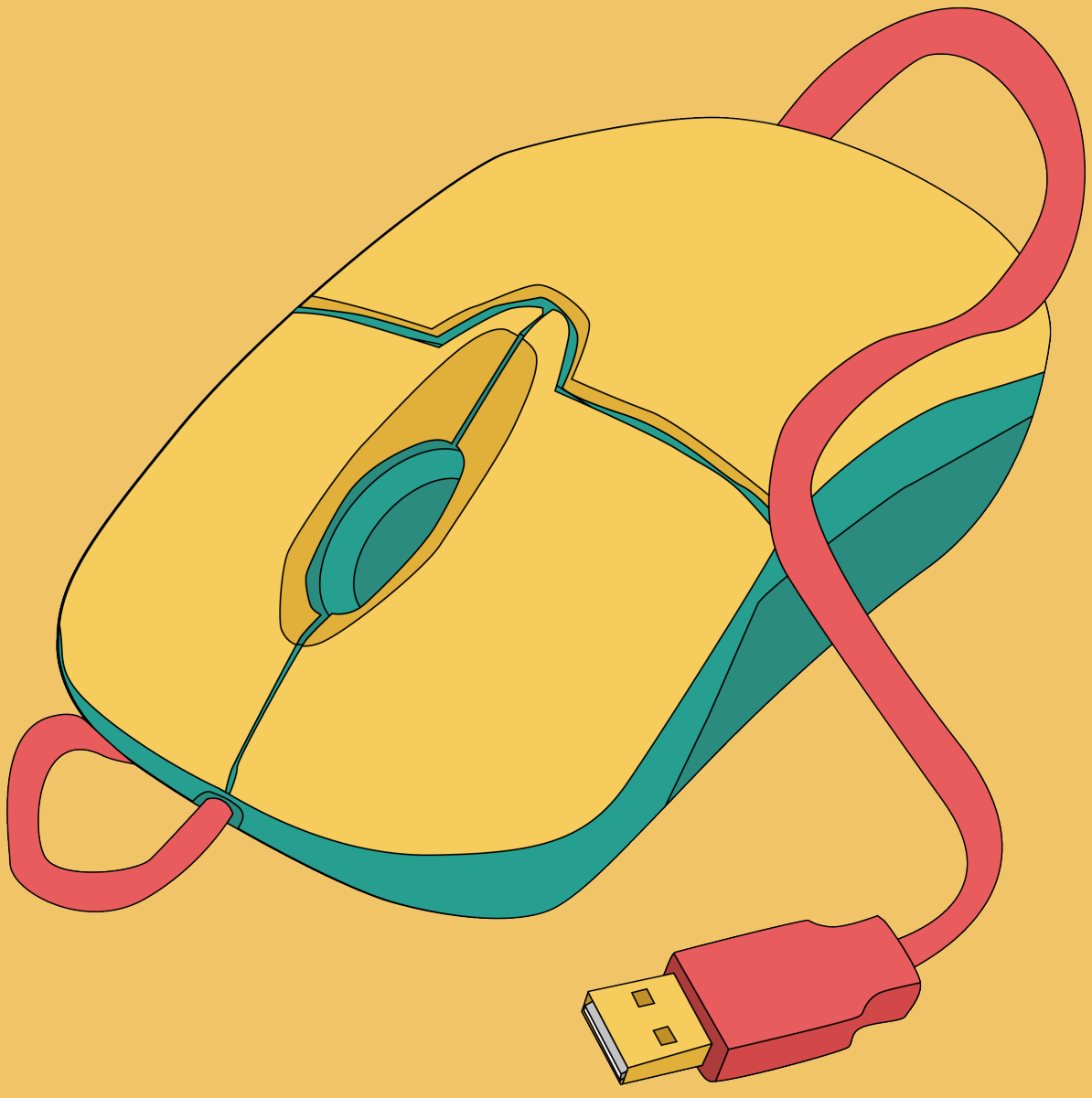
WORKSHOP FINDINGS



CONNECTED
ON THE JOURNEY

CO-DESIGN WORKSHOPS

Creating a toolkit to improve the online experience

This toolkit has been co-designed by people with lived experience of online support for eating disorders or eating distress, service providers and researchers. Co-design workshops were a key part of this design process.

Central to the workshop process was "ConnectED on the Journey -The Game." This game allows players to create a fictional character who is looking for online support for disordered eating. It then follows this character on their online journey, providing scenarios depicting challenges they may encounter online. This third person perspective can help people feel more comfortable discussing potential challenges and sensitive topics, and takes the emphasis off needing to disclose any personal information.

The 'game' provides the opportunity for players to consider possible solutions to online challenges.

The game can be used as a tool by service providers and/or researchers. Using the game to run workshops helps identify aspects of support services which could be improved and/or barriers that service users are experiencing, where more support may be beneficial. It also aids consideration about potential solutions.

Simplified game outline:

1. Character creation* – using different decks, participants draw cards to create a character at random.

2. Journey creation* – participants choose at random a service type and 3 cards from each of the 3 decks (before, during and after). Chosen cards are placed on the mat, face down, creating a 9-step journey for the character.

3. Uncovering journey and discussion –The first card is uncovered, and participants discuss possible solutions. Every 5 minutes the facilitator uncovers the next card, moving the discussion forward. Participants are encouraged to make a note of any solutions to each challenge.

4. Preparing presentation poster – the group disaply their solutions as a poster for discussion.

5. Presentation of poster and discussion.

*It is possible to shorten step 1 and skip step 2 by pre-building the game and placing prepared elements face down on the board.

Before you begin The Game, we suggest starting with a warm-up exercise. Some of our examples can be found in the *Game Assets* section.

Name Robin

Age 23 Non-binary

Ethnicity WHITE/OTHER

Interests Video games

Gym Make-up

Technology

Personality

Careful Shy

Impatient Easily bored

BIO

THEY ARE UNEMPLOYED AND HAVING PROBLEMS WITH FINDING NEW JOB.

FAMILY DOES NOT ACCEPT THEIR HEALTH PROBLEMS, THEY SAID ITS MADE UP AND FOR ATTENTION SEEKING

MISTRUST ONLINE SERVICES, AS IT NEVER MET THEIR EXPECTATIONS BEFORE.

Name Charlie

Age 62

Ethnicity Mixed

Male

Interests

Photography Gardening

Cycling

Reading

Personality

Extroverted

Doubtful Sceptical

Friendly

BIO

WHEN SPEAKING TO STRANGERS DOWNPLAYS THEIR ILLNESS.

THEY STRUGGLE WITH COSTS OF LIVING CRISIS AND CANNOT AFFORD PRIVATE HELP.

THEY HAVE SUPPORTIVE FRIENDS AND FAMILY, BUT ARE NOT CONVINCED THEY ARE ILL ENOUGH TO RECEIVE HELP.

CHARACTER CREATION

Examples from our sessions

GROUP 1
Name: Robin
Age: 23
Gender: Non-binary
Ethnicity: White/Other
Interests: Video games, make-up, gym, technology
Personality: Careful, shy, impatient, and easily bored
Bio:
They are unemployed and having problems finding new job
Family does not accept their health problems, they say it's made up and attention-seeking
Robin mistrusts online services as they have never met their expectations before

GROUP 2
Name: Charlie
Age: 62
Gender: Male
Ethnicity: mixed
Interests: Photography, gardening, reading, cycling
Personality: Extroverted, doubtful, sceptical, friendly
Bio:
When speaking to strangers, Charlie downplays his illness
Struggles with costs of living crisis and cannot afford private help
They have supportive friends and family but are not convinced they are ill enough to receive help

Both groups engaged with the characters and analysed their characteristics, looking at how different hobbies, personality traits etc., can affect their interaction with services and life in general.

Talking therapy

Video chat

They are doubtful about how the service can help them

BEFORE

Accessing online support is making ..... feel even more isolated

DURING

Session turned out to be different than expectations. ..... has mixed feelings and they are not sure what to do.

AFTER

They are scared they will not remeber everything they need to say

BEFORE

..... has been very unwell recently but decides to pretend everything is fine when meeting online

DURING

..... does not have a sense of closure at the end of the session and cannot reflect

AFTER

..... is very worried about seeing their face on screen

BEFORE

..... is worried about the confidentiality of the platform being used: is it end-to-end encryption? How is their data being stored?

DURING

..... forgets what happened during session because they had no time to reflect after

AFTER

USER JOURNEY - GROUP 1

Examples from our sessions. In this part of the session, players visualise and consider the character's recovery journey, the challenges they face and potential solutions.

Type of support: Talking Therapy
Platform: Video Chat

BEFORE THE SESSION

Scenario:
The character is doubtful about how the service can help them.
Proposed solutions:
• Access to info about people's experiences.
• Give Robin the ability to understand the process ahead.
• Give them a chance to understand how they are likely to benefit.

They are scared they will not remember everything they need to say.
• Give Robin tools to prepare responses in advance.
• Provide choices for how they interact.

Robin is worried about seeing their face on screen.
• Ensure they know they can keep the camera off and how.
• Possible support options from family and friends.
• Give information about the benefits of having the camera switched on – building connection and nonverbal cues.

DURING THE SESSION

Robin is worried about the confidentiality of the platform that is being used: is it end-to-end transcription? How is their data being stored?
• Give an option to access further information about security data, to allow Robin to make more informed decisions.

Robin has been very unwell recently but decides to pretend everything is fine when meeting online.
• Mistrust in relationship – check if user (Robin) is happy with the format of the session.
• Possibly include other questions/checks to ask about the user's state going into the session.

Accessing online support makes Robin feel more isolated.
• Offer Robin advice on how they might access peer support groups. community groups.
• Making them aware of other options.

AFTER THE SESSION

The session turned out to be different than expected. Robin has mixed feelings, and they are not sure what to do.
• Offer space to reflect on the experience of the service thus far.

Robin does not have a sense of closure at the end of the session and cannot reflect.
• Suggest post-session grounding techniques: take notes, and write about experiences.
• Give options related to the user's interests for post-session activities.

Robin forgets what happened during the session because they had no time to reflect after.
• Think about ways to 'record' the session.
• Discuss the benefits of recording sessions and activities they could think about doing between sessions

Talking Therapy via Video Chat

BEFORE

1 Problem → Doubtful how will help

Access to info about people's experiences.

Give Robin the ability to understand the process ahead.

Give Robin a chance to understand how they're likely to benefit

2 Problem → Might forget important points!

Give Robin tools to ~~pre-prep~~ prepare responses in advance

Provide choices for how they interact

3 Problem → Worried will see own face

Ensure Robin knows will have option to turn off camera. Possible support options from family/friends etc.

Give information about the benefits of showing camera → build connection & non-verbal cues.

DURING

4 Problem → Worried about own data

Provide GDPR info as a must.

Give option to access further information about security of data, to make a more informed decision.

5 Problem → Has been unwell, decides to pretend is OK.

? Mistrust in relationship.

Checking user (Robin) is happy with format of the sessions.

Possibly include other questions/checks to ask about user's state going into a session.

6 Problem → accessing online support causing problems.

Offer additional peer support groups, community groups to give feedback for experiences of support.

Making them aware of other options.

AFTER

7 Problem → Sessions different to expectations

Offer space to reflect on experience of the service thus far.

Explain 'normal' experiences of the process.

8 Problem → No sense of 'closure' after session.

Suggest post-session grounding techniques: take notes, write about experience, enter nature

Give options, related to user's interests for post-session activities.

Interactive options.

9 Problem → forgets sessions

Think about ways to 'record' the session:

→ perhaps summary of the session

→ this would help with reflections and other activities between sessions.

One-to-one Cognitive Behavioral Therapy (CBT)

Teams

They are sitting down for a meeting before they had a chance to prepare, struggle to get into the reflective mood

BEFORE

..... doesn't mind the online sessions, but is worried that this might replace the face-to-face / in person sessions

DURING

..... remembers things they forgot to mention

AFTER

The platform used is not very compatible with the device ..... has at home

BEFORE

The internet freezes or buffers during the session, meaning that something said was missed and might need to be repeated

DURING

..... purposely did not mention something and they second guess their decision now

AFTER

..... is anxious about having to download and install a new app of their device to access support

BEFORE

..... is worried because the session is taking place at home, and they are worried about their confidentiality – can anyone hear what they are saying?

DURING

..... does not have a sense of closure at the end of the session and cannot reflect

AFTER

USER JOURNEY - GROUP 2

Type of support: One-to-one CBT
Platform: Teams

BEFORE THE SESSION

They are sitting down for a meeting before they had a chance to prepare, and they struggle to get into a reflective mood.
• Comfortable place.
• Comfort items.
• Warm drink.

The platform used is not very compatible with the device Charlie has at home.
• Flexibility and adaptability to change platforms (telephone call/zoom/ mobile/ landline).
• Test call software.
• Wi-Fi Dongle.
• House calls.
• Pre-made packs.
• Alternative platforms.

Charlie is anxious about having to download and install a new app on their device to access support.
• Installation help.
• App info pack.
• Accessible software.
• Ring instead of app?

DURING THE SESSION

Charlie is worried because the session is taking place at home, and they are worried about their confidentiality – can anyone hear what they are saying?
• Prepared community space/hub.
• Call in advance about worries.
• Can type if video not needed or possible.
• Confidentiality agreement.
• Shared living – offer headphones, pre-made pack.

The internet freezes and buffers during the session, meaning that something that was said was missed and might need to be repeated.
• Patience.
• Feel open to ask questions.
• Contingency plan - what it might look like?
• Switching to alternative platform.
• Wi-Fi check plus dongle.
• Reassurance.

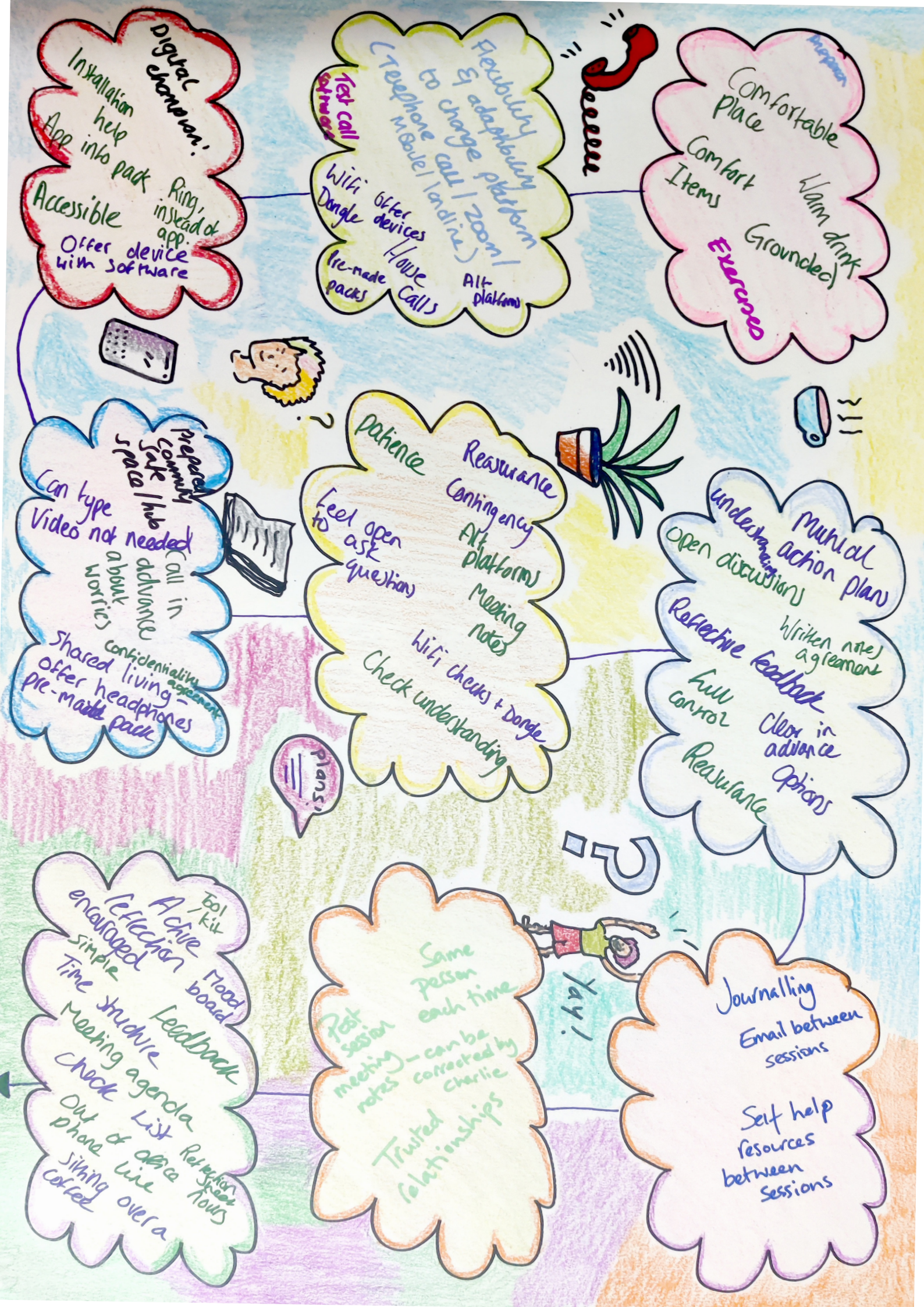
Charlie doesn't mind the online session, but is worried that this might replace the face-to-face/in-person sessions.
• Mutual action plan.
• Open discussion.
• Written notes.
• Reflective feedback.

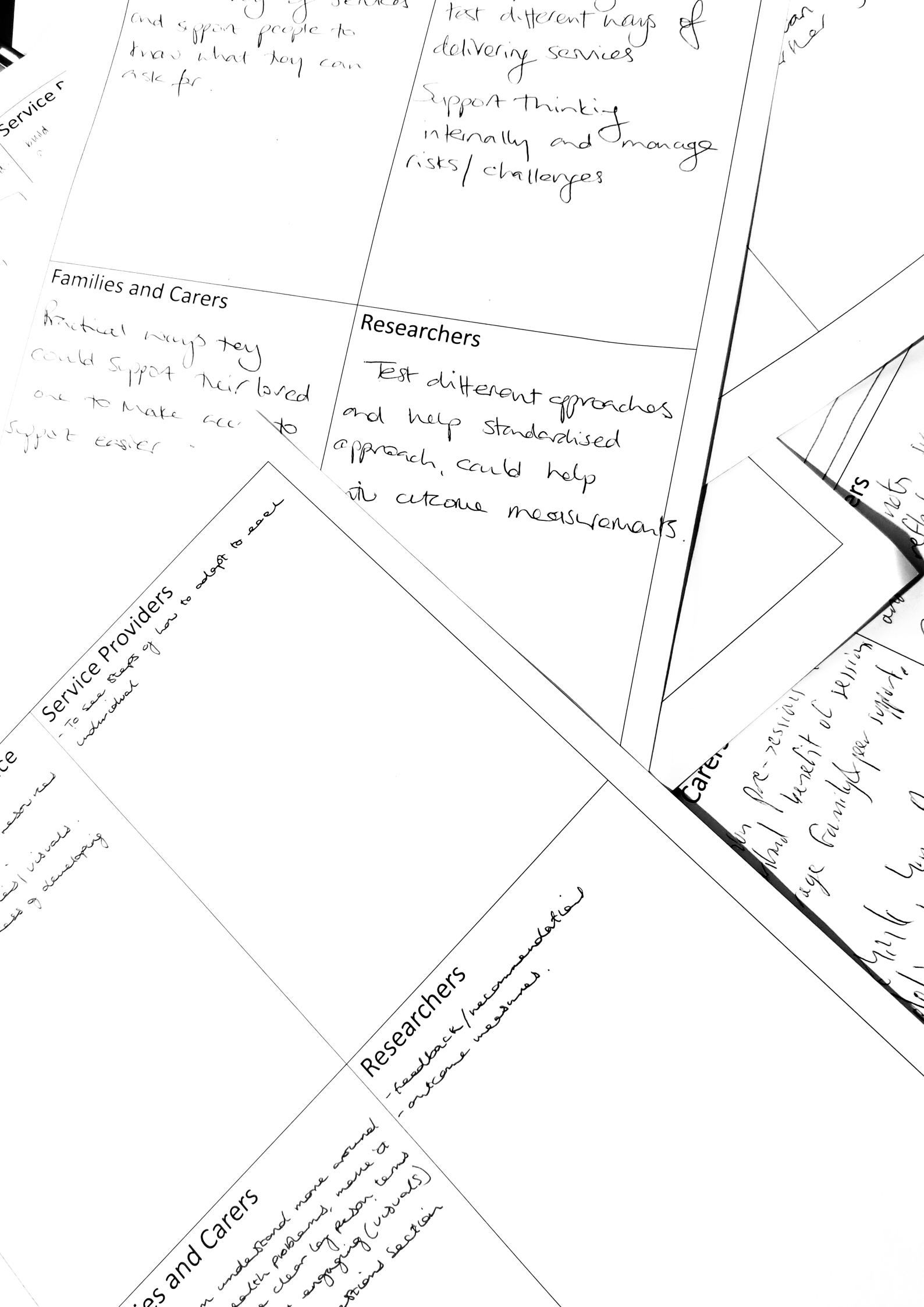
AFTER THE SESSION

The session turned out to be different than expected. Charlie has mixed feelings, and they are not sure what to do.
• Journalling.
• Emails between sessions.
• Self-help resources between sessions.

Charlie purposely did not mention something, and they second-guess their decision now.
• Can they check if they can have the same person for each session?
• Post-session meeting notes – can be corrected by Charlie.
•How could they build a working relationship with their therapist or online support?

Charlie does not have a sense of closure after the end of the session and cannot reflect.
• Ideas for reflection.
• Mood board.
• Feedback.
• Meeting agenda.
• Checklist.
• Refection sheet.
• Does the service have an office phone line or someone they can talk to before the next session?
• Is there someone they trust they can share their thoughts with over a coffee?


Digital change:
Installation help info pack
App
Ring, instead of app.
Accessible
Offer device with software
Flexibility adaptability platform
Eg change call / zoom / telephone call / landline)
Mobile
Test call software
Wifi Dongle
Offer devices
House Calls
Pre-made packs
Alt platforms
Comfortable Place
Warm drink
Comfort Items
Grounded
Exercise
Prepare/ Comm safe space / hub
Can type
Video not needed
Call in advance about worries
Confidentiality agreement
Shared living - offer headphones
Pre-made pack
Patience
Reassurance
Feel open to ask question
Contingency
Alt platforms
Meeting notes
Wifi checks + Dongle
Check understanding
Plans
Mutual action plans
understanding
Open discussions
Written notes/ agreements
Reflective feedback
Full control
Clear in advance
Options
Reassurance
Tool / kit
Active reflection
Mood board
Encouraged
Feedback
Simple
Time structure
Meeting agenda
Check List
Reception hours
Out of office
Phone line
Joining over a coffee
Same person each time
Text session
Meeting - can be notes corrected by Charlie
Trusted relationships
Try!
Journalling
Email between sessions
Self help resources between sessions


and support people to know what they can ask for.
test different ways of delivering services
Support thinking internally and manage risks / challenges
Families and Carers
Practical ways they could support their loved one to make acc to support easier.
Researchers
Test different approaches and help standardised approach, could help in outcome measurements.
Service Providers
- To see steps of how to adapt to each individual
Researchers
- feedback/recommendation
- outcome measures.

FURTHER FEEDBACK

*What can be offered to different stakeholders in improving online support? **Examples from our sessions***

PEOPLE WITH LIVED EXPERIENCE

- Testimonials might help people beforehand.
- Given choices or options if they feel something is not working.
- Peer support is readily available when needed, and where possible
- If someone doesn't think they need help, calling it therapy can be daunting.
- Empower them to seek support and engage with help.
- Support people to know what they can ask for.
- Explain the different ways to access resources and how to use them.
- Interactive activities.
- Tools for participants to record their plans for the session (key discussion, etc.).
- Pre-session questionnaire.

SERVICE PROVIDERS

- Safety of data, and how it is stored.
- Option of shorter sessions.
- Text calls to ensure the line works well.
- Personalize the experience for the patient or service user.
- Make service provision more accessible e.g., large print information, phone option etc.
- Consider partner organisations that may help to provide additional support to seldom heard or reached communities?
- How to help people overcome common fears and anxieties around therapy.
- Good practice guide to test different ways of delivering services.
- Support thinking internally and managing risks and challenges.
- Protocols around home Wi-Fi checks. Confirm IT setup is suitable for the calls and software.

FAMILIES AND CARERS

- Supporting loved one or person supported to take part in suggested activities.
- Consider a backup plan if things will get worse.
- Information packs.
- Support families and carers with any needs they may have when it comes of offering support.
- Access to knowledge.
- Ensure the person has a confidential safe space and privacy during sessions.
- Support families and carers to further access mental health support services through advice and signposting
- Frequently asked questions section or myths/facts.
- Information pre-session to help understand the benefit of the session to encourage family or carer support.

RESEARCHERS

- Understand what works well and collaborate with service providers to explore how service users experience, and could benefit from, online e-support.
- Audit and evaluate existing resources.
- Test different approaches and help standardised approach.
- Feedback/recommendations.
- Outcome measures.
- Anonymous notes summary sessions and reflections.

OUR RHED-C RESEARCH JOURNEY

WHAT THE RESEARCH HAS TAUGHT US

That service users want:

- Online support that is easy and accessible, including avoiding overwhelming functionalities and/or design.
- Support that is an additional option to in-person support – NOT a replacement to it.
- Help with being able to use existing online platforms better – no need to reinvent the wheel!
- To be able to hear online stories of eating disorders and eating distress recovery that are real and relatable.

You can read more about this in our paper(s)....

Branley-Bell, D., & Murphy-Morgan, C. N. (2023). Designing remote care services for eating disorders: HCI considerations and provocations based upon service user experience and requirements. https://europepmc.org/article/ppr/ppr621457

Murphy-Morgan, C., Brown, R., Love, C., & Branley-Bell, D. (2024). "Some distance between us": a UK mixed methods study exploring experiences of remote care for eating disorders during COVID-19. Frontiers in Psychiatry, 15, 1383080. https://doi.org/10.3389/fpsyt.2024.1383080

How the data directly links into the toolkit?

Co-design is a powerful way of ensuring that people with lived experience are at the heart of creating new interventions that address the needs of what people want.

Taking all the above, we wanted to create a resource that both people with lived experience, and service providers, would find useful and practical. The toolkit is a way of applying research findings directly to practical outcomes.

The research process:

We applied a reiterative process involving people with lived experience throughout the process. This has allowed us to take a phenomenological approach to capturing the realities of accessing online support for eating disorders and eating distress recovery. Through interactive workshops and interviews, our research participants were able to share with us the benefits and challenges of online support, and to advise on future support recommendations. This toolkit is a direct outcome of this work.

This example of co-designed can be useful for other researchers in the following ways:

See our *Purpose of The Workshops* resource to find out more about how we co-designed this resource and access. Another available resource is *"ConnectED on The Journey – The Game"* which is a creative tool to facilitate a group discussion about online support. It is an example of how using fictional character narratives can aid discussion about sensitive topics, facilitate creative group work and prompt deeper reflection.

You can also access our publications detailing our research, creative research methodologies and recommendations including the informing policy and practice development for online support for eating disorders and eating distress.

