

## P176

### P176 -“I’ve been diagnosed since 1970 and nobody has ever given me advice on diet or lifestyle”: A research priority setting workshop with CKD patients treated in primary care

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#### Purpose

The research agenda in CKD has traditionally been driven by investigators and/or commercial interests resulting in studies that may not optimally inform patient care [1]. However, many funding streams now call upon substantial ‘patient and public involvement’ (PPI) to support proposed research projects [2]. Patient involvement in research priority setting in kidney disease is uncommon and little is known about patient-driven priorities [1], particularly in non-dialysis dependent patients from primary care and in the field of renal rehabilitation. We sought to identify the top 10 research priorities for patients with non-dialysis CKD in the area of renal rehabilitation, healthy lifestyle, physical activity, and diet/weight management.

#### Methods

12 participants (9 people with CKD and 3 family members) attended a half-day workshop. The day was divided into three sections: (1) healthy lifestyle; (2) physical activity; and (3) diet/weight management. For each section participants were divided into two facilitated groups. Each group discussed a series of topics, before formulating research priority questions. This was then discussed and evaluated as a larger group. At the end of the day, all formulated questions were presented and numbered sequentially. Participants independently ranked their top 3 priorities from these questions. In order to discriminate between ranking and frequency, questions ranked #1 were given 3 points, #2 given 2 points, and #3 given 1 point. The discussion was audio-recorded and, along with flipchart notes made during the day, was transcribed. NVivo was used to analyse common themes and words.

#### Results

The top 3 research priorities (and exemplar quotes) were:

1. How can we improve GP communication? – 18 points, said by 58% - “How many people out there gotta go through what we’ve all gone through ... you sit there at home and you don’t know anything about this disease and we’re all sat there thinking blooming heck what have I got” John (pseudonym), aged 68
2. What can I eat/drink with CKD? – 17 points, said by 75% - “Alcohol, coffee, salt, potassium and protein, now each and every one of us don’t know anything about what is good and what is not good on those particular things” John, aged 68
3. What diet will help me maintain physical activity? - 12 points, said by 50% - “The exercise will tie in with what you eat because you have to eat enough to be able to do the exercise” Rose, aged 61

Other common themes around lack of “awareness” and “knowledge” on diet and weight management, and the need for improved measures of both were mentioned. Both psychological and social well-being was deemed as important as physical health. See Figure 1 for the most common words (and variations) from discussion.

## Conclusion

A recurring theme was lack of appropriate information from their primary care provider. This not only extended to lifestyle/physical activity/diet, but worryingly to CKD itself. Many patients had little knowledge of the condition and its effects. Research needs to focus on the most appropriate means of disseminating knowledge regarding CKD, lifestyle, diet, and exercise to these patients.