

the problem

Most research is conducted within health systems, yet 70% of people with a lived or living experience of eating disorders are not regularly engaged with the health care system¹.

Research retention rates are low, and it is difficult to keep people engaged in long term research processes, limiting outcomes².

Health administrative data lacks detail about individual experiences, and rarely includes carer perspectives^{3,4}.

Diverse lived experiences may not be meaningfully contributing to our growing body of knowledge⁵.

the aims

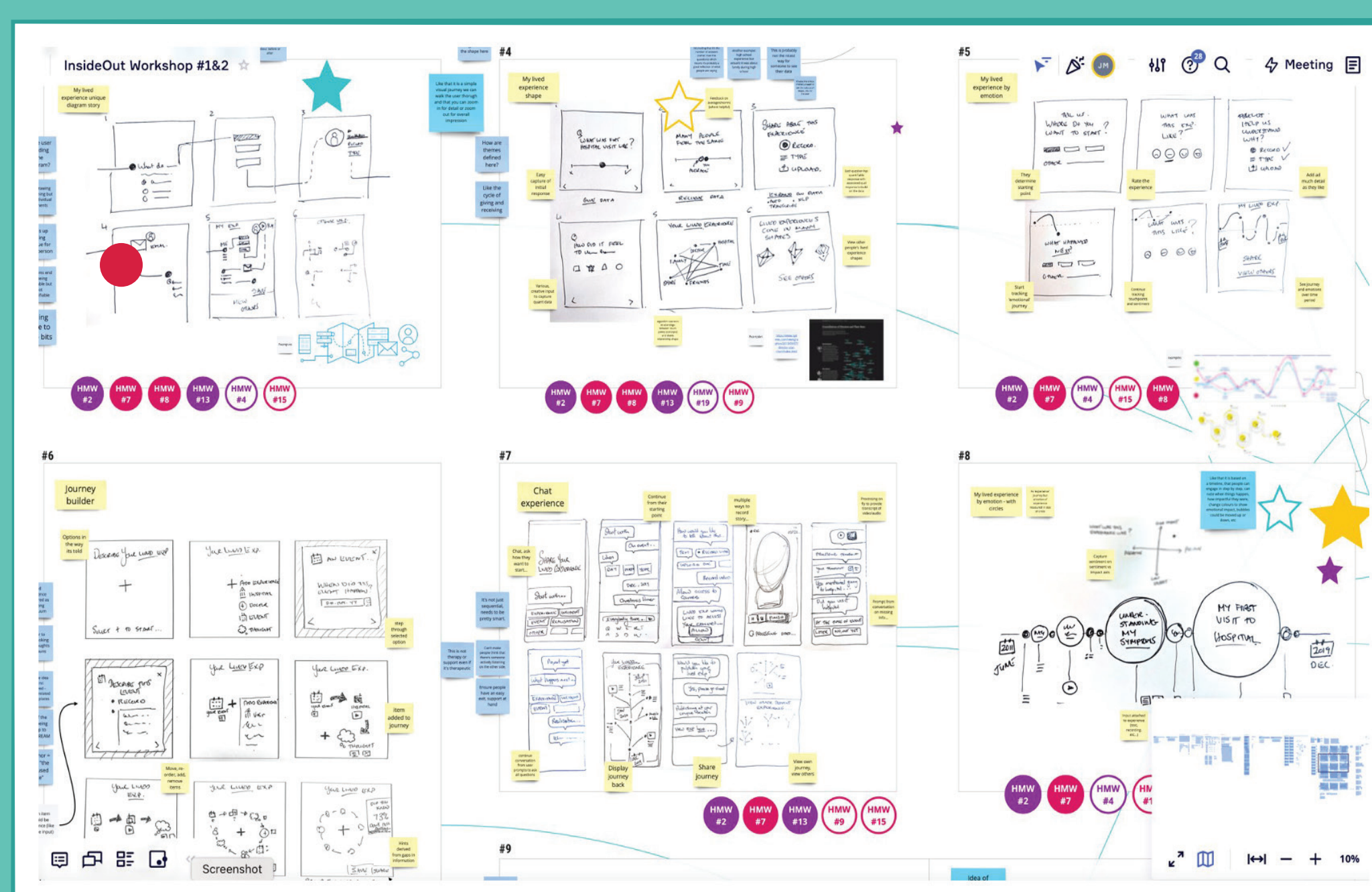
To establish digital capacity for continuously engaging with people in more personal ways while still maintaining research integrity.

To identify and measure personal experiences of illness and care, quality of life and costs not readily available in health administration data sets.

To create a direct mechanism for continuous engagement with people to follow their journey over time, to facilitate a dual flow of knowledge and understanding.

the literature

- Quantitative surveys capture the small details of many
- Qualitative interviews capture deep detail from a few
- Research engagement processes can alienate people⁶.
- High drop out rates in longitudinal research⁷.
- Research has limited reactivity to system changes and events⁸.
- Population diversity is often excluded by design and process⁹.
- Emerging methods and analytic procedures could be harnessed for complex information



Designing the solution

the consultation

- No one wants to fill in another survey!
- Research is important, but there is limited room for individual experience and expression
- People have told their story many times in a clinical way, but not in a personal way
- People want choice in how they engage in research
- Inherent control may improve engagement and retention
- Where does the story start? Where does the story end? Most research only takes a snapshot
- How can research be more of a two way process? Feedback may help longer term retention

the idea

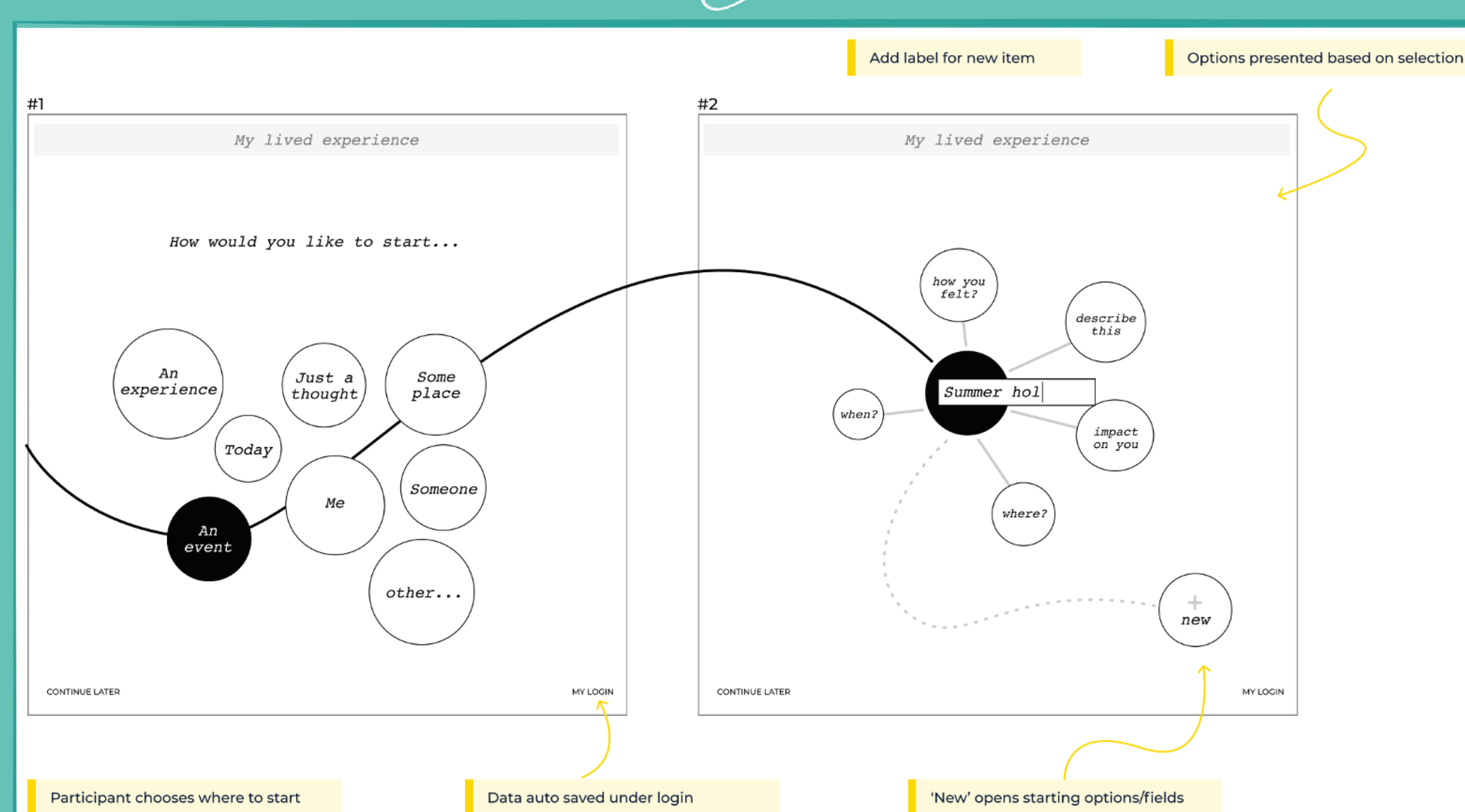
The National Eating Disorder Lived Experience Lifetime Survey - **livED** - will invite any person with a lived or living experience of an eating disorder, carers / families / supports, and people working in the sector, to contribute.

The survey will collect information of personal experiences of quality of life, lived experience, interactions with and barriers to health care systems, treatments, gaps and costs.

People will have a choice as to how, when, how often, and with how much detail they contribute. Their story starts where they want it to, and can keep going as long as they like.

the steps

- Literature review - how has lived experience informed research into eating disorders?
- Consultation study - how can we better engage lived experience in research design and conduct?
- Co-design process - how can we improve research methodologies from those who have lived?
- Digital conceptual design - how can we create an engaging, interactive and safe online space?
- Digital product design - how can we build a reliable online solution?
- Engagement process - how can we engage people in the online solution?
- Production - how can we move the solution into action?



Designing the digital solution

Organisation of data in different ways, including theme, time and task

"People have different experiences of **eating, exercise, and body image.** livED is a place to share yours, in the way you want to share it."



Participate

Engagement website

the solution

- livED is a natively built data collection platform
- Each person creates a unique profile with core information
- Users can be people with lived experience, carers, and/or practitioners
- People can engage with the platform when they like, how they like
- Researchers can set specific tasks based on profile information to personalise experience
- Specific surveys can be sent to react to novel situations (such as new Medicare items, COVID-impact)
- People can add to their story retrospectively and prospectively
- A choice is provided for people to link with larger health administration data sets, usually only identifying people with a formal diagnosis and treatment

You can choose the way you participate

Write a diary

A diary entry can be as short or as long as you like, with space for context, details and perspectives

Plot your timeline

Seeing what happened when can help us see patterns and connections

Record your story

If you don't feel like typing, you can talk, and we will turn it into text

Share an image

A drawing or an image can tell a 1,000 words.

Answer questions

Sometimes we just need a good prompt to get us started.

Tag to themes

One story can hold many themes, so tags identify those connections

Giving people a choice how to contribute lived experience

the next steps

- Ethics approvals - Ongoing creative data collection platform approvals is an interesting challenge!
- Digital security - Platform has just passed PEN testing
- Production - Ensure platform usability across different devices and operating systems
- Recruitment - Communications strategy to find and invite people to participate
- Retention - Creating an ongoing relationship with people to build trust in the journey
- Evaluation - Studying the usability and utility of the platform
- Analysis - Further learning more creative qualitative analysis with quantitative and mixed methods
- Learning - Approaching the data with a curious mindset
- Co-design - Continuing lived experience collaboration



update and contact

As of August 2023, the livED platform is under HREC review with the aim of data collection commencing late 2023. For more information and updates, please contact jane.miskovic-wheatley@sydney.edu.au