Investigating lifestyle determinants of muscle and physical function, and the impact on patient experience and support needs in kidney disease (DIME-KD)

IRAS Project ID: 242263
Chief Investigator: Professor Alice Smith

Leicester Kidney Lifestyle Team
John Walls Renal Unit
University Hospitals of Leicester NHS Trust
Leicester General Hospital
Leicester LE5 4PW

and

University of Leicester
Department of Population Health Sciences

DIME-KD Plain English Summary November 2024

Plain English
Summary of the Main Findings from the DIME-KD Study

Overview of the DIME-KD study

- DIME-KD is a research study which used questionnaires, interviews and measurements to improve our understanding of :
  - how kidney disease affects the lives of patients who live with it
  - how different aspects of a healthy lifestyle may help people with kidney disease
  - how researchers can develop and test new ways of helping people with kidney disease to adopt healthy lifestyle habits
  - how the COVID-19 pandemic affected kidney patient lifestyle, health and access to healthcare
- DIME-KD consisted of several different parts which focused on different aspects of kidney patient lifestyle
- People with kidney disease, their families and friends, and healthcare professionals who look after kidney patients all took part in DIME-KD
- Altogether, over 3,500 people took part in the DIME-KD study between June 2018 and July 2024
- We have used the results from the DIME-KD study to design and test a new web-based programme called "MyKidneys&Me" which helps kidney patients to understand their condition and look after their own health and wellbeing

Summary of the Main Findings from the DIME-KD Study

Muscle health in kidney disease

We already know that having kidney disease can cause the muscles to shrink and become weaker. This is an important problem because it makes people feel very tired.

To find out more about the nature and importance of muscle health in kidney disease, we sent questionnaires to kidney patients in the post, and also invited some of the patients to our research labs in Leicester for a series of tests of muscle size and strength.

The results showed that in people with kidney disease, the strength and power of the muscles is related to ability to carry out daily activities such as getting up from a chair and walking.

The results were also used to improve measurements of muscle size, strength and function which will help us to do better research studies in the future

So far we have published 5 research papers about muscle health in kidney disease (see list at the end of this report)

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Diet in kidney disease

We know that eating a healthy diet is important for everyone's health and wellbeing. For people with kidney disease, making healthy food choices may help to prevent muscle weakness, keep the heart and blood vessels healthy and even slow down the rate at which the kidney disease gets worse.

To find out more about the diet of people with kidney disease, we sent questionnaires to kidney patients in the post asking them about their daily eating habits. We analysed questionnaires from nearly 700 kidney patients which showed us their "dietary patterns" in the UK. This information helped us to design an online programme called "My Kidneys & Me" which supports people to understand their kidney disease and how they can look after their own health and wellbeing. We have included more information about this programme later on this report.

We have published a research paper about diet in kidney disease (see list at the end of this report)

Summary of the Main Findings from the DIME-KD Study

Other health conditions and kidney disease

We know that most people with kidney disease also have other health problems. We need to know more about what other health conditions kidney patients have so we can give them the right advice about how to live a healthy lifestyle.

We sent questionnaires to kidney patients in the post asking them about any other health conditions they have in addition to kidney disease. We analysed questionnaires from nearly 1,000 kidney patients which showed us the patterns of other diseases that UK kidney patients typically live with. This information helped us to design an online programme called "My Kidneys & Me" which supports people to understand their kidney disease and how they can look after their own health and wellbeing. We have included more information about this programme later on this report.

We have published a research paper about other health conditions and kidney disease (see list at the end of this report)

Summary of the Main Findings from the DIME-KD Study

"Self-management" with a kidney transplant

People with a kidney transplant have to take very good care of their health to keep their new kidney working well. It is important that they understand what they should do and how to do it. This is called "self-management". To help people self-manage well we need to know how they feel about it and what they need more help with.

For this part of the DIME-KD study, 11 people with a kidney transplant took part in a detailed one-to-one interview with a researcher to discuss their experiences and views of living with a kidney transplant and their role in their own care. The results showed that effective collaboration with the healthcare staff they know is essential to help people look after their new kidney. Patients wanted more education about looking after their own health, and more emotional support.

We have published a research paper about patient views of self-management with a kidney transplant (see list at the end of this report)

Summary of the Main Findings from the DIME-KD Study

"Patient activation" and kidney disease

It is important that people with kidney disease take good care of their own health and wellbeing. Patients need to understand their condition and how best to look after themselves in partnership with their healthcare team. This is called "self-management". In order to self-manage well, patients need knowledge about their disease, skills in looking after themselves, and the confidence to do so. This "knowledge, skills and confidence" to look after your own health is called "patient activation". In other health conditions, we know that patients with high levels of patient activation tend to have better health for longer than patients with low levels of patient activation. However, less is known about the benefits of patient activation for people living with kidney disease.

In the DIME-KD study, we asked people with kidney disease to fill in a questionnaire called the "Patient Activation Measure" (PAM) which asks them about their knowledge, skills and confidence to undertake self-management. The results show us that that the PAM is a reliable way of measuring patient activation and that kidney patients with higher patient activation coped better during the Covid-19 pandemic than those with low activation. However, the results also showed us that unfortunately most kidney patients have low patient activation. This is an important result as it means we should find ways of improving "knowledge, skills and confidence" to help kidney patients look after themselves well.

We have published 3 research papers about patient activation and kidney disease (see list at the end of this report)

Summary of the Main Findings from the DIME-KD Study

Living with kidney disease in the Covid pandemic

The DIME-KD study started in 2018 and we were in the middle of collecting questionnaires in 2020 when the Covid-19 pandemic started. All non-Covid research was stopped to allow the NHS to focus on Covid care and research. We quickly adapted the DIME-KD study and worked with 10 other hospitals in different parts of England to send a survey via email to kidney patients. The survey asked people with kidney disease and their "significant others" (family or friends) about the effect of the pandemic on their lives and how they accessed healthcare. 528 people filled in the survey in the Autumn of 2020. We sent another survey in the Spring of 2021 after the Covid vaccination programme started to find out how things had changed, and 241 people filled in this second survey. We also carried out in depth interviews over the telephone with patients, their relatives, and kidney healthcare staff to help us understand their experiences in more detail.

We have published 5 research papers about the effect of the Covid-19 pandemic on kidney patient lifestyle and healthcare (see list at the end of this report)

Summary of the Main Findings from the DIME-KD Study

Development of "My Kidneys & Me"

The overall purpose of our research programme is to design, develop and test ways to help people with kidney disease look after themselves well, in partnership with their healthcare team. This is called "self-management". Before we could start doing this, we needed to understand more about :

- The usual lifestyle habits of people living with kidney disease in the UK
- How different lifestyle habits might affect health and wellbeing
- What kidney patients, their relatives and friends, and kidney healthcare staff think and feel about self-management
- What sort of help and support do people with kidney disease need to improve self-management?

The DIME-KD study used questionnaires, interviews and measurements to collect a lot of this information and we have used the results to design and develop an online education and self-management programme called "My Kidneys and Me".

We have published a research paper about the how we developed "My Kidneys and Me" (see list at the end of this report)

Summary of the Main Findings from the DIME-KD Study

List of research papers published from the results of the DIME-KD study

Muscle Health and Kidney Disease

- Wilkinson TJ, Palmer J, Gore EF, Smith AC. The validity of the 'General Practice Physical Activity Questionnaire' against accelerometery in patients with chronic kidney disease. Physiother Theory Pract. 2020 Dec 2:1-10. doi: 10.1080/09593985.2020.1855684.
- Wilkinson TJ, Gore EF, Vadaszy N, Nixon DGD, Watson EL, Smith AC. The utility of ultrasound as a valid and accurate diagnostic tool for sarcopenia: sex-specific cut-off values in chronic kidney disease. J Ultrasound Med 2021; 40:457–467. DOI: 10.1002/jum.15421
- Wilkinson TJ, Gore EF, Baker LA, Smith AC. Novel assessment of viscoelastic skeletal muscle properties in chronic kidney disease: association with physical functioning. Physiologia 2023, 3(3), 451-460; https://doi.org/10.3390/physiologia3030032
- Wilkinson TJ, Gore EF, Baker LA, Watson EL, Smith AC. Muscle power and physical dysfunction: a model for tailoring rehabilitation in chronic kidney disease. Nephrology 2021 DOI: 10.1111/nep.13920
- Wilkinson TJ, Ashman J, Baker LA, Watson EW, Smith AC. Quantitative muscle ultrasonography using 2D textural analysis: a novel approach to assess skeletal muscle structure and quality in chronic kidney disease. Ultrasonic Imaging 2021, https://doi.org/10.1177/01617346211009788

Diet and Kidney Disease

- Wilkinson TJ, Lightfoot CJ, Smith AC. Comparison of dietary patterns and daily food intake across kidney disease stages in England: a-posteriori cluster analysis. J Renal Nutrition 2024, 11:S1051-276(24)00157-2. doi: 10.1053/j.jrn.2024.07.010

Kidney Disease and Other Health Conditions

- Hawthorne G, Lightfoot CJ, Smith AC, Khunti K, Wilkinson TJ. Multimorbidity prevalence and patterns in chronic kidney disease: findings from an observational multicenter UK cohort study. International Urology and Nephrology 2023; 55:2047–2057. doi.org/10.1007/s11255-023-03516-1

Self-Management with a Kidney Transplant

- Memory KE, Wilkinson TJ, Smith AC, Lightfoot CJ. A qualitative exploration of the facilitators and barriers to self-management in kidney transplant recipients. J Neph 2022, 35(7):1863-1872. doi: 10.1007/s40620-022-01325-w

"Patient Activation" and Kidney Disease

- Lightfoot CJ, Wilkinson TJ, Patel NA, Jones CR, Smith AC. Patient activation and psychological coping strategies to manage challenging circumstances during the COVID-19 pandemic in people with kidney disease. Journal of Nephrology 2024, https://doi.org/10.1007/s40620-023-01851-1
- Lightfoot CJ, Wilkinson TJ, Memory KE, Palmer J, Smith AC. Reliability and Validity of the Patient Activation Measure in Kidney Disease. Clinical Journal of the American Society of Nephrology 2021, 16 (6) 880-888 DOI: 10.2215/CJN.19611220
- Wilkinson TJ, Memory KA, Lightfoot CJ, Palmer J, Smith AC. Determinants of patient activation and its association with cardiovascular disease risk in chronic kidney disease: a cross-sectional study. Health Expectations 2021, http://doi.org/10.1111/hex.13225

Living with Kidney Disease in the Covid-19 Pandemic

- Wilkinson TJ, Lightfoot CJ, Palmer J, Smith AC. Navigating the COVID-19 infodemic in those living with kidney disease : access and trust in health information sources and the association with anxiety and depression. Current Medical Research and Opinion 2021. https://doi.org/10.1080/03007995.2021.1984221
- Kanavaki AM, Lightfoot CJ, Palmer J, Wilkinson TJ, Smith AC, Jones CR. Kidney Care during COVID-19 in the UK: Perspectives of Healthcare Professionals on Impacts on Care Quality and Staff Well-Being. International Journal of Environmental Research and Public Health 2021. doi.org/10.3390/ijerph19010188
- Lightfoot CJ, Wilkinson TJ, Palmer J, Kanavaki A, Smith AC. Patient and staff experiences of remote kidney healthcare: lessons learnt from COVID-19. Journal of Nephrology 2021. DOI: 10.1007/s40620-021-01175-y
- Lightfoot CJ, Wilkinson TJ, Patel NA, Jones CR, Smith AC. Patient activation and psychological coping strategies to manage challenging circumstances during the COVID-19 pandemic in people with kidney disease. Journal of Nephrology 2024, https://doi.org/10.1007/s40620-023-01851-1
- Ford EC, Sohansoha GK, Patel NA, Billany RE, Wilkinson TJ, Lightfoot CJ, Smith AC. The association of micro and macro worries with psychological distress in people living with chronic kidney disease during the COVID-19 pandemic. PLoS One 2024:19(10), e0309519 https://doi.org/10.1371/journal.pone.0309519

Development of "My Kidneys & Me"

- Lightfoot CJ, Wilkinson TJ, Hadjiconstantinou M, Graham-Brown M, Barratt J, Brough C, Burton JO, Hainsworth J, Johnson V, Martinez M, Nixon AC, Pursey V, Schreder S, Vadaszy N, Wilde L, Willingham F, Young HML, Yates T, Davies MJ, Smith AC. The Codevelopment of "My Kidneys & Me": A Digital Self-management Program for People With Chronic Kidney Disease. J Med Internet Res 2022; 24(11):e39657. doi: 10.2196/39657