

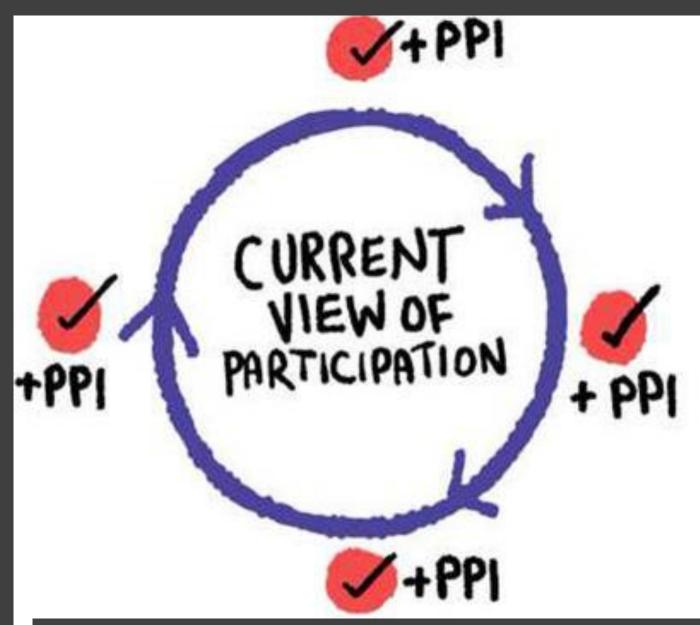
Patient and Public Involvement (PPI)

- Research that is done 'with' or 'by' the public, not 'to', 'about' or 'for' them.
- Patients or other people with relevant experience contribute to how research is designed, conducted and disseminated.
- This is unique and separate to participation and engagement.

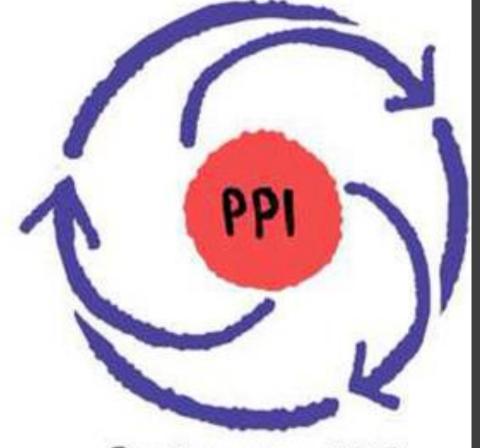


Reference: NIHR Involve:

https://www.peopleinresearch.org/public-involvement/



HOW THE GROUP SEE IT:



PATIENTS ARE THE AXIS

Image from: Knowles SE, Allen D, Donnelly A, Flynn J, Gallacher K, Lewis A, McCorkle G, Mistry M, Walkington P, Drinkwater J. More than a method: trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production. Research involvement and engagement. 2021 May;7(1):1-4.



Think: Values

Equality vs Power

Truth and Honesty

Transparency

Inclusivity

Space for idea exchange

Trust

Mindful of human experience



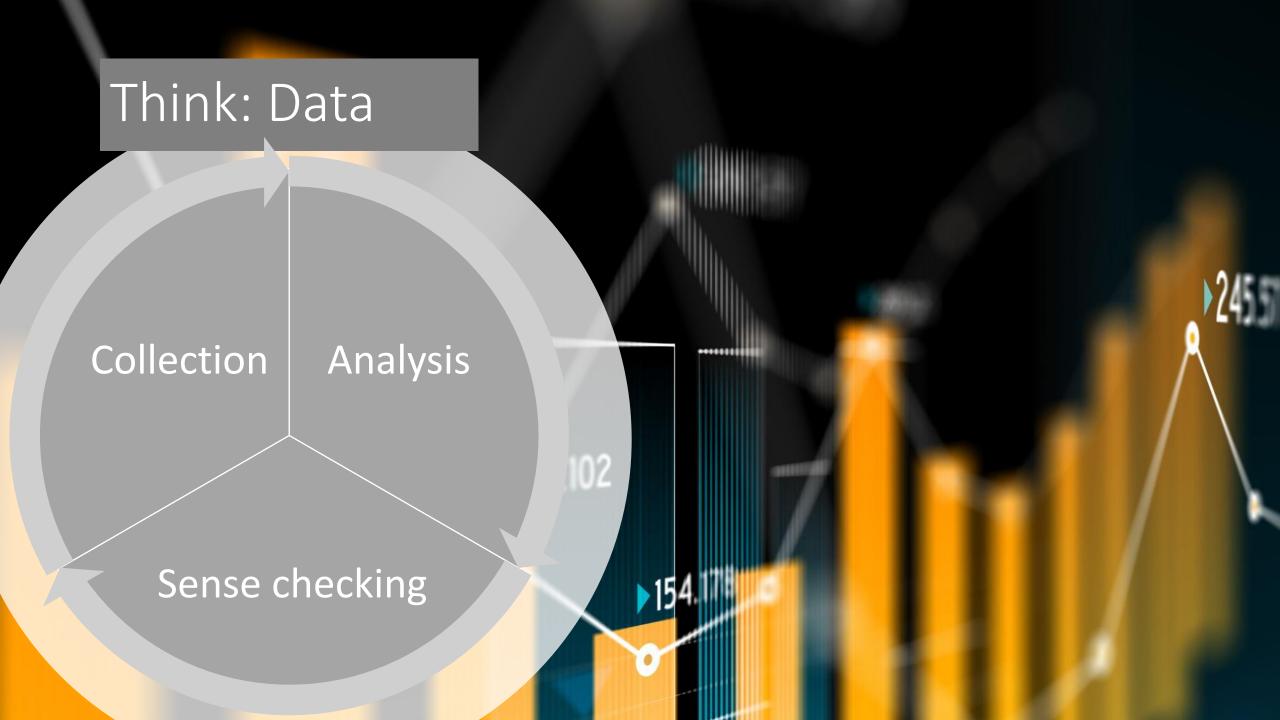
Protocol / Ethics development

Primary outcome

Clinic visit / study requirements

• Timelines







Think: Communication

- Media advertisements
- Participant information sheet
- Informed consent
- Participant expectations
- Study updates and findings



Think: Emotions and Feedback

- Regular meetings
- Receive <u>and</u> Provide
- Document input for impact evaluation

Think: Costs

• Involvement is <u>not</u> FREE

• Facilitate involvement

• Choice is important



Think:
Cake...
Fruit Cake



Figure 1: Workflow for PAINSTORM.



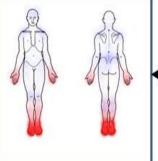
WP1 cohorts

Population (eg. UK Biobank and GoSHARE) Diabetes and chemotherapy neuropathy Retrovirus Extreme Mendelian pain disorders

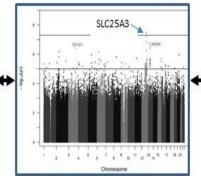
Case definition and harmonisation using international criteria

Advanced Pain **Discovery Platform** (APDP)

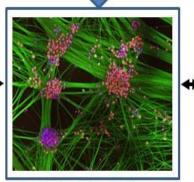
PAINSTORM Consortium: WP2 NeuP assessment: Uncovering mechanisms of neuropathic pain



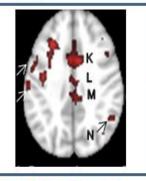
Heat map of Neup (red) and nociceptive pain (blue) in patients with diabetic neuropathy. These often co-exist necessitating rigorous case definition and harmonisation.



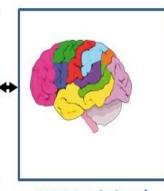
WP3 genetics: Including rare and common variants. Data shown is a Manhattan plot of metaanalysis of NeuP GWAS reveals significant linkage (p<5x10-8) with the locus of SLC25A3.



WP4 Biobanking/cell models. Human iPSC derived sensory neurons with the typical morphology and molecular profile of human nociceptors expressing Brn3a (red) and elaborating axons expressing NF200 (green).



WP5 Physiological Electrophysiology **Functional** imaging



WP6 Psychology/ Co-morbidities



WP7 Data integration: Data will be stored securely and integrated. Prospective data will enable prediction of NeuP. Innovative data analysis and multi-modal assessment to develop composite pain biomarkers. Open access and user friendly interfacing will aid future data mining.

Further Reading

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