

Terms of Reference (Sep2022)

1. Constitution

The Advanced Therapy Medicinal Products (ATMP) Engage Public and Patient Involvement (PPIE) Working Group - enables UK based stakeholders with an interest in ATMPs to come together to discuss PPIE activity related to the delivery of ATMPs in the NHS for research and eventual clinical adoption.

Membership of the group reflects key NHS, industry, private, public and third sector organisations including key patient groups with an interest in ATMPs. The group will share knowledge and expertise and contribute to identifying programmes of activities to:

- i. Avoid duplication of effort
- ii. Encourage further collaboration
- iii. Identify areas for development

2. Overarching Aims

- a. *To ensure that patients are at the heart of the pathway from ATMP research to adoption.*
- b. *To raise the patient and public profile of ATMPs by developing and influencing communications / events with relevant stakeholders, including supporting the development of clear patient and public facing information.*
- c. *Identifying, upholding and sharing best practice on PPIE with respect to ATMPs*

3. Governance arrangements

3.1 ATMP Engage will report directly into the National Institute of Health and Research (**NIHR**) **ATMP Coordinating Group** via a co-chair.

3.2 The group will also report into the Advanced Therapy Treatment Centre (**ATTC**) **Network** via co-chair.

3.3 The co-chairs will seek to map interdependencies with ATTC Network and Cell Gene Therapy Catapult (CGTC) projects and identify where joint working may benefit our group's aims and objectives.

3.4 The group members will feedback to their respective organisations.

4. Deliverables

On an annual basis, subgroups will be established to deliver outputs based on the overarching group's agreed priorities. The results of these prioritisation exercises are listed in the appendix.

5. Membership

The PPIE Working Group membership will evolve over time and a wider membership is welcomed. The co-chairs will try to ensure the group is as cognitively and demographically diverse as possible.

Membership currently consists of representatives from:

Organisation	Name	Role
Adaptimmune	Julia Decesare	Director, Clinical Scientist
Advanced Therapies Wales	Andrew Owen	Project Manager
Anthony Nolan	Dawn Hart	Director of Patient Services
BSGCT	Gerry McLachlan	Board Member
Cardiff University	Cheyne Drew	Research Fellow and Clinical Trials Manager
Cardiff University	Emma Lane	Reader in Neuropharmacology
Centre for Patient Reported Outcomes	Lee Aiyegbusi	Research fellow and a Deputy Director
CGTC	Finn Willingham	Head of ATTC Network Coordination
CGTC	Kamilah Lakhani-Powell	ATTC Business Programme Manager
Cystic Fibrosis Trust	Lorna Allen	Senior Involvement Manager
Cystic Fibrosis Trust	Candice King	CTAP Involvement Coordinator
Euro GCT	Amanda Waite	Project Manager
Euro GCT	Jen Lorigan	Information Officer
Genetic Alliance UK	Nick Meade	Director of Policy
Genetic Alliance UK	Jennifer Jones	Research Associate
Genetic Alliance UK	Sophie Peet	Policy Analyst

Imperial College London	Nicoletta Charolidi	Manager of the Centre of Excellence for Advanced Therapeutics and Knowledge Exchange Practitioner, London Advanced Therapies.
Janssen	Rachel Howell	Patient Engagement & Advocacy Manager
MW-ATTC	Nisha Sungum	MW-ATTC Programme Manager
NA-ATTC	Catherine Van Niekerk	Lead Project Manager
NHSE	Kiran Moyo	National Programme of Care Manager
NHSE	Ben Doak	National Senior Programme of Care Manager (Innovative Treatments)
NHSE	John Spoor	Head of Commercial Medicines Policy Analysis
NHSE	Alice Williams	Public Engagement lead at NHS England
NHSE	Sophie Parslow	Programme Support Manager
NIHR	Emily Pickering	Public Engagement and Involvement Manager
NIHR	Andi Skilton	Senior Manager for Public Engagement and Involvement
Oxford AHSN	James Rose	Head of Clinical Innovation Adoption
Patient and Public Voice Partner	Stella O'Brien	Patient and Public Voice
Patient and Public Voice Partner	Joanna Calder	Patient and Public Voice
Patient and Public Voice Partner	Laurence Woollard	Patient and Public Voice
The Christie	Manon Pillai	
Welsh Blood Service, Clinical Services	Mark Briggs	Head of Cell and Gene Therapy

Appendix

Deliverables 2022/ 2023

Working groups were established to progress the three higher priority projects

Priority	Project
Higher	Develop a charter, or similar, that sets out expectations of PPIE involvement.
Higher	Work with researchers and charities to further raise the profile of ATMPs.
Higher	Develop work to address equity of access.
Lower	Support the development of the PPIE e-learning module being produced by the ATTC Network.
Lower	Influence conference programmes and other events to include PPIE in ATMPs.
Lower	Explore the use of video produced in 2022 to support future webinars, presentations, and learnings.
Lower	Build stronger links with the NIHR ATMP coordinating group, Education and Workforce subgroup.
Lower	Ensure patient views are shared by increasing collaboration to avoid repeatedly asking patients for their experience.
Chairs' Action	Expand membership of PPIE Working Group as described in the Membership section e.g. wider charity representation, other PPV partners.
Chairs' Action	Increase the group's profile and draw attention as a source of support and advice.
Chairs' Action	Stay connected to the Centre for Patient Reported Outcomes' research on PROs for ATMPs.

Deliverables 2021/ 2022

To ensure patient and public engagement toolkits are available to those that need them.

- 1) To identify any gaps within the toolkits available
- 2) To support increased patient and public engagement across the development of ATMPs
- 3) To compile case studies of participant experience in ATMP studies and licenced products to provide an online repository for future participants to refer to
- 4) To develop and share ATMP patient and public facing information and resources
- 5) To share knowledge about ATMP events where PPIE involvement / experience can be shared or leveraged to influence best practice in ATMP research and adoption
- 6) Work collaboratively with other national workstreams and build partnerships to raise the profile of PPIE in the ATMP sector
- 7) To support the understanding of, and action to address, equality and equity of access and where there are issues of health inequality
- 8) To hold ATMP stakeholders accountable for their PPIE activities, if any by defining expectations and best-practices (e.g., within a Charter)