



Lived Experience Advisory Forum

How do we involve service users in research?

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Who are we?

- Carers and Service Users with lived experience expertise include, depression, anxiety, psychosis, forensics, OCD, eating disorders and more
- No formal entry requirements except, lived experience, interest in mental health research and willingness to learn
- LEAF is made up of representatives from consultancy groups in the research themes. We have established groups in Psychosis, Mood and Anxiety, Dementia, Learning Difficulties and developing groups in Brain and Body and Understanding Personality and Complex Needs



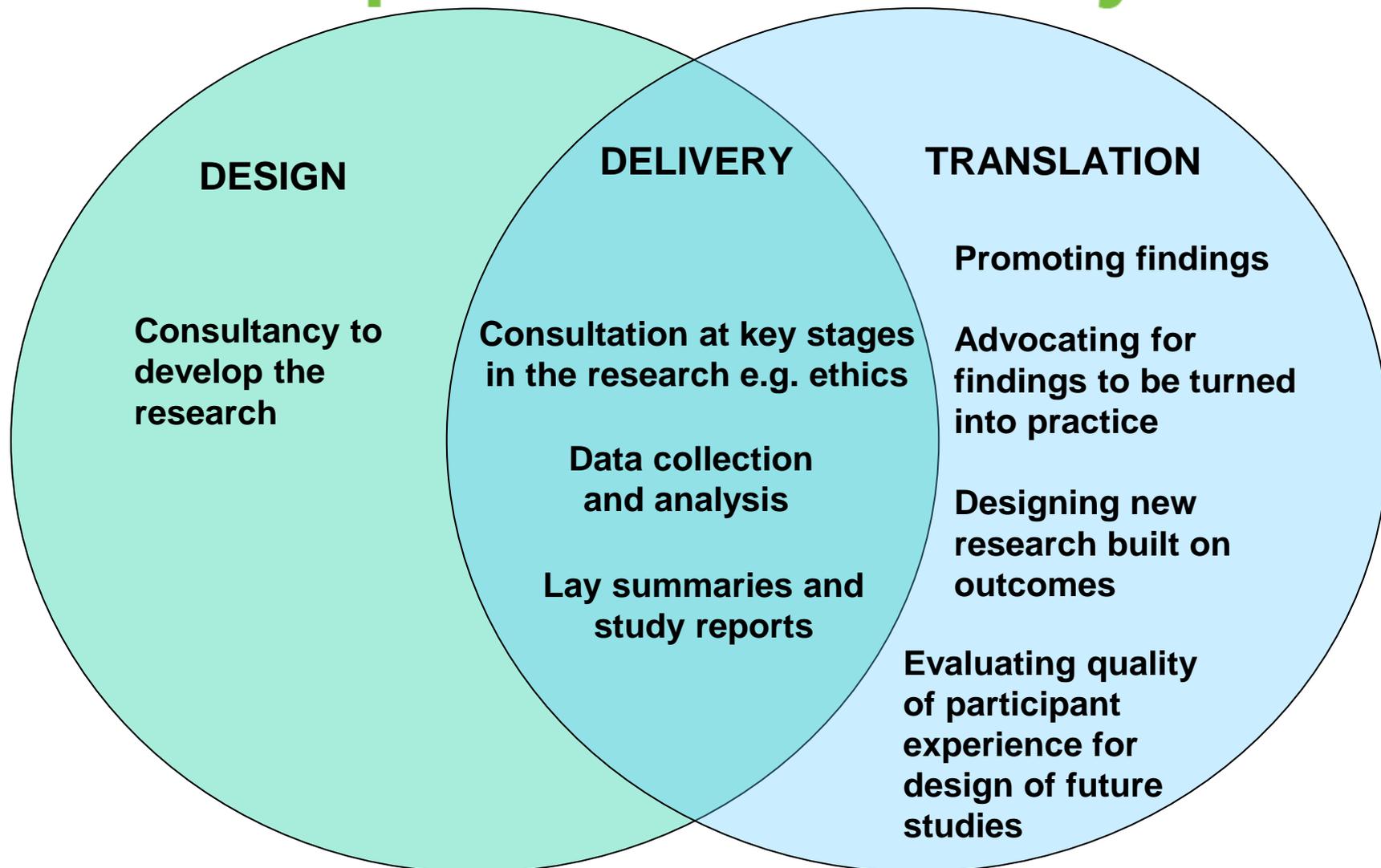
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How do we do it?

- Critical friendship model to co-design research proposals and implement across the research cycle. Building relationships and breaking down them/us barriers
- Regular LEAF meetings and email consultations-specialist design groups in research themes.
- LEAF in all aspects of research culture, leadership, governance, events and communications.
- Development of research focused on lived experience priorities and evaluation of experience of research participants. Ongoing development of Reviewers and Peer Researchers.



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Closing the translation gap

New Treatments

- The Brain and Body consultancy group helped develop research aimed at developing a psychological treatment for people with high functioning autism.
- The study builds on earlier research by Hugo Critchley and Sarah Garfunkel which looked at how fear is learned and unlearned.
- Some of you may have already taken part in Braveheart which looked at how the heart and anxiety work together.
- Sarah Garfunkel also found out that people with high functioning autism could benefit from a therapy to help prevent anxiety.
- This is very welcome as very few therapies target this specific need.



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Sometimes we find out what we already knew!

SPFT service users and carers took part in a study' led by Alan Simpson in East London looking at how collaborative and recovery focused care plans were in England and Wales.

This study, called COCAPP for short, found that quite often care planning was not collaborative and did not share risk assessments with service users.

Staff valued care plans but found the administration often got in the way of spending time with clients.

Most service users were not aware of their care plan and carers were often excluded from them.

COCAPP is holding an implementation event on the 21st of July to develop action plans with the trusts that took part. There are still 3 spaces left!

LEAF is developing some local research about how to make care planning more recovery focused, inclusive of family and meaningful to service users.