

Ethical Considerations: Remuneration with Arfan Hanif

Summary

- **The problem with the term health inequalities.** [4:53](#)
 - How commissioning has changed, and why the word health inequalities is a code to end up diluting things.
 - How representation matters in mental health.
 - The role of research in making decisions on whether or not to retain participants, and why research is important.
 - The importance of black minority ethnic communities in health.
- **How important is it to have a representative board?** [9:54](#)
 - There has been historical research on health inequalities, but it has not been acted on. There is a lack of representative leadership in health services, local authority services or organisations that provide services.
 - The commissioner should be informed or informed by research.
 - Touchstone has been paying service users 20 pounds for half a day and 40 pounds for a full day because they value their time.
 - Benefits could be compromised.
 - There are no rules set by the commissioner or any organisation. The main concern is that when paying someone, they might restrict what they can say.
 - Academics should have equal status.
- **The value of time and money.** [16:36](#)
 - True research takes the approach that academics are the experts, but to be impactful, they need to know what's actually needed.
 - Ethical boards, particularly with mental health, should pay.
 - In this case, an ethics board or academics, it is about the trust of human beings. It is about recognising their personal responsibility.
- **Safeguarding the vulnerable and how to make them feel safe.** [23:59](#)
 - When someone says very complex and very vulnerable, you think that you have a problem with his particular issues.
 - When someone is very complex, very vulnerable and you want to see them as a problem, you've already given a negative view of it.
 - Anna: Playing devil's advocate, if there wasn't a systematic way of approaching things, how do we safeguard?
 - How to create a culture where everyone feels safe, included and accepted without using almost judgmental words.
 - The only vulnerability is being prejudiced or discriminated against the system, which is where her vulnerabilities come from.
 - In higher education and institutions, it's not the same across each institution.
- **See it as an investment.** [35:19](#)
 - Anna explains how the research needs to be valuable, and how to ensure that people are not selling their stories to be paid more.
 - The people who abuse the system are the most in power.
 - The NHS was set up to serve the public, but it has gone the other way.

- The importance of trust and recognising that there is a lot of unethical activities that take place in academia, including racism, sexism, homophobia, etc.
- **Giving your power away to help others.** [42:55](#)
 - The importance of equal partnership, trust and giving power away to be able to make the difference that you want to make in the world.
 - Service user training and development opportunities.
 - The importance of recognition and acknowledgement for a participant and how it can have long-term benefits for the individual and their friends and families as well.
 - Arfan shares his thoughts on ethics and remuneration to reinforce the value of lived experience in the research he does.