Lived Experience Journey Map

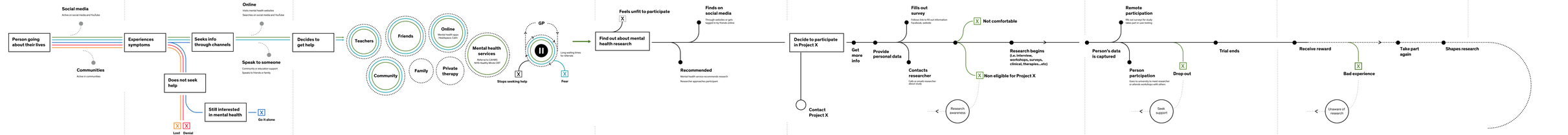
Cultural Context in Mental Health

Common Good

STAGES: UNAWARE OF MENTAL HEALTH | AWARE OF MENTAL HEALTH | SEEKING MENTAL HEALTH SUPPORT | AWARE OF MENTAL HEALTH SCIENCE & RESEARCH | ENGAGEMENT AND ONBOARDING | PARTICIPATION | FOLLOW UP | GOVERNANCE

TOUCHPOINT

Journey of young person with anxiety or depression participating in mental health research



LIVED EXPERIENCE INSIGHT

Highlights from interviews

About

This map illustrates the key states of the process from a person with lived experience of anxiety and depression. It highlights key areas of problems, needs and expectations for mental health research.

It shows the journey of online and offline behaviours to gain support for mental health, and highlights how they may contribute to mental health health research. It show key differences for Black, Asian and minority ethnic communities in the UK.

Key Mindsets

- Unaware
- Self determiner
- Proactive
- Denier
- Reluctant seeker

Problem

- Lacks the tools / support mechanisms to recognise, communicate and deal with emotions
- Has no one to turn to for support
- No language to describe feelings
- Mistrust of Health Care Practitioner / Institutions
- The system is not relevant to me

Problem

- Unable to talk with others and belief in own responsibility to resolve issues
- Fear communities will find out about issues

Problem

- GPs are not equipped to recognise early-stage anxiety and help people so allowed it to get worse
- Long waiting list for interventions
- Young people are not seen as a high priority for referral
- Belief that support services will not understand specific cultural and ethnic background
- Fear of confidentiality

Needs

- Counsellors or therapist who can relate to background or prior experience
- Consistency with counsellors or support "I do not want to constantly relell my story to a new person, it's always good to have that level of prior understanding"
- More understanding and knowledge in types of mental health
- Better tools to access information and services that provide support

Problem

- "Looked into online counselling support here in Spain but too expensive...you talk online via text or email"
- Counsellors or therapist leave

Expectation

- Professionals will provide people with useful tools
- Ability to track progress

Barrier

- Question if their experience will add value to the research
- Uncertain what is mental health research is "it sounds medically academic not approachable"
- Overwhelmed by information about the research study

Barrier

- Language is too clinical or academic "we know what words we struggle with...we're bombarded with clinical terms"
- Difficult first step to apply: send an email or call someone when people might feel social anxiety

Problem

- Not eligible because of ethnicity "I wanted to take part in a IEEG study but my hair was too thick"
- Location of the study "when you have anxiety it can be really difficult to complete simple tasks let alone travel"

Needs

- Transparency where their information is going to be used and stored

Barriers

- Time - young people are busy with school, university and work "It's difficult to find the time when I have lectures in the day
- Recurring depression and anxiety makes it hard to get out of bed and be social

Problem

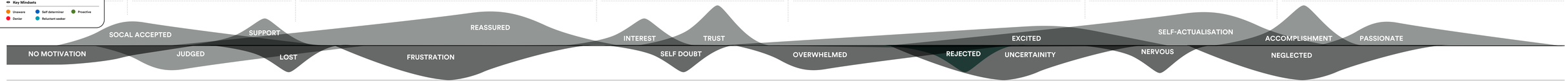
- Reports about the outcomes are too academic and not digestable

Expectations

- Reward: "Personally I don't expect anything, it's more the fact it is being used for something useful"
- Researcher being in contact: "to be honest nothing has ever happened after the research, this is the first time someone has actually rang me about it ...it's quite nice really"

Expectation

- "Make research collective, if you have a group of likeminded people who want to do similar research but want to take it in different directions they can collect the data all in one go...then take it in their different directions afterwards"

FEELINGS

Emotions people with lived experience may encounter