

1. Background

NESSIE is one of 13 evidence synthesis groups (ESGs) funded by the National Institute for Health and Care Research (NIHR) Evidence Synthesis Programme. We aim to address knowledge gaps or to answer a specific need in healthcare, public health and social care. Our evidence synthesis projects have a direct impact on decision-making, patient and client care, reducing inequalities and identifying future research needs.

Core aim of NESSIE is to include people with lived experience of a health/social care condition, their caregivers/families and support organisations in the production of the evidence syntheses.

2. Methods

NESSIE has three PPIE co-investigators who:

- guide and oversee ESG PPIE activities, supported by a nominated PPIE lead for each evidence synthesis project.
- provide expert advice for best ways to approach PPIE in each project, networking, and co-producing lay summaries and dissemination material.

We aim to recruit 3-5 people with relevant lived experience of a health/social care condition or their caregivers/families.

We document and report PPIE involvement using the ACTIVE framework and GRIPP2 reporting checklists.

3. Examples of NESSIE's PPIE activities in evidence synthesis projects

Treatment orders

AIM of PPIE: advise and provide insight into development of a qualitative and a quantitative review relating to legally-mandated non-custodial drug and alcohol treatment orders for improving health outcomes for justice-involved adults

- Virtual meetings with group of 5 people and family members with lived experience of treatment orders with input from expert professionals and researchers
- Helpful in determining the positive and negative aspects of treatment orders and their effect on people
- Provided valuable insight towards inclusion of studies for the qualitative review
- Helped our understanding and presentation of findings, some of which were potentially sensitive
- Meetings tailored to allow time and opportunity for questions and reflection
- We provided 'debrief' information for members to mitigate any distress

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Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS)

AIM of PPIE: produce an evidence map that is useful and usable for people affected by ME/CFS

- Virtual meetings with closed group of 10 people from 3rd sector groups, DHSC working group (including people with lived experience), researchers and with a further small group of people with lived experience
- Contributed to early-stage protocol writing and provided constructive feedback on results
- Helped with description/coding of evidence map themes and layout of the final evidence map
- Gained knowledge and understanding that our aims were to present current research and identify where important gaps in ME/CFS research exists
- We achieved a sensitive approach to an often-misunderstood health condition, including awareness of fatigue and careful time planning to meet the needs of the PPIE groups ensuring successful reflection and feedback

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"I thoroughly enjoyed the meetings ... it isn't easy to talk about but I'm glad I am giving back something to help" (PPIE Family member, Treatment orders review)

"I found it very beneficial. It was very helpful to see and hear different points of view. Things that weren't as important in my head were to other contributors and vice versa" (PPIE member, Exercise review)

Exercise for secondary prevention and health-related quality of life in people with existing cardiovascular disease

AIM of PPIE: ensure review considered opinions and thoughts of people with lived experience and people providing/researching exercise programs

- Virtual meetings involving people with lived experience, a caregiver, and charitable representatives
- Helped clarify researcher's understanding of different types of exercise and how these are delivered
- Helped align terminology with that of British Heart Foundation
- Encouraged a real-world focus
- Informed our dissemination plan
- Meetings were tailored to allow opportunities for views and opinions using agreed ground rules

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4. Reflections

Every evidence synthesis requires a tailored, flexible PPIE approach based on project and topic-specific issues.

PPIE provides invaluable insights and input from people with lived experience and their caregivers/families.