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Understanding the role of patient and public involvement in renal dietetic research

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Cover Page Footnote

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Understanding the role of patient and public involvement in renal dietetic research

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Abstract

The objective was to consult patients on a proposed recruitment strategy to a patient and public involvement exercise. We wanted to explore the reasoning and willingness of patients to become co-researchers within a grant application. Eighteen people using the renal health service informed the consultation by action research so that their experiences could be used to guide the overall methodology. Twelve people took part in semi-structured interviews. NVIVO 10 and Framework Analysis were used to interpret emerging themes from the data. The recruitment strategy, informed by research expertise, became an experience-based expert design. The design took into account the limitations of attendance, the informational and physical needs of these service users. Service users wanted to share their experiences with people who would listen and were in a position to help make the changes. This gave them a sense of purpose and autonomy in their treatment and helped them cope with living with renal disease in society. However, feelings of doubt as to whether they could personally 'make a difference' as a co-researcher, were common. Consulting service users enabled the research team to recruit more people to interviews to explore motivation considering the unique personal and social needs of this service user group. Service users may need additional and continued support if they are to successfully take part in a clinical study research advisory group.

Keywords

Patient involvement, public consultation, patient co-researchers, renal, dietetics, service users, qualitative health, action research

Introduction

Patient and Public Involvement (PPI) are actively encouraged within the United Kingdom's National Health Service (NHS).¹ It is a practice model of involving service users within the research process rather than research being conducted on them.² This is a core democratic principle that people who are affected by research have a right to say what and how publicly funded research is undertaken.³

The advantages of the PPI approach for health researchers are that it leads to the development of interventions which are relevant and acceptable to service users. As such, there has been a call for establishing effective methods for engaging service users⁴ and increased reporting of PPI, so other researchers can learn from patient consultation exercise models of practice, including the practicalities of inviting service users to become co-researchers.⁵

However, few studies in renal research report on PPI and the impact this may have had on research design.⁶ One criticism⁷ is that the majority of NHS PPI activities have

consulted health professionals on the design of health service delivery⁸ but that such studies lacked detail on the exact nature of service user involvement, even when PPI was undertaken.⁹ This approach appears to reinforce a professional-centered practice where professionals decide what services are appropriate for patients' needs.^{10,11}

Perhaps some of the problem lies in a lack of confidence that service users can really embrace technical research decisions.¹² This could be helped by considering an Involvement Enterprise Model.¹² This model's philosophy is simple in that different people are suited to different things. All co-researchers bring expertise to different stages of the research process, each informed by their experiences, whether academic or experiential; thus, giving them all credibility as a co-researcher. One PPI study reported on a positive impact on the development and implementation of a self-management programme for chronic renal disease in primary care.¹³ Informal methods, such as telephone calls/attending outpatient visits were suggested as an effective method for co-working with patients.¹⁴ Likewise, a Kidney Research and Education Initiative successfully embedded patient involvement in

designing research proposals alongside renal professionals. This was achieved through consulting and recruiting service users to an advisory group to help develop a recruitment strategy for service users and their carers.^{13, 15}

Nevertheless, none of these consultations considered in-depth nutritional programmes, although these are an important intervention in renal disease management.^{16,17} Understanding the motivation underpinning PPI involvement in research is a crucial step for successfully recruiting service users to play an active part in research for health service development.¹⁸

To maintain ongoing PPI, we plan to use this study to inform recruitment of people onto our future research advisory group. This will involve the co-design and development of a new approach to renal nutrition self-management services and other clinical research studies within dietetics.

Objectives

- To conduct a patient advisory group (PAG) to advise on the recruitment strategy to a PPI exercise
- To conduct a PPI exercise using semi-structured interviews to explore motivation for continued involvement in renal dietetic research

Methods

Step one: Patient Advisory Group

A patient advisory group was set up to consult on recruitment and strategy of the qualitative interviews guided by the involvement enterprise model of PPI.¹⁹ This was with patients as the own experts on their experience of living with illness and accessing services.¹¹ The aim of this group was therefore to seek opinion on best evidence, for example, interview topics, and how to collect this information.²⁰ Convenience sampling was undertaken due to the funding time frame and clinical practice commitments.²¹ Patients undergoing haemodialysis in an outpatient setting were approached informally by the lead researcher, Andrew Morris, (AM) and invited to join the PAG.

AM designed a recruitment poster (figure 1) as an initial starting point for a consultation on a potential recruitment strategy. This was similar to the vignette approach in qualitative research.²² The group were asked to comment on the appropriateness of the poster as one method to recruit patients for involvement in designing a new renal dietetic service. Comments were recorded using written notes during the consultation. All participants in the advisory group were invited to join the qualitative interview stage if they wished.

Step two: Qualitative interviews

Participants

Inclusion Criteria

- Eighteen years of age or over
- Experience of engaging with the renal dietetic service
- Experience of following renal dietary advice
- Able to understand and converse in English

Exclusion criteria

- No experience of following renal dietary restrictions
- No experience of engaging with the renal dietetic service

Recruitment

Posters were placed within the Trust's Renal Department outpatients and inpatient settings for eight weeks. The final PAG version of the recruitment poster (figure 2) asked for people who had experience of both following a renal diet, and of using the current renal dietetic service, and who would also be willing to discuss their service experiences. Volunteers for the study were asked to initiate contact by their preferred method with the researcher so the study could be explained further. All volunteers were provided with an opportunity to ask questions. Prior written information on the study was sent by post and also given when attending the dialysis unit.

Procedure

Semi-structured interviews were audio recorded. AM conducted all twelve interviews and recorded each interview duration. The recordings were transcribed by intelligent verbatim (an edited form of transcription) by AM. Participants were invited to discuss their experiences of the service, which included a section on becoming co-researchers. These included:

- What are your thoughts about becoming a co-researcher?
- Tell me about your experiences of research participation?
- What do you feel you get out of taking part in research? Why is this?

Prompting questions were used to explore the topics in more detail such as uncovering motivation for participation and exploring research participation skills. The interview schedule was informed by a literature review.

Data analysis

A Framework approach was deemed appropriate.²³ This is a systematic method of analysing and interpreting qualitative data with a clear audit trail, which allows the five distinct stages of the analysis to be reviewed, increasing rigour.²⁴ The stages were: familiarisation, development of the thematic, themes, indexing, charting

Figure 1. Recruitment Poster

Interested in diet and nutrition?

Help design a self-management programme and receive a £40 shopping voucher

We are looking for people who would be interested in taking part in a discussion on what to include in a self management programme for renal nutrition. You will need to be over 18 years and have followed a renal diet advice given by a renal dietitian at this trust.

What is involved?

Prepared to discuss your experiences of self-managing a renal diet in a small group with two researchers and offer opinions on what would be required within a self-help programme based on your experience.

It's expected it will take up to an hour.

The discussion will be recorded on a voice recorder.

What will be paid for?

- Travel to and from UHCW
- Parking on site
- Time will be reimbursed in the form of a shopping voucher which can be used at

When is it?

September 15th in the afternoon at the University Hospital Coventry and Warwickshire NHS Trust.

I'd like to take part

To register your interests please contact Andrew Morris in person, by telephone, or e-mail for an information sheet.

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and synthesising and, finally, mapping and interpretation. NVivo 10 qualitative data analysis software (QRS International Pty Ltd, Australia) was used for data management. A reflective diary was kept throughout the analysis process. Data was reviewed until saturation was felt to be achieved.

The lead researcher reflected on their current situation; a renal dietitian interested in the impact of dietetic practice, had no diagnosis of renal disease and did not follow a therapeutic diet. Preconceptions of how the current system worked or when dietary advice should be given were set aside to reduce any potential for bias that AM brought to the study as a health professional.²⁴ Being transparent with these assumptions is an essential part of

this methodology to prevent personal and professional beliefs over influencing qualitative research.²³

Ethics

University Hospital Coventry and Warwickshire NHS Trust reviewed the protocol and gave ethical approval on 17 September 2015.

Results

Six patients agreed to take part in a consultation as part of a patient advisory group. All six agreed to form a temporary advisory group for 3 months, the time envisaged to recruit and carry out qualitative interviews.

One of the PAG members took part in the qualitative interviews.

Part One: Patient Advisory Group Consultation findings

The PAG feedback on the recruitment poster included that the colours were not bright enough to catch people's attention, the monetary reimbursement voucher for participation was not prominent enough and the font size of the print too small to be read from a distance in the waiting room. A comparison between both posters (Figure 1 and Figure 2) shows how patients' feedback informed the revised co-designed recruitment poster which was displayed in an outpatient and inpatient setting.

Analysis of the comments and discussions of the advisory group reported three themes which were recommended as barriers to participation and mutual collaboration which informed the recruitment strategy for part two. These were time; practicalities of taking part in research; and ethical considerations.

Time

Time was an important consideration for recruiting to a PPI event. Patients would not want to come back to the hospital for another occasion. It was discussed that even when on the hospital site, they were aware of their time, which they protected as it was valuable. It was advised that time would be best spent whilst either waiting within transplant clinics or in a dialysis unit.

"I wouldn't come back on a non-dialysis day; what about interviewing when people attend hospital." (member 1)

"Attendance is an issue; it's another trip to hospital." (member 4)

Recruitment practicalities

Patients expressed views about the practicalities of recruitment. Patients were on haemodialysis and therefore did not want to attend for an unrelated medical procedure, for example, to take part in research, even with financial remuneration. This was because of their own time and time engaging with clinical environment, for example traveling to and from the renal unit.

Patients thought the health professional poster contained too much detail and unattractive colours for it to be accessible to all patients. The type face needed to be larger to account for any visual impairment.

"Blue colours are nice but not eye catching." (member 2)

"People don't have time to read a lot of information...it needs to be shorter." (member 3)

"Unable to read the small print; I'd need my glasses for that." (member 6)

Ethical considerations

Participants expressed both sides of the financial reward ethical debate, for example, paying patients as an incentive to participate in research above transport cost reimbursement. Several expressed concern that vouchers were being offered and voiced their concerns and inferences that they considered it to be morally wrong to accept money for participation, which reflected a consumerist society. However, they did also recognise that patients would, in reality, be attracted to the voucher as living with renal disease meant giving up paid employment.

"The £40 should be first... I know that is a bit wrong, but people want incentives." (member 3)

"Not sure about the money voucher, as everyone seems to be after freebies...but then I'm not working 'cause of this, so I'd take it. Every penny counts when I go food shopping for the family." (member 4)

Part Two: Qualitative interview findings

Twelve patients took part in the semi-structured interviews, which lasted from 19 to 61 minutes. The results of the service development needs around renal nutrition will be reported elsewhere.

Four themes emerged helping to explain why renal patients volunteer for research and their needs for continuing support: advocacy for renal disease, helping other patients, health service feedback, and future involvement. These are described below and illustrated with verbatim quotes. Table 1 shows the development of subthemes and subsequent themes.

Advocacy for renal disease

Participants felt that taking part in this consultation and future service research was a chance to tell other patients, health professionals, and society in general, for example, restaurateurs and chefs, about living with renal disease. It was a need that had not been met previously whilst accessing the service. By taking part in this PPI, it gave patients a platform to express their experiences of renal disease and associated medical management. Participants expressed frustration that renal disease had not been spoken about within the wider healthcare agenda. They therefore perceived that their health condition was not that well understood within society.

"It can be very difficult being a renal patient. What a lot of people don't realise is that it's a life support, and after two weeks you would just die. They don't realise that you need a special diet." (Mark)

"It needs a celebrity to get kidney problems before people take notice of kidney disease... like what's happened with cancer." (David)

Table 1: Themes and sub-themes

Codes	Subtheme	Theme
Poor food service Action required Little insight by others	Unawareness of renal disease Restaurants don't understand renal diet Taking part in research Frustrated at lack of awareness	Advocacy for renal disease
Opportunities Solutions Helping	Taking part helps others Supporting others on HD Research is an opportunity to help Practical solutions	Helping other patients
Volunteering Knowing	Opportunity to give feedback Opportunity for wider society to understand renal services	Health service feedback
Co-operation Questioning Comparison Sense of worth	Physical limitations to participation Involvement meaning Wanting to help Questioning their skill set Comparing skills to health professionals	Future involvement needs

These feelings were magnified when family and friends were not that well versed with renal disease and its treatment. Participants felt that this lack of knowledge and understanding of renal disease and its treatment was a source of frustration and were keen that renal disease had more impact with medicine and society in general to make daily lifestyle choices, such as making it easier when eating out at restaurants or discussing their health needs with a non-renal health professional.

“There’s more people knowing as over the past few years it’s been made more aware especially GP’s. I think restaurants would be quite surprised how many renal patients there are, and they could think, well, they would go on to the web and find out which restaurant deals with renal needs; but it isn’t just renal patients here; there are renal patients everywhere.”(Sarah)

“I think it is about educating other people. I get from other people when you go dialyzing, they don’t understand that you have to keep going “It’s like, oh, you don’t have to go again. But why?” They just don’t understand and it’s very hard to explain sometimes.” (Michael)

“They all know about things that are in the news, like wheat intolerance, but in terms of renal wise, they wouldn’t even be aware of the diet.” (Jim)

Helping other patients

Patients welcomed opportunities to participate in research, both as participants and co-researchers. Research presented opportunities of informing other people to help them manage their experiences of current renal care delivery. For example, several patients learnt how to self-manage and negotiate their healthcare, expressing a need to share their learning with other newly diagnosed patients.

“I like being consulted on service improvements as everyone needs to eat and people need to know what it’s like, how to do this and where to go for that, so I’d want to be part of any service improvements.” (Mary)

“It’s important to research how dietitian services are given, as everyone needs to eat.” (Mark)

This altruistic perspective was common amongst individuals offering to provide peer support for free in a ‘buddy’ system. This offer to help did not have any limitations attached to it, due to the fact that it did not involve any perceived ‘onerous tasks’ to cope with (whilst living with renal disease), such as meeting a peer in their own time, i.e., not within a clinical environment.

“ If there is anyone who is having problems and wants to talk, then I’ll talk to them because you know ...sometimes it can help...with the diet like...it’s good to support each other...you know before or after dialysis.” (Bob)

“Yeah and also you want someone at the same time frame that you are on...you want someone after you go on dialysis or after you come off dialysis - so one who is doing the morning and you’re doing the twilight shift - and you arrange to meet up.” (Mark)

Health service feedback

Accounts of how renal disease had impacted patients’ lives were told in context to the dietetic care they had experienced. These were mostly times when there was most conflict felt, in that the perceived support did not match the experiences patients were going through, such as inappropriate information giving. A sense of wanting the health professional to know what renal disease was like and the effect of their service and the disease had on lives was one of the main reasons for taking part in qualitative research.

“Diet was too much to handle then (on diagnosis of kidney failure) and too detailed and complex to get your head around.” (Marion).

“People are coming to terms with loss of health and a relationship at that time – diet is not a priority.” (Sarah)

Patients give up valuable time to take part in research and want something in return to help themselves and others. This service was to help them self-manage their condition better.

“People don’t mind taking part in research, as long as there is something practical that comes out of it.” (Jim)

“I enjoyed taking part and hope that useful support comes out of it for others.” (Jo)

Future involvement needs

Eleven patients expressed an interest in taking part in a wider study on developing renal services after discussion about the role of a co-researcher and the requirements/practicalities were explained to them. However, several patients did not like working in a group environment as they did not like large groups; several wanted a one-to-one consultation process due to hearing impairment.

All participants expressed concern that they may not be able to join an advisory group with equal status to other professional members, whom they perceived to be an authoritative source of renal nutrition and renal medicine. However, others were happy to attend a bi-annual meeting at the hospital, because they wanted to carry on acting as an advocate for renal patients and renal disease.

“I’d like to take part, but I’m not sure what I can tell the experts. You know, dietitians come and see *me* on dialysis, not the other way around.” (Frank)

“I’m not good in groups due to my hearing, so I’d struggle in a research meeting.” (Steve)

“I would want to know what you are expecting of me, so I can decide if I could help out.” (Jo)

Discussion and Conclusion

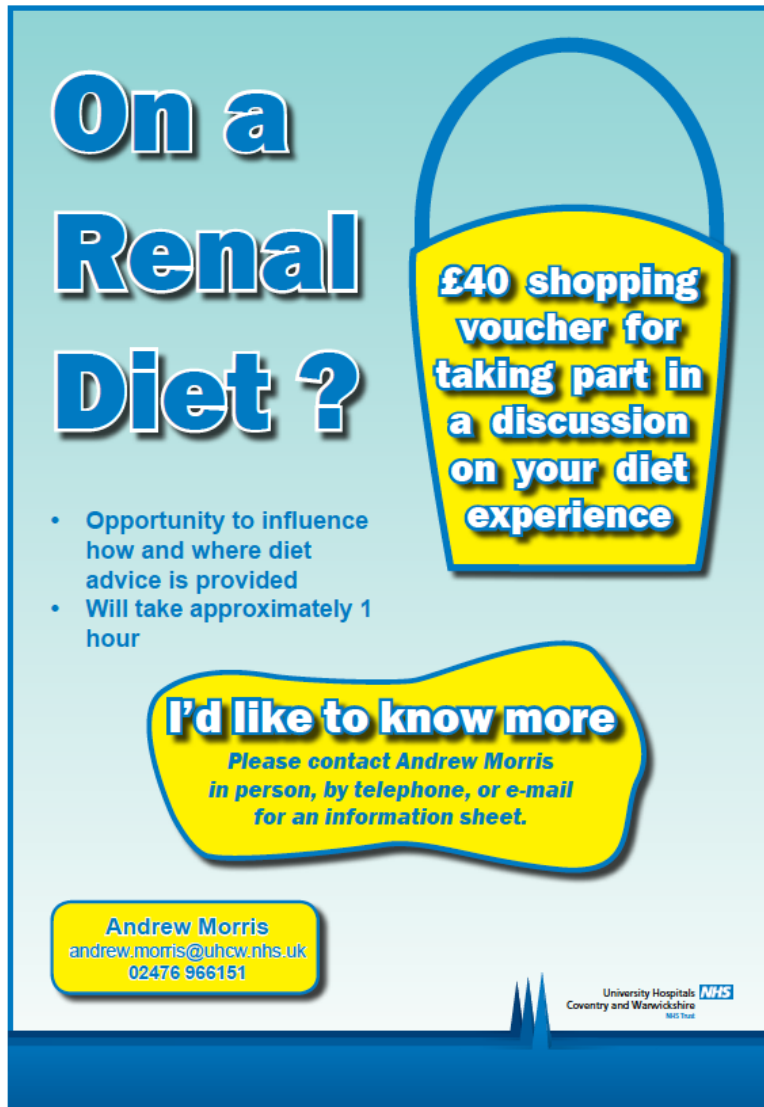
Discussion

This article adds to the literature on PPI by helping understand renal patients’ motivation to participate in current and future renal dietetic research. This study offered an alternative PPI approach to traditional methods of asking for feedback on a health professional study design.⁷ This approach of involving patients at every stage of the research process has previously been reported as lacking in earlier PPI initiatives.⁶

Recruitment to PPI studies has been challenging for researchers, such as in physiotherapy PPI²⁶ and dementia PPI²⁷ who also reported difficulties recruiting.⁷ This has similarly reflected recruitment strategies with larger clinical studies.⁵ Patients have initially expressed interest but not turned up; dropped out, despite promises of remuneration⁵, or felt less inclined to participate due to multiple trips to clinical environments.²⁶ However, this study experienced fewer barriers recruiting patients than suggested by much that is reported in the current literature. We suggest this may be attributed to our recruitment strategy on consultation with a PAG and taking their feedback into account, for example, a patient’s clinical management of specialty, since people attend hospital many times in renal medicine and thus do not want to attend on a separate occasion.

Future recruitment strategies need to take this time management aspect into consideration, for example, taking opportunities to talk to people about research participation when attending out-patient clinics. Providing contact details (email, telephone, and address) for patients to contact the researchers to ask further questions via written material are a successful recruitment process informed by the PAG. This approach was incorporated into this PPI recruitment. These suggestions were taken into account on the PAG co-designed recruitment poster which took into account practicalities of attending outpatients. For example, increasing the font size of writing on the poster (fig. 2) helped with issues of reading posters from a distance in a busy waiting room where people may be preoccupied with their medical appointment. The PAG offered advice on the amount of information that could be assimilated within ‘a glance’ at the poster which was

Figure 2. Recruitment Poster



situated in an outpatient's clinic. The poster highlighted an incentive, which patients did say was important, particularly to those on a limited income as a result of end stage renal failure which restricts the hours available for employment.

However, one theme reported that ambivalence was found to this monetary enticement to participate. Potential barriers to participation in a clinical research study were identified through the one-to-one interviews. Such barriers may reflect the ethical aspects of participation, for example, practicalities and morality around remuneration² that patients consider when being invited to participate in co-research participation.¹² This potential ethical dilemma

reflected by our findings in this study may affect recruitment, as patients do not wish to trouble researchers or the people they perceive to be involved in their treatment about their feelings around co-participation which includes remuneration.¹⁸ However, other PPI studies have suggested monetary incentives are one way to get people to complete and return research questionnaires.²⁷ One way to promote participation, which may be perceived as being more acceptable to certain individuals, could be informed by this study's themes. Stating that involvement within a PPI means advocacy for renal patients (nationally and internationally) addresses the theme that this group felt to be under-represented within society. The theme around advocacy for renal patients appeared in this study to provide more motivation than the

recommended national health research reimbursement strategies. Therefore, we propose that a more holistic approach to 'reimbursement' would be to suggest that participation in clinical research is an advocacy role for fellow renal patients.

A trial of this approach by the PI received positive feedback. The lead researcher fed back this approach at a local Kidney Patients Association annual general meeting and demonstrated advocacy in research by showing the numbers of different institutes and researcher around the world that have read co-designed renal dietetic research from the Trust.²⁸ The potential meaning of this, i.e., patients experiences are not only informing their service but potentially other services or research around the world, had a strong impact on the patients in attendance. They reported they could see and understand the impact their participation was having within society and within an international context.

Employing this unique PPI approach by adjusting the PPI strategy and improving the recruitment poster to a patient steered strategy meant achieving sufficient numbers for a qualitative enquiry in which to explore health experiences in depth²⁹ thus bringing significant clinical meaning to potential healthcare service improvement and development.³⁰ However, only four of the 12 participants had actively contacted AM by telephone or email as encouraged on the poster. The other eight people agreed to participate after requesting a face-to-face discussion with AM whilst on haemodialysis reflecting confidence, reassurance and trust: participants did not need to go out of their 'comfort zone' by taking the initiative to contact someone outside of the communication sphere in which the professional is currently known to them (i.e., when talking about food). Therefore the poster may not have been essential to the recruitment process in this instance. The researchers could have approached the people directly, as an outpatient on dialysis, without using any recruitment posters. However, on discussion with all eight people, they unanimously reported that they had seen the poster and were aware that the PPI study was taking place.

One potential reason why patients may appear reluctant to offer support when seeing the recruitment poster is the undefined capacity of a health professional acting as researcher and maintaining a clinical role.¹³ Health professionals are inviting patients into a shared decision making with equal status. This is a different relationship to the traditional patient-clinician relationship perceived by most patients.³⁰ In one research study, the patient-health professional boundary became blurred in health service research to redesign services where both interviewer and interviewee had no understanding of the researcher's role.⁸

However, in the research reported here, this may not have been the case. Fifty percent more people were recruited in person then via the recruitment poster. This may have been due to the already established patient-dietitian relationship formed in renal clinical practice. This working partnership is reflected within co-research Kidney Research and Education Initiative¹³ and has been developed during co-research health care service design.³¹ An important goal in the area of patient experience is the empowering of 'patients as equals'. This is an extension to the clinical setting where the patient-dietitian relationship is already established. This can be seen within renal dietetics where the established professional relationship has encouraged patients to take control of their dietary treatment plans. Hence, it can be argued that the clinician-patient relationship within a research environment should be equal too. As such, this would not be a different relationship as suggested elsewhere.⁴ The relationship already exists, so it would require it to continue in a different perspective, one where the service users are giving feedback on the service provided, as opposed to their diet or medical treatment. This would be important to note for future recruitment strategies, since all participants in this study felt less confident in joining and advising within an advisory group.

The strength of this study is that patients were advised on each stage of this PPI, for example recruitment to a PPI. We propose that the reason service users would continue to engage with a study relates to their motivation to help others in a similar situation. Thematic analysis included peer review by co-authors and reflexive journaling by the PI to ensure the authenticity of the findings.

There are several limitations to this study. The original poster was designed by the PI. Future recruitment could invite patients to design the poster themselves. Motivated people may have self-selected due to their interest and/or altruism, and this may not be typical of all those who could potentially get involved. Motivation and willingness to help others may not be felt by all patients, and the monetary reward may be more important than the need to help other patients, and so this needs to be further explored. Additionally presenting a summary of results back to the service users for the purposes of member checking would have verified authenticity further, but due to limited time and resources, this was not possible.

However, in such a situations where you are developing co-researchers, member checking could be disadvantageous in enabling additional reflection and responses to change over time. Such considered responses may be different to their 'in the moment responses' and therefore less true of any impulsivity involved in PPI engagement.

Conclusion

Consulting patients about the actual recruitment strategy to a PPI study allowed larger numbers of patients to be recruited to interviews to explore desire, motivation and support required by appropriate methods that consider patients' unique personal and social needs. Some of the barriers to participation in clinical research included time constraints, recruitment practicalities and ethical considerations.

Recruitment in person was found to be more successful when recruiting numbers of patients, compared to recruiting via a poster. However, posters were found to have encouraged more confident patients to take part. All patients were aware of these posters, thus helping face-to-face discussion around recruitment.

Motivation to participate was found to be a strong desire to act as an advocate for people with renal disease. This motivation can be supported through researchers explaining the potential positive impact that taking part in a research study can offer. Therefore, advising patients that they can make a difference within a research environment can be important. Patients expressed positive views around the role that motivation (i.e., advocacy for renal disease) can play. This motivational aspect can be supported and used for positive benefit at each stage through the already established clinical working partnership and current training support available.

Implications for Training

Clinicians need to consider how they might continue to establish their working alliance with their patients into the area of research. This would potentially help both patients and clinicians within the research process since a working relationship is already established. Training for clinicians on PPI, such as INVOLVE, would therefore offer additional benefit.

Service users may need on-going support and training in order to establish and participate in an advisory group, especially since they are coping with managing a chronic and life-limiting condition.

A Needs Assessment Analysis³ would facilitate identification of those current and required research skills needed in order to be effective in the role of co-researcher. Training courses, such as UNTRAP at the University of Warwick provide bespoke programmes to meet patients' co-researcher skills requirements. We recommend this approach offers much additional benefit for both patients and the professionals involved in the provision of their care.

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Conflicts of Interest

No conflict in interest is declared. All views are the authors alone and not those of the NHS or NIHR.

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