

Embedding Patient and Public Involvement in the Alleviate Pain Data Hub



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Overview of Alleviate

Alleviate is the Pain Data Hub for the Advanced Pain Discovery Platform (APDP).

Aim: To create an online and safe Hub to access pain data.

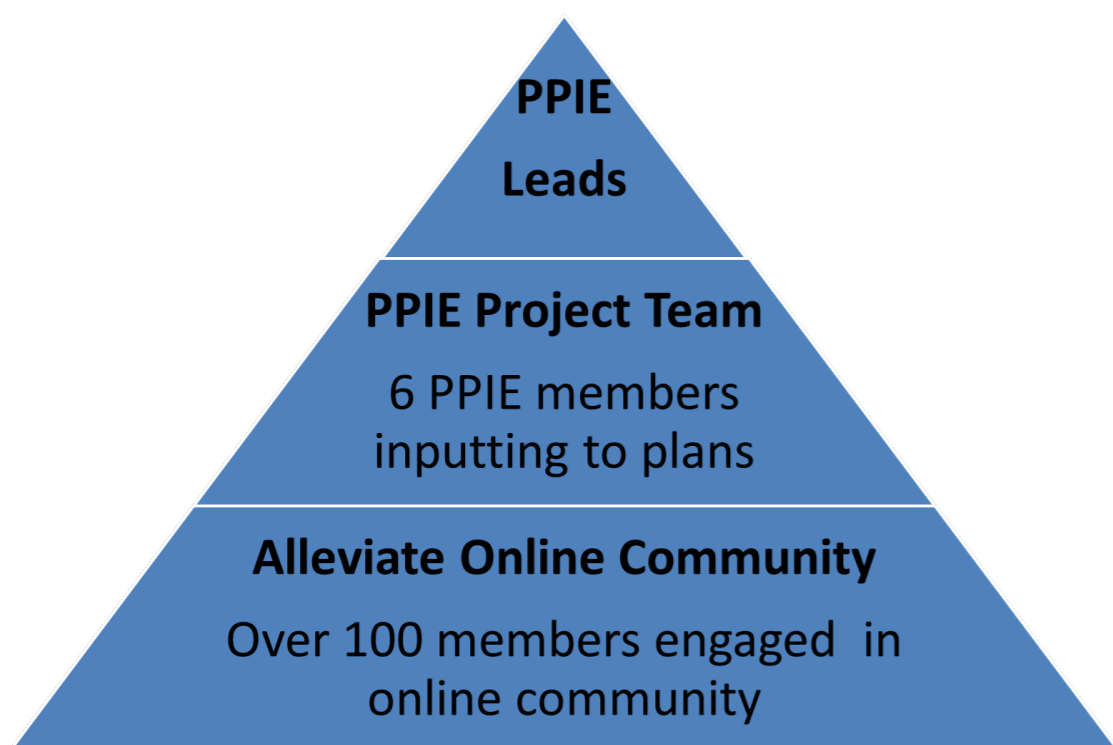
Purpose: This will be a key resource for the national pain research community and for people living with long term pain.

Patient and Public Involvement and Engagement (PPIE) has been embedded within the Alleviate Pain Data Hub from inception and throughout the research cycle.



Involvement in the Alleviate Team

- The Alleviate PPIE strategy was developed by patient partners to be open and inclusive.
- This has different options for people living with pain to be involved and engaged with the Hub.

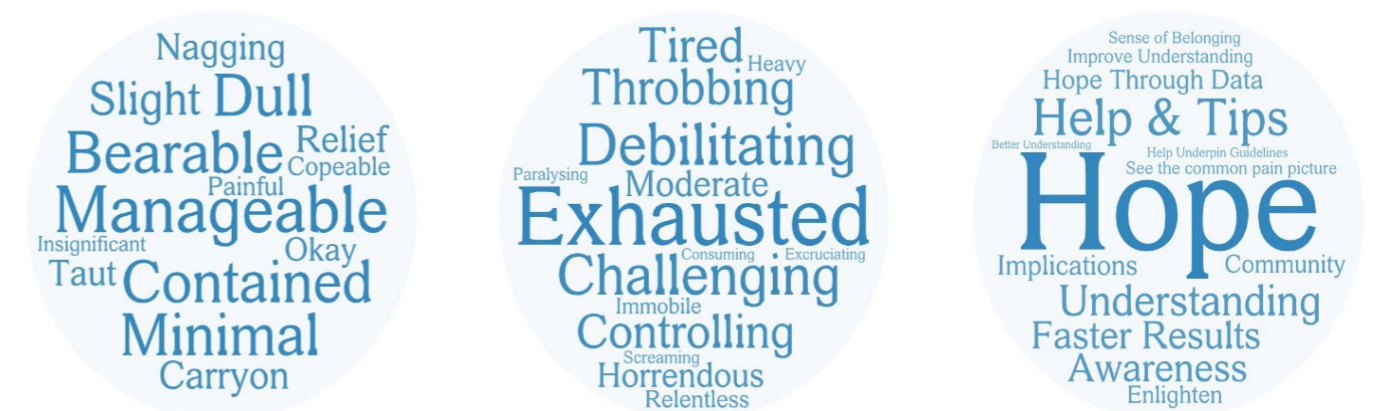


Involvement Community

An Online Pain Community was developed to engage with people living with pain across the UK. Over 140 people living with long term pain have signed up to the Alleviate newsletter.

The community have been involved in:

- Attending community meetings
- Providing feedback on the development of the Hub
- Input into communication strategies
- Website & social media development



Feedback from the Alleviate pain community on what words describe their pain on a good day vs pain on a bad day & what the Alleviate data hub means to them.

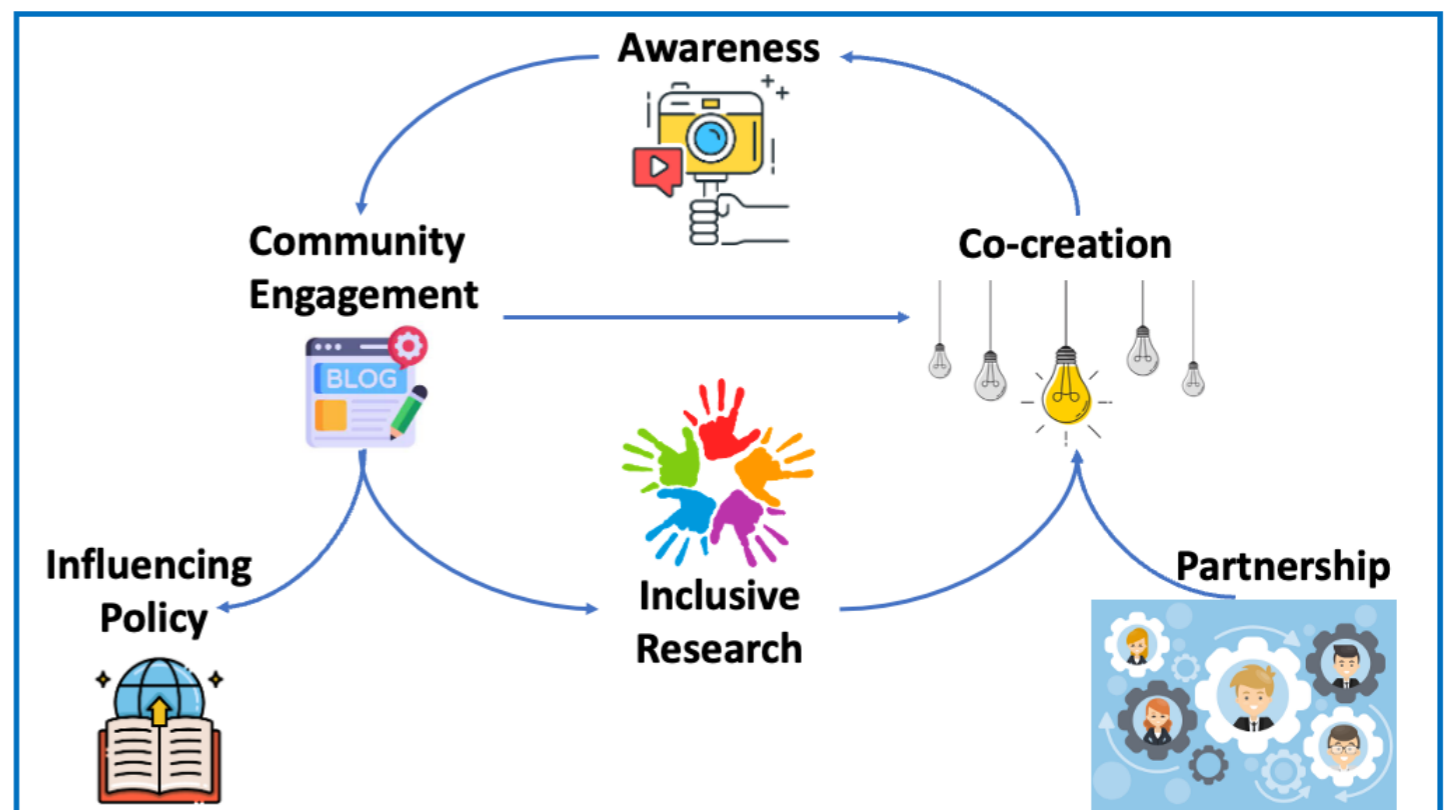
Involvement Training for the Research Team

Patient partners have led training for the Alleviate research team and researchers across the APDP:

- sharing a personal journey of pain
- the impact that living with pain has on daily life
- how to support, empower & grow PPIE in pain research

Impact

Meaningful PPIE has had significant impact on the development of the Hub & the research team.



We would like to thank our patient partners and the wider Alleviate community for continuing to provide meaningful input and context to the development of Alleviate.

