

# Challenging the Narrative in Brain Injury Research

## Experts By Experience Shaping the Development of a Research Hub

Nora Brennan MSc BSc (hons) MCSP, Claire Farrington-Douglas MRes MSLT, Rosie Scott & Headway East London.

### Background






Headway East London is a charity that supports those affected by brain injury through specialist services.

Historically **externally driven** engagement in research.



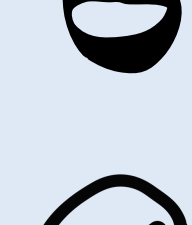



Reflection on how research is done and if this is working for us as a community:

- Lack of follow up from researchers
- Topics not a priority
- Lack of impact on their lives

### How - Research in Practice

-  **Accessible** - Ensure accessibility for everyone. The focus of the project must be clear
-  **Experiential** - Ground in the perspectives of people with lived experience.
-  **Impactful** - Commit to making meaningful impact and changing people's lives.
-  **Funded** - Enable rigour and impact by being well-funded.
-  **Diverse** - Include a diverse mix of voices and contributions, including marginalised groups

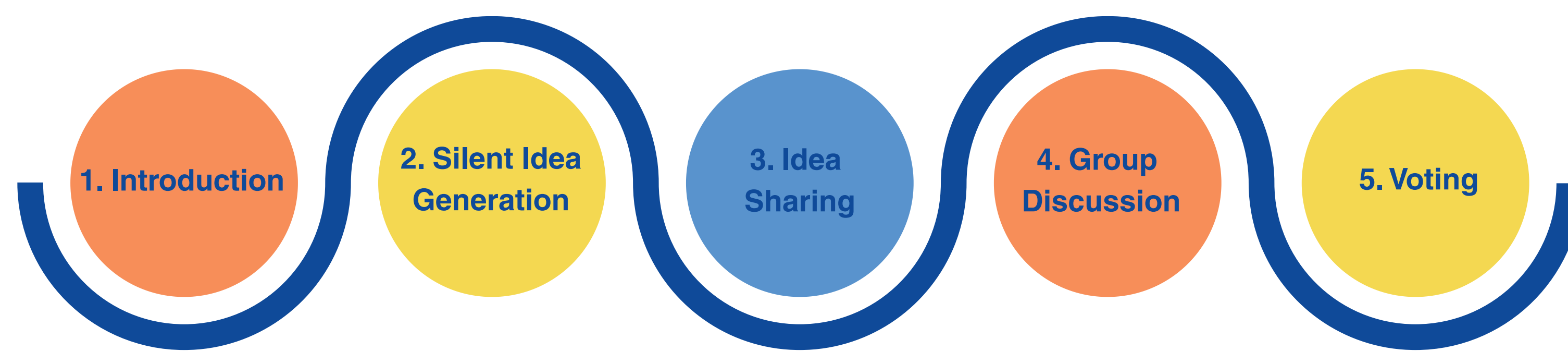
### What - Research Focus

-  **Belonging** to and building a meaningful **community**.
-  Working as a community rather than staff and service users – **not “us and them”**.
-  Understanding the impact of **peer support**
-  **Impact of creativity** on recovery, identity and purpose.
-  Highlighting lived experiences of **invisible disabilities**
-  Importance of **meaningful roles** and projects after brain injury

### Future plans

- ✳ Finalise and publish strategy
- ✳ Publish processes and protocols - “How To” Guide
- ✳ Establish Brain Injury Research Hub:
  - Research **coproduced** throughout
  - **Professional network** to provide **peer support** and mentoring

### Approach



Nominal Group Technique Perry & Linsley 2006

### Outcomes

- ★ Recruited a Research Advisory Group of members, staff and volunteers.
- ★ Coproduced draft Research Strategy.
- ★ Successful NIHR application to support the development of a specialist brain injury research hub.

### Impact

By **challenging the narrative** of who are the **experts** in research, Headway East London will continue to develop its regional Research Hub with the aim of **coproducing research** that has real world **impact** for those affected by brain injury.



For research to be **meaningful**, for the research to make a **tangible difference** to the lives of people, it needs to involve a wide range of voices, seeking **opinions that differ**, that may be uncomfortable to hear, and which may challenge preconceived ideas.

...we can begin to **ask the questions that matter most** to people...so we can make better informed suggestions for practical change....

...involving organisations like HEL from the very beginning, building the questions and the methodology....**together we are the answers we are looking for.** (Mark Holloway, HeadFirst & University of Plymouth)

