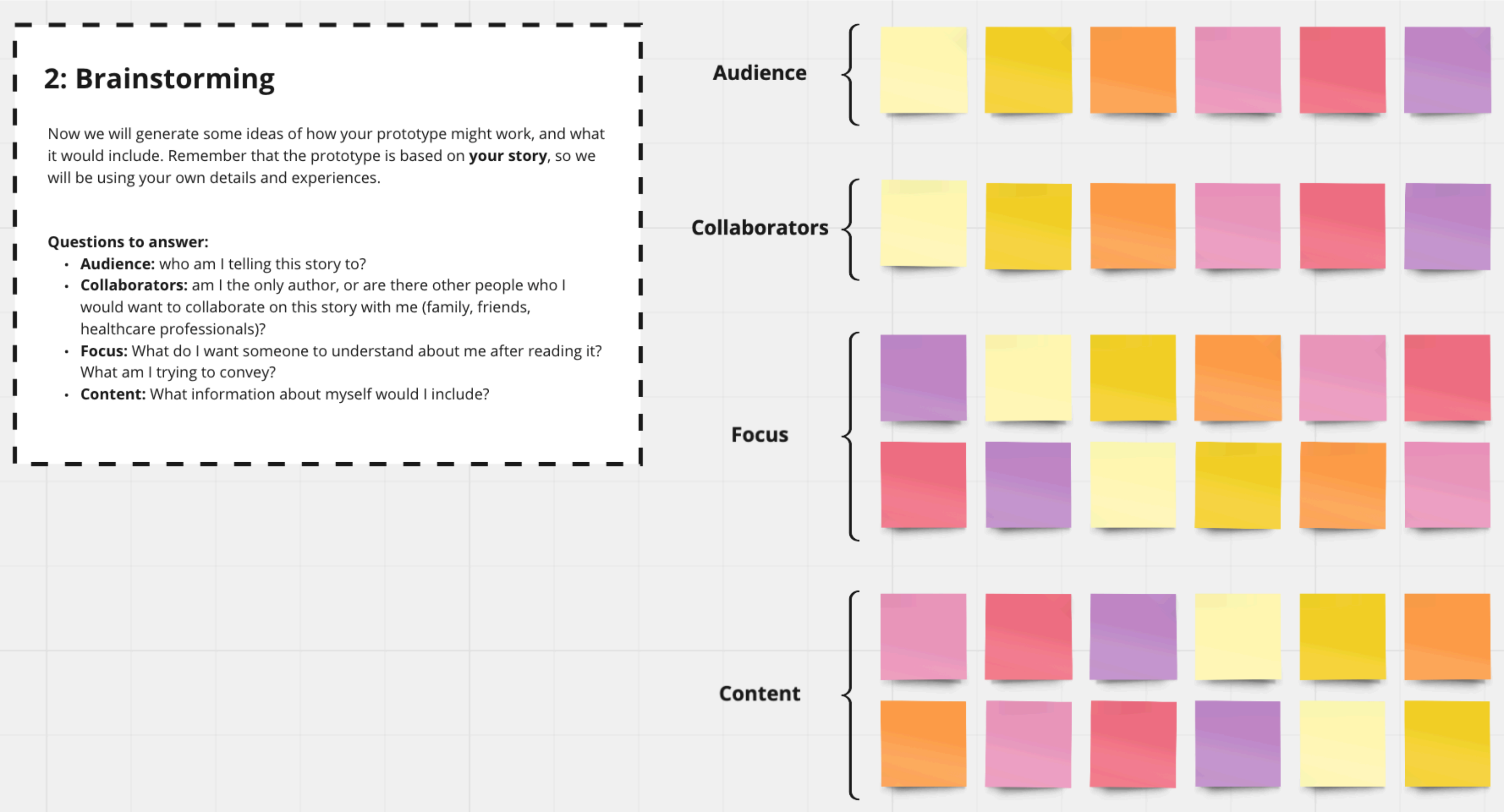
Figure 7: Screenshot of Miro board, Concepts. Image. Source: author's own.

1.6.3 Brainstorming

After discussing the concepts, I invited the participant to do high-level brainstorming about how their prototype might work (Figure 8). I structured the brainstorming into prompts, asking participants to answer the following questions:

- **Audience:** who am I telling this story to?
- **Collaborators:** am I the only author, or are there other people who I would want to collaborate on this story with me (family, friends, healthcare professionals)?
- **Focus:** What do I want someone to understand about me after reading it? What am I trying to convey?
- **Content:** What information about myself would I include?

As we discussed, their answers were noted down onto sticky notes.



2: Brainstorming

Now we will generate some ideas of how your prototype might work, and what it would include. Remember that the prototype is based on **your story**, so we will be using your own details and experiences.

Questions to answer:

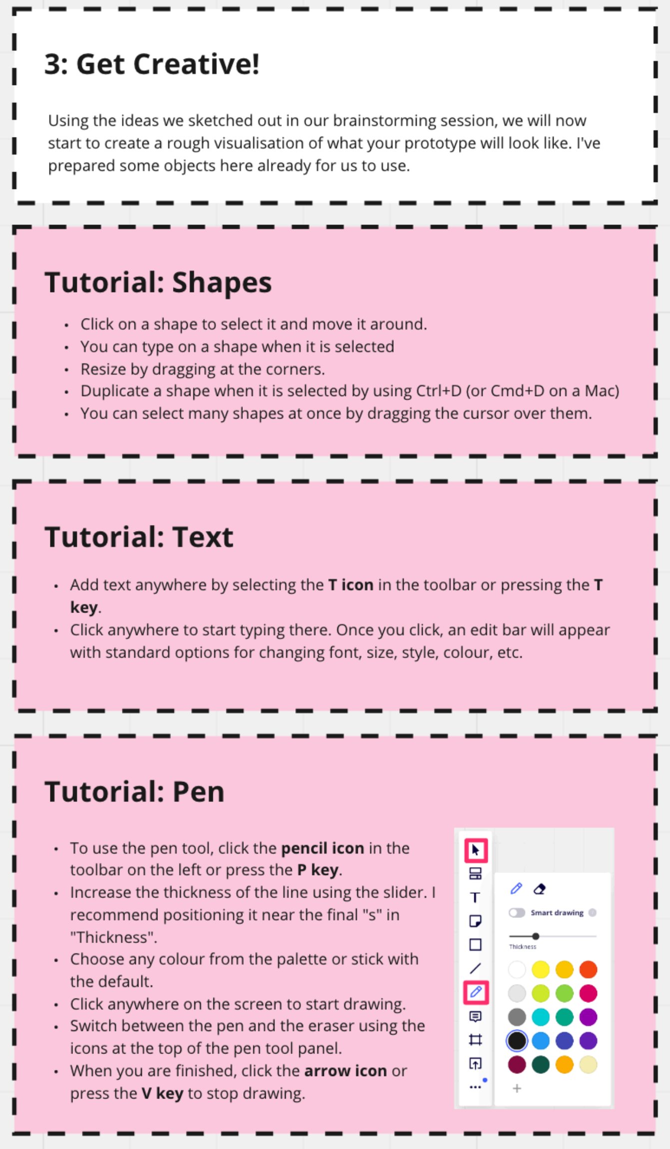
- **Audience:** who am I telling this story to?
- **Collaborators:** am I the only author, or are there other people who I would want to collaborate on this story with me (family, friends, healthcare professionals)?
- **Focus:** What do I want someone to understand about me after reading it? What am I trying to convey?
- **Content:** What information about myself would I include?

Figure 8: Screenshot of Miro board, Brainstorming. Image. Source: author's own.

1.6.4 Co-Design

In the final activity, participants were given a set of components that I had prepared based on the visual concepts. These included images and shapes that I had used to create the concepts, as well as objects from Miro (e.g. sticky notes, arrows). I also introduced them to using the Shapes, Text, and Pen tools in Miro (Figure 9).

Using these combined with the objects that I had already set up, participants were invited to use the tools with me to assemble their own ideas. We referred back to the ideas generated from the brainstorming activity to help guide the co-creation process. Screenshots of the co-design activity for each participant can be found in Chapter 5 of the thesis.



3: Get Creative!

Using the ideas we sketched out in our brainstorming session, we will now start to create a rough visualisation of what your prototype will look like. I've prepared some objects here already for us to use.

Tutorial: Shapes

- Click on a shape to select it and move it around.
- You can type on a shape when it is selected
- Resize by dragging at the corners.
- Duplicate a shape when it is selected by using Ctrl+D (or Cmd+D on a Mac)
- You can select many shapes at once by dragging the cursor over them.

Tutorial: Text

- Add text anywhere by selecting the **T icon** in the toolbar or pressing the **T key**.
- Click anywhere to start typing there. Once you click, an edit bar will appear with standard options for changing font, size, style, colour, etc.

Tutorial: Pen

- To use the pen tool, click the **pencil icon** in the toolbar on the left or press the **P key**.
- Increase the thickness of the line using the slider. I recommend positioning it near the final "s" in "Thickness".
- Choose any colour from the palette or stick with the default.
- Click anywhere on the screen to start drawing.
- Switch between the pen and the eraser using the icons at the top of the pen tool panel.
- When you are finished, click the **arrow icon** or press the **V key** to stop drawing.

Figure 9: Screenshot of Miro board, Co-creation. Image. Source: author's own.

1.7 Workshop 3 Participant Evaluation

In the final workshop with participants, I conducted a semi-structured interview to get additional feedback on their experience.

Tool and Methodology

- Do you feel the final prototype accurately represents your perspective on health storytelling? If not, what should be changed to make it reflect you better?
- Part of the goal of this project was to use your story to create the final prototype. Do you have any thoughts/reflections on this process? How does it feel to see your story expressed in this way?
- If a tool like this existed, would it be useful to you in helping to understand and articulate your health story (both to yourself and others)?

Participant Feedback

- Overall, how would you describe your experience participating in this project?
- Is there anything in particular which you felt did or didn't work, or that you think could be improved for next time (e.g. logistics)?
- Do you have any other comments?

2 *Scoping*

2.1 Introduction

During the scoping phase, I made prototypes based on published, publicly available health stories. I also interviewed a relative with multimorbidity. The goals of the scoping were to: firstly, try out the reflexive analysis process before starting the fieldwork; secondly, develop empathy with the illness experience; and thirdly, begin to immerse myself in health stories.

In this chapter I have shown the two most polished of the scoping prototypes. The first is based on Anatole Broyard's (1992) memoir *Intoxicated by My Illness*. The second is based on the story of Alice Alcott from Arthur Kleinman's (1988) work *The Illness Narratives.*

2.2 Anatole Broyard

Anatole Broyard was an American writer and a literary critic for the *New York Times*. He became well-known in 1954 after publishing an essay describing his father's death of cancer. His book *Intoxicated by My Illness* (1992) is a collection of further essays, describing his own diagnosis and struggles with cancer. Broyard died of prostate cancer in 1990.

Broyard's essays clearly convey his idea of himself as a cultured, literate man. He uses a great deal of metaphor in his writing, seeking different ways to describe his illness experience. Of these, the following quote particularly stuck with me:

> I see the balance of my life - everything comes in images now - as a beautiful paisley shawl thrown over a grand piano.
>
> (1992, p.127).

In my prototype, I used the paisley shawl as a basis for the design. The paisley pattern is formed of organic, concentric shapes, which gave me the idea of stories as grouped nodes. Each node could contain multiple episodes, containing different parts of the story. Episodes could also be colour-coded to make it easy for a viewer to identify themes. Larger groupings could also be drawn freehand by the user, combining multiple nodes into a single category.

The palette used for the design is drawn from traditional colours used in paisley, combined with the black and ivory of piano keys. I used transparency to play on the ideas of *organic* and *ephemeral* which emerge in Broyard's story.

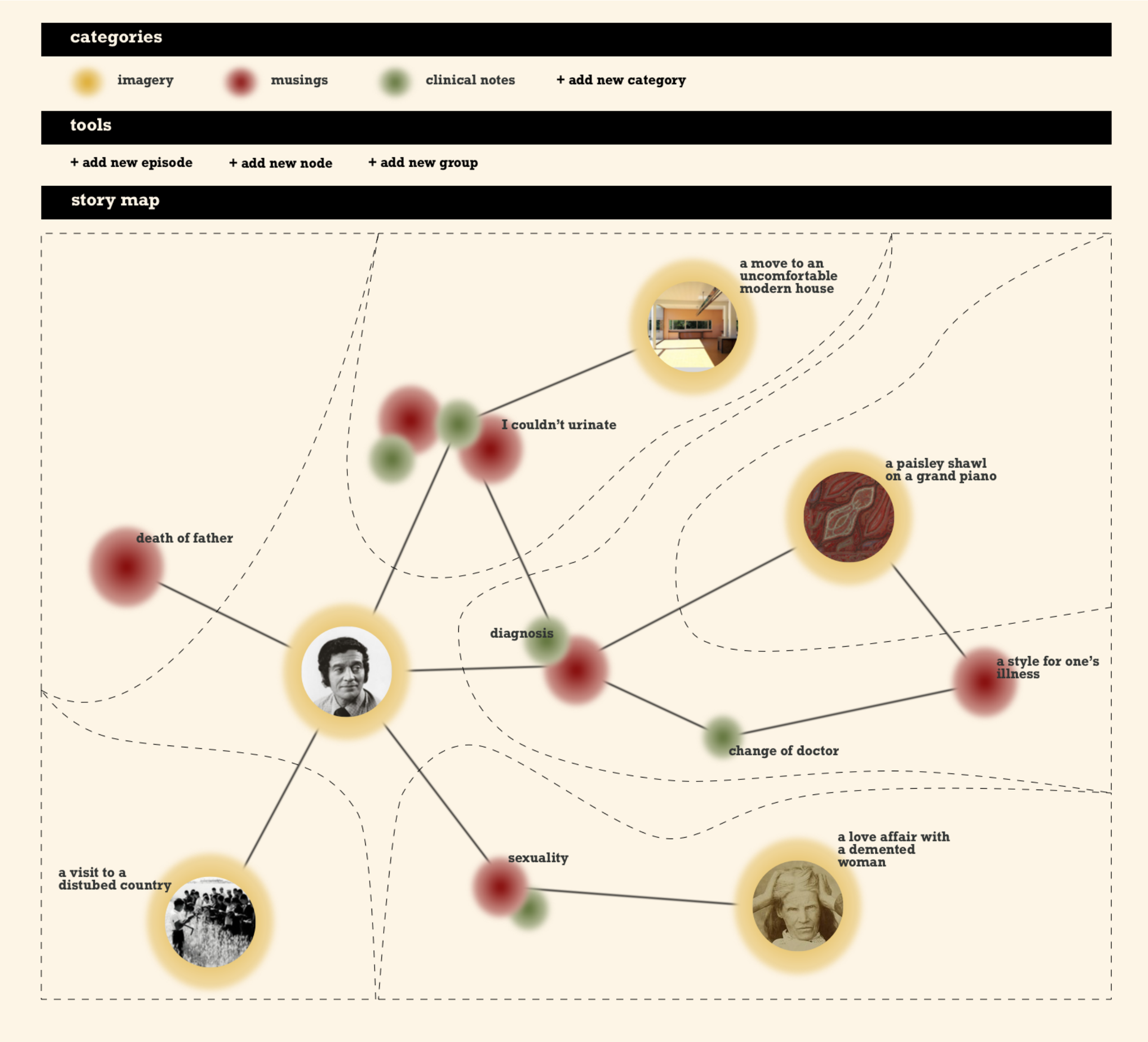
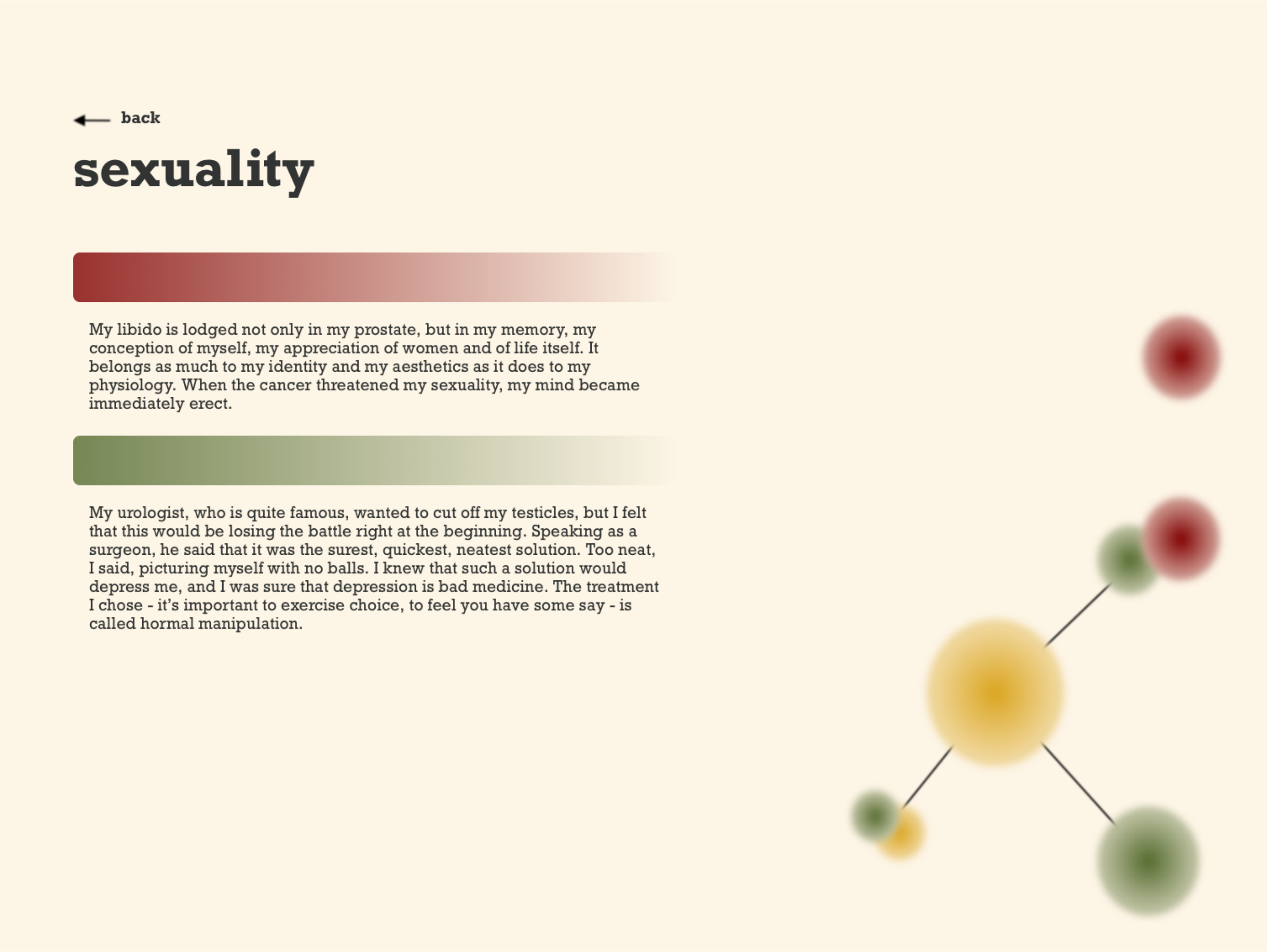


Figure 10: Anatole Broyard's organic story map. Illustration. Source: author's own.



sexuality

My libido is lodged not only in my prostate, but in my memory, my conception of myself, my appreciation of women and of life itself. It belongs as much to my identity and my aesthetics as it does to my physiology. When the cancer threatened my sexuality, my mind became immediately erect.

My urologist, who is quite famous, wanted to cut off my testicles, but I felt that this would be losing the battle right at the beginning. Speaking as a surgeon, he said that it was the surest, quickest, neatest solution. Too neat, I said, picturing myself with no balls. I knew that such a solution would depress me, and I was sure that depression is bad medicine. The treatment I chose - it's important to exercise choice, to feel you have some say - is called hormal manipulation.

Figure 11: Left - concept for node detail view with colour-coded episodes within (text from Broyard (1992)); Right – sketch of organic grouping idea. Illustration. Source: author's own.

2.3 Alice Alcott

Alice (a composite which Kleinman (1988) assembled from several different health stories) is an elderly woman with diabetes and chronic depression. Coming from an old New England family, she has a great deal of pride. She struggles with being able to express the despair that she feels over her illness, and also with the knowledge that her condition will likely progress to cause further health problems over time.

Alice's story is very emotional. She has a lot of significant relationships in her life (such as with her children), but she also feels a great deal of grief and loneliness. For her story, I used the metaphor of a house modelled on traditional New England wooden homes. The palette is inspired by Barbara Cooney's (1985) picture book *Miss Rumphius*, a story about an elderly woman in New England recovering from an illness.

Each room within the house represents a different period within Alice's life. Rooms within the house could open and close, like a dollhouse, to allow them to be accessed by others. The house itself could also completely unfold into a linear presentation, showing a timeline of events in Alice's life.

My idea for the house involved interaction, which I was unable to express using my limited knowledge of digital animation, so I experimented with using paper models to convey this.

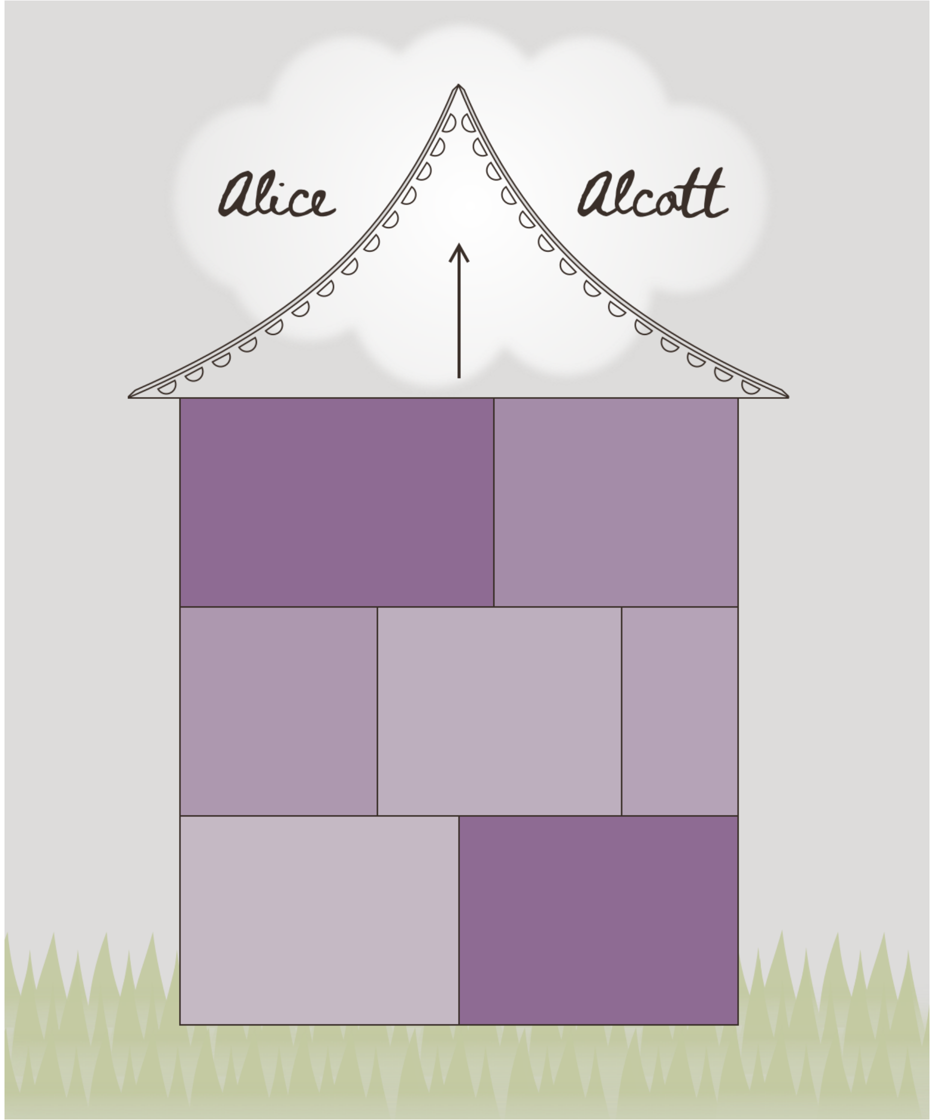


Figure 12: Concept for Alice Alcott's house. Illustration. Source: author's own.

Figure 13: Paper model of the house, showing rooms unfolding into a timeline. Image. Source: author's own.

Figure 14: Paper model of the house, showing rooms opening to allow access. Image. Source: author's own.

3 Prototype Design Conventions

In creating the participant's final prototypes, I have used certain conventions to create a coherent look and feel across all of the designs. These conventions are listed these here as an aid to the reader.

Interface Components and Layout

- 12 column web layout
- Flat design, as common in contemporary design toolkits such as Twitter's Bootstrap (https://getbootstrap.com/) and Google's Material Design (https://material.io/design)
- Standard web components such as panels, modals, buttons, etc.

Look and Feel

- Rounded, organic shapes
- Gradients and transparency to create depth
- Photographs mixed with flat vector illustrations
- Deep, rich colour schemes that are high-contrast (I have used the standard HTML colour codes as a reference but not adhered to these)

Typeface

"Now" by Alfredo Marco Pardil
https://www.behance.net/gallery/31329675/NowOpen-Source-Typeface

Icons

Font Awesome
https://fontawesome.com/

Text

Where possible, text is taken directly from the participant or a relevant source. Where I was not able to do this, I used generic filler text generated by https://loremipsum.io/ .

4 Participant Health Stories

Following Workshop 1, I transcribed the portion of the interview which focused on their health story. In doing the transcription, I have followed the guidance from Atkinson (1998) in prioritising readability. This was the most suitable approach for my use, as the focus of the project was on narrative, so creating a readable narrative of each participant's story was an important factor. I did not attempt to mimic the participants' speech patterns or accent, although I have included the occasional word of dialect where a substitution would make a substantial change to the text.

After transcribing each person's interview, I edited and rearranged the text to create a (roughly) chronological version of that person's story using their own words. During this process, I attempted to honour their stories by leaving blocks of text intact as much as possible and making changes for readability only. (For example, if the participant did not use a complete sentence, I have completed it rather than having the reader guess the phrase.)

The final version of the story was reviewed and edited with the participant, who may have made further additions. This version is included here, along with images of the objects that they selected to represent their health stories in Workshop 1. Of the participants, only M chose not to include an object in the project.

5 Lee

5.1 About

Gender	Female
Age	31
Conditions	Psoriatic arthritis, fibromyalgia, polycystic ovary syndrome (PCOS), Raynaud's disease
Lifestyle	Lee is married and has a son who is 2 years old. She works for a health charity that does work not related to any of her conditions. Her job involves working with people with long-term health conditions and running a support group.

5.2 Lee's Story

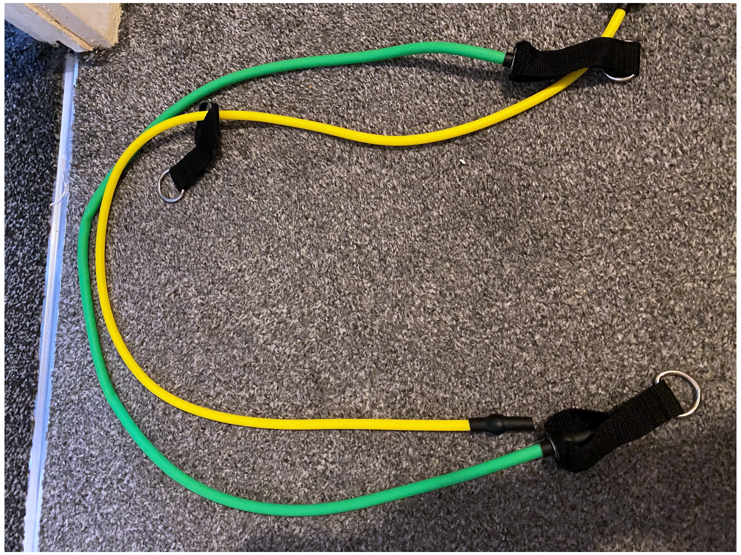


Figure 15: Resistance bands. Image. Source: participant.

5.2.1 When I was diagnosed

I've had psoriasis since I was 8, and as I got older my immune system started to attack itself. I was first diagnosed with psoriatic arthritis when I was 22. I spent 18 months before that in absolute agony. I couldn't walk to the toilet during the night. My feet were killing me: it was like somebody stabbing the bottom of them. I kept going to the GP, and I was just given anti-inflammatories. I remember them saying to me, "I'm not going to refer you anywhere because you're too young for arthritis." I felt like the doctors used my age against me, my age and my weight. I never questioned it, and when I think back now, well, I should have questioned it. I should have looked up what my pains were, and maybe if I had an idea it could have been arthritis, I would have pushed for it.

It took 18 months of to-ing and fro-ing, and then eventually she said, "Ok, I'll make that referral to the rheumatologist, but I still don't think it's anything to worry about."

It probably took about 6 months for her to get the appointment through. When I walked in the first thing the doctor said to me was, "You've got psoriatic arthritis. I can tell that with the way you're walking and your joints." She could see that my fingers were swollen, and my toes were all disjointed.

That led onto a diagnosis of fibromyalgia in 2016, because I had been experiencing joint pain as well. The rheumatologist had an inkling that I had fibro; she tested me. I was just in awful pain all over. I went to the GP for pain meds, and she said, “Is it for your fibromyalgia?”

I said, “I don’t have fibro.” She read out the letter from the rheumatologist that *she* had received. So, I found out from the GP. Apparently she had been sitting for a year with that letter.

I always say I’m lucky that I’ve got arthritis and fibro. If I just had fibromyalgia, I would have been discharged from the rheumatologist straight away. If they think it’s fibro, they’re like, “Sorry, there’s nothing we can really do to help. Just take pain meds. Just exercise.” But if it’s your arthritis, they’re like, “Right, we can get a steroid injection, we can do different things.” So, I always say I’m lucky I’ve got the two of them, because they will take me seriously.

PCOS came because I had unexplained infertility. They were still very reluctant to say that I had it, even although my hormone levels were all over the place. I actually fell pregnant, and they phoned me up 6 months later to say, “I’m really sorry. You’re going to have to get infertility treatments; you’ll never be able to conceive naturally.”

I’m like, “I’m 6 months pregnant!”

And they’re like “Have a really good pregnancy, we’ll see you at the end!” At the end of it, they were like, “We still don’t know how that happened, you must have just been fertile for that month.” I’m not going to question why, I’m just happy that it did. The Reynaud’s came because I was pregnant. They said, “Oh, it will go away.” It never, ever did. It just heightened it, and I’ve still always had it.

5.2.2 Since then, my life has changed

When I was first diagnosed with psoriatic arthritis, I got put on methotrexate, which is a chemotherapy-based drug. It’s quite strong, and it made me ill. In my mind at that time, I was like, “I want to have a child. I’m going to have to come off this at some point.” I went through different ranges of drugs that didn't work. They were reluctant to take me forward into anything else because I wanted to get pregnant. That took 3 years, so 3 years without a drug. I've got a better understanding of how it affects me now. I take leflunomide and that helps arthritis.

I probably went a bit naively in and not understood how my arthritis impacted me. I was trying to battle through everything, and then I realised that I need to reduce my working hours, I need to work part time, and I need to prioritise myself. I just took a step back from some things. Over time I've just got a better understanding in how my condition affects me and became a bit more confident in managing it. Self management is such a big thing. You only maybe see a rheumatologist every year, or every 6 months. There's a huge chunk of the year where I'm going without any health professional, so I need to do something to get me into a place where I want to be.

5.2.3 Where I am now

I used to not be able to walk very well. Since I had my wee boy I've went through quite intense rehab and paid for private physio. In February I started working with a personal trainer again. He was helping me get back to rehab, and we started doing resistance band training. The resistance bands are my go-to thing to help me stretch in the morning. Some days I can't do it because the pain's too high. The days I can do it, I feel so much benefit from it, and it helps me manage all my conditions.

At the start I always struggled with getting into the swing of it. I was a bit heavier, so I was always fatigued. With my pain and fatigue, my go-to would have been food. I sort of consumed my feelings with what I *thought* I was in control of, which I really wasn't.

I remember the personal trainer saying, "Do something that you love." That was dancing about the living room with my little boy, and just moving. That was my starting point. And now, I feel so much more energised. It's a control thing.

Exercise is the one thing *I'm* in control of. I can control what I'm eating, and I control my exercise. They're the two main things that I'm focusing on just now, and that helps physically, mentally, emotionally. I've spent a year in good health, and it's nice to have that reminder that this is what it feels like to exercise.

The thing that made me reluctant to exercise was that it's always a go-to thing for consultants. If you've got arthritis, or fibro, the two things they say is exercise or yoga. And it's repeated and repeated. You know the health benefits, but actually there is so much pain that you couldn't even think about doing it.

5.2.4 The people around me

My husband has been very understanding from day one. He knows that some days he might need to help me get dressed or get in and out of the shower. He's really supportive. My mum as well, she's great. Although there's times where she'll say, "Do you *really* need to be taking your medication?" It's probably a generational thing. But she gets it better now than when I was younger.

My phone is a lifeline. I connect to so many other people who have arthritis online. I'm good friends with people now from all over the UK and I've met up with some people. I have different friends groups for different things. I have a friends group that if I wanted to go out, I know I could rely on that group, and then I've got the group that I can go to and say, "This is really sore, have you had this?" And they say, "That happened to me!" Having people that get it really does help.

I have friends that I grew up with that I probably don't tell as much. And there's the friends that maybe never will get it. In their eyes, you look like you can still do everything that you can do, and you still have days out with the family, so that must mean that you are ok. People see what they want to see. In some respects, I like that people think I'm fine, because I am. It's just that I've got all these different things to manage, different barriers and hurdles. It's made me prioritise what's really important to me.

5.2.5 Looking forward to the future

Obviously, having one child just allows other people to ask the question of, “When’re you having another?” I think they’re always things that are asked of you as a woman. I feel like I’m in such a good place, I don’t know if it would be worth the lack of medication, the pain, the IVF cycle if I had to go through that again.

I hope I’ll still be doing the wellbeing stuff and self management. Still working within that, helping other people. Hopefully managing it better. Being able to run after my son and play football with him, living my life through him, and getting him into different things.

6 Rhona

6.1 About

Gender	Female
Age	38
Conditions	Myalgic encephalomyelitis (ME), borderline personality disorder (BPD), fibromylagia, post-traumatic stress disorder (PTSD), depression, anxiety, chronic migraines, irritable bowel syndrome (IBS), Raynaud's disease, postural tachycardia syndrome (PoTS)
Lifestyle	Rhona lives with her partner, 3 children from a previous marriage, and her stepson. She is a stay-at-home parent.

6.2 Rhona's Story

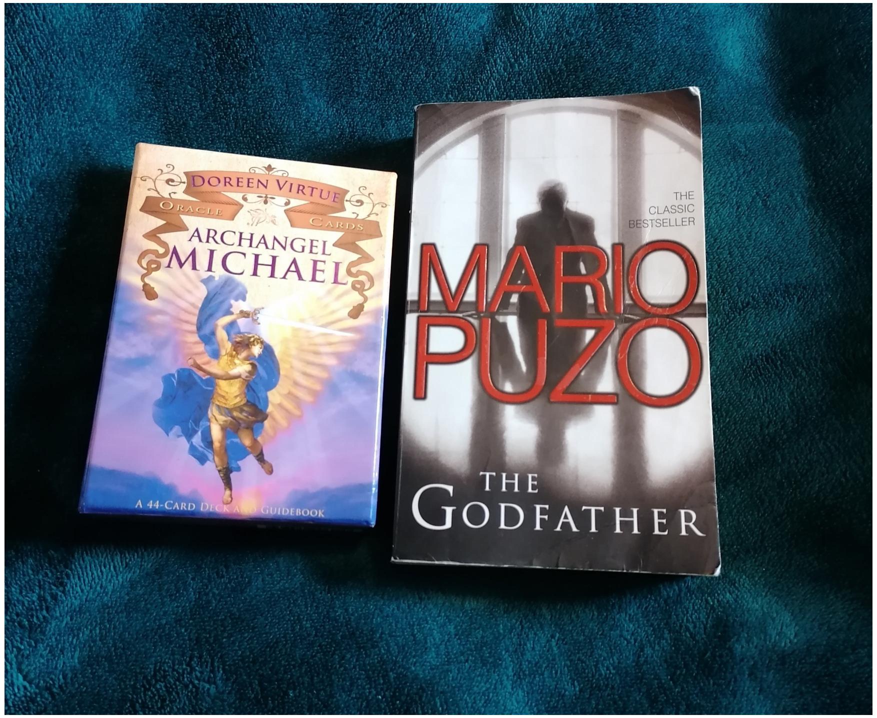


Figure 16: Blanket, angel cards, and "The Godfather" by Mario Puzo. Image. Source: participant.

6.2.1 When I was diagnosed with ME

When I got diagnosed in 2014 with ME, that was a starting point. Before that, everything just melted into one. Because I have borderline personality disorder, I had a really bad upbringing. Ever since I can remember, my life was just the one way: always chaotic and busy, full of bad energy. When I got ill, I had to stop. I was bedridden for months; I couldn't do anything at all. That was the turning point in my life, when I realised that sometimes you just have to *slow down*. It was getting ill that helped me escape from all that chaos and realising it was quite toxic. So, I think 2014 was probably the starting point in my journey. I feel like I became an adult, and that's when I always go back to. I don't like to think about my life before then.

I had just moved house. I had the flu straight after moving house, then I had an infection, and then I had sinusitis and chronic migraines for 9 days. At the time, I had just completed a year's training to be a pupil support teacher. My oldest daughter, she’s on the autistic spectrum. I went through the pupil support system so I could support her going through school. So, I had just finished my training. I had been offered a job at a high school, and I’d been offered a second job at a care home. Then I got the flu. I had to turn down both jobs, thinking I would get better and maybe try and get something later on.

I was ill for *months.* I went to the doctor and I said, “Look, I’m not well. I can’t get over this flu virus.”

He said, “Oh, I think you’ve got post-viral fatigue disorder.”

I said, “But, I’ve always been fatigued. This feels quite normal to me. It’s just a bit more extreme.”

He referred me to the specialist, and the specialist said, “Your doctors wrote that you’ve had this since 2004, they’ve just never diagnosed you.”

When I got that diagnosis, I finally felt like somebody was *listening* to me. I was always told I was lazy, but I was just more fatigued than everyone else. They always just brushed me aside. They never took it seriously. And when I got the diagnosis I was finally like, “Stuff youse all! I told you, I’m not imagining it!”

My mum was still here then. They all thought, my mum and my sisters, that that’s what I had. They’d all talked about it without me. It was like they were beginning to accept that I wasn’t just being lazy, I wasn’t just ignoring people: there were reasons for it. It was a relief for everyone.

6.2.2 When I was diagnosed with borderline personality disorder

It was the same with the borderline: I’d been fighting since I was 15, telling them that something wasn’t right in my head. I didn’t feel normal. I didn’t feel things like everyone else. They kept giving me excuses after excuses. When I finally got diagnosed in 2018, it was a big weight off my shoulders. It was the most amazing feeling. It did make me feel a bit uneasy for months, but it was just such a relief to know that it’s not my fault.

Family, friends, people that knew my parents, still to this day don’t believe. They think I had a perfect upbringing: I had *far* from it. They think, “Oh no, you mustn’t have that, you’re just depressed.” *No*. This is worse than that. A lot of people outside the family didn’t accept it.

It did have a knock-on effect. I’d been diagnosed, I’d been in counselling, I’d been in therapy, I’d done <domestic violence counselling> for people who’ve been in abusive relationships, and that’s when I started realising what my childhood was like. That had a knock-on effect through all my sisters. We all slowly started realising we had post-traumatic stress disorder, and we’re the way we are for a reason. Everybody’s mental health went down fast. We triggered each other all the time. It was really hard to speak to each other and build each other up again. Some things we still can’t talk about. But we have to deal with it, because *I* have to deal with it, so I’m making *everybody* deal with it. It’s a lot to take in, when you don’t realise you’ve had an abusive childhood until you’re 36. You’re like, “Oh, it wasn’t that good after all.”

6.2.3 The people around me

I feel like in my family the attitude is, “People have it worse than you, so you just have to get on with it. If you need help, tell me.” But they’re a lot more caring now, and they’re a lot more patient with me. They understand my limitations a lot more now than before, which has been nice. It’s been quite helpful. My 3 sisters can be supportive of me. We have an unwritten rule that regardless of whether we bicker, if something bad happens, we’re all there straightaway. If somebody needs money, we’re there straightaway. If somebody needs looking after their kids, we’re all there straightaway.

I have a partner. I wasn’t with him in 2014 when I was diagnosed with ME, but I was with him a year before I got diagnosed with borderline. He’s had to learn relearn *life* because I’d be triggered all the time, but he is really supportive of that. Friends and family are really supportive as well, actually, but I do isolate myself a lot. I don’t try and tell them things.

When I got diagnosed with ME, I started a support group on Facebook. There were so many people I knew who had fibro and ME, and there was nothing out there for anybody. We all felt alone. We haven't done it for a long time because of COVID, but occasionally we would meet somewhere like a coffee shop and have a cup of coffee. Maybe only 5 or 10 people would turn up, but it makes you feel like you're less alone. It can be a bit dangerous at times, because you tend to bounce off each other. But it's good that I can message, "Am I overreacting? Is this normal? Am I supposed to feel like this?" Sometimes, especially when it's mental health, you're not rational. Just to have somebody else say, "This is normal for BPD, you're going to be *fine*. It will pass.", sometimes that's just what you need. And it's non-judgemental, because they have it as well. Even though I'll never be cured, the one thing to recovery is support systems. For me, that's a really important part. Even though I isolate myself from everyone, they all understand that I'll come back in a few days' time and I'll be fine again.

6.2.4 Where I am now

My IBS and Reynaud's diagnoses were when I was a teenager. Everything else came between 2014 to now, so it's been a *lot* the past few years.

I feel like my health is not as bad now as it has been in the past, but it has gotten worse recently. My mental health's a lot worse than my physical health, still. I think it's had a knock-on effect because of COVID, because we've obviously all been not able to go out anywhere. I've not been able to do as much. I'm not able to stay up later: I find that quite harder than I used to before. But I'm not bed-bound, so that's a bonus. For me, that's a huge big deal.

I've gotten used to having to rest all the time. If I do too much I know I'm going to be exhausted, so I'm kind of used to that. In the past year I've put on a lot of weight as well. It has had an impact on my mental health, but about my physical health, I'm not sure about that. I could be better, but I could be worse, is the way I look at it. I know my limitations a bit more now, so I can see if I need to not be as active, or if I need to rest.

6.2.5 My three things

Sometimes with borderline you can lose your identity: you don't have an identity, so you take other people's identities on. It's hard to know who you are, so I like to have things that are physical that I know are *me*. You can look at it and remind yourself of who you are. That's my 3 things. These things are my 3 important things in life; these are my 3 things that go with me everywhere.

6.2.5.1 My blanket

I always have a blanket wherever I go. If I go to somebody's house and they don't have a blanket, I get really upset with them, so I usually have a blanket in the car. I feel like it gives me security, and I get cold quite a lot. Also, I can hide underneath it, if I don't want anybody in my space. I've passed this on to every child that comes into my house: everybody has a blanket. It's just a comfort thing. I always have one, all the time.

6.2.5.2 My book

I have read Mario Puzo's *The Godfather*[1] a million times. I love reading. It's my favourite thing to do. Sometimes I can't read because of the migraines, or the cognitive issues I have. So, when I want to start reading again, I find I have to read something familiar to get back into it. I always go to that book. That book has been with me through every aspect of my life since I was 18. Every year I've read it a couple of times, and it's helped me get through so much. I know it and can read it without having to read it too intently. It's such a comfort to me.

6.2.5.3 My angel cards

When I first got diagnosed with ME, I felt like I had to go on this journey. Part of the journey was to try and be a bit more

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[1] Puzo, Mario. (1998) *The Godfather*. London: Arrow Books.

spiritual. Less the future and the past, and trying to be more in the present. It's helped me through a few things. I haven't used my angel cards for a while, but I like to have them there as a comfort. I don't have my parents anymore; I don't necessarily go to people for guidance. So, if I need guidance, I sometimes just pull a card out. It *might* not make any sense to me, but it's just how I interpret things. It can bring me back down to earth, because usually I do a bit of meditation at the time.

6.2.6 Looking forward to the future

The immediate future's looking quite good, because I'm trying to move house and merge two families together, although it is stressful.

I dream that I could work in the future, because I can't work just now. That has a big effect on my mental health. I'm just not *well* enough to do it, but I sometimes find that hard to accept. I've changed my goal slightly. I used to think, "I'll go back and work in schools." Now I think there's a big gap in pastoral services: anything where you support kids emotionally with their mental wellbeing, and their relationships with other people. I would like to do more of the emotional looking after the kids. As a society, we neglect it. We end up with 40-year olds who can't cope with life, because we're not teaching them coping strategies when they're young. If I can help *one* person, *one* kid, not go through what I've been through, that would be my dream.

I've got 4 kids. I know they'll be leaving soon. I'll be by myself, and that terrifies me. They're all getting older, and I'm thinking, "Who's going to talk to me?" It sounds quite negative, but I feel like it could be quite a lonely future. But, I have so much I want to do, and because I won't have to look after the kids, I'll be able to do a bit more for myself.

I don't look too far in the future. I think if I do, I might get disappointed. I would rather stay in the present and have small-term goals, rather than long-term goals. If I could work, that would be the best thing ever. Or even study again, *something* to keep my brain going. I live by the rule that you don't know what's in front of you. Your cards are dealt, and you'll get whatever you're dealt.

6.2.7 Telling my story

I'm quite open with people. I'm quite honest. I don't really have anything I don't want to tell people. If somebody asks me, I'm generally telling them. I do get asked quite a lot about my health, especially if it's somebody who doesn't know me, or know my background. I don't mind telling them, because I like talking. I just talk, and then people hear all about me.

On my support group on Facebook, I try to be open and honest to get people talking so we're not feeling like we've got symptoms that we're a bit unsure about. I find that talking helps, and I find that people don't get enough chance to talk. I know a lot of people with chronic illnesses, and we're all so lonely because we spend so much time by ourselves. I feel like if I can be open with them, people start to open up, and it just makes them feel a bit better.

I don't like telling health professionals my story, especially mental health professionals. I find that really frustrating because some of them are incredibly ableist. They don't understand that when I can't process my emotions, it's because my brain is too fatigued to do it, is not able to do it. The cells of my body are fatigued, it's not because I'm just *tired*. I tend not to be as open with mental health professionals as I am with, say, the doctor, for instance. Although, I'm quite paranoid about doctors. I have very bad post-traumatic stress with doctors, which I didn't realise until very recently. I try to avoid going to the doctor if I can. So, there is a group I *don't* like to tell who could probably help me a bit more, but any random person I quite like telling my story to.

7 M

7.1 About

Gender	Female
Age	39
Conditions	Relapsing-remitting multiple sclerosis (MS), chronic depression, early menopause
Lifestyle	M has a partner and two teenage daughters from a previous marriage. Because of her health, she is currently unemployed.

7.2 M's Story

7.2.1 Suffering with depression

About 13 years ago, I started suffering with depression. At the time that I was particularly bad, my cousin had a baby boy and he died. It was horrific, absolutely horrific. When he was born, she had post-natal depression. She didn't want to look after the baby, but she didn't want to give him to just *anybody*. She cared about who it was who was looking after him. So, he used to come to my house. We used to take him for the weekend, to let her get a break. You know, it's hard work, when you just have a baby. She would bring him on a Friday and come pick him up on a Sunday.

He died at 4 weeks. It was totally out of the blue. They didn't know what it was that he had died with, so they did tests, and it turned out to be meningitis. In amongst all of that, I was kind of losing my head. I couldn't function, and that was when I was diagnosed with depression. I think it probably was there in the background before that, but that was when I was diagnosed.

I think you're always inclined to look for a reason. A reason why. Depression is one of those things: it's a chemical imbalance in your brain, there doesn't actually have to be a reason. But because that was such a significant thing that happened to me, I always kind of put it back to then, when <Baby S> died. It was horrific at that time, but you just get up and get on with it. You try and soldier on as much as you can.

<Baby S> would be 16 now. It's difficult seeing babies who came out of the hospital just about the same time as him. You see them starting high school, and celebrating their 16th birthday, and you always just think, "<Baby S> would be 16." It's *stupid* things that are difficult. So, that was kind of the start of me being unwell.

7.2.2 When I was diagnosed with MS

I have relapsing-remitting MS. That was diagnosed in March 2015. I was walking home from work and felt a wee bit dizzy. I righted myself, and when I opened my eye, I had a shadow on my eye. I went to bed that night, got up the next day, and it was still there. I went to the optician's on the Wednesday. I didn't realise how bad it was until they covered my good eye: I couldn't see anything because it was right in the centre of my vision.

She referred me to the hospital. I was attending the eye clinic, and after a couple of months there they came back and they said, "It's not your eyes. Your eyes are not the problem."

I'm thinking, "Well, I can't fucking see out of one of them, so clearly there's something wrong."

And they're saying, "We're going to refer you to neurology."

You get to the stage where you're like, "I must be dying. I must have a brain tumour." I think it's human nature to think the worst, when nobody seems to know what's going on. You always just think worst case scenario. When I was diagnosed with MS, it came as a bit of a shock to me because *nobody* had mentioned MS. But I was relieved that finally somebody knew what was going on.

Everyone goes through a different experience when they are diagnosed. It's difficult to try and concentrate on the things that you *can* do rather than all of the things that you *can't*. It takes a long time for a person to get to that stage. I think I've arrived there quite quickly. The way I see it, I have got a "get out of jail free" card. There are not many benefits to having a lifelong condition, so I am going to abuse it, if I can. Parking as close as you can to the front door? Yeah, I'll have some of that! It's about trying to make the best with what you've got.

7.2.3 My life with MS

Since then, my MS has changed. I've had a couple of relapses. One was particularly bad, and I couldn't even get out of bed. But my medication is designed to give you longer between relapses, and if you do have a relapse, it has less of an effect on you. The past two years when I see my neurologist, it's always the same:

"Do you think you've had a relapse since I saw you last?"

And I'm like, "No, I've had good days and bad days, but I don't think I've had a relapse."

I had an MRI, and then he wrote to me and said, "Actually, you *have* had a relapse since I saw you last. But we believe that that's within the realms of what is acceptable for your medication, so just carry on taking your medication." So, the medication's obviously working if I've not even known that it was a relapse. And it was the same this year, just keep taking the tablets.

The thing is, I'm such a wuss. I'm so scared of needles. When I was diagnosed they were talking about all of the different medications, and it is really quite confusing because there are quite a few medications now. And he's saying, "The injectables are working really well now."

I said, "I won't be able to give myself an injection. I know what I'm like and I won't be able to do that."

And he said, "Oh, you know, it's fine, it's in an EpiPen, so you won't actually see the needle." I was in the RAF. I did all of the drills; I gave myself an injection in the leg. I know what an EpiPen is, I know you don't see it, I'm still not going to jag myself in the leg with it!

I said, "Look. If it makes you feel better, I'll say that I'll do that, but I know for a fact I *will not* give myself an injection." There's no way I'm going to inflict pain on myself, not a chance. So, I just take a tablet every day and that's it.

You get a wee bit more used to it. I am very much for the moment. If I'm feeling tired, I go to bed and I have a sleep. I usually have a sleep in the afternoon, and then I'll feel alright for the evening and can still get to sleep at night. I have no problem with going to bed. I think previously I would've viewed a day in bed as a wasted day. Whereas now, I don't see it as a wasted day: I am healing. If we have a family thing on and I'm there, I know that I have to plan two days of doing nothing. Even simple things, moving things from one place to the other, I just can't do it. I can't hold things. So, I kind of build that into the plan.

There's lots of things that I can't do now, but I try not to focus on that. I focus on the things that I *can* do. And so, I consider myself very lucky in that there is still so much that I can do. I personally think attitude makes a big difference in what you're doing. I've always been quite a positive person, and I think that does make a difference.

A lot of people have not been so fortunate as I am. It depends on what kind of MS you have. I have relapsing-remitting MS, so I'll have a relapse and then eventually I'll get better. One of the girls who comes to our MS group, she is the same age as me and she has primary progressive. She really struggles with walking. If we're out together, she is there struggling with her crutches. It's difficult not to get mad, and you think to yourself, "For God's sake, just get in your fucking buggy." And then you think, "Actually, no. If I was in her position I would be trying to walk. Even if I was slow, I would still be the same, I would be trying to walk."

I know that she thinks, "We're the same age. How is it that you can still do everything and I can't?" But again, it's different types of MS. Life's not fair, that's just how it is. Some people just wake up one day and they can't walk. Or some people are in the process of walking and then their legs just stop. I was very lucky, I had a wee while to acclimatise to it. It didn't stop me from walking straight away.

MS is so frustrating cause it's so different for everybody. When you're diagnosed the doctors tell you that, "Everybody's different." And you kind of go, "Yeah, right", but actually everybody *is* different. You can't really pinpoint a thing that's the same cause it is really different for everybody.

7.2.4 The people around me

I've separated from my husband since being diagnosed, and a big part of that is MS. It's not so much the condition itself. Being diagnosed with a lifelong condition makes you view things differently. I'm not in a wheelchair yet, but I could end up there. So, if there's anything I want to do, I'm going to do it now. He really just didn't want to change. And I'm like, "No. Actually, I want to go out and do stuff. I want to say that I've lived a life. This is not making me happy, and I'm only going to do what makes me happy now.” You feel like you have a finite amount of time.

I have a partner now, and I had MS when we met. He understands it as much as he can. I’ve said to him, “Don’t treat me as though I’m ill. I’m fine, there’s still so much that I can do, don’t treat me as if I’m a fucking idiot.” And so, he is just normal with me. If I’m having a bad MS day and he’s like, “You’re a lazy bitch”, I try not to take it personally. I’m just like, “Yeah, it is what it is. If I’m having a bad day, I’m having a bad day.”

My friends are friends who I’ve met since being diagnosed. I go to an MS group; we have a group chat every week. One of the girls, <L>: you know when you meet somebody, and you just click? <L> and I just clicked. We get on really well, and <L> has MS, which helps. She understands, I don’t need to go into all of the details of explaining what a bad MS day is like because she already understands all of that. There’s lots of things that go on with this illness that I wouldn’t tell my mum because she would just worry about everything. I can speak to <L> about it, because I know she gets it.

Going to the MS groups helps a lot: seeing other people with the same condition, and how they get on with it. It’s good to see how people cope with different things, it’s about not reinventing the wheel. If somebody has been through it before, “Oh, what did you do when you had to do this?” I think that’s part of the reason I’m not embarrassed about any of it.

I had to go see the urology nurse, because I was getting no notice and I had to go to the bathroom. You have to keep a bladder diary for three days. When you go to the bathroom, you need to log what time that’s at and also how much liquid you passed. I was totally confused by this. I was at the bingo one night, out having a cigarette, and I was saying to them, “How are you supposed to know how much you pee?”

One of the old ladies that was there, she says, “<M>, I know the answer to that, cause I had to do that. What you do is: you take a pound, and you go to Poundland, and you buy a jug. You use that, and after those 3 days, once your bladder diary’s finished, just put it in the bin.”

And I was like, “You know what? That is so simple, why did I not even think of that?” And it *is* so simple, but bladder movements are one of those things that people don’t talk about. And so, I talk about everything with everybody. I’m not embarrassed about any of it now because how are people going to know if nobody talks about it?

7.2.5 When I was diagnosed with early menopause

When I first went to the doctor about it, I thought it was an MS thing. I was lying in bed at night and it felt like the soles of my feet were *burning*. After about 3 weeks, I went to the doctor and I said, “I know that feet generally are an MS thing, but I’m lying in bed at night and it feels like my feet are on fire. You need to give me something, I can’t put up with it anymore.”

And she said, “Yeah, feet generally are an MS thing, but not always. It could be something else. We’ll do some bloods.”

She phoned me the next day and said, “I’ve got your blood results back. It could be early menopause, <M>. It only happens in 1% of women, so it’s unlikely. What we have to do now is wait 4 weeks and then we’ll run the bloods again.”

Waited the 4 weeks, got the bloods done again. She phoned me, “<M>, it *is* early menopause.”

I said, “Yup, that sounds about right, that’s the kind of luck I’ve got! The big guy upstairs is like, ‘Nah, you’ve not got enough to be getting on with.’” I am not devastated, I’ve got two children who are in their teens. I’m not planning on having any more, so it’s not the end of the world.

It was then a long, drawn-out process because previously MS patients couldn’t have HRT[2]. She had to write to my specialist to see if I was allowed it. Since I started on HRT, I’ve not had any issues. The sweats have gone, I don’t have the burning feet at night or anything like that. Menopause has got a bit of

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[2] Hormone replacement therapy, a treatment to reduce the effects of menopause.

a bad write-up. It’s not all bad, there is some good in it. Actually, I love it. I don’t have a period every month, it’s absolutely fantastic.

7.2.6 Looking forward to the future

I like to think that in the future I would be content, that I’d done everything that I wanted to do. My girls are in their teens now. I say to them, if there is something that you want to do, go out and do it. I’ll give most things a bash.

I love going on holiday. My MS seems to be easier to manage when I’m on holiday. A lot of people with MS seem to have an aversion to heat and they just can’t function if it’s a wee bit warm. I seem to be the opposite. The cold absolutely cripples me. In the heat I seem to be so much better, it’s so much easier to move around.
I consider myself very lucky. I know that it could be so much worse, I have friends from the various groups that I go to that are so much worse than what I am. I may well end up there, but I’m not there yet. MS is one of those things that the less you do, the more you lose. So, you might decide, “I’m not going to go for a walk today.” And then, it gets to the point where it’s not a choice: even if you wanted to walk, you can’t. So, while I still can, I do a wee bit of everything. Even as much as sometimes I don’t want to, I still make the effort because I would like to have a choice.

What I always say is, “I’m living my best life.” I am. I’ll be happy, as long as I don’t have any regrets. I don’t have any regrets up to this point in my life. I’ve done everything that I want to do so far, and I’ll carry on doing that for as long as I can. It’s not belittling the situation that I’m in. You need to play with the hand that you’ve been dealt, and that’s it.

8 Sharon

8.1 About

Gender	Female
Age	51
Conditions	Secondary breast cancer, myalgic encephalomyelitis (ME)
Lifestyle	Sharon lives independently near her family and works part-time. She is supported by her friends and two siblings. She is single and has no children.

8.2 Sharon's Story

Figure 17: A compass. Image. Source: participant.

8.2.1 When I was diagnosed with ME

I've had ME for 20 years. 20 years ago, ME wasn't as well known or understood as it is today. I was about 30 at the time; I was at university. Up until then, I was very active. I used to go hillwalking. I did about an 18-mile round cycle a good few times a week and thought nothing of it. I was just finishing my second year. You get the lovely long summer holidays, and I was *exhausted*. I couldn't understand why I was so tired. I didn't think too much about it, just carried on trying to exercise and be fit. That's where the societal thing comes in. When we get like that we just "push on through" and carry on.

I struggled through my third year at university. By the end of it I knew something was wrong, but it was all minor symptoms and nothing seemed to connect. I was having gut problems, I was having digestive problems, I was having *overwhelming* fatigues. I'd be cycling home literally almost falling asleep on my bike, desperately struggling to keep my eyes awake, not understanding why I was so tired.

I was struggling so much I didn't stay on for fourth year at university. I tried all sorts of things to get better. Family were the first ones to say they thought it was ME, I didn't really know what ME was at the time. I found out a bit about it and thought, "Well, I seem to fit that picture quite well." I don't remember back then when I first went to a GP, but at some point within the first 5 years I did get a diagnosis.

I've moved around quite a lot, so I've seen quite a number of GPs, and none of them were very sympathetic, understanding, or knowledgeable about the condition. I was sent to see a psychologist; I was told I was depressed. *I* was the one saying to *them*, "It's ME", it wasn't the other way around.

8.2.2 My life with ME

Looking back, I can see that life was quite chaotic for about 10 to 15 years as I kept trying to get back on my feet and back to "normal". I would manage that for a few months, then my physical health would start to deteriorate, I would start to struggle, and no matter how hard I tried, I couldn't avoid hitting the crash zone. Boom and bust as it's now referred to.

I was back being very physically active, working full time, enjoying myself. But my health kept plummeting and plummeting deeper and for longer, and I ended up having significant lengths of time off work. I was getting a better understanding of what my triggers were and how to manage them, but not really getting on top of the condition. There was a lot more awareness growing about ME and there were support groups, which helped. I was meeting other people who were having possibly very different symptoms, but there was a sense of acceptance. No questions, no eyebrows being raised, no "there's nothing really wrong with you" type thing. In the back of my head I've never really been comfortable with the label of ME. I think a lot of that comes from the sense of that it's not an acceptable condition to have, because it's so misunderstood.

I ended up at one point struggling so much that I was off ill for a year. I saw a GP who was very sympathetic. Didn't really know what to do to help me, and at that time, I didn't really know what to do to help myself. I would go in and say, "I think I need to be off work for a month", and she would say, "Fine, come back and see me in a month's time". And then I would come back in a month and say, "Oh, I'm feeling a little bit better, but I think I need a few more weeks off." That carried on for a *year*.

In reflection I can see I needed more guidance. I needed her to be saying: "Ok, you say you're feeling a bit better? How does that look to you?" Then I would be able to say, "Oh, well I was able to get up by lunchtime, and make myself one hot meal today." And there's me thinking I'm going to get back to work in a few weeks' time! She would have hopefully been able to see the bigger picture.

8.2.3 When I was diagnosed with breast cancer

I ended up being made redundant on the grounds of ill health. By then I was living with my sister, because I was struggling too much by myself. I'm single, and I don't have kids. And that's where I was when I got my primary breast cancer diagnosis back in 2012. It was in my right breast. It was a *tiny* lump. I moved down to <Location > to stay with my mum whilst I went through treatment, which ended up being a mastectomy and not the chemotherapy and radiotherapy I'd been told I was going to have.

I had reconstructive surgery. Not that I wanted it, but it was strongly recommended by the surgeon. I was humming and hawing, and his advice was, "Well, get it done, if you don't like it you can have it undone. It's no big deal." It wasn't until after I'd had the operation and came around that I realised: it's not like a pair of shoes you take home, and you walk around in, and you think, "Actually, they're a bit uncomfortable, I'll take them back to the shop." I'm not going back through another major ordeal to get this taken out. Back then in 2012, there wasn't a very good understanding about knowing the person. There was certainly no counselling about, "Why do you want reconstructive surgery?" It was just, "This is what you do." Questions were raised if you *didn't* want surgery, which just seems totally wrong to me. I still wish I'd never had the reconstructive surgery.

Anyway, I didn't need any other treatments, no radiotherapy or chemotherapy. I had a scare once. I was having quite a bit of discomfort in an area where I'd had surgery well after it healed, a few years down the line. They called me in, gave me a scan and checked me over, and it was fine. There *was* a lump there, but it was benign. So that was very reassuring.

I kind of restarted life down in <Location>. I managed to get a part-time job, not as stressful as my other jobs had been, managed to move out of Mum's and gain some independence again. My last ME crash was just before I turned 50, which is 18 months ago. I was probably feeling the best I had felt in ME terms. I had been well for maybe a year. I'd been my most stable, and I had made a lot of big changes to my life to make it manageable. I was nowhere near leading the life that I had led before. In my everyday life I wasn't the person that I am in my head, but it was a good life, and it was manageable. It was great.

And then I was slammed with the secondary breast cancer diagnosis within 6 months after my 50th birthday. Took me into a whole different area.

8.2.4 Receiving a secondary cancer diagnosis

I was diagnosed with secondary breast cancer last year, 2019. I was having discomfort down my chest. I kept thinking, "I'm getting a chest infection", but nothing else would happen from it. I did end up going to a GP once or twice. They never made the connection that: chest discomfort, this woman's had breast cancer, maybe they are connected. And *I* didn't. I was aware that you could get a re-occurrence of cancer, but I wasn't aware of secondary cancer. Which seems odd now.

Eventually the chest discomfort went into my back. That was starting to feel quite sore, but I'd just started yoga at the same time, so I was thinking, "Oh, it's the yoga that's doing it, I've just been doing funny moves." Then I had two small lumps on my chest. This would have been the winter of 2018. I phoned the <hospital> about it, because that's what I'd done before. I *still* don't understand this, because I actually had two lumps on my chest, but they said, "Oh, don't bother coming in, just go and see your GP."

Because they reassured me, I didn't think it was urgent. You know, I was really worried about it, but I was doing my usual, "I'm overreacting, let's not make a big deal of this, let's not go for an urgent GP appointment." So, I waited until I got an appointment, which was about 6 weeks because it was over Christmas. Finally saw the GP and she didn't know what to make of it, or at least that was what she said to me. She said that she would send me to the <Hospital> in <Location> to get scanned. In January I went for scans, and it was clear on the day of my first scan that they suspected there was cancer. I'm really appreciative of them for being so honest with me. Of course I was highly stressed and in tears, and they were fantastic, very supportive.

It was a whirlwind of tests for the next couple of weeks, and a very messy time with getting the diagnosis. I was led to believe it was a regional occurrence. I thought it was in my bones, and was told, "No, it's not in your bones". It came across as they were telling me it was regional. I had my proper appointment with the oncologist the week after that and it was a double whammy because I was told it was secondary, which I thought I had just narrowly escaped. Which made it even worse news to hear, in a way.

8.2.5 Where I am now

It's changed over the 18 months since diagnosis. The first 6 months, it's a horror story. You'd wake up every morning and think, "Oh, shit. I'm back, it's not been a dream." It was something I had to come to terms with every day. A lot of numbness as well, and of course there's the whole cycle of treatments and appointments to cope with at the same time.

I found a lot of inner strength and wanted to be an active participant with my health as I always have done. I've always been curious about, "What can I do to make things better for myself?" I've done a lot of work up until now: psychologically, changing my diet, meditating, trying to exercise when I can. I did a lot of research on what I could do to help myself, and I found that really helpful.

I came across a book called *Radical Remission*[3]. Somebody's done research on hundreds and hundreds of people who've beaten the odds and has been able to narrow down what everyone has done to 10 things that they all have in common. It was reassuring because I was doing most of those things already, but it gave me the impetus to keep going with them and to try a few new things on the list too. I felt I was giving myself the best chance.

The oncologist said my response to the treatment was amazing. The tumours disappeared very, very quickly after a few chemotherapy sessions. I'm classified as being "No Evidence of Active Disease" group, which is the best position you can be in. There are now no tumours, there's still the *cancer* but there are no tumours. That's as good as it can get.

Because of that, the diagnosis often feels very surreal. It's there in the background every day, but it's not always a conscious thought now. I can regard it quite dispassionately at times. On the other hand I've got constant symptoms from the treatments, which are bothersome and a reminder. It doesn't take much for the fear to come back. Any slight ache, pain, or other unusual symptom and that fear that I thought I had worked through returns. There's often grief around it as well, and that's just a cycle of having to work through again and again. Oddly enough, it happens mostly when I'm really enjoying myself. I'm having such a good time, living life to the full, and thinking, "I don't know how many more times I'll get to do this."

<Cancer support group>'s been very supportive, and I've met a couple of women there. We've stayed in touch with each other. They're probably just a year down the line from me, and their disease has progressed. That is a real wake-up call to me of, "God, that could be me in a year's time." There can be times of a real sense of urgency of having to live life to the full *right now*, and that means doing more than I can because

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[3] Turner, Kelly A. (2014) *Radical Remission: Surviving Cancer Against All Odds*. New York: Harper Collins.

of the ME. There's a real sense of tension and constraint there.

8.2.6 The people around me

My sister has been the most understanding and supportive. She's the one who's able to see when I'm tired when other people can't. When I say, "I'm planning to do X, Y, and Z", she'll very gently, subtly help me to stop. I've got a brother who I'm close with as well, but I've never been too sure about where he stands in terms of the ME or understanding the root cause of it. I've never really had that open conversation with my brother. Probably because I don't want to know what he thinks, in case it's hurtful.

Mum didn't really get it, and she would be the one to say, "We all get tired" or "I've got a bit of ME too". She'd be the one to push me. We've never seen eye-to-eye on ME. It's absolutely changed since my secondary cancer diagnosis. Mum's become Super Mum, and *she'll* be the one now saying, "Oh, you're doing too much, you need to rest more." Really looking out for me.

The whole family have been fantastic. Friends have been fantastic. The amount of love and support I have felt coming my way since my diagnosis has truly overwhelmed me. It's such a devastating diagnosis on the one hand, on the other hand, if you're going to have any life-threatening condition it's a good one to have because people *get it*. Or think they get it. There's no question marks over it; there's understanding and compassion from people. The NHS and voluntary sector, other support agencies, are set up and geared towards providing a lot of really good quality support.

It's chalk and cheese compared with the ME world. The NHS are very good at acute care, but they don't know what to do with a lot of chronic conditions. It's easy to feel quite abandoned and to find it difficult to have a mutual understanding of why I'm struggling, what I need, and what my concerns are. It's quite interesting having these two different conditions, one of which has seriously affected my quality of life to the point I've lost my house, my career, the lifestyle that I really enjoyed. I was invisible for most of the 20 years I had ME. When I was unwell with it, I was isolated, at home, alone, and left to it by the outside world. It wasn't until I was able to make the effort to socialise that things would change. People weren't really around for me. As is often the case with long-term conditions, you're just left to get on with it.

The opposite was true with the secondary diagnosis, I've never had so many offers of help and support. Particularly in the first year, because that's when I was going through chemotherapy, which again, people think they understand. Or they *do* know how challenging and debilitating that can be, and that people need extra help. And it's short-term so people are able to help out, rather than long-term, which is absolutely understandable.

One friend in particular, we were reasonably close before my diagnosis, but she was a fantastic support. She would drive me to hospital, and she would sit in sessions with me, keep me company. She was there at the drop of a hat. Another friend who lives at a distance, every few weeks he'll send me a card or a little gift in the post. He remembers when I'm going for appointments and he'll keep in touch by text, with the understanding that there's no pressure for me to respond, he just wants to encourage and support me. It means the world, it *really* makes a difference. Other friends kept in touch regularly by phone virtually. And I got so many cards from people wishing me well, even from people I didn't know directly, which was really touching.

8.2.7 Looking forward to the future

I still hold on to that *Radical Remission* perspective, but I hold onto that in a more realistic way, by which I mean it *might* happen for me. But at the same time, I know it might not. It means I live with a lot more gratitude than I did before my diagnosis. I'm interested in the spiritual side of life and meditation, being very grateful for the good things in my life. This has brought it to a new level, and to a real understanding of coming back down to the basics of how much there is to be grateful for in life. I'm very conscious of making the most of doing what I can do, whilst I can do it. I've moved beyond the stage of having to make every day a good day and a special day. That didn't last long at all, because that's just impossible. But I will often notice when I'm doing something boring, or mundane, or unnecessary. I'll be questioning myself, "Is this really how I want to spend my time?"

And often I will say, "Yes! Because this is normal life, and this is almost *downtime*. We all need downtime. We can't live in that special moment all the time."

I was told that I might have 2 to 10 years. I understand that that's just figures plucked out of general data that they have and doesn't specifically apply to me, but it *still* sticks in my head. I'm thinking about the 10 year mark. I live with that grief of thinking that I probably won't grow old, I won't know what that feels like. Even if I get 10 years, that's 25 years of life I'm going to miss out on potentially. Of course, none of us know when we're going to go.

I hope that Mum goes before I do, God bless her, not that I *want* her to go! And I want to see my niece and nephews grow up, I want to see what they make of their lives. I'm carrying on as independently as I can for as long as I can. I've put my house in order, and that feels good. I've got my will sorted out; I've got power of attorney sorted out. I've got end of life plans loosely sorted out as well, funeral sorted out. Again, this is back to understanding the person. To me, this is all important. I'm a planner. I like to know everything's in order, as much as is possible. So, I feel I'm okay now about whatever comes next.

8.2.8 Telling my story

During the last 18 months I've come across a lot of people who are involved in my care, and I've been in a lot of different wards, particularly when I was hospitalised during chemotherapy. You'd get these awfully lengthy forms to fill out, and it took me a good number of times to figure out that this is them *trying* to build up a picture of who I am. I've now written myself a list which is in my emergency bag, so I can say to them, "I'm single, I live alone, I do this, these are my supports, this is their situation." Which is one of the reasons I'm interested in this project, because I can understand that gives them a fuller idea of who I am as a person, what my coping mechanisms are like. I tend to underplay how I'm feeling. My response tends to be, "Oh yeah, I'm not feeling too well, but I'm *ok*." I'm putting on a brave face really, and feeling uncertain about being able to tell them what I’m worried about.

It’s easier to tell my story than it used to be because I’ve got a better understanding of myself, and a broader perspective, so I’m not so bogged down in feeling I have to explain all the symptoms. I’m not currently in crisis, nor unduly worried about my health, and crucially I understand my health ailments. Telling one’s story when uncertainty abounds and one is feeling ill would be more challenging.

I can now see that an app which patients can work through by themselves in their own time so that they remain in control of the story and work at their own pace could be a very useful tool. Such an app could also help patients to see their situation in a wider light and hep them to identify strengths and weaknesses within their own circle and to identify priorities.

Knowing how to tell one’s health story isn’t easy. But it’s good to do it. It’s helpful. It’s a helpful thing to revisit, and to view one’s own journey, and where I’m at, and what I’ve been through. To remember, and to share, somehow.

9 Tedhead

9.1 About

Gender	Male
Age	53
Conditions	Myalgic encephalomyelitis (ME), chronic depression, irritable bowel syndrome (IBS)
Lifestyle	Tedhead is married and has 3 stepsons. He has a PhD in medical technology and before his illness he worked as a medical engineer at a university.

9.2 Tedhead's Story

Figure 18: Tedhead's former boat, "Irene", and a serving tray representing his wife's care. Image. Source: participant.

She went down last October in a pouring driving rain.
The skipper, he'd been drinking and the Mate, he felt no pain.
Too close to Three Mile Rock, and she was dealt her mortal blow,
And the Mary Ellen Carter settled low. …

Well, the owners wrote her off; not a nickel would they spend.
She gave twenty years of service, boys, then met her sorry end.
But insurance paid the loss to them, they let her rest below.
Then they laughed at us and said we had to go. …

All spring, now, we've been with her on a barge lent by a friend.
Three dives a day in hard hat suit and twice I've had the bends….
But we've patched her rents, stopped her vents, dogged hatch and porthole down.
Put cables to her, 'fore and aft and birded her around.
Tomorrow, noon, we hit the air and then take up the strain.
And watch the Mary Ellen Carter Rise Again….

And you, to whom adversity has dealt the final blow
With smiling bastards lying to you everywhere you go
Turn to, and put out all your strength of arm and heart and brain
And like the Mary Ellen Carter, rise again.

Rise again, rise again - though your heart it be broken
And life about to end
No matter what you've lost, be it a home, a love, a friend.
Like the Mary Ellen Carter, rise again.

-Selections from *The Mary Ellen Carter*, by Stan Rogers (BluegrassNet, 2020)

9.2.1 Living with depression

I’ve had depression since my mid-teens. I had a miserable time through high school, and when I did my first degree at university, I was quite depressed. I went to a lot of talking therapies, and they never did a great deal for me. In the end, I went to a GP and got prescribed drugs and they’ve worked very well for me. I have very limited side effects and very positive benefits from it. Although my depression affected the first decade or so of adult life, so long as I stick with my drugs I keep a lid on it.

9.2.2 When I became unwell

I was working at the <University>. I worked in the department of surgery as a lecturer and researcher. My background was engineering. I led a team and we designed, made, tested, and experimented with new surgical devices for a guy who was a respected general surgeon. Most of that was keyhole surgery, and that sort of stuff.

My IBS, the way it presented was urgency. I would just desperately need to go to the toilet all of a sudden. I would call it my 10-minute warning: I'd get 10 minutes' warning, and after that, whatever I was doing, it was coming out. That was very difficult to deal with. I had my bowels checked out with a colonoscopy, and that all came back clear. I saw a dietician and didn't really make much progress on that, but I started to recognise there were trigger things for the IBS and the urgency. So, I started to address those myself through diet.

One of the things was I used to really love was craft ales, and that was one of the triggers. In fact, that's a repeating story in trying to manage my condition is that I have to dispense with things which I find that aggravate my condition. And it's not a static thing that once you dispense of an aggravating factor, that that's you fixed. Something else will come along and start upsetting your body, and you then have to try and work out what that is and get rid of *it* as well. No one really understands why it's not a once and for all type thing. It's not like that, and no one knows why. But it's a common theme right across – I think it's an autoimmune type of issue.

In 2003, I was unwell on and off for a period of about 18 months or 2 years with an ME-like illness which came and went. That's a very unusual presentation. Normally you get it and you get it, it just comes. But for me, it came and went, and then disappeared. For 7 years I was perfectly healthy.

And then, as it happens the onset was very sudden and I know the date: it was the 7th of September 2010, nearly a decade ago. It was a Tuesday morning, and suddenly I was just so exhausted I could barely get out of bed. That persisted for quite a number of weeks and then slowly improved. After a few months off, I got back to work part-time, and then I got back to full health. That lasted a few weeks, then it would suddenly reoccur again. It was on again, off again, up, and down. Slowly, it regressed to the point where after 2 years, I had to retire from work.

Diagnosis took a couple of years and just speaking generally about the ME community, that's typical. It takes a long time to get a diagnosis. I was quite unusual: I had quite a good idea what ME was. When I got unwell, I had a good idea that if this didn't clear up it was going to be ME, and it was. My GP was slow off the mark to describe it as such. I signed up for a research study, and to be eligible to go on the research study I had to have a diagnosis of ME, so the research physician himself diagnosed me. He went into my history, gave me a diagnosis, and then recruited me to the study, which is kind of an odd way of getting it. Normally you get a diagnosis from your general practitioner.

When you're really ill, you're cognitively so impaired, and physically so unwell, that it doesn't really matter what anyone says to you. It just goes in one ear and out the other. You can't think through the implications. You can't lie there in bed and think, "Oh my god, my life has changed forever." It's very hard to describe the cognitive impairment that comes with severe ME. You can't think; you can't dwell on anything; you're not really on the planet.

I was very fortunate: I think the drugs I took for the depression enabled me to stay optimistic. And also, I accepted this is what it's like and I'm going to have to get on with it. I don't know why I adapted particularly well to it, but I did. Maybe because I knew of it beforehand, so I knew that there's no point rushing around trying to find treatments. A lot of newly diagnosed people go crazy doing all sorts of new things they think that will make them better, and the old timers are kind of like, "Been there, done that, and it doesn't work so don't waste your time and your money on it".

9.2.3 Since then, my life has changed

Until about 2016 my health was constant. I would describe it as mild ME: every few weeks you'd get a flare up and it would knock you back into bed, and then after a few days it would subside. My average day was quite okay. Looking back, I'm really surprised how much I did. I would pull the boat out of the water, hitch it up to the back of the car, tow it over to the west coast, and sail out of Oban. I did that once a year over several years. Then about 4 years ago, my health just started to go downhill, for reasons that I've never been able to identify.

I was able to keep sailing right up until about 2 years ago. I had to wait for spells when my stamina and my health were good, but it was an enormous source of tranquillity and peace for me, and it was one of the few things from my old life that I was able to keep doing. There were lots of sailing trips I would've liked to have gone on which would have been beyond my stamina, but all the same, I could keep doing the thing I loved. That was something I clung to and enjoyed for a long time. Unfortunately, my health just dwindled to the point where I couldn't maintain it and I had to get rid of the boat. That was a big blow to me. It hit me really hard, and I still dream about sailing quite a lot.

Now my ME is kind of moderate. Typically I'll wake up at 9, be in bed until 11 in the morning, and then get up. I'll usually be able to potter around and do something outdoors during the day: a bit of weeding in the garden, or walk the neighbour's dog. Not always, but usually. I'll have a nap in the afternoon, spend the evening watching TV until about 8 or 8:30 and then just go to bed. I am significantly limited in what I can do. Some of the disabling factors are not the physical ones, but the cognitive ones. Fortunately, for me the cognitive losses are not great, but word recall is a real problem for me.

9.2.4 My experience with ME

I've known the song "Mary Ellen Carter" for a long time, and there are quite a number of parallels between that song and ME, but one striking issue which *isn't* parallel. In the song, the ship is ultimately saved by the strenuous effort of her loyal crew. In ME, such effort is futile. Indeed, it's often counterproductive. Straining to try and make myself better through exercise or pursuing non-existent cures drains away what little energy I might have. Failed treatments just crush my hope. So, the message of the song which might be expressed as "salvation through effort" does not apply to folk with ME.

Biographically, the ship represents your life. That's what the singer's intending, that it represents your life and the battles in your life, and the sinking is obviously contracting ME. The thing about that song is that it offers *hope*. There's hope that the ship can be rescued and returned to service, that you can go return to your normal life. Unfortunately, in ME, there is no such hope, and the way in which you have to deal with ME is to accept that this is your life now. Your obligation is to live without the hope of returning to your former life. You have to live with the constraints that you now find yourself in, because there isn't even a *treatment*, let alone a cure. But that, for me is too negative. I have to live with some hope, and that song is the song of hope. There isn't a cure or a treatment now, but one day I'm kind of hoping divers will come down, fix me up, and re-float me to the surface.

The other significant parallel of the song is the line which says, "The owners would not save her, not a nickel would they spend." There is an almost universal dismissal of ME by formal health authorities: the NHS, research bodies, royal colleges, universities. And so, the hope and the resilience expressed in the song reflects the fact that you're going to have to deal with it yourself. You're going to have to be resilient towards people, authority figures, who are dismissive. At least to some degree that is lessening now, which is a good thing. Things are very different even in the 10 years that I've been ill, and they're certainly very different from what they were 20 or 30 years ago.

9.2.5 The people around me

It is inescapable that you involve your family and loved ones, some friends, in your health. You lose some; they don't keep up anymore. I'm fortunate that I've not had too many of those that have dropped away, but I can also understand it. I'm not too much fun to be with. I don't go out much; I don't drink; I sleep most of the time. Socialising with me isn't much of a prospect.

The biggest impact is on my wife: my wife is my carer. Before I got ill, I was really healthy. I would leap out of bed at 6:30 every morning and bring my wife breakfast in bed. I did that for the first 10 or 12 years of our marriage. Now it's the other way around. For the last 10 years she's brought *me* breakfast in bed. She does it every day. And that's what the tray represents: the impact on people around you.

Fortunately, in Scotland we attach quite a high importance to carers, and there's a lot of political goodwill. Your GP will always inquire about how your carer is getting on. And there are lots of schemes and financial things available to carers to help them cope with the pressures of caring for someone who's unwell in the long-term.

When I became unwell, there was no support group in my area. There had been one, and it had died a death. So, I established a support group. As a result, I knew many dozens of people with ME, and we would meet up from time to time and do stuff.

9.2.6 Looking forward to the future

There are no formal treatments for ME. At a very early stage, I kind of accepted that it's wasting time and money, and also wasting *hope*, burning up your hope trying all these sorts of cures that do nothing. Very sadly, a lot of people try a lot of things, and it's just a waste of time.

However, people are beginning to think FMT, faecal microbiome transplant[4], is a possible candidate for a range of conditions, particularly those which are autoimmune conditions. There is *limited* evidence, and I have to say the evidence is very limited, that it's helpful in ME. So, whereas previously I've kind of made a big personal point of avoiding all the Mickey Mouse treatments that come along, this is one that I thought could make a difference. This is actually one that's worth investing in. So, next week, I am going down to England for two weeks to have a poo transplant.

So, how do I feel about the future? The answer is complicated. If you had asked me 6 months ago before I started considering this, I would have said I'm hopeful because that's my nature, but not really based in any evidence. As far as I could see at that time, there are no treatments. And that *is* the case, it's not just my personal opinion. You just have to live with the condition as it comes along.

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[4] Faecal microbiome (or microbiota) transplant is a process in which faeces from a healthy donor are transplanted into the patient. Among other things, it is used to treat an infection of *Clostridioides difficile*, a bacteria that lives in faeces. Also referred to as a poo transplant.

Now, I feel very ambivalent. There's part of me says the chances are that this is not going to work out. Fortunately, the side effects are minimal, or non-existent really, so it's very unlikely that I will be *worse*. I just could've wasted a whole load of money and not made myself any better. But there's a part of me that says, "Yeah, let's feel a bit of hope. Let's hope that I'll be better in a few months' time." So that's how I feel. It's complicated, and I'm torn.

The final part of that answer is that I have in my mind this kind of dream. One of my stepsons is in Australia, and I have a dream that one day I'll sail to Australia. I couldn't do that unless I was back to former fitness, and I don't know whether I'll ever do it anyway. But it's a *dream*. It's something I hang onto. In a way that kind of sums up how I feel about the long-term future: not today, not tomorrow, not this year, not even this decade.

9.2.7 Telling my story

I very rarely tell my story to friends, family, or other people. I don't know why. There aren't that many people who sit and listen, for a start, and I would hate it to sound as if I was self-pitying. I can't stand self-pity. If anyone had the idea that by articulating my story I was pitying myself in some way, I would be mortified. I'd hate that. So, there are two occasions on which I have to tell my story. The first is to students, which I do a lot. 9 out of 10 students have never come across ME before, so it's a good educational thing for them.

The second is going to a health professional. It's difficult: you're always aware that they may treat you with complete scepticism. I did a Masters and a PhD in Medical Technology, and then worked for 12 years in a medical department. So, I can kind of use the language and style of communication that medics would use, and I think they *must* treat me with less scepticism than the ordinary ME patient would get. I think I'm fortunate, and I don't think I'm representative. If I had just continued in engineering and knew nothing about medicine, when I went to the doctor I would feel very hesitant, reluctant, and anxious about saying what I thought, because I would probably just be dissed. "It's all in your head, pull yourself together."

10 Further Exemplary Quotes

10.1 G1: Seeing the Big Picture

Participant	Quote	Comments
Lee	When I'm going to appointments, and it's, "You should have tried". Well, here's all the things that I've tried and here's how I'm still feeling. Or, you know, I am being able to achieve these things, so that's a huge thing and being able to reflect on that. Because, when you're going to an appointment, the first thing they say is, "How are you?" And the first thing you do, you're like, "Oh, I'm fine." So, actually being able to be like, "Oh, actually there was a couple times there that I wasn't able to do much that week and here it is here for you." I think that would be brilliant.	Relates to **G3: Challenging Scepticism** and the sub-category of **Evidencing what has happened**.
M	[This tool]…would be very, very beneficial regardless of who you're seeing. And it will act as a reminder because you do forget. And also…you forget words. This is an MS thing. You forget words, simple words… Your mind just goes totally blank. And so, having a tool like that would make that process easier, and make it easier for you to describe the word that…you can't remember.	Touches on experience of having MS, also relating to **G2: Conveying the Illness Experience**.

10.2 G2: Conveying the Illness Experience

Participant	Quote	Comments
Rhona	This would be so beneficial to me. It would give me more confidence...within my story. And confidence telling people, especially medical professionals. It would take the pressure away, and I think that would be really important. I totally 100% can see this being so useful to me.	Shows how conveying the illness experience is also important for personal mental health/wellbeing.
M	I think that it would really help... Not so much for me, because I will just say it, no matter how embarrassing it is. I think for other people it could maybe...help them get things across a wee bit more, you know, some things that they might not want to say about their moods or anything like that. I think it would be easier for them.	Illustrates sub-category **Supporting communication**.
Sharon	It's partly...[finding things hard to express], and partly, more with friends and family, just not wanting to always be talking about health. But, at the same time, possibly, wanting them to know where I'm at. So that would enable them to be kept up to date, but whilst I'm meeting them or having interactions with them, we're not focusing on that directly. And that element, I think, would be really, really useful."	Illustrates sub-categories **Supporting communication** and **Getting support**.
Tedhead	I very rarely tell my story to friends, family, or other people. I don't know why. There aren't that many people who sit and listen, for a start, and I would hate it to sound as if I was self-pitying. I can't stand self-pity. If anyone had the idea that by	Shows how people with health conditions may feel uncomfortable talking about their health to others, even close family and friends.

articulating my story I was pitying myself in some way, I would be mortified. I'd hate that.

10.3 G3: Challenging Scepticism

Participant	Quote	Comments
Lee	They will suggest things like, "You should try yoga" or "You should try swimming". And when you say, "But I do these things", it's almost as if they're like, "Oh, but do you really?" …So, being able to evidence that would be great, because I think that they do definitely just think, "…Oh, but did you?"	Shows discomfort/frustration at having expertise over health challenged or not recognised.
Rhona	I don't like telling health professionals my story, especially mental health professionals. I find that really frustrating because some of them are incredibly ableist.	Illustrates point that people may want to select which healthcare professionals to share their story with, rather than having them added by default.
Sharon	I've moved around quite a lot, so I've seen quite a number of GPs, and none of them were very sympathetic, understanding, or knowledgeable about…[ME].	Relates to sub-category **Education and advocacy**.
Tedhead	When you're working in consensus with a healthcare professional, you hopefully work on a consensual relationship, and both sides share stuff and feel your way forward in what is a difficult and unknown territory for everyone, really. But, as I've said before, there are times when you need to organise a rebuttal and say, you know, I'm not accepting this treatment, or your perception of my illness is misguided…it's not just me that's saying so, I have scientific basis for rebutting the way you're approaching my care.	Relates to sub-category **Education and advocacy**.

10.4 Validation of the Methodology

Participant	Quote	Comments
Lee	…I know it's…my story, but it's just been really interesting how you've went away, put it all together, and then discussed it with me and went through it all. And it's really helped me, actually. Even for the first week, being like, "These are the things that help me." …Just reminding myself that.	Using the project for self-reflection.
Sharon	I'm quite amazed at what you've been able to achieve just from a couple of chats between us, and how accurately you've managed to translate those discussions, as well. It's difficult to think back now to the first meeting, which was the most intense one, I think, it was trying to find a way to relate my story to you. But, I do remember at the time thinking, even having done that…was a useful process to go through. It's a long time since I've done that, if ever. And the last session we had where we were playing around, that was good fun. Seeing the basic layout that you had then, as I seem to recall, and then we played around with it a bit more, and I had the easy job of just being able to come up with any ideas and send them your way to do something with.	Interest/enjoyment at seeing the prototype evolve (dialogic approach), increased sense of wellbeing from sharing one's story.
Tedhead	I have been impressed with…the way you've followed everything up, you know, with the transcripts, to check that I'm happy with stuff. I thought that was professional.	Positive feedback on dialogic approach.

10.4.1 Remote Fieldwork

Participant	Quote	Comments
Lee	I think that it's done on Zoom makes it so much easier. It makes the conversation flow easier as well, but also when you were sharing things, like in the second workshop when you were sharing stuff. It was actually so easy to do, so easy to interact with it as well. So, although I was like, "Oh, I don't know...how this will work." But at the same time it was just really easy and straightforward, and you explained everything.	Ease of participating, positive feedback on planning and execution of workshops.
M	I've not come up against any issues or anything. The technology is fine. It's not what I'm used to using, but...I'm a dinosaur as far as my girls are concerned, so that's nothing new. I've not had any problems having to work anything or do anything.	Ease of participating, accessibility.

11 *Implications for Design*

11.1 Introduction

In this chapter, I summarise the implications for design presented in Chapter 6 of the thesis. This provides a more convenient reference which can be used by designers and developers working in digital health.

The first section of this chapter gives a summary of the high-level requirements for a health storytelling tool. The following sections summarise the requirements organised according to the overarching goal categories (described in Section 6.3 of the thesis). For each category, I have given the following information:

- Who the primary audiences are for this particular goal (i.e. potential collaborators)
- What research participants wanted to be able to do to achieve this
- Functionality needed to support this goal
- Examples from the individual participant prototypes which illustrate this

For further information about the individual prototypes (including images and links), the reader should refer to Chapter 5 of the thesis.

11.2 High-Level Requirements

Examination of the findings shows that health storytelling tools must include the following areas of functionality:

- Ability to record information, including personal experiences outside of one's biomedical health, to enable self-reflection and insights
- Ability to share information and allow others to communicate with the storyteller in a way that reinforces the storyteller's expertise and ownership of their story
- Personal and emotional modes of storytelling, particularly in support of mental health
- Features which allow the storyteller to limit access by collaborators and retain their privacy

Analysis of the participants' story forms also shows that:

- Stories need to be open-ended and easily extendable
- Stories should be modular
- Tools should not unnecessarily limit the way in which stories are told (e.g. forcing stories to be organised either by condition or by timeframe)

11.3 G1: Seeing the Big Picture

11.3.1 G1.1 Recording memories

Primary audiences: family/friends, self

Findings: what participants wanted	Implications for design/functionality
• Looking back and remembering what has happened (both good and bad) – this included both events related to health conditions as well as generally in their lives • Expressing one's own perspective on events outside of the medical record • Celebrating "small wins" (Lee) to wellbeing	• F1.1, F1.6: Tracking mental and physical health • F1.2: Recording written accounts of events (journaling) • F1.3: Visual representations and media • F2.1: Privacy and access controls for collaborators, to control who can see more personal memories
	Key examples from prototypes
	• Rhona – burrow of stories, private stories • M – light and dark memory garden

11.3.2 G1.2 Self-reflection

Primary audience: self

Findings: what participants wanted	Implications for design/functionality
• Gaining insights into one's health (and oneself in general) over time • Reflecting on personal wellbeing • Thinking about goals and plans for the future	• F1.1: Tracking mental health • F1.2: Recording written accounts of events (journaling) • F1.5: Goals
	Key examples from prototypes • Lee – recording outcomes of self management activities • M – memory garden (photo wall) • Sharon – daily trail notes, treatment paths • Tedhead – hope flower

11.3.3 G1.3 Daily self management

Primary audiences: healthcare professionals, alternative healthcare professionals, self

Findings: what participants wanted	**Implications for design/functionality**
• Remembering details of what one has done to share with others • Evidencing what has happened • Spotting trends in how activities affected one's health • Planning for future events/obstacles	• F1.1, F1.6: Tracking mental and physical health • F1.4: Recording activities • F1.5: Goals
	Key examples from prototypes • Lee – strategies and player profiles • Sharon – daily trail notes

11.3.4 G1.4 Understanding one's conditions and treatments

Primary audiences: self, healthcare professionals, alternative healthcare professionals, disease-mates

Findings: what participants wanted	**Implications for design/functionality**
• Understanding patterns in one's health over time • Making sense of treatment options • Recording and understanding research around one's condition and/or potential treatments	• F1.5: Goals • F1.6: Tracking physical health • F2.4: Recording knowledge and research, and sharing that information with others
	Key examples from prototypes • Sharon – treatment paths • Tedhead – research rutters

11.4 G2: Conveying the Illness Experience

11.4.1 G2.1 Supporting communication

Primary audiences: family/friends, healthcare professionals

Findings: what participants wanted	Implications for design/functionality
• Detail what has happened for others (but also choosing how much to share) • Assistance in articulating emotional events • Being able to communicate indirectly about one's health without having to speak to someone directly • Coordinating/sharing information amongst healthcare professionals	• F1.1, F1.6: Tracking mental and physical health, and sharing that information • F1.3: Visual representations and media • F2.1: Privacy and access controls for collaborators • F2.2: Discussion and messaging features – including the ability for collaborators to leave more abstract responses (e.g. emoji reactions) • F2.3: Exporting a short summary of one's story in an easily shareable format
	Key examples from prototypes • Rhona – shared stories, ability to "seek guidance" from others, exporting stories • Sharon – broadcasting to friends, cloud cover • Tedhead – hope flower

11.4.2 G2.2 Getting support

Primary audiences: family/friends, disease-mates, official bodies, co-workers

Findings: what participants wanted	**Implications for design/functionality**
• Helping others understand the illness experience, particularly to challenge scepticism • Articulating difficult experiences • Asking for advice from others, particularly disease-mates • Getting assistance from organisations (e.g. government, charities, workplace, school)	• F1.1: Tracking mental health • F1.2: Recording written accounts of events (journaling) • F1.3: Visual representations and media, particularly abstract representations of emotions • F2.2: Discussion and messaging features which allow collaborators to communicate directly with the storyteller • F2.3: Exporting a short summary of one's story in an easily shareable format
	Key examples from prototypes • Rhona – shared stories, ability to "seek guidance" from others, exporting stories • Sharon – broadcasting to friends, cloud cover • Tedhead – hope flower

11.4.3 G2.3 Inviting alternate perspectives/sense-making

Primary audiences: family/friends, disease-mates

Findings: what participants wanted	Implications for design/functionality
• Asking for help from others in understanding one's illness experience • Getting alternate perspectives on what had happened	• F1.7: Tracking treatments and outcomes • F2.2: Discussion and messaging features which allow collaborators to communicate directly with the storyteller
	Key examples from prototypes • Rhona – commenting on stories, ability to "seek guidance" from others • Sharon – broadcasting to friends, treatment paths

11.5 G3: Challenging Scepticism

11.5.1 G3.1 Evidencing what has happened

Primary audiences: healthcare professionals, family/friends

Findings: what participants wanted	Implications for design/functionality
• Evidencing to others what has happened by showing details of one's health and activities over time • Providing descriptions of one's life and experiences to illustrate the challenges of the one's health conditions • Having one's expertise recognised by healthcare professionals	• F1.1, F1.6: Tracking mental and physical health • F1.2: Recording written accounts of events (journaling) • F1.4: Recording self management activities and outcomes • F2.1: Privacy and access controls, to limit access to important but potentially unfriendly collaborators • F2.3: Exporting a short summary of one's story in an easily shareable format
	Key examples from prototypes • Lee – self management strategies and player profiles • Rhona – stories illustrating her experiences, privacy/sharing controls, exporting stories • Tedhead – daily logs

11.5.2 G3.2 Sharing knowledge about conditions and treatments

Primary audiences: disease-mates, healthcare professionals

Findings: what participants wanted	**Implications for design/functionality**
• Asking for help/advice from others and also communicating one's own knowledge • Recording and sharing research on one's condition and treatments	• F2.1: Privacy and access controls to manage collaborators • F2.2: Discussion and messaging features which allow collaborators to communicate directly with the storyteller • F2.4: Recording knowledge and research and allowing others to view/edit this information
	Key examples from prototypes
	• Rhona – commenting on stories, ability to "seek guidance" from others • M – mail feature • Tedhead – research rutters

11.5.3 G3.3 Education and advocacy

Primary audiences: healthcare professionals, advocacy groups

Findings: what participants wanted	Implications for design/functionality
• Recording and sharing research on one's condition and treatments • Coordinating collaborative advocacy efforts through discussion and planning	• F2.1: Privacy and access controls to manage collaborators • F2.4: Recording knowledge and research and allowing others to view/edit this information • F2.5: Features supporting collaborative advocacy work
	Key examples from prototypes
	• Tedhead – research rutters

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