

Title of the project:	
Development of an effective, age-specific, international resource for phosphate education in children with CKD and on dialysis. IMPACT study: IMproving Phosphate control in Children with CKD	
Principal investigator	Year of award
Evelien Snauwaert (Ghent University Hospital) Rukshana Shroff and Louise McAlister (Great Ormond Street Hospital, London, UK)	2021
Please provide an overall summary of the project (max 500 words)	
This research aimed to explore the barriers and facilitators to adherence to a reduced phosphate diet and phosphate binder medication in children and young people (CYP) with chronic kidney disease (CKD). A multi-stage, mixed-methods design was used to develop a comprehensive understanding of both professional and patient perspectives. The study comprised four stages. First, an online survey of 22 UK paediatric renal dietitians was conducted to assess whether they felt adequately equipped with educational materials to support families. Second, a systematic evaluation of 28 text-based phosphate educational materials (PEMs) used nationally and internationally was undertaken to assess their content, readability, and quality. Third, two questionnaires, the Phosphate Understanding and Knowledge Assessment (PUKA-c for CYP and PUKA-a for caregivers), were developed and validated to assess phosphate-related knowledge and challenges with adherence. Finally, online focus groups were conducted with CYP and caregivers to explore real-world experiences of managing dietary phosphate restriction and taking phosphate binders. Findings from the dietitian survey indicated a clear perceived need for improved educational resources, particularly materials designed specifically for CYP and adaptable for use across diverse cultural groups. Respondents emphasised the importance of incorporating the perspectives of CYP in the development of future resources to ensure relevance and usability. The review of PEMs found that while most materials were written at an appropriate reading age (approximately 10–11 years), they were often not suitable for younger children. Many lacked visual appeal and included few images, limiting engagement. Key practical information, such as suitable lower-phosphate alternatives, guidance on identifying phosphate additives, and advice on taking phosphate binders, was frequently absent. In addition, inconsistencies in dietary recommendations were identified, with some materials conflicting with published guidelines, potentially leading to confusion for patients and families. A total of 44 CYP and 33 caregivers from three UK paediatric renal centres completed the PUKA questionnaires. Most participants demonstrated good knowledge of phosphate management; however, this did not correlate with serum phosphate levels, indicating a gap between knowledge and effective implementation in daily practice. Dietary restrictions were perceived as more challenging than taking phosphate binders, reported by 59% of CYP and 71% of caregivers. Forty-six participants also took part in 13 focus groups. Several key themes emerged, including the need for practical, actionable advice; a preference for personalised and flexible strategies; the importance of developing self-management skills; and the significant social impact of dietary restrictions on CYP and their families. Participants also described their experience as a journey requiring ongoing adaptation, acceptance, and perseverance. Based on these findings, practical strategies are being developed to improve education, motivation, and adherence among CYP with CKD and their caregivers. These resources aim to guide both the content and delivery of dietetic support and will be made available to clinicians nationally and internationally. Enhancing the accessibility, consistency, and personal relevance of phosphate education is essential to improve adherence, optimise biochemical outcomes, and reduce long-term complications affecting bone and cardiovascular health in this population.	
How was the grant used for the project? (max 200 words)	

Grant was 15,000 euro.

- Recording equipment for focus groups
- Transcribing and translation of recordings from focus groups
- Purchase of qualitative research package NVIVO
- Financial compensation to participants for their time and contribution.
- Remuneration of collaborators

Please list all publications completed, with links to open access publications where available

- McAlister L, Shaw V, Shroff R. Phosphate education for paediatric chronic kidney disease: do renal dietitians consider educational resources are adequate? *BMJ Paediatrics Open*. 2025;9(1).
- McAlister L, Shaw V, Shroff R. Dietary phosphate educational materials for pediatric chronic kidney disease: are confused messages reducing their impact? *J Ren Nutr*. 2024;34(5):401-9.
- McAlister L, Shaw V, Pugh P, Joyce T, Snauwaert E, Bathgate F, et al. Development of a Questionnaire to Assess Phosphate Knowledge in Children With Chronic Kidney Disease and Their Caregivers. *J Hum Nutr Diet*. 2025;38(3):e70067.
- McAlister L, Shaw V, Pugh P, Joyce T, Snauwaert E, Bathgate F, et al. Barriers to and Facilitators of Phosphate Control in Children With CKD. *Kidney International Reports*. 2025;10(12):4252-63.

Are any other publications planned?

No

Please list all presentations relating to the project

1. **The European Society of Paediatric Nephrology (ESPN) 55th annual meeting, Vilnius, Lithuania. October 2024.** Abstract accepted for 3 minute presentation: Dietary phosphate educational materials for paediatric chronic kidney disease: is inconsistent messaging reducing their IMPACT?
2. **KRUK Driving Discoveries Conference 2023 and 2024**
Oral presentation 2023: Dietary Phosphate Educational Materials for paediatric chronic kidney disease: is inconsistent messaging reducing their IMPACT?
Oral presentation 2024: Exploring the *real-life* challenges to phosphate control in children with chronic kidney disease. The IMPACT study.
3. **GOSH conference 2024.** Digital abstract accepted. To be published in *BMJ Open*. Phosphate education for paediatric chronic kidney disease: do renal dietitians consider educational resources are adequate?
4. **International Paediatric Nephrology Association (IPNA) 2025.** Digital poster accepted. Exploring the real-life challenges to phosphate control in children with chronic kidney disease – the IMPACT study
5. **11th and 12th International Paediatric Nutrition Conference 2023 and 2024**
2023. The IMPACT study
2024. How to deliver the nutritional message - results from the IMPACT study
6. **UK Kidney Week (UKKW) June 2024**
Oral presentation: **Exploring the real-life challenges to phosphate control in children with CKD - the IMPACT study**
7. **British Dietetic Association MASTEMIND webinar. January 2024**
A research journey: Exploring poor dietary adherence in paediatrics
8. **EWOPA conference June 2025**
Unpacking the lived experience of phosphate management in children with CKD and their caregivers
9. **AIM London research group November 2024**
Exploring *real life* challenges to phosphate control in children with chronic kidney disease