



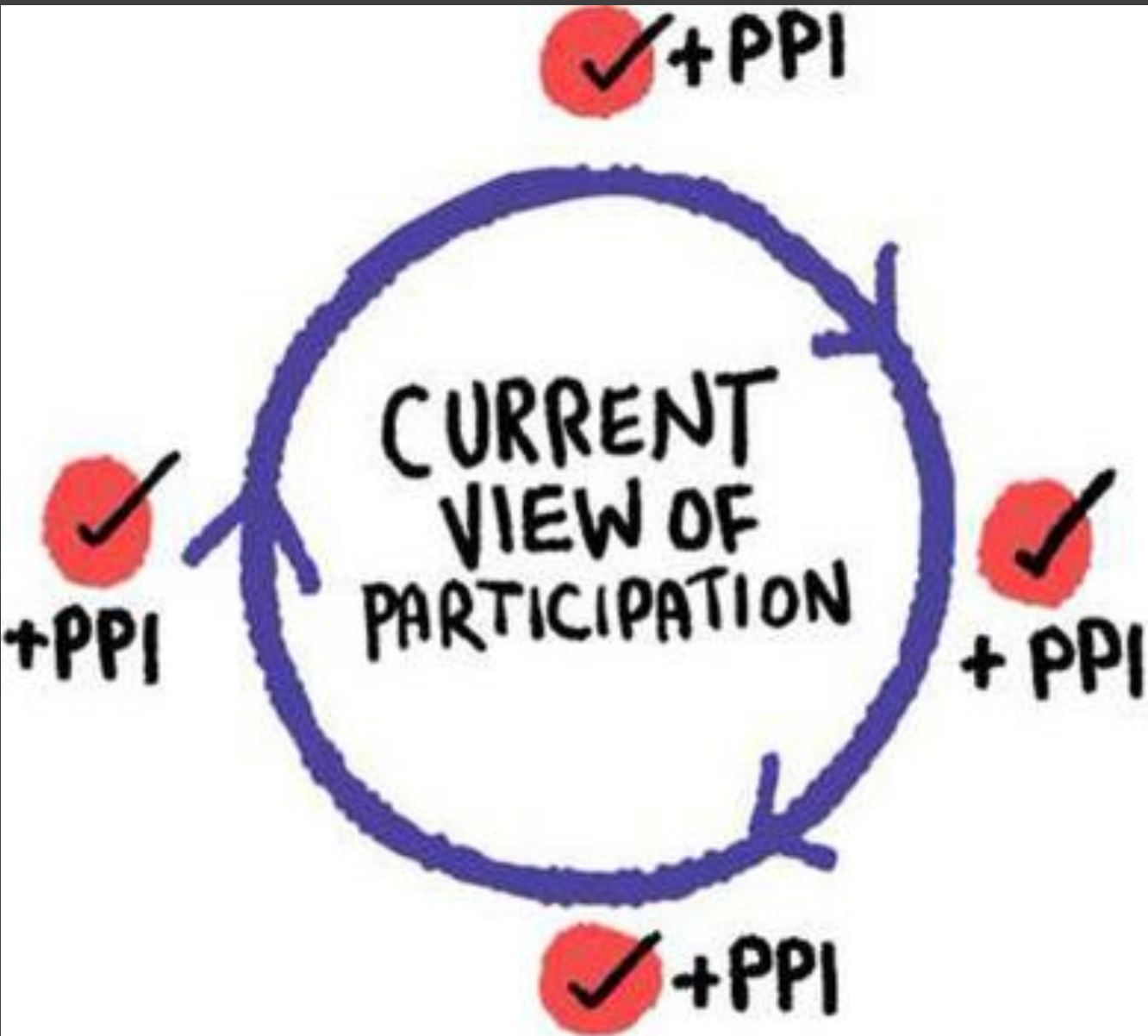
The “How Tos”: Incorporating Patient Partners in the Conduct of Clinical Pain Research

Kathryn Martin and Lynn Laidlaw
IMMPACT XXV – 28 October 2001

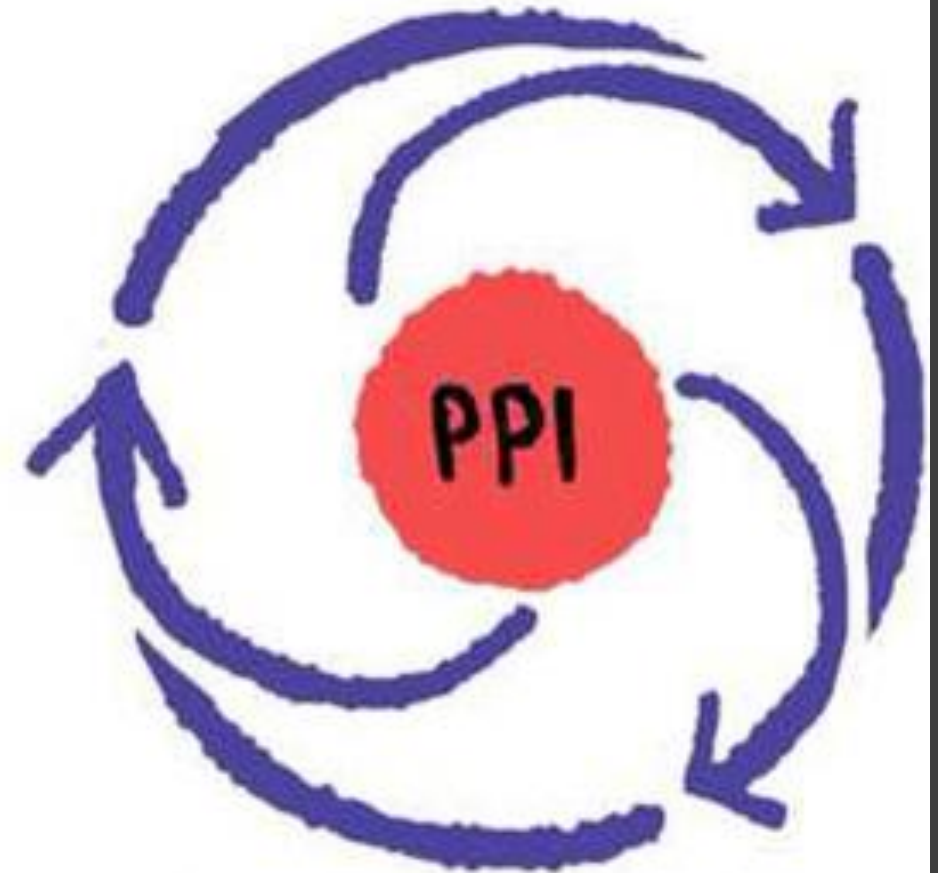
Patient and Public Involvement (PPI)

- 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.*





HOW THE GROUP SEE IT:



PATIENTS ARE
THE AXIS



Think: Values

Equality vs Power

Truth and Honesty

Transparency

Inclusivity

Space for idea exchange

Trust

Mindful of human experience

Think: Methods

Protocol / Ethics development

- Primary outcome
- Clinic visit / study requirements
- Timelines



Think: Data

Collection

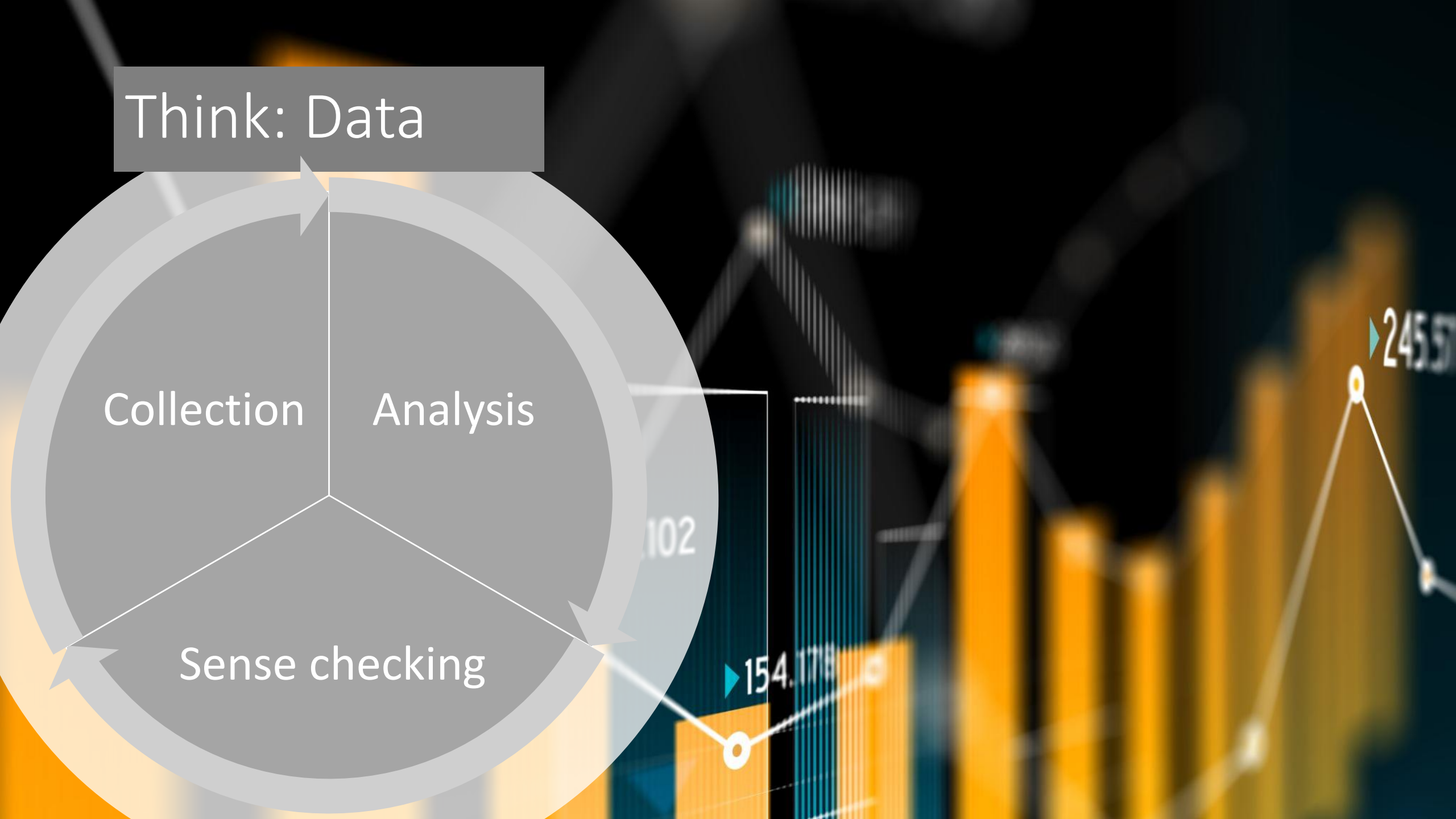
Analysis

Sense checking

102

154,178

2455





Think: Communication

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



Think: Emotions and Feedback

- Regular meetings
- Receive and Provide
- Document input for impact evaluation

Think: Costs

- Involvement is not FREE
- Facilitate involvement
- Choice is important

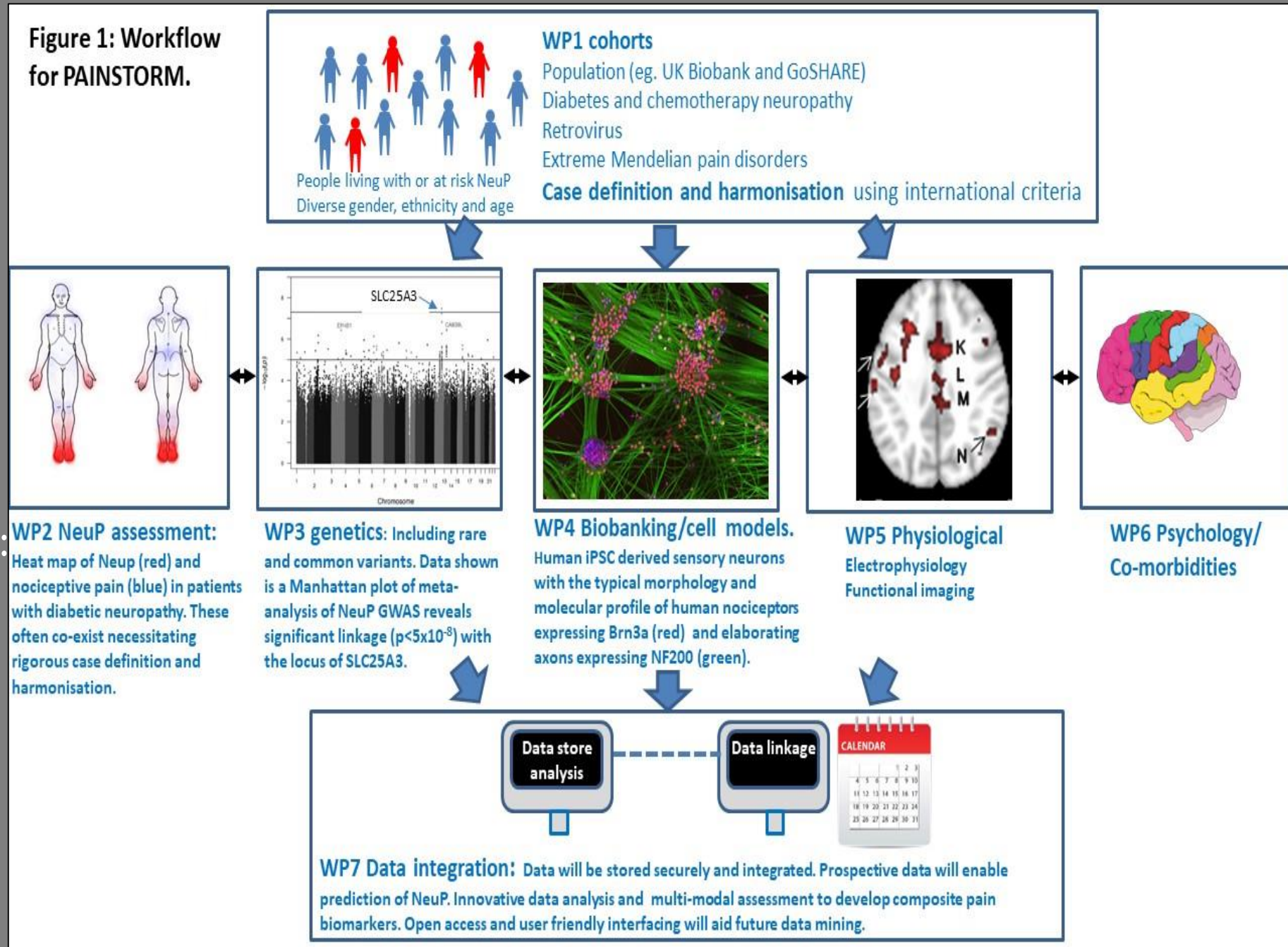


Think:
Cake...
Fruit Cake



Advanced Pain Discovery Platform (APDP)

PAINSTORM Consortium:
Uncovering mechanisms of neuropathic pain



Further Reading

- Locock L, Kirkpatrick S, Brading L, Sturmey G, Cornwell J, Churchill N, Robert G. Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement. *Research involvement and engagement*. 2019 Dec;5(1):1-1.
- Bruhn H, Anderson AS, Hickman A, Macaskill EJ, Treweek S. Letter on “Sharing trial results directly with trial participants and other stakeholders after the SARS-CoV-2 pandemic hit the UK—experience from the ActWELL trial”. *Trials*. 2021 Dec;22(1):1-5.
- Goulao B, Bruhn H, Campbell M, Ramsay C, Gillies K. Patient and public involvement in numerical aspects of trials (PoINT): exploring patient and public partners experiences and identifying stakeholder priorities. *Trials*. 2021;22(1):1-2.
- 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.
- Payment guidance for members of the public considering involvement in research. National Institute for Health Research. 05April2021. Version:1/0-April 2021. <https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372?pr=>
- Scholz B, Bevan A. Toward more mindful reporting of patient and public involvement in healthcare. *Research Involvement and Engagement*. 2021 Dec;7(1):1-4.
- Staley K, Barron D. Learning as an outcome of involvement in research: what are the implications for practice, reporting and evaluation?. *Research Involvement and Engagement*. 2019 March;5(14):1-9.
- Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*. 2013 Dec;13(1):1-8.
- Stones S. The irreparable damage of cancer. (blog) simonstones.com



 @lynn_laidlaw



kathryn.martin@abdn.ac.uk

Let's keep thinking about patient involvement in chronic pain research