



**AUT CENTRE FOR
PERSON CENTRED RESEARCH**



Co-designing an interactive website resource: a space to share stories and strategies for people experiencing changes to their memory and thinking

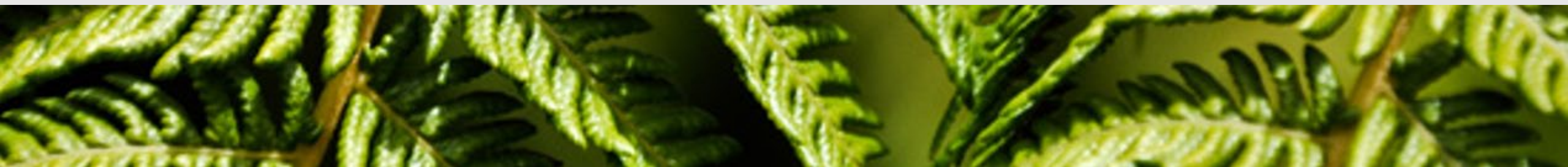
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Where we started

- To develop new knowledge about living well with Mild Cognitive Impairment (MCI)
 - How do people live well with MCI?
 - What helps them to live well?
 - What strategies do they find helpful?
 - What are the best supports?
- To develop an interactive online resource for people with MCI and their families

Overarching goal: To embed the perspectives of people living with MCI in BRNZ



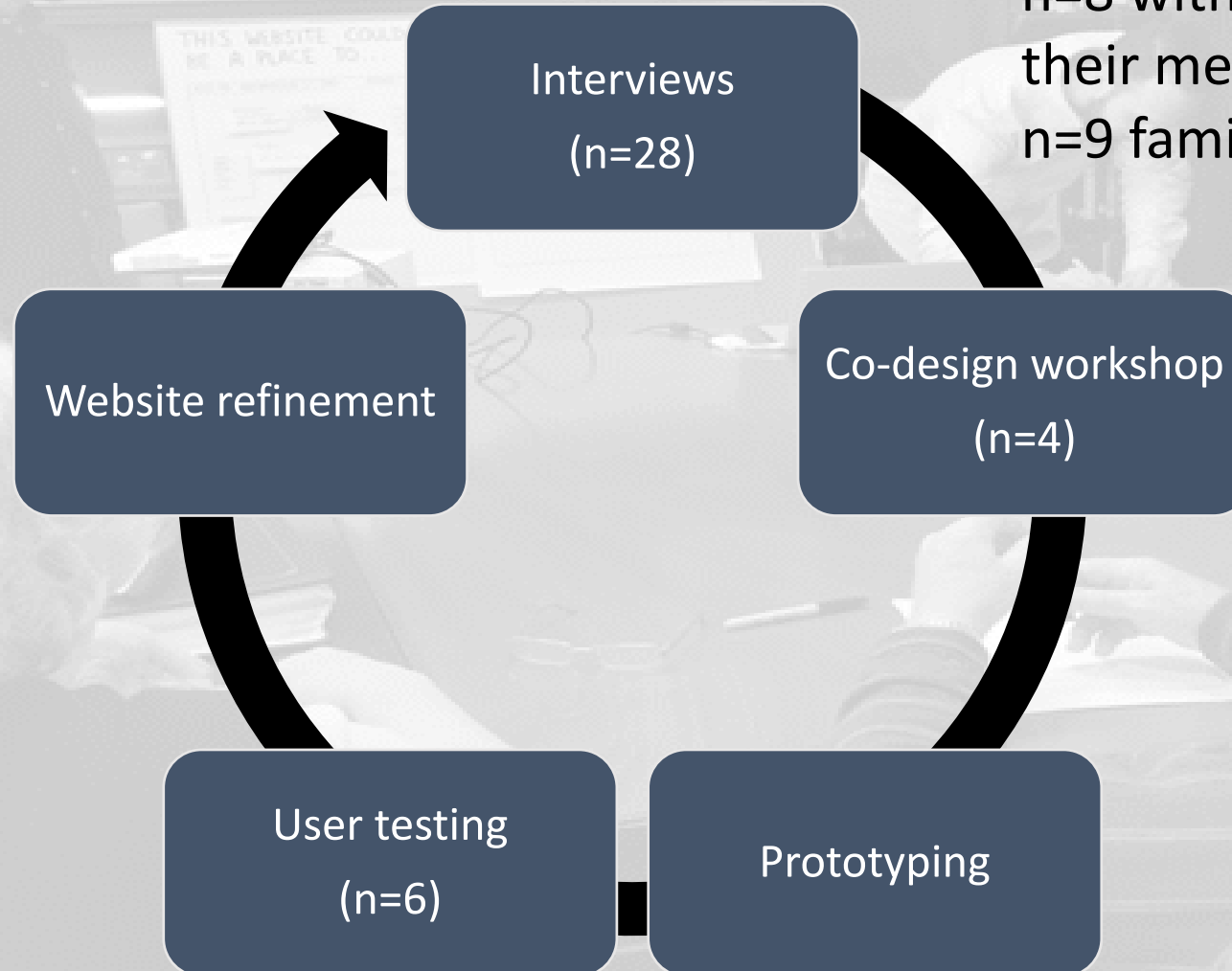
A design for health collaboration

Together, we make
future-focused
health and wellbeing
experiences.





What did we do?



n=11 with formal MCI diagnosis
n=8 with self-reported changes to
their memory and thinking
n=9 family members

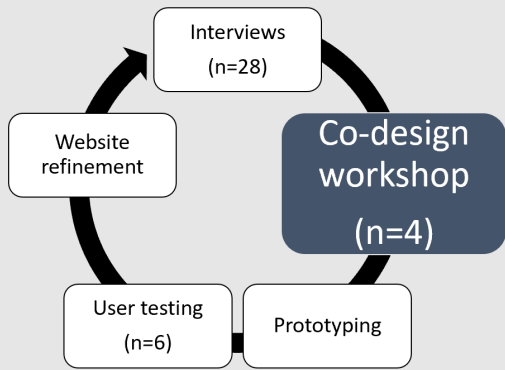


Who are we designing for?

- The blurry edges of an MCI diagnosis
- Not everyone identifies with MCI
- Potential to limit our sample to people who are already accessing health services
- Need to consider when it would be most timely for people

Agreed focus: People experiencing changes to their memory and thinking, whether or not they have a formal diagnosis of MCI





OUT AND ABOUT

APPOINTMENTS

NOTES NOTES
NOTES

APPOINTMENTS
DIARY AND
CALLING

SOCIALISING

MUCH LESS
INCLINED

SOCIALISING
WITH FRIENDS
A.S.A - EMCA
MILK
MILK

NAMES - remembering
picked person when
introduced with note
on forehead, flash
several times
photo in front of
address book with details

SOMEONE
RECALLING
NAMES
NOW NOT NEXT WEEK

THINKING

most words,
train of thought
forms

patients
categorising
sequencing
ordering

WANT TO STILL
BE PART OF
WHAT'S NEW/HAPPENING

THINKING
USE DAILY MANNER
TO ASSIST MEMORY

NO LONGER IN
MAIN STREAM

fear of new learning

REALISATION
NOT IMPORTANT

LEARNING
NEW THING
DIFFICULT
- FEAR OF
FAILURE

FEELING

feeling
OUT OF THE
LOOP
RETIRED IS NOT
A SATISFYING DESCRIPTION

LOSS OF IDENTITY
FEEL LIKE A
GHOST

descript

SHUT OUT -
NOT RELEVANT

FACELESS
w/OUT VALUE

DOING

POWERLESS / NOT
ABLE
CHANGE

relinquishing
dreams

MULTI TASKING
NOT V. GOOD

BELONGING

ACKNOWLEDGING
VULNERABILITY

life, goals
how to die

- realistic -

people no longer
interested in your
views

being treated as
child

VALUES
CHANGE

PEOPLE MAKE
ASSUMPTIONS ABOUT
ME AND ACT
ACCORDINGLY

FACELESS

AROUND THE HOME

COOKING

MAKING
TEA

Use of Main
cereal

using recipe - file on
computer - then
have to do steps by
visual people
interesting -
get all ingredients first

freezer
knowing what's in it

CLEANING

LESS THAN
TIDY SELF

RELAXING

BETTER AT
ALLOWING SELF
NON WORKING TIME

RELAXING
TV
AROUND

TECHNOLOGY

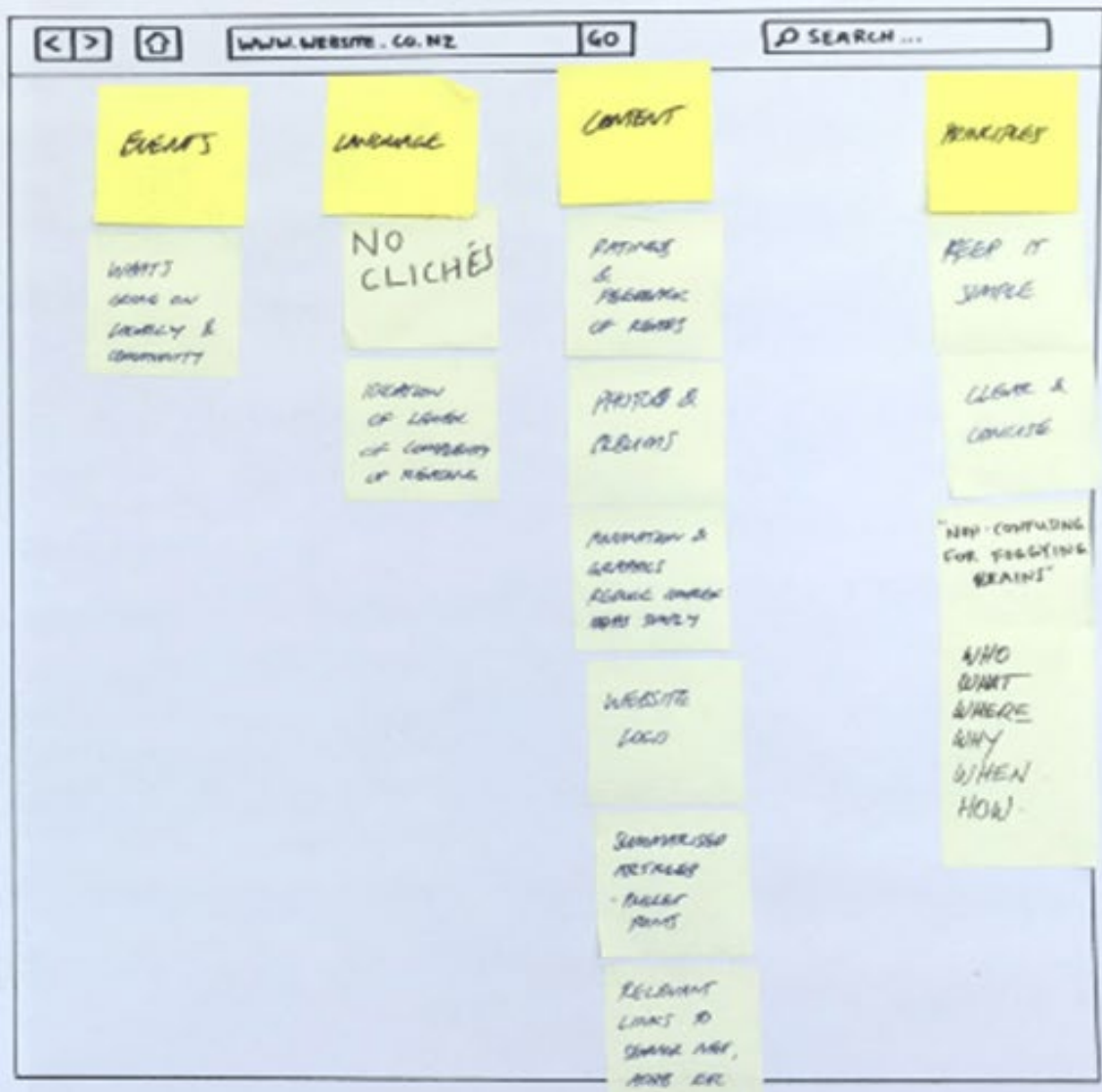
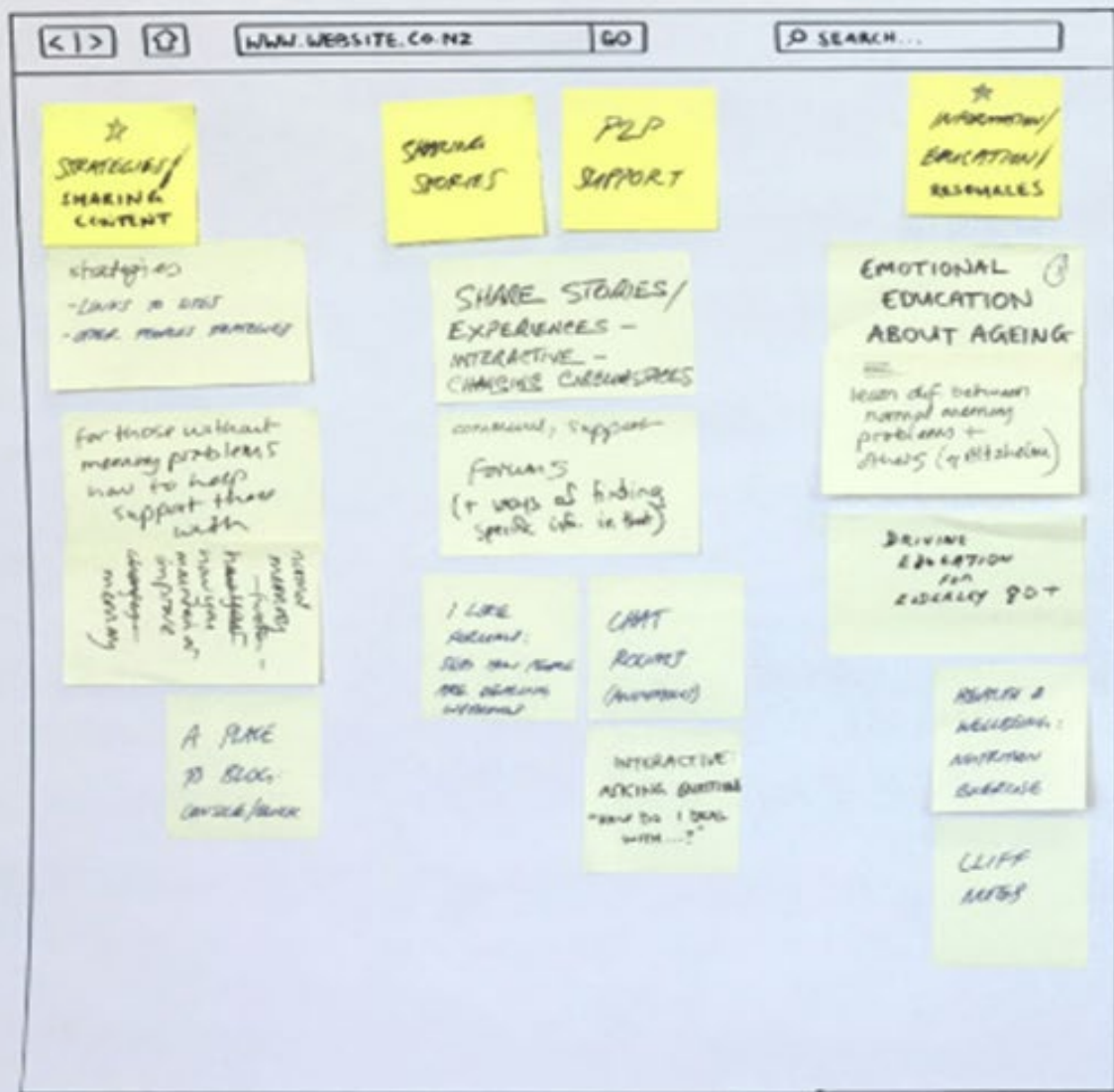
FORGOTTEN
FORGOTTEN
PASSWORDS

computer's autobiography
- to keep
file what happened in (year)

EMBRACING (TRYING
TECHNOLOGY)
TRYING TO WRITE AND
HOW TO SPELL

making for elderly
eg Mitsubishi

THIS WEBSITE COULD
BE A PLACE TO...

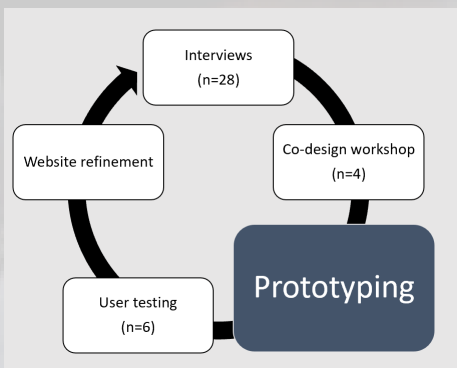


LOSS OF IDENTITY
FEEL LIKE A
GHOST

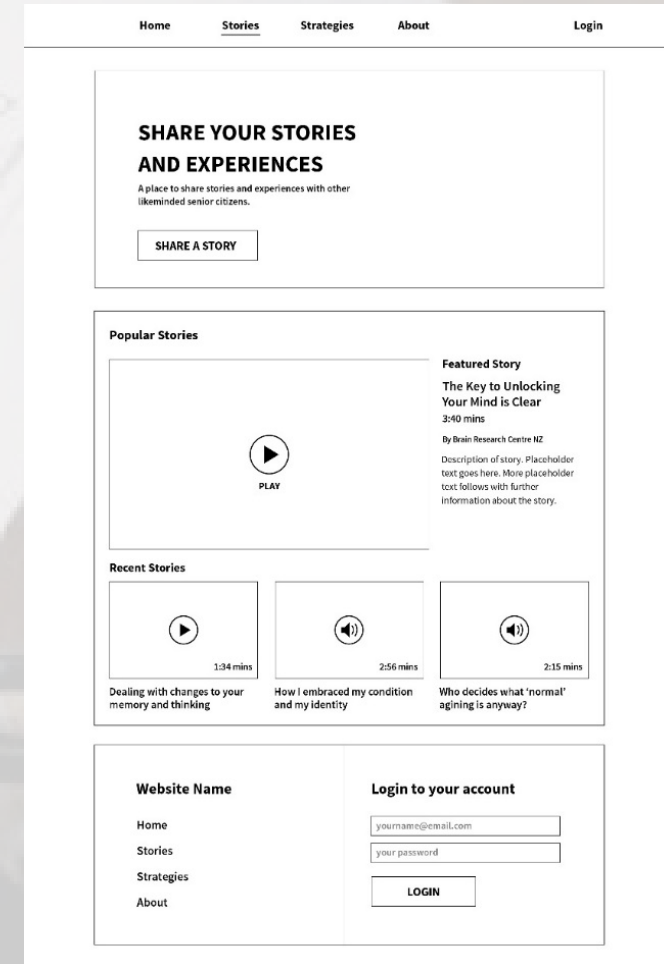
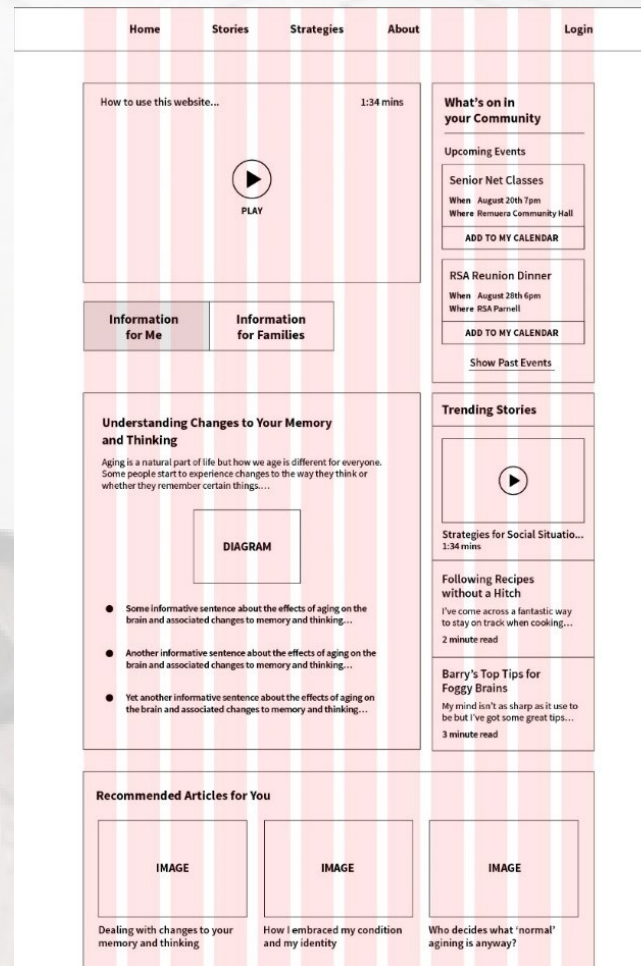
PEOPLE MAKE
ASSUMPTIONS ABOUT
ME AND ACT
ACCORDINGLY

LEARNING
NEW THINGS
DIFFICULT
-FEAR OF
FAILURE

SHUT OUT —
NOT RELEVANT



Developing wireframes





Prioritising content

Sharing Strategies

Share everyday strategies for managing changes to your memory and thinking, and learn new strategies from others

Sharing Stories

Share your experiences and stories about how changes to your memory and thinking impact on your day-to-day life, and learn about the experiences of others

Peer-to-Peer Support

Connect and interact with people who are going through similar changes to memory and thinking

Information & Education

Find out more about cognitive changes, their relation to the ageing brain, and how to 'live well' with changes to your memory and thinking

Events

Find out about things that are happening in your local or wider community e.g. Senior Net classes.

For Families

Information for family members on how to better support those experiencing changes to their memory and thinking



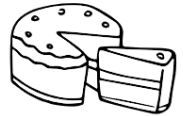
Learn

All about the ageing brain



Explore

What other people find useful

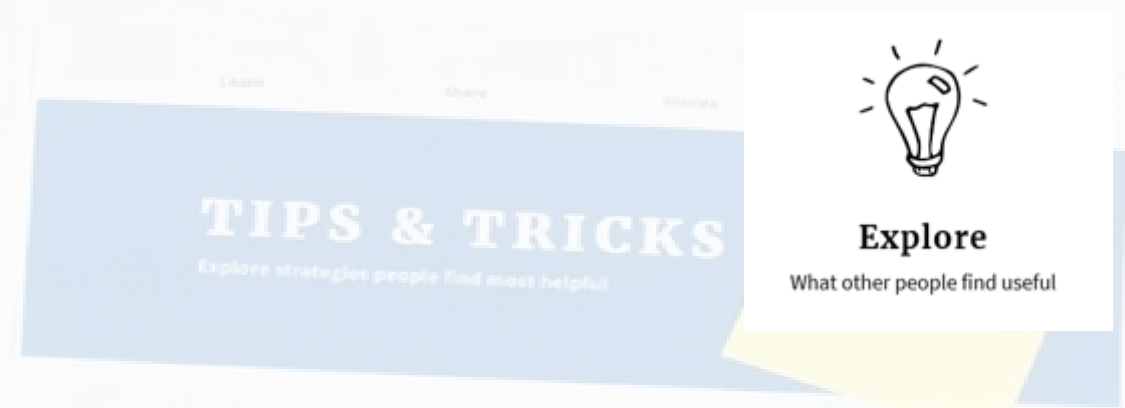


Share

Tips & tricks or stories about changes



Developing content



Tips & Tricks

Stories

Tips & Tricks

Stories



The Importance of Shirt Pockets

By Bobby Parsons

If you were to inspect all the shirts in my wardrobe, you may notice that each one has a pocket over the left breast...



Yellow flag for the car

By Harriet McBride

I can still drive, but sometimes when I go to the supermarket I'll forget where I've parked the car. It can be very frustrating and also quite fright...



Getting a diagnosis

By Cory Matthews

My mother was behaving differently and I wasn't sure whether it was normal for her age. She was repeating herself more often, telling me things that she had already said earlier,

PRIMARY
VS
SECONDARY
PREVENTIVE?

MINDS
CHANGING
CHANGE



Learn

All about the ageing brain

CHANGES

What is Grey Matters?

As we reach 65 many other organs in your body change but we will experience subtle changes to our memory and think that we are forgetting things more often than usual. Finding names or faces that should be familiar is frustrating and the same goes for the things we should know. Grey Matters is a place where you can find out more about these changes and how to cope with them.

EXPLORE

What is mild cognitive impairment
<https://vimeo.com/373781882>
(video)

Three
Points of
Value:

1. Learn about MC1

2. I'm not alone in this journey

3. To help solve specific problems

Over time, importance moves this way.

Popular Tips & Tricks

Get On/Off the Car

Life with a car is not always easy. It can be a lot of work to get in and out of the car, especially if you have a disability.

A Yellow Flag for the Car

I have a yellow flag for the car. It means I have a problem with the car that I need to be aware of. It's a warning sign that I need to be careful of the car.

Share your story...
A story or tip or trick that you have found useful.



Developing content



Share

Tips & tricks or stories about changes

What would you like to share?

Tip/Trick

Story

Name

Description

Describe your tip/trick: What is it for? How does it work?

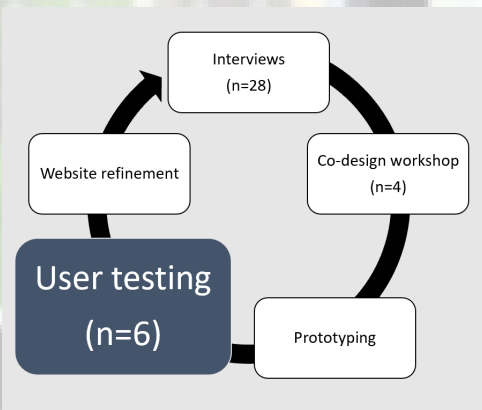
Upload media



Add a photo



Add a video



Content

Positive
Actionable
Credible

Usability

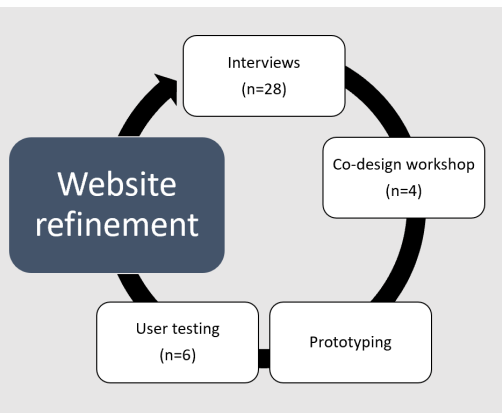
Simple
Intuitive
Easy to navigate

Functionality

Purpose
Guidance
Interactivity
Searchable

Look

Resonance



GREY MATTERS

Minds grow, change and age



Learn

All about the ageing brain



Explore

What other people

- Update and diversify imagery
- Reconsider website name
- Refine 'learn' section
 - Positive language
 - Actionable recommendations
- Confirm content
- Technical capability
 - Optimising for multiple devices
 - Interactive capacity
 - Plan for moderating content



Final reflections

- Co-design process helped to challenge assumptions about
 - Who the user is
 - Users wants, needs or concerns
- Positioned end-users as experts
- Hopefully contributing to a more usable, useful and engaging end product
- Future role of website in
 - Providing a space to share and learn
 - ... and potentially also a tool for raising awareness
- Watch this space we hope to launch publicly soon!







**AUT CENTRE FOR
PERSON CENTRED RESEARCH**

Acknowledgements



Professor Kathryn McPherson
Our participants and co-designers
Brain Research New Zealand
Project team
Centre for Person Centred Research
Good Health Design team

Always in conversation . Engaging with diversity . Connecting as people . Pushing the boundaries