Summary of discussion

What are the things that have hindered you most in your "Recovery journey"?

- Given minimal information – 'go home and rest' no real guidance
- Lack of information
- Lack of communication then and now
- Not personalised – feeling disempowered
- Lack of understanding of young stroke – doctors / nurses did not understand why
- Hospital records not shared – Collation of information
- Impersonal – shunted through the system.
- Contradictory information between hospital and rehab
- Lack of communication Stroke Foundation
- No support – no rehab
- Tried to be positive but hit more hurdles
- Isolation living regional
- Stigma
- Not spoken "to" but spoken "about"
- Public health system

What are the things that have helped you most in your "Recovery journey"?

- Self-Advocacy
- Being positive
- Once in contact with Stroke Foundation, found a lot of information.
- Work have been very supportive and understanding
- Style of help and care – private rehab – linked up with stroke foundation
- Connection in stroke community – peer engagement
- Empowerment with health professionals
- Self-determination and resilience
- Connection with real life stories
- Books & Information about your own brain – passionate professional proficient communicator of knowledge and accessible in media "I care for your Brain – Dr Sullivan"
- Seeking own information – many resources

What should the ideal YSS "Recovery journey" look like?

- Expectation setting should be realistic / Know your boundaries given not by professional / clinical but by lived expert mentor understands the journey
- Not just counseling for the Stroke survivor but also the family – understanding the changes and limitations
- Community awareness
- Language (not a burden on the community) – Asset to the community – SHIFT the reductive language
- Connection with a Lived Expert mentor