KitNewCare

Sustainable Care, Lasting Impact

PPI Consultancy Group Report

(Updated version replacing the initial "PPI Multi-stakeholder Panel Installed")

Introduction:

The KitNewCare project is dedicated to transforming kidney care through innovative research and a commitment to sustainable practices. Recognising the importance of diverse viewpoints, the project proposal initially envisioned the establishment of a PPI Multi-stakeholder Panel composed of externally recruited patients, caregivers, and public representatives. This panel was conceived as a new structure created specifically for the project, ensuring that patient and stakeholder voices are integrated into decision-making processes.

However, as the project advanced —and following consultations with Work Package leaders and PPI experts— it became clear that this external recruitment model was neither the most meaningful nor the most operationally suitable approach for KitNewCare. Expert guidance highlighted that, for a project of this type, PPI is most effective when integrated *within* existing structures of the consortium rather than built as a separate external entity.

Consequently, the consortium agreed to adopt a revised and more coherent approach: the establishment of the EKPF PPI Consultancy Group, a structure based on the existing European patient network of EKPF, involving individuals with lived experience, caregivers, and patient advocates who are already active in ongoing EKPF engagement processes.

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The EKPF PPI Consultancy Group constitutes the project's mechanism for achieving Milestone 1 ('PPI Multi-Stakeholder Panel Installed') as defined in the Grant Agreement, by providing a functioning structure for regular and diverse patient involvement within the consortium. This consultancy group serves as a recurring, structured consultation mechanism through which KitNewCare gathers patient insight, particularly via the EKPF Annual Summit and targeted follow-up engagement with clinical sites.

Importantly, this approach:

- preserves the intent of the original milestone,
- strengthens internal alignment across the project,
- follows evidence-based PPI principles, and
- ensures coherence with Deliverable 6.3 and other project documentation.

This milestone therefore provides an updated and accurate description of the PPI structure implemented in KitNewCare, replacing the initial concept of an externally recruited panel with a sustainable, meaningful, and realistic approach to patient involvement.

Description:

This milestone outlines the revised structure for Patient and Public Involvement (PPI) in KitNewCare. Rather than establishing a new standalone multi-stakeholder panel, the project implements a PPI Consultancy Group anchored in EKPF's existing network. This group integrates PPI into the consortium's internal processes and ensures regular patient involvement throughout the project.

The consultancy group is consulted annually (during the EKPF Annual Summit) and through targeted bilateral communication with clinical sites and partners. This structure enables continuous PPI in governance, co-design activities, and implementation, maintaining flexibility while ensuring that patient input remains central to decision-making.

Definition PPI Consultancy Group:

The PPI Consultancy Group is an internal advisory structure composed of individuals with lived experience of kidney disease, caregivers, and patient advocates from the EKPF network. It serves as a platform through which patients provide perspectives on project activities, participate in workshops and consultations, contribute to the identification of needs, barriers, and priorities, review relevant materials such as informed consent forms or patient-facing documents, and support the co-development of PPI strategies at clinical site level. This approach embeds PPI within the consortium in a way that is meaningful, sustainable, and closely connected to project implementation, fully aligning with expert recommendations on best practices for patient involvement.

In 2025, the EKPF Annual Summit included a dedicated workshop in which patients and caregivers worked directly on the optimisation processes being developed within KitNewCare, providing feedback and practical recommendations. This demonstrates that the Consultancy Group mechanism is already active and delivering meaningful involvement.

Objectives of the PPI Consultancy Group:

1. **Foster meaningful patient and public engagement:** Create structured opportunities for patients and caregivers to actively contribute to KitNewCare's activities and decisions.
2. **Ensure diverse perspectives:** Integrate viewpoints from patients with varied experiences, caregivers, and advocates to inform implementation and evaluation.
3. **Promote transparency and accountability:** Strengthen open communication and clear decision-making by incorporating patient insight throughout the project.
4. **Enhance research quality and impact:** Ensure that patient needs, preferences, and experiences inform project activities, contributing to more relevant and effective outcomes.
5. **Empower patients and the public:** Enable patient representatives to shape aspects of the project, including providing feedback on tools, processes, and educational materials.
6. **Build trust and collaboration:** Establish a constructive, open relationship between patients, clinicians, researchers, and partners across KitNewCare.

Composition of the PPI Consultancy Group

The PPI Consultancy Group brings together representatives from kidney patient associations across several European countries, ensuring that the perspectives integrated into KitNewCare reflect a wide range of national contexts, experiences, and organisational backgrounds. The representatives involved include:

- **Patients with lived experience of kidney disease and carers/caregivers**, encompassing individuals who have directly experienced kidney disease at different stages (from early CKD to advanced disease, acute kidney injury, and post-transplant care) as well as family members, friends, or others who provide ongoing support. Their combined perspectives illuminate both the personal impact of kidney conditions and the practical challenges faced by those who care for patients in their daily lives.

- **Advocates for patient rights and empowerment**, including individuals active within patient organisations or civil society initiatives. Some are themselves patients or relatives, while others are professionals, volunteers, or long-standing advocates dedicated to representing the needs, rights, and preferences of the kidney community.

Together, the composition of this consultancy group ensures broad diversity in gender, age, ethnicity, socioeconomic background, and cultural perspectives. The participation of members from a variety of European countries further enriches the viewpoints represented, strengthening the group's capacity to provide meaningful, inclusive, and contextually relevant insights for the project.

Conclusion

The updated structure —the EKPF PPI Consultancy Group— achieves the core purpose of the original milestone, ensuring meaningful, diverse, and regular patient involvement in KitNewCare. The shift from an externally recruited panel to an internal consultancy model reflects:

- expert advice,
- improved contextual alignment,
- efficient use of existing networks, and
- enhanced integration of PPI across the project.

Through this model, KitNewCare ensures that patient perspectives continuously inform research design, implementation, optimisation processes, and sustainability strategies

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