KitNewCare

Sustainable Care, Lasting Impact

PPI Multi Stakeholder Panel: Concept note

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, KitNewCare is establishing a Patient and Public Involvement (PPI) Multistakeholder Panel. This panel will serve as a cornerstone for collaboration, designed to ensure that the voices of patients, caregivers, advocates, and other stakeholders are considered throughout the research process.

This report outlines the initial concept for the KitNewCare PPI Multistakeholder Panel. It details the panel's composition, objectives, and formation strategies. Additionally, the report highlights the significance of an online discussion forum designed to facilitate ongoing dialogue and knowledge exchange among stakeholders.

Description:

This document serves as a working concept note, outlining our initial plans for Patient and Public Involvement (PPI) within the KitNewCare project. We acknowledge that our approach to PPI will likely evolve and adapt as the project progresses and our understanding of the panel's valuable contributions deepens.

Definition PPI Multistakeholder panel:

PPI Multistakeholder panel: A patient public involvement multistakeholder group is a collaborative forum comprising patients, public representatives and other

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relevant stakeholders, aimed at ensuring active participation, input, and representation of diverse perspectives in healthcare decision-making processes.

Objectives PPI Multistakeholder panel

- **Foster Meaningful Patient and Public Engagement:** The panel will establish a platform for patients and the public to actively participate in KitNewCare's decision-making processes.
- **Ensure Diverse Perspectives:** The panel will bring together a broad range of experiences and viewpoints to inform the development, implementation, evaluation, and recommendations within KitNewCare research.
- **Promote Transparency and Accountability:** Open communication and clear decision-making will be fostered by actively involving the PPI panel.
- **Enhance Research Quality and Impact:** By incorporating patient and public preferences, needs, and experiences, the panel will contribute to more relevant, effective, and impactful KitNewCare research.
- **Empower Patients and the Public:** The panel will create opportunities for patients and the public to actively shape KitNewCare research, such as providing feedback on educational modules developed by CSH.
- **Build Trust and Collaboration:** The panel will facilitate the building of trust and mutual understanding between patients, the public, healthcare providers, and policymakers.

Composition PPI Multi stakeholder group

To ensure comprehensive understanding of the experiences and needs of individuals affected by kidney disease, the KitNewCare project actively seeks a diverse range of participants for the PPI Multistakeholder Panel. This diversity will facilitate inclusive and patient-centered decision-making throughout the project.

The panel will be comprised of the following groups:

- **Patients with Lived Experience of Kidney Disease:** Individuals who have directly experienced kidney disease, including those at various stages (early, advanced, post-transplant) and with different types (chronic kidney disease, acute Kidney injury). Representation will be sought across a spectrum of ages, genders, ethnicities, socioeconomic backgrounds, geographic locations, and cultural backgrounds.

- **Carers or caregivers**: Family members, friends, or other individuals who provide support and care for patients with kidney disease, offering insights into their perspectives, challenges, and needs. We will ensure representation from individuals of different ages, genders, ethnicities, socioeconomic statuses, geographic locations, and cultural backgrounds to reflect the diversity of experiences and perspectives within the patient population.

- **Advocates for patient rights and empowerment**: Individuals actively involved in patient advocacy organisations or initiatives, advocating for the rights, needs, and preferences of kidney disease patients and caregivers.

This inclusive approach to the PPI Multistakeholder Panel composition ensures a well-rounded understanding of the lived experiences of individuals affected by kidney disease, ultimately leading to more impactful inclusive and patient-centered healthcare decisions.

PPI Multistakeholder panel formation

The KitNewCare project seeks to establish a diverse and representative PPI Multistakeholder Panel. To achieve this, we will utilise a two-pronged recruitment approach:

- **Collaboration with Clinical Centers:** We will partner with each of the participating clinical centres: Medical University of Warsaw (MUW), University Medical Center Utrecht (UMCU), Instituto de Investigación Sanitaria de la Fundación Jiménez Díaz (FJD), and Università degli Studi di Modena e Reggio Emilia (Unimore) to identify and nominate two willing volunteers from their patient populations. Ideally, these volunteers will represent a gender-balanced perspective, aligning with EU guidelines on gender balance in research teams: https://rea.ec.europa.eu/gender-eu-research-and-innovation_en#:~:text=Gender%20balance%20is%20the%20balance,teams%20and%20in%20leading%20roles.

- **Open Call through Communication Channels:** We will launch a call for participation through our communications partner, ICONS. This call will be disseminated via a dedicated news release on our website, supplemented by targeted social media marketing campaigns across the project's social media channels.

This multi-faceted approach aims to attract a broad range of patients and the public, ensuring the PPI Multistakeholder Panel reflects the diverse experiences and perspectives relevant to KitNewCare's research objectives.

Timeline:

1. **Active Recruitment Begins:** April 2024. We will initiate efforts to recruit patients and public participants for the PPI Multistakeholder Panel.

2. **Ongoing Recruitment:** We anticipate that participation in the panel may be fluid, with individuals joining and departing voluntarily. To ensure a consistently engaged and representative panel, we will maintain an ongoing recruitment effort throughout the project lifecycle.

Governance and Stakeholder Engagement:

- **Terms of Reference:** To ensure clear expectations and effective functioning, a formal Terms of Reference document will be developed and finalised for the PPI Multistakeholder Panel prior to its inaugural meeting. This document will outline the panel's composition, roles, responsibilities, and operating procedures. The Terms of Reference will be reviewed biannually to maintain its relevance and effectiveness.

- **Liaison with Advisory Group:** The Chair of the PPI Multistakeholder Panel will serve as a designated representative on the KitNewCare Advisory Group. This role facilitates the exchange of information and perspectives between the panel and project leadership. The Advisory Group convenes annually, and the Chair will ensure patient feedback is effectively communicated during these meetings

Online Discussion board

To facilitate ongoing dialogue and knowledge exchange, KitNewCare will establish a dedicated online forum for stakeholders interested in sustainable nephrology. This platform, potentially hosted on Discord or a similar social media platform, will provide a space for patients, healthcare professionals, and other relevant stakeholders to:

- Share their perspectives and insights on key areas of focus in sustainable nephrology.
- Discuss and evaluate project metrics and data presented through dashboards.
- Collaborate on brainstorming sessions to identify and develop strategies for promoting sustainable practices within the field of nephrology.
- Provide feedback on research tools and materials, such as information letters, consent forms, surveys, interview questions, and study results interpretation.

This interactive forum fosters a collaborative environment where all stakeholders can contribute valuable input and ideas, ultimately enriching the KitNewCare research process.

Conclusion

The KitNewCare Patient and Public Involvement (PPI) Multistakeholder Panel represents a significant step forward in creating a collaborative environment for kidney care research. By actively engaging patients, caregivers, advocates, and other stakeholders, KitNewCare aims to ensure diverse perspectives are incorporated throughout the research process. Through meaningful participation in the panel, stakeholders will contribute valuable insights that will inform research design, implementation, and evaluation. This collaborative approach will ultimately lead to the development of more relevant, impactful, and sustainable solutions for the future of kidney care. Furthermore, the establishment of a dedicated online discussion forum strengthens this collaborative environment. The forum will provide a platform for ongoing communication and knowledge exchange, further enriching the research process.

KitNewCare believes that the PPI Multistakeholder Panel will play a crucial role in enhancing the quality, relevance, and impact of its research. Through active patient and public involvement, KitNewCare is committed to developing and implementing sustainable solutions for the future of kidney care.