

ETHICAL AND SOCIAL CONTEXT

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networks and funders.

What does inclusive practice mean?

Inclusive practice = working within groups representative
of society + not just those in
research groups

How do [?] we access these viewpoints?

People that engage need feedback - value + respect
- encouraging them to become the researchers

Inclusivity = let the community own + run it (patient owned
co-op)

Carnegie trust - empowers communities

co-ops in terms of delivering tech

Initiatives to train + pass on to others

Sustainability

Keep it relevant overtime? AI different in 5-10yrs?

patient involvement

how is it measured?

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- ETHICS OF DATA SHARING
- SERVICE USERS INCLUDED
 - DIVERSITY
 - LIVED EXPERIENCE
- RELATIONSHIP WITH THERAPIST VS. DIGITAL TOOL
- WHEN IS IT APPROPRIATE TO WORK WITH PERSON W DIGITAL
 - E.G. SOMEONE WITH COMPLEX NEEDS
- WHO SHOULD PAY : PUBLIC VS PRIVATE
 - || WILL ||

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+ OPEN PUBLISHING INCL. NEGATIVE RESULTS.

- A GOOD THING
- ① NEWMIND + NETWORK CHALLENGED RESEARCHERS TO TAKE P.P.I. TO THE "NEXT LEVEL" - FROM SANDPIT → DRAGON'S DEN
 - MORE INVOLVEMENT OF 'ETHICISTS'? (IN ADDITION TO PPI?)
 - ② DO GUIDELINES EXIST? → YES, BUT...
 - DO RESEARCHERS KNOW ABOUT THEM?
 - ARE THEY "ENFORCED"?
 - IS THERE REGULATION → AT WHAT LEVEL?
E.G. USABILITY IN EU DIRECTIVE/REG. MEDICAL DEVICE
 - ③ ROLE OF CHARITIES?
WHO + HOW ARE PEOPLE BEING REPRESENTED
 - ④ ETHICAL DUTY OF RESEARCHERS?
 - TO EDUCATE ^{AND/} OR BE EDUCATED
 - CONVEYING THIS TO PEOPLE INVOLVED
 - "REFLECTIVE" APPROACH - BEING ITERATIVE
 - AS WE LEARN MORE
 - AS TECH CHANGES - "PAUSING"
 - RELATIVE TIMESCALES OF TECH. DEVELOPMENT + LEARNING ABOUT IT - "MOVING TARGET"
 - ⑤ FRAMEWORK FOR REPORTING ABOUT ETHICALLY IMPORTANT THINGS
E.G. DATA SECURITY OF AN APP

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BPS, BACP guidelines

practitioners
not academics

ETHICS FIRST

≠ REC

patients set priorities

- Who decides what research we do?
- Who decides how we do it?

- engagement is a specialist skill & time consuming

- involve service users throughout - coproduction
- power - who has it?
- conflicts of interest
- ethics doesn't really apply for fundamental tech research
- challenges of ethics being ~~different in diff~~ understood differently in different areas
- ethics understood differently by participants & researchers