NIHR | Oxford Health Biomedical Research Centre

OH BRC YOPAG[1] Group 'A PPI Co-production model'

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Our purpose: interconnected themes and intergenerational benefits
An intergenerational, cross-theme collaboration within the BRC

[1] Oxford Health Biomedical Research Centre Young and Older Person Advisory Group

Mission statement

- To serve as a resource of people and knowledge that empowers and equips intergenerational YPAG and Patient and Public Involvement (PPI) participants within OH BRC research.
- By fostering skills, networking, and knowledge exchange, we aim to integrate and enhance meaningful co-production and co-research partnerships across OH BRC themes and beyond.

Overarching aims

1. **Empower and Equip Stakeholders**:
    1. To enable and empower patients, the public, and researchers by building **skills**, fostering knowledge exchange, and enhancing competencies in PPI methodologies to create 'research-ready communities' and 'community-ready researchers.
2. **'Integrate PPI Across Research Projects**: To ensure meaningful **intergenerational** integration of PPI in all stages of research across OH BRC themes, facilitating equal partnerships between public contributors and researchers while addressing power dynamics.
3. **Enhance Quality and Innovation**: To continuously **improve the quality** of PPI activities, foster innovative engagement methods, and ensure that contributions from the public and patients are impactful, transparent, and aligned with research goals.

YOPAG PPI members

- BRC themes Depression Therapeutics, Molecular Targets, E-Co-Flourishing and YPAG
- Open to other members
- Bio (the ‘Why’ of joining)
- Links to themes, NeurOxYPAG, PAR

YOPAG PPI's role

- Work with researchers in various ways (co-authoring, co-design, collaborate, production, research)
- Help to avoid tokenism, patient benefit
- Challenge assumption
- Provoke thoughts and actions
- Provide viewpoints on potentially uncomfortable topics
- 'Shapeshift' to create change within the research environment
- Leverage PPI expertise and experience
- Foster a research community

Objectives & Aims

Objective 1 - Maintain a Comprehensive Portfolio (process)

- Showcase the activities and achievements of the YOPAG group.
- Develop an up to date glossary of terms for clarity and accessibility.
- Champion a visual map to navigate the ‘ecosystem’ of the OH BRC.
- Maintain a “Toolkit” that outlines the research cycle and essential research skills (e.g., statistics).
- Clearly articulate the aim of YOPAG and its role within the OH BRC.

Objective 2 - PPI Enabling and Empowering

- **Training and Skill Development**: Identify shared training needs and organize training sessions in collaboration with the BRC PPIE team. Provide resources to build competencies in PPI methodologies, promoting the idea of ‘research-ready communities’ and ‘community-ready researchers.’
- Address potential **invisible skill gaps** to ensure inclusivity and effectiveness in PPI engagement.
- **Capacity Building**: Develop tools and frameworks to empower both patients, the public, and researchers, fostering active engagement throughout the research process.

Objective 3 – Integration of PPI

- **Embed PPI across OHBRC Themes:** Identify productive strategies to ensure that PPI is integrated at every stage of research, from design to dissemination.
- **Promote Collaborative Models:** Refine and implement co-research models that recognize and address inherent power differentials between researchers and public members.

Objective 4 – Enhancement of PPI impact

- **Quality Improvement:** To enhance and evaluate the quality of PPI activities using feedback and self-reflective practices.

- **Innovative Approaches:** To develop and promote innovative methods which meaningfully involve patients and the public, ensuring their contributions are impactful and integrated.

Objective 5 – Networking and Collaboration

- **Build a Networking Framework:** To create intergenerational forums/platforms for skill-sharing and collaboration between researchers, YOPAG, and PPI participants across BRC (Biomedical Research Centre) themes.
- **Expand Partnerships:** To develop partnerships with researchers which facilitate co-design, promote co-production and enable co-authorship opportunities for YOPAG and PPI participants together with researchers. To expand the reach and impact of PPI and YOPAG by involvement with external organizations, community groups, and research funding bodies.

Objective 6 – Support for funding applications

- **Funding Opportunities:** To identify and investigate funding opportunities for projects involving PPI.
- **Support in Grant Writing:** To provide guidance in supporting of researchers and PPI participants for co-development and funding applications. To ensure that patient benefit is central to all future research projects by active engagement with PPI.
- **Sustainability of PPI Initiatives:** To secure funding that ensures long-term sustainability of PPI and successful research project outcomes in the best interests of patients

Portfolio

Portfolio overview

Research cycle

Research skills

Toolkit

Glossary

Map

Tools and Resources

- **(the below are suggestions for us to discuss)**
- **Website (forthcoming)**
- **Training Workshops:** Organize workshops on effective communication, conflict resolution, and participatory research methods.
- **Technology Solutions:** Use project and file management and communication tools that are user-friendly for all age groups to facilitate better collaboration.
- **Documentation and Reporting:** Maintain comprehensive records of all activities, decisions, and changes in the project to track progress and learn from the process.

Key activities

- **Workshops and Training Programs**: Conduct regular workshops to train researchers and public members on PPI principles, methodologies, and best practices.
- **Networking Events**: Organise events to facilitate networking between researchers, patients, and the public, fostering collaboration and partnership opportunities.
- **Consultancy Services**: Offer consultancy services to research projects seeking to integrate PPI, providing tailored advice and support.
- **Evaluation and Feedback Mechanisms**: Implement robust evaluation and feedback mechanisms to assess the effectiveness of PPI activities and identify areas for improvement.
- **Public Engagement Campaigns**: Run campaigns to raise awareness about the importance of PPI and recruit diverse public members to participate in research.

How to evaluate

1. **Develop Robust Feedback Mechanisms:**
    1. Implement regular and structured feedback loops that involve all stakeholders, including underrepresented groups.
    2. Use digital platforms or face-to-face meetings for collecting feedback to accommodate different age groups and tech-savviness.
2. **Promote Self-Reflective Practices:**
    1. Encourage regular self-assessment and reflection sessions for the research team and PPI contributors to identify strengths and areas for improvement.
    2. Foster a culture of openness where constructive criticism is valued and acted upon.
3. **Ensure Transparency of Power Differentials:**
    1. Clearly communicate the roles, responsibilities, and decision-making powers of each member involved in the PPI process.
    2. Establish clear guidelines for conflict resolution and ensure that all voices are heard and valued equally, preventing power imbalances.
4. **Adopt Participatory Action Research Models:**
    1. Utilize participatory action research (PAR) as a collaborative approach that involves participants in the research process, including problem identification, data collection, and analysis.
    2. Design research activities that are accessible and engaging for various age groups to ensure meaningful intergenerational involvement.
5. **Evaluate and Adapt:**
    1. Continuously evaluate the effectiveness of the implemented strategies through both quantitative and qualitative methods.
    2. Be flexible in adapting approaches based on feedback and the evolving needs of the PPI group.

Assessing, recording, monitoring (?) measuring success

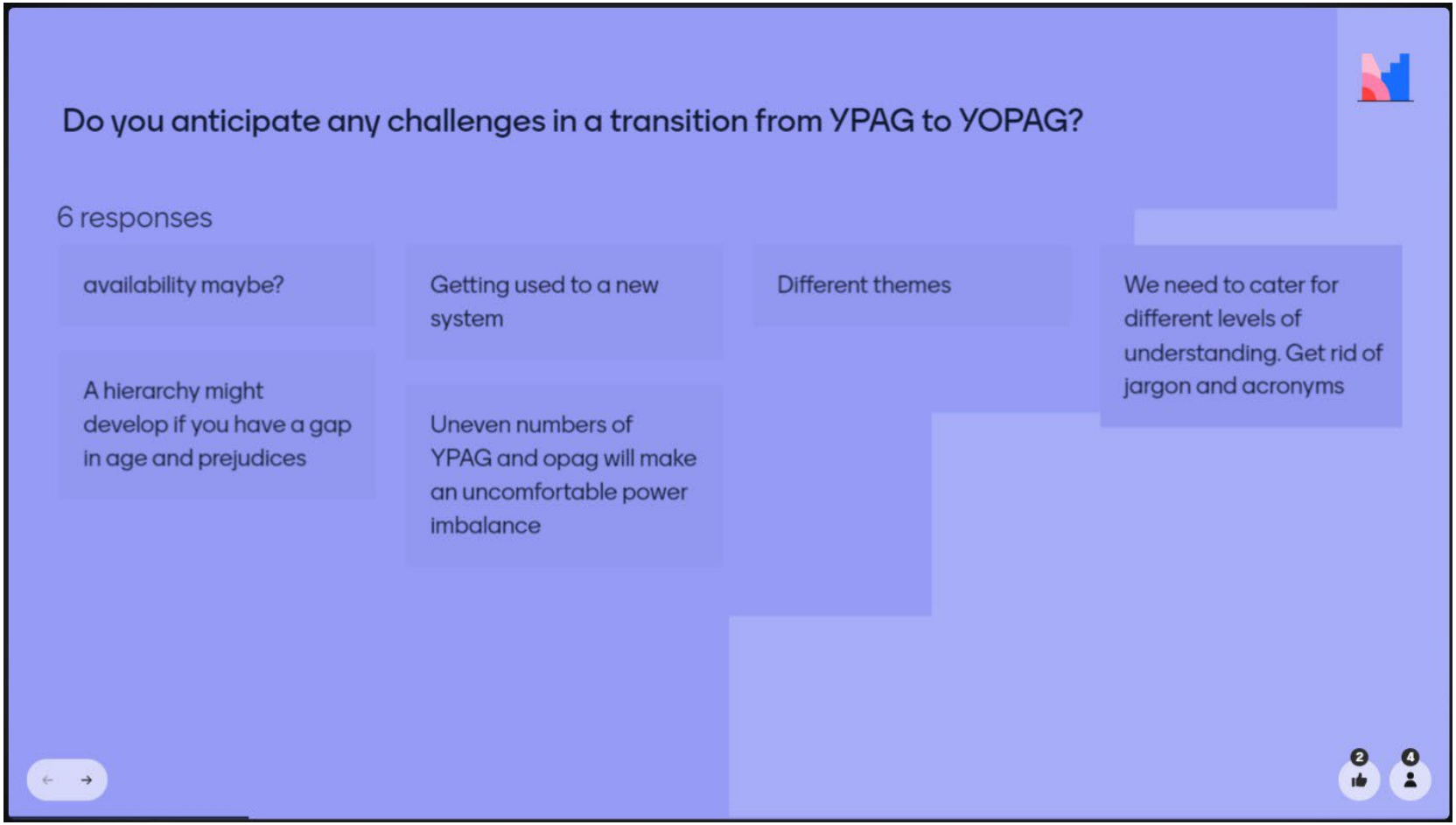
- **Impact Assessments**: Regularly assess the impact of PPI activities on research quality and outcomes.
- **Stakeholder Feedback Loop**: Gather feedback from all stakeholders, including researchers, patients, and the public, to continuously refine and improve the PPI processes.
- **Publication and Dissemination**: Document and share successful PPI case studies and outcomes through publications, conferences, blogs and online platforms.

Evaluation – Feedback loops

How has research been improved?

- Julia: "*I honestly think this should start with monitoring the feedback i.e. I wrote to you regarding suggestions, you decided to effect them. We need then to think about 'how' they improved the research. Did they make it clearer, change the emphasis, make it easier to understand/more accessible, etc.*"

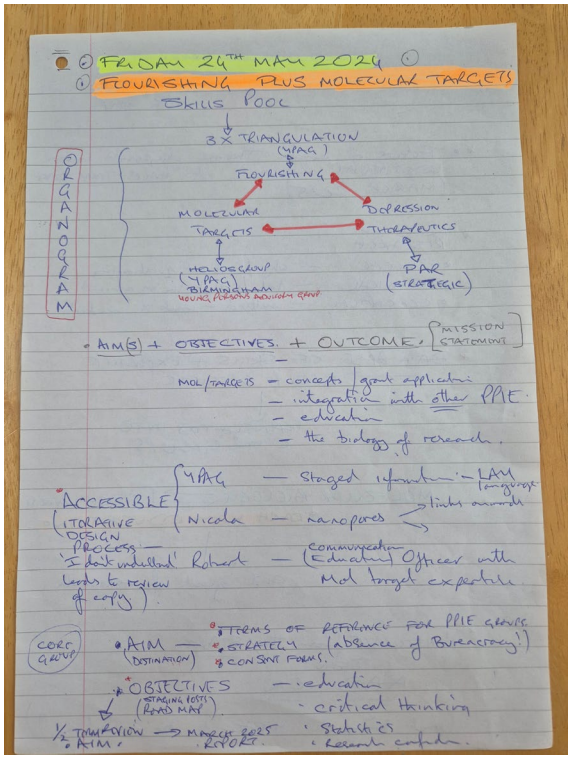
Feedback on transitioning from YPAG to Adult advisor

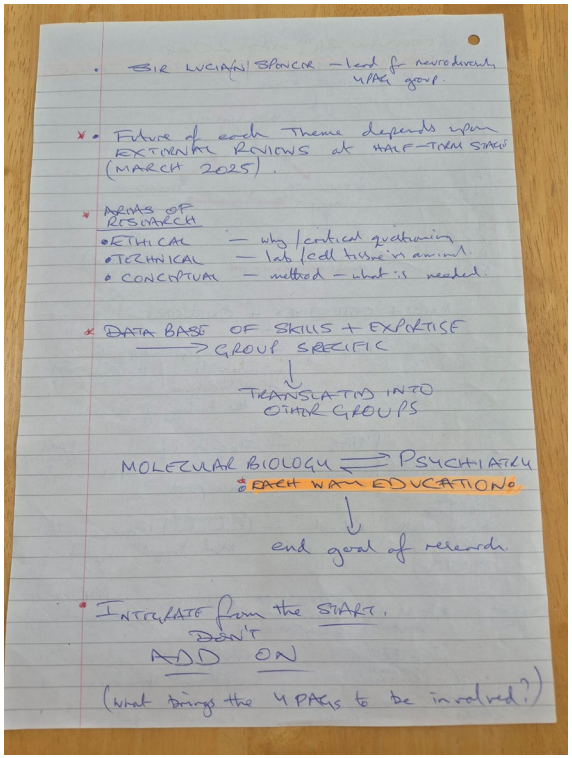


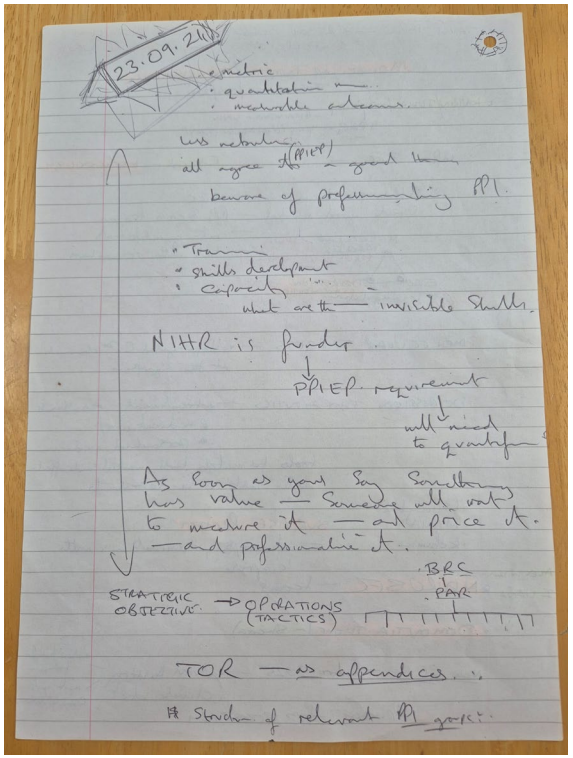
Achievements so far

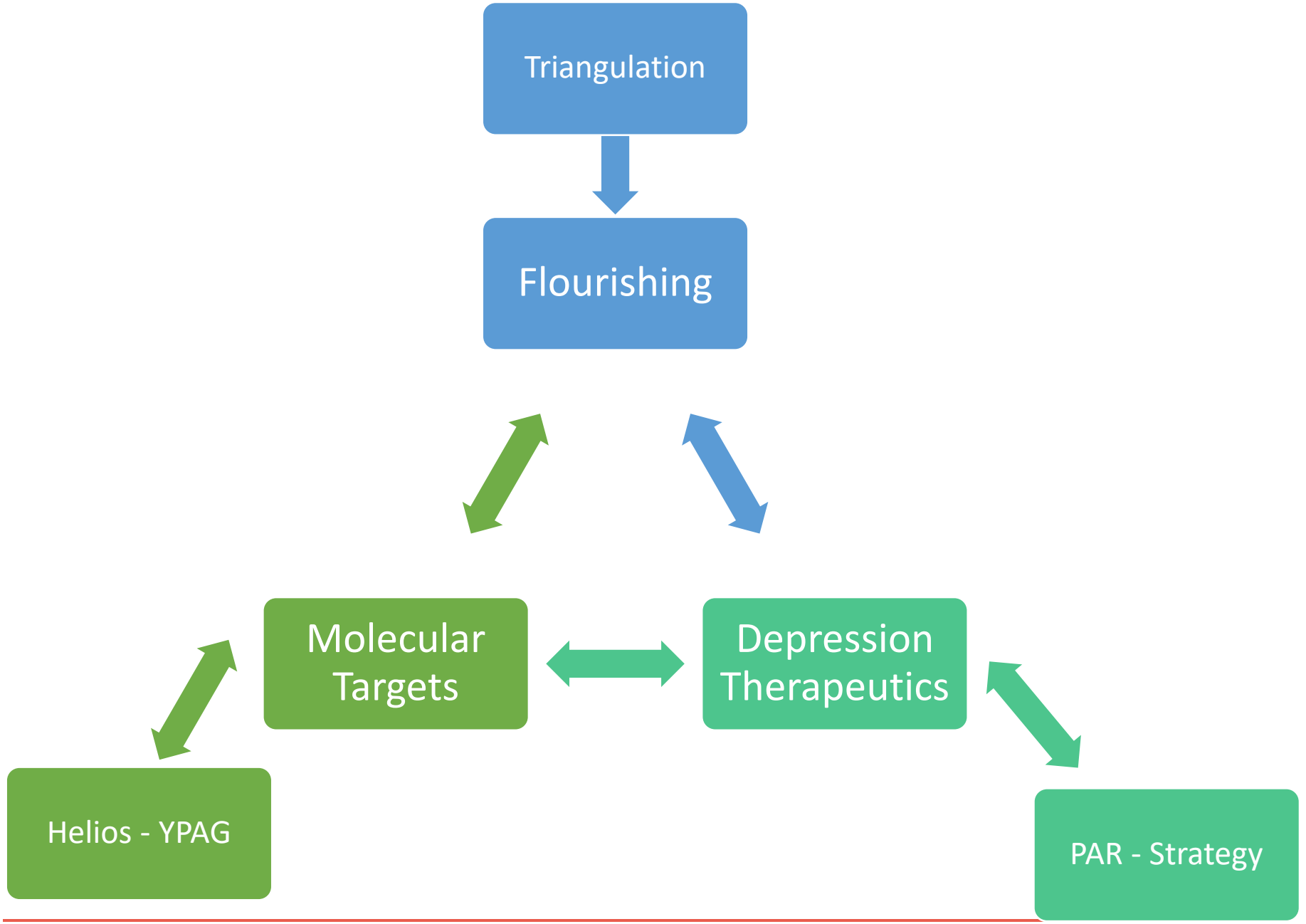
- Identified intergenerational workings as a need and connected /triangulated (?) three BRC themes, PAR (Patient and Research) and PPIOG across
- One ‘use case /case study’ has been the founding of the PPIE group for Molecular Targets
- For YPAG to add how the group has impacted (e.g., Asher could be talking about her resent presentation to the BRC, Sophie could be talking about the journey from YPAG to adult advisor
- Similarly for Roger and Julia to add their experience

Notes


FRIDAY 24TH MAY 2024
FLOURISHING PLUS MOLECULAR TARGETS
SKILLS POOL
3 X TRIANGULATION (YPAG)
FLOURISHING
MOLECULAR TARGETS
DEPRESSION THERAPEUTICS
HELIOSGROUP (YPAG) BIRMINGHAM
PAR (STRATEGIC)
ORGANOGRAM
AIM(S) + OBJECTIVES + OUTCOME
MISSION STATEMENT
MOL/TARGETS – concepts / grant application
– integration with other PPIE
– education
– the biology of research
ACCESSIBLE
YPAG – staged information – LAY language
Nicola – nanopores
links animals
Robert – (Communication Education) Officer with Mol target expertise
CORE GROUP
AIM (DESTINATION)
TERMS OF REFERENCE FOR PPIE GROUPS
STRATEGY (absence of Bureaucracy!)
CONSENT FORMS
OBJECTIVES (STAGING POSTS ROAD MAP)
education
critical thinking
Statistics
½ TERM REVIEW → MARCH 2025 REPORT
AIM


SIR LUCIAN SPENCER – lead for neurodiversity YPAG group
Future of each Theme depends upon EXTERNAL REVIEWS at HALF-TERM STAGE (MARCH 2025)
AREAS OF RESEARCH
ETHICAL – why / critical questioning
TECHNICAL – lab / cell tissue in animal
CONCEPTUAL – method – what is needed
DATA BASE OF SKILLS + EXPERTISE
GROUP SPECIFIC
TRANSLATED INTO OTHER GROUPS
MOLECULAR BIOLOGY ⇄ PSYCHIATRY
EACH WAY EDUCATION
end goal of research
INTEGRATE from the START
DON'T ADD ON
(What brings the YPAGs to be involved?)


23.09.24
metric
quantitative
measurable outcomes
less nebulous
all agree it (PPIEP) a good thing
beware of professionalising PPI
Training
skills development
capacity
what are the invisible skills
NIHR is funding
PPIEP requirement
will need to quantify
As soon as you say something has value – someone will want to measure it – and price it – and professionalise it
BRC
PAR
STRATEGIC OBJECTIVE → OPERATIONS (TACTICS)
TOR – as appendices
Structure of relevant PPI groups


Triangulation
Flourishing
Molecular Targets
Depression Therapeutics
Helios - YPAG
PAR - Strategy

Patient & Public Involvement Engagement Participation

PPI

Information

No ethics needed,
But data protection procedures (DPS, DPA, DPIA).

PPE

Information

Neither ethics or data protection procedures.

PPP

Information

Ethics and data protection procedures are a must.
Participants are excluded from co-production and study design to avoid bias.

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