"We're Seen as the Alcohol, Not the Brain Injury"

NIHR | National Institute for Health and Care Research

Understanding Alcohol-Related Brain Injury (ARBI) Through a Co-produced World Café Research Project in Kent and Medway

Julie Stace - Co-occurring Conditions Project Manager, Kent County Council Public Health

julie.stace@kent.gov.uk

Alcohol-Related Brain Injury (ARBI) affects memory, decision-making, executive functioning and daily living skills. Despite frequent contact with services, many people experience delayed recognition, fragmented support and stigma.
This NIHR-funded project sought to bring together people with lived experience and professionals to better understand ARBI and identify opportunities for system improvement across Kent and Medway

Aim: To explore lived and professional experiences of ARBI and identify opportunities to improve:

- Early recognition
- Support and rehabilitation
- Multi-agency working
- Recovery pathways
- Future commissioning and service deployment

Co-produced Methodology:
The project was delivered collaboratively with the Kent Analytics Team, frontline professionals and people with lived experience.

World Cafe Workshop Design:

- 6 facilitated discussion tables
- Focused research questions
- Mixed professional and lived experience participation
- Health, social care, housing and substance misuse representation
- Separate reflection and participation space
- Hybrid attendance options
- Lunch and networking opportunities
- Real-time presentation of findings and Q&A

> *"People saw the drinking, but nobody looked at what the drinking had done to my brain."*

Reflections and Learning:

This project significantly changed my understanding of co-production.
I learned that:

- Meaningful co-production requires preparation, trust and ongoing support.
- Accessibility extends beyond the event itself and includes travel, fatigue, processing time and confidence.
- Equal participation does not mean treating everyone the same.
- Lived experience expertise is essential for designing effective system change.

"It was a long day. By the afternoon I was struggling to concentrate."

"Being able to step out of the discussion for a break helped."

"It's not just about being in the room, it's about being able to participate."

"Sometimes we need more time to think before moving on to the next question."

> *"Every service knows a bit about me, but nobody knows the whole story."*

Key Findings:

1. ARBI Is Frequently Missed

Participants described years of service involvement before receiving an explanation for their cognitive difficulties. Cases closed to services due to "non-engagement " reflect a lack of professional curiosity around cognitive impairment, trauma and executive dysfunction
"Nobody ever explained I had a brain injury."
"I'd been in and out of services for years before anyone mentioned ARBI."
"People saw the drinking, but nobody looked at what the drinking had done to my brain."
"If someone had recognised it earlier, things might have been very different."

Implication: Earlier recognition and greater professional awareness are needed.

2. Stigma Shapes Experiences

Many participants felt they were seen primarily as people who drink rather than individuals living with cognitive impairment.

"We're seen as the alcohol, not the brain injury."
"People assume you're lazy or not trying when actually you're struggling to process information."
"Alcohol dependence is treated differently from other illnesses."
"I needed support and understanding, not judgement."

Implication: Trauma-informed and person-centred approaches are essential.

3. Systems Are Fragmented

Information is often held by multiple services but is not routinely shared. Participants described a "postcode lottery" in access to support.

"Every service knows a bit about me, but nobody knows the whole story."
"One service would say one thing and another service would say something completely different."
"People fall through the gaps because nobody joins the dots."

Implication: Stronger multi-agency pathways and coordinated care are required.

4. Support Should Not Wait For Diagnosis

Participants emphasised that intervention should begin when needs are identified.
Key needs included:

- Housing support
- Nutrition
- Thiamine treatment
- Risk management
- Community Support
- Mental capacity assessment

Implication:
Pathways should be needs-led, not diagnosis-led.
"I didn't need another assessment. I needed help."
"People's lives can't be put on hold while services decide who is responsible."
"Support should start when the need is identified."

5. Recovery Requires Long-Term Support

Successful recovery was linked to:

- Stable accommodation
- Consistent support
- Peer networks
- Meaningful activity
- Trauma-informed care

Implication:
Recovery is broader than abstinence and reduced hospital admissions.
"Recovery is about having a life worth living, not just stopping drinking."
"Having somewhere safe to live made all the difference."
"I needed routine, purpose and support, not just treatment."
"Recovery takes time, but it is possible."

6. Workforce Development Is Needed

Participants identified a need for ARBI-specific training across:

- Hospitals
- Primary Care
- Social Care
- Housing
- Mental Health
- Substance Misuse Services

Priority Areas

- Executive functioning
- Capacity
- Confabulation
- Early identification
- Trauma-informed practice

Challenges:

- Recruiting professionals and people with lived experience to the event.
- Organisational processes made reimbursing lived experience participants difficult.
- Balancing diverse communication styles required skilled facilitation.

Innovations:

- Co-produced methodology
- Mixed lived experience and professional discussions
- Dual-room participation model
- Real-time feedback and validation of findings
- Reflection on accessibility and cognitive inclusion

> *"We've lived it. We know what works and what doesn't."*

Future Plans:

Building on the findings, next steps include:

1. Developing a Kent and Medway ARBI acute hospital protocol.
2. Informing future business case and commissioning discussions.
3. Strengthening multi-agency collaboration.
4. Expanding ARBI workforce training.
5. Improving information sharing across services.
6. Developing training and confidence-building opportunities for people with lived experience.
7. Coproducing an ARBI patient passport.
8. Embedding co-production within future system redesign work.

Impact:

- Raised awareness of ARBI across partner organisations.
- Generated evidence to inform pathway development.
- Strengthened partnerships across Kent and Medway.
- Increased lived experience involvement in service design discussions.
- Identified priorities for workforce development and system improvement.

Key Message:

Improving outcomes for people with Alcohol-Related Brain Injury requires more than better diagnosis. It requires joined-up systems, trauma-informed practice, and genuine co-production with people whose lived experience can drive meaningful system change

Scan for more info: