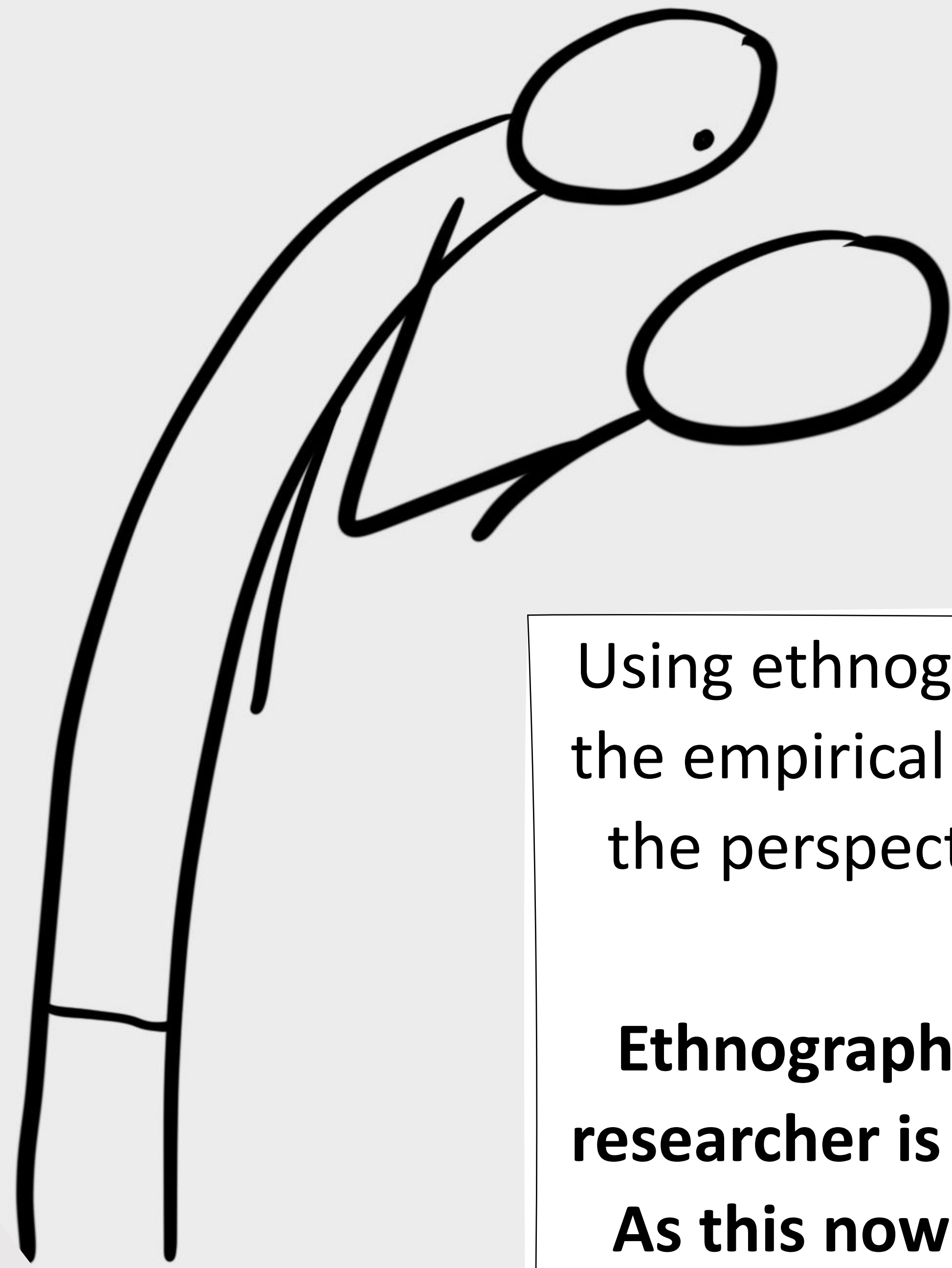


THE ETHICS OF EXPLORING SOCIAL COGNITION IN HD USING ETHNOGRAPHY DURING A PANDEMIC



Using ethnography to study social cognition will begin to address the empirical gap in our knowledge of everyday life with HD from the perspective of both people with HD and their companions.

Ethnography moves into the messiness of real life in that the researcher is an observer of the participants in their own space.

As this now needs to include Covid safe strategies (i.e. online observation) risks to all parties may be seen as greater due to the nature of HD alongside exploring the intimacies of interaction remotely.

Whilst our fears often do not come to fruition, researchers using this methodology with people with HD and their companions need to consider:

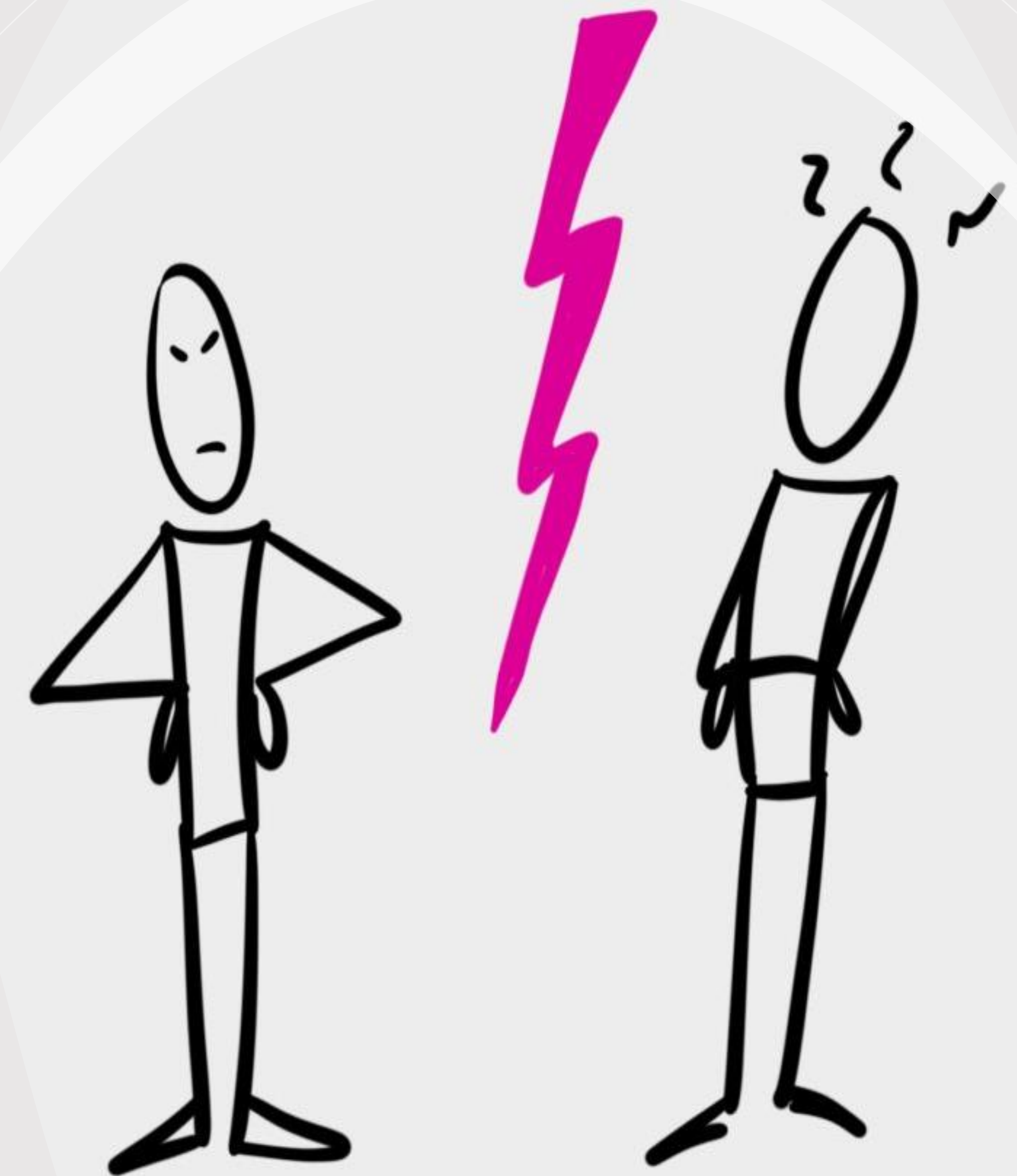
- Involving a **patient participant group**
- Building trust and rapport amongst the community **through the life of the project and beyond**
- **Family dynamics**
- **Tensions which may have been worsened by the pandemic**
- **A distress strategy**
- **Adjusting the way we as researchers do things** and not the other way round
- Giving more structure, planning and prompting **to optimise HD engagement**
- **Fluid revisiting of consent**
- **Access to technology**
- **The limitations of technology in this population**

Ms Alex Fisher, University of Birmingham/BSMHFT, alexandra.fisher@nhs.net

Dr Anna Lavis, University of Birmingham,

Professor Hugh Rickards, University of Birmingham/BSMHFT

Professor Sheila Greenfield, University of Birmingham



Thoughtful preparation although time consuming may enable equitable access to all interested participants but also reduce risks.