Thematic summary of suggestions and ideas about the potential roles, opportunities and place for an international endometriosis network

1. Whole-System and Cross-Disciplinary Collaboration

- Need for specialists and primary care to work together on endometriosis and adenomyosis pathways.
- Build bridges across disciplines, sectors, and international contexts (UK, Australia, etc.).
- Focus on non-silo, collaborative research that includes both primary and secondary care.
- Develop cohesion and synergy – learning from each other without duplication or repeated actions.
- Collaborate and develop community roles and engagement in partnership, for example with sonographers and imaging.

2. Equity, Access, and Inclusion

- Pay attention to structural factors and inequities that shape diagnosis and care.
- Avoid over-representing those with deep infiltrating disease while excluding underserved communities.
- Prioritise adolescents, underserved populations, and those without diagnosis or access.
- Build systems to register patient interest and diversify public involvement (PPIEE).
- Work with primary care to ensure endometriosis research is equity informed and equity focussed

3. Research Priorities and Data Use

- Opportunities to study symptoms, delays, access, and care gaps using GP data.
- Explore early and accessible diagnosis and transitions to long-term condition management.
- Share knowledge and models (e.g., Sheffield community research model).
- Support recruitment for RCTs from undiagnosed and primary care populations.
- Work with public and patient partners to promote care pathway research and research equity.
- Ensure primary care input when general practice routinely collected data is used in epidemiology and machine learning algorithms.
- Developing resources and knowledge for adenomyosis in primary care, as well as focussing on endometriosis.

4. Knowledge Sharing, Resources, and Capacity Building

- Develop unified patient information sheets and resource packs for GP practices.
- Share ethics templates, consent forms, and guidance to reduce duplication.
- Create notice boards for current research opportunities.
- Run educational sessions (e.g., imaging, physiology, GP training).
- Advocate for GP/primary care streams at congresses and in medical training curricula.
- Support early/mid-career researchers (EMCRs) through collaboration opportunities.
- Dissemination of guidance and research (opportunities and outputs) across disciplines and across publishing silos.

5. Guidelines, Policy, and Advocacy

- Influence guideline development by generating primary care research evidence.
- Ensure general practice is embedded in global and national guidelines.
- Strengthen the global voice for endometriosis/adenomyosis from a primary care perspective.
- Engage professional bodies so the network gains visibility and influence.
- Become a resource for guideline developers
- Advocacy to ensure that primary care research and inclusion is considered in guideline development.
- Need an adenomyosis guideline, as well as an endometriosis one. This needs to represent and include primary care
- Work with advocates and influencers in partnership.
- Become a resource for liaising with journalists.

6. Rethinking Care Models

- Consider specialist primary care services focusing on symptom management and holistic care.
- Promote preliminary diagnoses in general practice and preventative treatment earlier.
- Shift focus from purely diagnosis to symptoms, access, and living well with long-term conditions.
- Develop systems approach to following up symptoms from early on in first contacts with GPs

- Sharing learning from other real world care pathways, and longitudinal symptom management.
- We need to think about post diagnosis support – including ongoing care for people who do not receive a diagnosis after a long wait for one.
- Strengthen the role of primary care in supporting people (treatment, education, holistic care) while they are waiting for specialist input.