

## 'Throwing out the rule book'

Sharing learning from co-created and co-produced research with those with lived, living or learned experience of substance use and/or mental health challenges.

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# Better Together Research Project

## CONNECTED CO-PRODUCTION AND CO-RESEARCH IN AN ONLINE RECOVERY COMMUNITY

An evaluation of a co-produced online model of support for those with lived experience of addiction and/or mental health through co-research

### Research Aim

This study explores the experience of people who have used Better Together to avail of support during and post COVID 19 with substance misuse and/or mental health challenges.

### Research Approach

Mixed method approach – online surveys and focus group

Ethical approval – IT Carlow Ethics Committee and HSE Ethics Committee

Selective sampling

### Research Objectives

Measure the **presence** of six principles of **co-production** in the Better Together online support group

What is the **impact** on community connection, personal resources and functioning for all those participating in the Better Together online support group?

What **role** does Better Together have within the recovery community?

What is the **value** of co-production in the Better Together online support group?

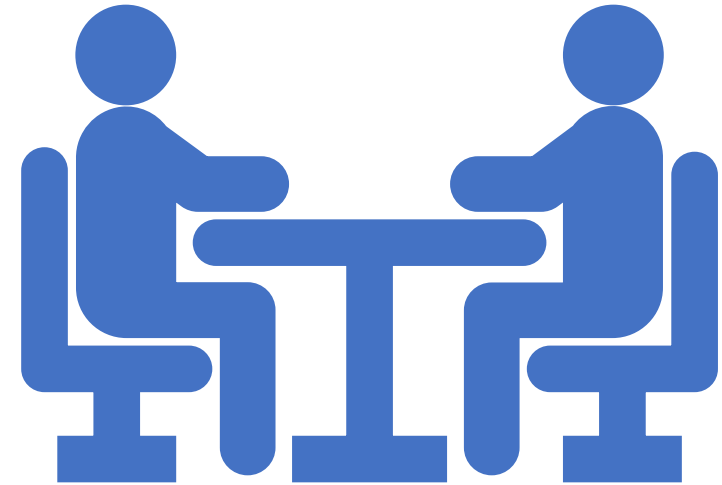
## Research Advisory Member Experience

*'I am privileged to have been part of this amazing research project, working with a team who inspired me to reach higher, do better, and believe that anything is possible' (Participant Quote)*

*'I learned that we are not just a number or a label' (Participant Quote)*

# Research journey

- Individuals with different backgrounds, experiences and skills/knowledge
- Imposter syndrome
- We all had the same level of experience of co-produced research **NONE**
- Varying education and literacy levels
- Individuals at different stages of their recovery and with different challenges
- Different levels of traditional research expertise (from none to experienced)
- Co-creation allowed us to learn from each other
- *'A lot of time and effort was made for each person to find their area of skill and interest so that we all felt we had a place' (Advisory Team member quote)*



# Spheres of learning

- Educational inputs (ethics/research design/methodology/data collection/findings and analysis)
- Lived experience (this is what I hear/this is what this means to me/this is what is important to me/this makes me feel)
- Shared meaning making and the learning from completing a co-produced research project



# What this project **ACTUALLY** involved

- **Voluntary** Research Advisory Group
- 2 Ethic Proposals (HSE and IT Carlow)
- Risk Assessment
- 50 participants engaged in research survey (73 questions in total)
- 4 participants engaged in focus group
- 6 Research educational inputs



# Voluntary Research Advisory Panel

- This panel consisted of;
- 8 individuals with lived, living or learned experience,
- 1 Community Based Drug Initiative Worker,
- 1 HSE Drug Education Officer,
- 1 SERDAFT Development Worker,
- 1 HSE Counsellor
- and SETU Lecturer



Meet some of the Research Advisory Panel



# Timeline of project – BT Research Advisory Group Meetings

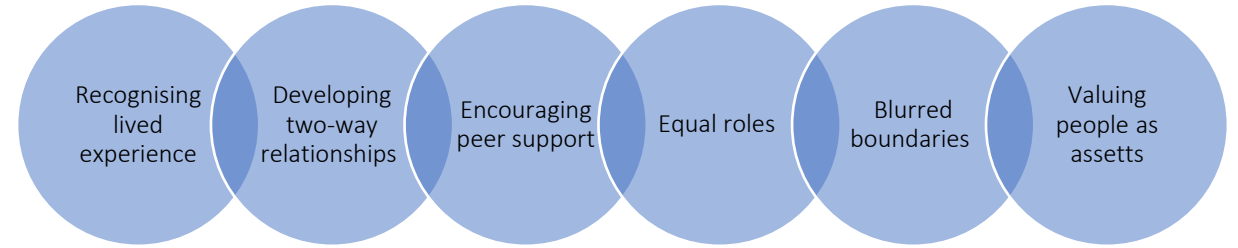
- Ethics/Methodology - **7** online meetings (5th May- Oct 20th, 2021)
- Research Design/Data collection- **8** online meetings (17th Oct-28th Nov 2022) includes online information session and focus group session
- Findings – **4** online meetings (5th Dec- 19th Dec 2022)
- Analysis – **8** online meetings (30th Jan- 25th July 2023)
  - Full day in person analysis workshop (5 hours)
- Research Recommendations- **2** online meetings (11th Sept and 15th Sept 2023)
- Summary – **29** online meetings ranging from half hour – hour meetings
  - 5 hours in person analysis workshop
- **Total commitment – 34 hours approx**

*'You taught me to speak up because what I say matters too'  
(Participant Quote)*

**(This does not include pre-post meeting preparation or write up of research project)**



# Co-production Principles



## **Recognising lived experience**

*'I learned that we are not just a number or a label' (Participant Quote)*

## **Developing two -way relationships**

*'it's great to have the support online as I struggle in groups and to talk about certain topics' (Participant Quote)*

## **Encouraging peer support**

*'I had nowhere else to turn to. Every door was locked and every phone unanswered. Only Better Together was there for me' (Participant quote)*

**Equal roles** -*'I was able to share deeply without fear, I learned to trust, share my experiences, listen and learn from others' (Participant Quote)*

## **Blurred boundaries from co-existence to co-design**

*'Everyone matters on BT, we are all valued, no one is more or less than' (Participant Quote)*

## **Valuing people as assets**

*'Do it once and it will change everything for you' (Participant Quote)*

# Significant findings

## Pre- Post Covid

32 participants had never used online treatment supports prior to COVID (82%).

25 participants used BT during Covid 19 restrictions/lockdowns (60.9%).

*'I had nowhere else to turn to. Every door was locked and every phone unanswered. Only Better Together was there for me' (Participant quote).*

Post lockdown 30 participants have continued to engage with BT (83%).

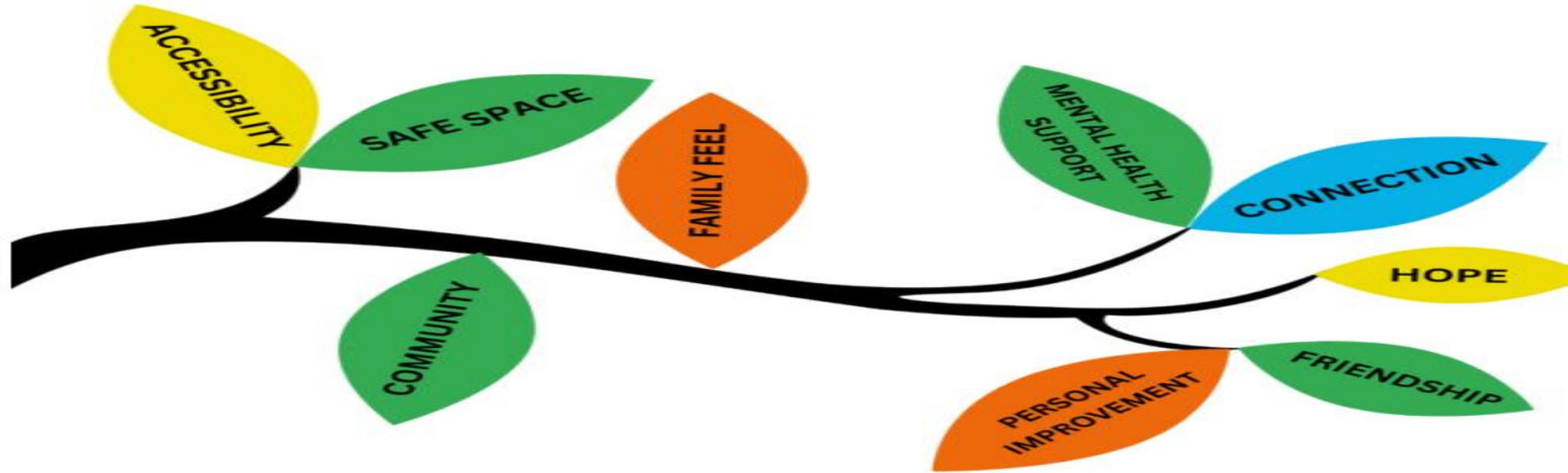
*'Because it is important to me, and I love the connection' (Participant quote).*

*'It's discrete and supportive in a way that hasn't been emulated anywhere else (that I have experienced)' (Participant quote).*



# Why individuals continued to engage

Figure 1: Reasons for continued engagement



'You can get support just by logging onto your phone, which doesn't happen with any other service' (Participant Quote)

'It's the biggest support that I have in my life, the connection, kindness, support. Especially the counselling' (Participant Quote)

# Emerging Model of connectedness

## **SUMMARY**

Participants stressed the importance of co-production principles in their recovery, which had a positive impact on their community connection, personal resources, and functioning. Participants cited 'safety', 'support', 'connection', and 'non-judgmental space' as factors that supported their continued engagement with Better Together.

Participants strongly linked social connection with improved internal and social resources.

Participants reported improved functioning and skills/knowledge, relational, and facilitative factors. These improved functioning factors were also noted by referrers. This research uncovered an emerging model of connectedness that is unique to Better Together. This model includes appraisal, companionship, emotional support, tangible support, useful information, happiness/fun, 'recovery is possible', and hope.

# Retention rates and engagement levels



67% of respondents have been linking into Better Together for one year or more. This suggests that retention rates and engagement levels are high within this online recovery community.

Table 10: Voluntary support hours provided

NAME OF GROUP	NO OF SESSIONS PER WEEK	DURATION	SUPPORT SESSIONS PER WEEK
CHECK-IN	5	1.5 HRS	32 INDIVIDUALS RECEIVING 150 HRS SUPPORT
SPIRITUAL	3	1.5 HRS	24 INDIVIDUALS RECEIVING 79.5 HRS SUPPORT
REFLECTION	3	1.5 HRS	33 INDIVIDUALS RECEIVING 118.5 HRS SUPPORT
CREATIVE HEART	1	1.5 HRS	27 INDIVIDUALS RECEIVING 40.5 HRS SUPPORT
FEEL GOOD FRIDAY	1	1.5 HRS	32 INDIVIDUALS RECEIVING 48 HRS SUPPORT
ANXIETY SUPPORT GROUP	1	1.5 HRS	33 INDIVIDUALS RECEIVING 49.5 HRS SUPPORT
<b>TOTAL</b>	<b>14 WEEKLY SESSIONS</b>	<b>21 HRS SUPPORT SESSIONS</b>	<b>486 HRS OF SUPPORT EACH WEEK</b>

- 'Again, lived experience is shared and many nights I have empathised with my peers, and there is learning from all of this. We learn to value ourselves, treat others with empathy and the most valuable lesson is that I am not alone' (Participant Quote)
- 'Everyone's lived experience is a vast wealth of knowledge which is very much used to help in everyone's recovery or challenge' (Participant Quote)

## SUMMARY OF TABLE

Better Together provides 21 hours of voluntary support sessions per week, which totals 84 support hours per month. Better Together provided 486 collective individual hours of support per week, 1,944 hours per month, and 23,328 per year collective individual hours of support based on research data. This is a snapshot of weekly engagement from the period of data collection.

Participants log on 'depending on their needs/week' (59%) and over a third log on daily with 'check in' and 'reflection' capturing the highest numbers (12 and 13 respectively).



'I used to log on daily but no longer feel the need for as much support. Having the option to log in to any meeting as needed and feeling right at home is one of the unique factors of Better Together' (Participant Quote)

66% of Better Together participants are women, this is not in line with national service user demographics which reveal that men make up 78% of those attending drug and alcohol services, with women accounting for 28% (HRB, 2022).

'For me it works well as it provides a very safe space for people as they are usually in their own homes when engaging with Better Together and this reduces their anxiety. Also, the feeling of being in a space of non-judgement is very important' (Participant Quote)

'Provides support for those who work, have time restraints or childcare issues' (Participant Quote)

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# What other services participants are using

*Table 12: What other services are you engaging with?*



'Work in partnership with all the other services people might engage with and maybe provide education about how people with lived experiences are experts in their own recovery this must be respected' (Participant Quote)



# Preparation and engagement

**WAITING LIST**

## Stakeholders

Preparation for treatment was much better/better

Learning or training opportunities **(95%)**, increase in personal skills and resources **(95%)**,

harm reduction **(90%)** and noticed better engagement in attending appointments **(86%)**.

Stakeholders/referrers reported that Better Together had an invaluable impact on engagement with training/employment **(90%)**, relapses **(89%)** and waiting lists **(84%)**

## Participants

Interestingly users of Better Together reported similar results –

knowledge improved **(97.5%)**, decrease in episodes of relapse or self-harm **(86.4%)** and improved engagement with appointments **(80.4%)**.

Stakeholders/referrers record higher percentages than Better Together participants.

*'A safe online community for people to share their living experience. A place to give and receive support from counselors, peers, and other service users. A place of non- judgement and acceptance. A varied program of support, check-in, reflection, spiritual, anxiety group, creativity, and music' - Participant Quote*

# Role of Better Together within the recovery community

## SUMMARY

Participants and stakeholders/referrers agreed that Better Together has an extremely valuable role to play within the recovery community. Its unique blend of peer support, counselling, and social connection that is self-directed and self-selected, meets individual and group needs without waiting times, and is accessible daily. This has increased personal gains and improved preparation and engagement in other types of treatments. The connection that is offered through Better Together (support, Togetherings, wellness weekends) has had a positive impact by improving well-being, reducing experiences of internal and external stigma, and helping people to connect to their communities.



# Value of co-production principles

## SUMMARY

Both participants and referrers acknowledged the value of co-production principles in addressing improved connection, supporting recovery journey, recovery outcomes, and supporting statutory, voluntary, and community services. Participants and referrers widely praised Better Together for its innovative response to people's needs during the COVID-19 lockdowns. This online recovery community is open to all challenges and is available online in a safe space. It removes the requirement for travelling to and from appointments, the necessity for time off from work, and mitigates childcare constraints.

This service reduces carbon footprint. It provides daily support and values the importance of social connection, which for many, is something absent from their lives.

'It gives so many opportunities to people who may never have the courage to step into a place of recovery' (Participant Quote)

# Value Tensions

What are the differences in values between those using and those providing services?



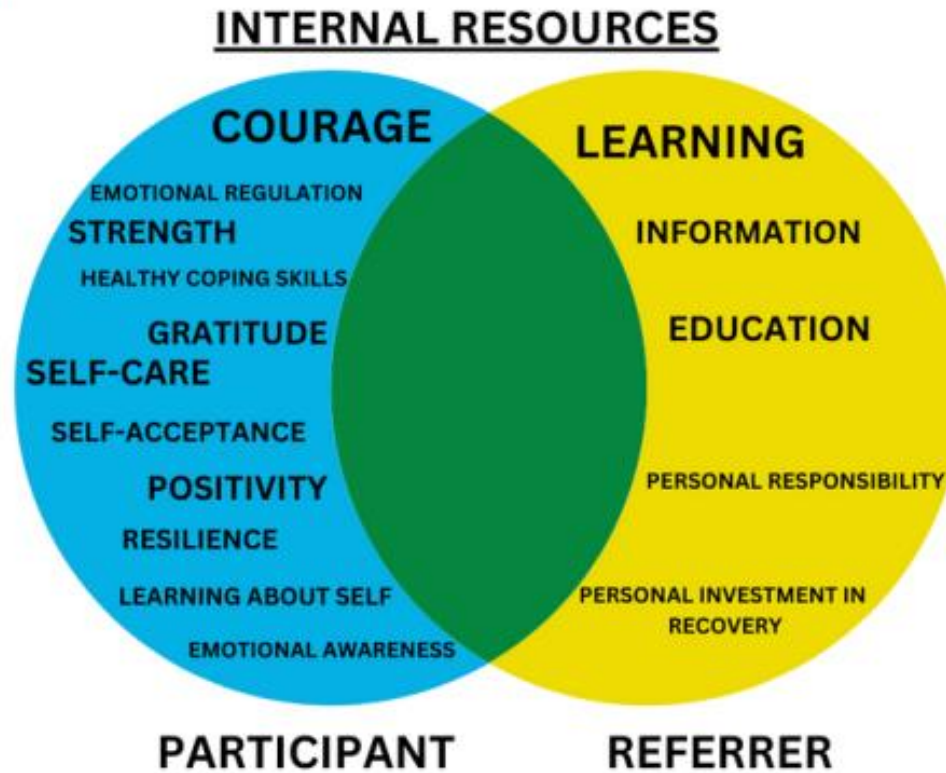
## What is important to you in your recovery journey?

- Participants see Better Together as 'a support network for all people in all walks of recovery'
- According to participants Better Together always supports or provides the following:
- **Recovery is possible** – 35 responses (94.5%)
- **Safe space** – 34 responses (89.7%)
- **Accessibility** – 34 responses (89%)
- **Connection**- 32 responses (82%)

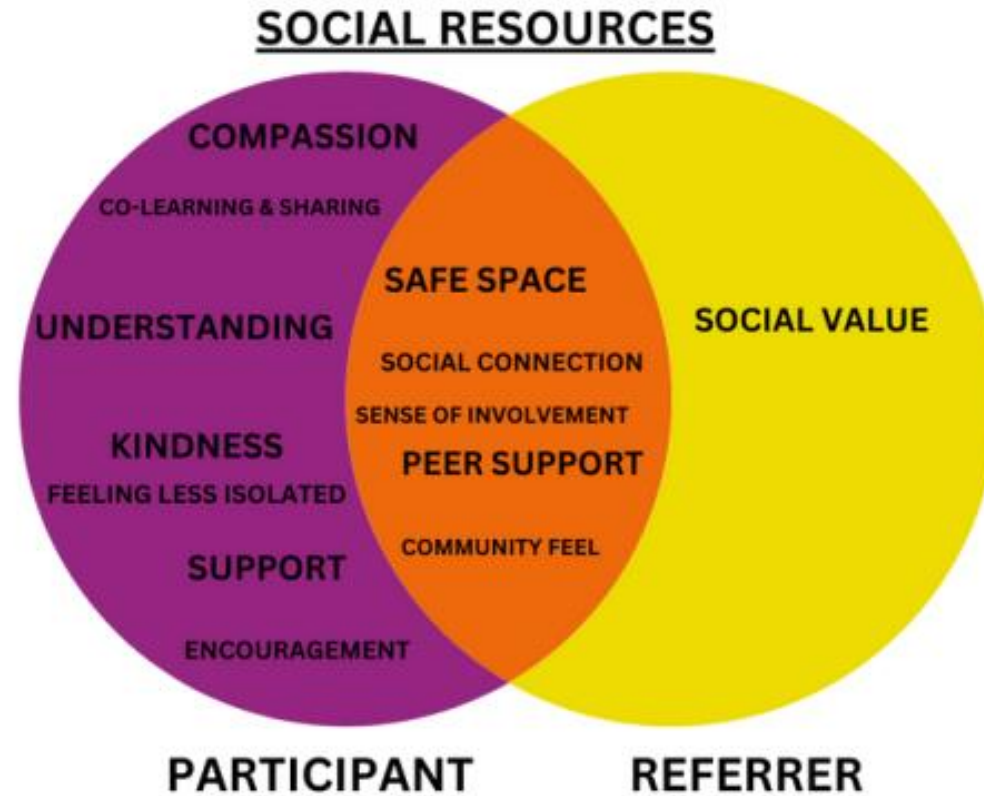


# Developing Personal Resources: Value Tensions

*Table 3: Internal Resources*



# Developing Personal Resources: Value Tensions



# National Drugs Strategy

- National Drugs Strategy priorities are 'health led' and 'justice orientated'
- This can lead to a challenge focused perception of people who use services as being no more than a problem to be solved fixed.
- There is no acknowledgement of building social capital or its value in promoting health through seeking more supportive communities.





# National Drug Strategy 2017-2025

- Recovery is possible = 0
- Safe space = 0 (26 safety protecting society from)
- Accessible – 3
- Social connection = 0
- Peer support = 1 (can be beneficial)
- Non judgemental = 0
- Social capital = 1
- Lived experience = 0
- Mutuality = 0

## Reducing Harm, Supporting Recovery

A health-led response to drug  
and alcohol use in Ireland 2017-2025



# Research Impact on Service Delivery and Policy Making

- Research highlights that social connection should be an integral part of service delivery and policy development
- Develop model of connectedness – challenging view of the valuing social connections, friendships, fun, kindness

*'I experienced stigma when a service felt that we should not meet up socially' (Participant quote)*

- Research has highlighted how social connection and peer led support is undervalued within service delivery, research and policy, and data collection

*'is a real opportunity for people to invest in their recovery, that is not replicated anywhere else' (Participant Quote)*

# Research Impact on Service Delivery and Policy Making

- Those with lived experience want autonomy, equal partnerships and decision making in their recovery, treatment design, research and policy

'It is very important to offer people a range of different services and give them the option to access services remotely. The learning from recent years is that the recovery community needs to adopt to changes in circumstances and capabilities and to meet people where they are rather than prescribing services that may not suit everyone' (Participant Quote)

Community building – social connections, Togetherings, socialising, making friends, addressing loneliness and disconnection of those with lived experience

*'I very much value the online aspect of Better Together because it made it possible for me to connect when I was no position to leave my house BUT was desperate for connection' (Participant Quote)*

- Development of outcomes scale
- SERDATF committed that research tendered going forward will use co-production principles

'I am excited to do more research' (Participant Quote)

# What's Next For This Research Project?

- Minister Naughton launched research findings in February 2024
- Set up a lived experience ethics committee for SERDATF research
- Shortlisted for National Education Award 2024 – 2 categories
- Shortlisted for Operational Excellence Awards 2024
- Submitted an abstract to Lisbon Addictions 24
- Completed a research recommendation regarding women specific services - Mna Le Cheile Change Event
- Further action on research recommendations – policies created, funding application for peer support workers and research position, peer support training and education bursaries
- Physical Hub – podcasts, social gatherings



Thank you for listening,  
any questions?



“It takes a village to raise a child; and it takes a community to heal a person”



*Thank you*