

# Patient Perceptions of the Challenges to Recruitment Into a Renal Rct Registry : A Pilot Questionnaire Based Study

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## Research

**Keywords:** Trial methodology, registry based randomised controlled trials, recruitment

**Posted Date:** April 28th, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-452468/v1>

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# Abstract

## Background

Randomised controlled trials (RCTs) are the gold standard for demonstrating the efficacy of new therapies. Despite this, nephrology trials, especially of patients with end-stage renal disease (ESRD) are much fewer in number than other medical subspecialties. Recruitment difficulties are cited as a particular challenge. Using registries to conduct RCTs is a reasonably new practice but is appealing as it combines the benefits of both observational studies and clinical trials. There is limited literature on patient motivators, barriers, and consent to these registries. The purpose of our study was to establish the factors that motivate and/or inhibit patients from joining a registry for randomised controlled trial, and to determine what information matters to patients when making an enrolment decision to participate in such a registry.

## Methods

We conducted a cross-sectional questionnaire-based study at a dialysis centre in Southwest Ireland representing a catchment patient population of approximately 430,000. Quantitative data were coded and analysed in SPSS (v16). Descriptive statistics were produced, and open-ended questions were analysed by thematic analysis.

## Results

87 patients completed the questionnaire. Reasons for participation in the registry included personal and altruistic benefits. Barriers were time and travel requirements associated with registry participation, data safety concerns, risks, and side effects, along with concerns that registry participation would impact their current treatment. Although 29.8% of patients expressed, that they would have concerns regarding their data being stored in a registry, 79.3% of patients were still willing to consent to have their data uploaded and stored in a registry for conducting RCTs. It was important to patients to have their GP (general practitioner) involved in the decision to participate, despite little day-to-day contact with their GP for renal dialysis management.

## Conclusion

Challenges to recruitment to registries for RCTs exist but addressing the identified concerns of potential participants may improve recruitment to registries, and by extension, to RCTs conducted using the registry.

## Background

Randomised controlled trials (RCTs) are the gold standard for demonstrating efficacy of new therapies (1). Despite this, nephrology trials, especially of patients with end-stage renal disease (ESRD) are much fewer in number than other medical subspecialties (2). Among the reasons cited for this are recruitment

difficulties and lack of funding (3, 4). Using registries to conduct RCTs is a reasonably new practice (5, 6), attracting attention from trialists and trial methodologists (6-8). Patient data within registries provides an ideal platform for the conduct of RCTs due to the availability of case records, participant randomisation and follow-up data (5, 6, 9, 10). Registry based randomised controlled trials (rRCTs) combine the benefits of clinical trials and observational studies (11-13). rRCTs are appealing due to their low cost, significant reduction in trial workload (5, 14, 15), improved generalisability of study findings, ease and rapidity of enrolment, the potential for complete/long term follow-up (5, 6, 14-18), as well as the ability to infer causality (17). Literature on patient consent to rRCTs (19-21) is limited, even more so for kidney randomised trial registries (kRTR). The inadequate data that exists focuses mainly on oncology (20, 22, 23). There is a need thus to identify strategies that are effective at increasing participation in rRCTs (24). The PRioRiTty study identified 20 unanswered questions around trial recruitment (25). Priority 2 was “What information should trialists communicate to members of the public who are being invited to take part in a randomised trial in order to improve recruitment to the trial” (25). The objective of our study is to contribute to this evidence base and establish what information matters to patients when making an enrolment decision to participate in a registry for conducting RCTs. This will enable appropriate personnel to provide patients with important and relevant information regarding registries for conducting RCTs, giving patients the confidence to enrol in such registries, and ultimately to mitigate poor recruitment, a major reason RCTs fail (21, 26).

## Methods

### Questionnaire design

A questionnaire with both closed and open-ended questions was distributed to renal dialysis patients at a major dialysis centre in Southwest Ireland (Additional file 1). The questionnaire was designed by EM, FS, and AOK. Section 1 of the questionnaire evaluated patients’ self-assessed knowledge of terms/concepts associated with RCTs on a 5-point scale (poor, fair, good, very good, excellent). Section 2 asked patients about their views on participating in a kRTR, their willingness to discuss and receive information on the registry, methods of receiving this information, questions regarding data storage, likelihood of consenting to a kRTR and why, and concerns about participation. Responses to closed-ended questions were tick box or via a Likert scale. Sufficient space was left to allow patients to respond to open-ended questions.

### Data collection

The study took place in the CUH (Cork University Hospital) renal dialysis unit in the South West of Ireland (Figure 1). End of year statistics from the National Renal Office show that at 31 December 2020, 2004 patients were receiving haemodialysis in the Republic of Ireland. 168 patients, which represents 8.4% of the total haemodialysis population were dialysed in CUH. Geographical region determines the dialysis site for patients and they attend their closest dialysis unit. In Ireland, the mean distance between patients’ homes and the dialysis unit at which they attend is 29km(27). Thus we have no reason to believe our study sample is not representative of the general dialysis population in Ireland. Patients in the study were

approached and consented to take part in the study in a six-week period during their normal dialysis schedule (3-times per week; 4 hour sessions). Data were collected in the morning, afternoon, and some night shifts, to capture a representative sample of the CUH dialysis population. This is particularly relevant as younger patients with day-time jobs were more likely to be part of the night shift. Dialysis patients are long-term patients and are well known to the nurses in the dialysis unit. Patients that were actively unwell (elderly and frail) and those with cognitive impairment (those that suffered a stroke), as assessed by the senior nurse manager, were not approached to participate. Patients who were sleeping were not disturbed. Eighty-seven patients, 52% of the total CUH dialysis population, completed the questionnaire. Fewer than 5 patients refused to participate, citing feeling unwell/tired as the reason for non-participation.

Patients completed the questionnaire themselves in the presence of a researcher, unless they asked for assistance with transcribing answers. In this instance, the researchers (EM and AOK) transcribed the patient's answers. After completion of Section 1 of the questionnaire (answers to Table 1), the researchers provided patients with an explanation of each of the terms: healthcare registry, kidney research registry, clinical trial, randomisation, and informed consent, to ensure clarity for the remainder of the questionnaire. FS compiled the explanations of each term and provided training to EM and AOK on imparting this knowledge to patients. EM and AOK collected the data and used the same explanations to describe the terms to patients. Following these explanations, Section 2 of the questionnaire was then completed by the patients.

## **Data treatment**

Quantitative data were coded and analysed in SPSS (v16). Descriptive statistics were produced. Open-ended questions were analysed by thematic analysis. They were analysed iteratively to explore emergent themes. Thematic analysis (28) was conducted in the first instance by EM with debriefing sessions with co-author FS to discuss similarities or differences in coding labels. This process involved re-reading the transcripts several times which resulted in data immersion (28, 29). After familiarity, data were coded, then codes were examined for patterns and similarities, and grouped together to form themes. The STROBE cross sectional reporting guidelines were followed to write this manuscript (30).

# **Results**

## ***Patient Characteristics***

All 87 patients were receiving renal dialysis in a hospital setting. 69% were male. The median age was 67 years.

## **Quantitative Findings**

### ***Patient understanding of trial and registry related terminology***

Patients were asked to assess their understanding of terms/concepts related to RCTs (Table 1). The term registry, whether a 'healthcare registry' or a 'kidney research registry', was not well understood. 37.9% and 34.4% of patients reported a 'poor/fair' understanding of 'healthcare registry' and 'kidney research registry' respectively, with only 27% having a 'very good/excellent' understanding of each term. Over a third (36.8%) of patients had a 'very good/excellent' understanding of 'clinical trials'. 'Randomisation' was poorly understood with 57.5% of patients reporting only 'poor/fair' understanding. Patients showed greatest understanding of 'informed consent' with more than 80% having a 'good/very good/excellent' understanding of its meaning.

**Table 1** Patients' self-reported understanding of key clinical trial and registry terms/concepts.

Research phrase	Self-reported percentage understanding (%)				
	Poor	Fair	Good	Very Good	Excellent
'Healthcare Registry' (n=87)	18.4%	19.5%	34.5%	20.7%	6.9%
'Kidney Research Registry' (n=87)	14.9%	19.5%	37.9%	23.0%	4.6%
'Clinical Trial' (n=87)	16.1%	14.9%	32.2%	27.6%	9.2%
'Randomisation' (n=87)	34.5%	23%	23%	14.9%	4.6%
'Informed Consent' (n=87)	6.9%	10.3%	36.8%	31.0%	14.9%

**Patient's openness to receiving information on a kidney randomised trial registry, from whom, and how.**

91.7% of patients 'strongly agree/agree' to receive and 89.5% 'strongly agree/agree' to discuss information about potential participation in a kRTR during dialysis/during a regular clinic visit. <3% 'disagree' and 7% were ambivalent. 76% of patients 'strongly agree/agree' to being contacted by telephone outside of working hours by a researcher to discuss participating in a kRTR. 86% of patients 'strongly agree/agree' to receiving information by post with an option to discuss it at the next dialysis/clinic visit.

54.1% of patient's preferred method of receiving information about the kRTR was receiving verbal information during their dialysis treatment with the option to consent to the kRTR after the discussion. 28.2% of patients preferred to receive information by post (consent at next visit to dialysis unit). The least popular methods to receive information were by email (9.4%) and by telephone (8.2%). Figure 2 represents patients' preferences regarding whom they would like to receive and discuss information with about the kidney randomised trial registry. Consultants represent the largest group.

## Patient data storage concerns

29.8% of patients 'strongly agree/agree' to having concerns about their medical data being stored in a kRTR. As a result, 24.1% of patients 'strongly agree/agree' to not wanting their data uploaded and stored in a kRTR as they considered their information private. Despite that, only 10.3% of patients were 'not likely/very unlikely' to consent to their medical information being uploaded and stored in a kRTR (Table 2).

**Table 2:** Patients views on their data being uploaded and stored in a kidney randomised trial registry (kRTR).

	Strongly disagree (%)	Disagree (%)	Neither agree nor disagree (%)	Agree (%)	Strongly agree (%)
I would have concerns about my medical data being stored in a kidney randomised trial registry (n=87)	11.5	44.8	13.8	26.4	3.4
My medical information is private and I do not want it uploaded to a kidney randomised trial registry (n=87)	12.6	46	17.2	21.8	2.3
	Very Unlikely (%)	Not Likely (%)	Neutral (%)	Likely (%)	Very Likely (%)
How likely would you be to consent to your medical information being uploaded and stored in a kidney randomised trial registry (n=87)	5.7	4.6	10.3	56.3	23

## Patient perspectives on participation and healthcare/carer's influence

In Section 2 of the questionnaire, patients read a short paragraph that explained in more detail the randomisation, the consent process, and the benefits of signing up to a kidney randomised trial registry (see Additional file 1). Researchers EM and AOK assisted with the explanations. Following this, 37.9% of patients were 'very likely', 42.5% were 'likely', 13.8% were 'neutral', 3.4% were 'not likely' and 2.3% 'very unlikely' to join the kRTR.

58.8% of patients thought their dialysis doctors should be involved in conducting clinical trials while 41.2% felt their doctors should focus on patient treatment and let somebody else conduct the trials. When

signing up to participate in a kRTR, 67.8% of patients would have discussed it with somebody. The majority would have discussed it with their spouse/partner (35%), their GP (15%), their child (13.3%), parent (6.7%) or friend (1.7%). 28.3% selected 'other' and the top preference was their consultant. 51.2% of patients felt it would be 'important/very important' for their GP to be involved in their decision to partake in a kRTR while 48.8% felt it was 'of little importance/moderately important'. Regarding patients' views on getting involved in other aspects of study processes, such as study design or conduct, 62.4% reported it was 'important/very important', while 11.8% said 'moderately important' and 25.9% of patients said it was 'of little importance'. Finally, 94.7% of patients felt it was 'important/very important', to participate in medical research by means of a clinical trial to improve healthcare treatments for others.

## **Thematic Analysis**

Of the 80.4% of patients who would be 'likely/very likely' to consent to participate in a kRTR, 87% provided at least one reason why. Reasons were not ranked.

### **Theme: Motivators for participation in a kidney randomised trial registry**

#### *Self-benefit*

This emerged as a strong theme (n = 32). Patients would participate in a kRTR "to help myself", "beneficial for myself", "personal benefit", "own self-interest/benefit", "to improve my health, "to improve my own situation", and for "better health".

Within the theme of self-benefit, patients cited reasons orientated around learning: "to learn more about my condition", "to understand my condition", "like to know more about it" (n=1), "to learn better/improve quality of life" (n=4), "for further knowledge" and for "education". Patients were also motivated to participate for benefits related to their own care process: "if it would help to get off dialysis", "reduce dialysis hours", "so treatments can be given to me correctly", "knowing you are being looked after by experts in that field", "to help my own care" and "open to better treatments because I have bad kidneys", "to improve kidney care", "to improve healthcare".

#### *Help research, science and medical advancement*

This was an equally strong theme (n = 31). Patients said they would be likely to agree to participate in the kRTR for "research purposes", because it would be "good for research", "beneficial for research", "to help research", "bettering research" or making "medical discoveries". Others said it was because "I love research", "I believe in research", it is "good for" and "helps science" and it would be "advancing medicine". Others felt "more research is necessary" and that it is "essential every effort is made to improve the situation for people with kidney issues" or help "find a cure for kidney problems" and to "find answers to why they are sick". Patients also felt it was an "important study", they would participate because it was "for a good cause...if it is an advantage to the study" and because it is "valuable research", it might "find new improved treatments", and it would be "basically positive to clinical trials (to improve procedures)".

### *Help others*

Helping others was another dominant theme (n = 19), “to help others”, “to help someone else” “to help others on dialysis”, “helping others” “to improve someone else’s situation”, “to improve others health”, “for others benefit”, “benefit to other patients not in the trial” or “ultimately be beneficial to all”. Linked to this was the help/benefit of future generations of patients, e.g., “it will help those who come after me”, “to help people in the future”, “so others can benefit in future studies” and “very important for the future”. Three patients were willing to “help” in general and other patients were “eager to make a contribution”, “excited to participate in something new”, to “better things” and another believed that their participation would “save time for staff and patients”. One patient believed participation “would help” as “more information is always good”.

### *Why not do it?*

Other patients (n=5) agreed to participate because they believed “there’s no harm in it”, they had “no reason not too” or they would “be interested” or because if they were “asked to participate”.

There were just two responses to why people would not participate in a kRTR so we were unable to theme them. Worth mentioning are the reasons cited: “have no interest, have “no complications so leave it”, “distance” and “inconvenient”.

## **Theme: Concerns of patients when being recruited to a kidney randomised trial registry**

### *Risk (incl. data protection) and side effects*

75.9% of patients (n=66) responded. Reasons were not ranked. Risks and side effects were important (30%; n=20). Ten patients wanted to know more “about the side effects” and “what level of danger there would be” and others wanted more information (n=8), for example “what is involved in a clinical trial”, “if trials went wrong what would happen”. One patient was concerned about being “a Guinea pig in the drug trials”. Concerns about the safety of patient medical information was also cited frequently: “who would be entitled to view the information” “how safe is my information” “what would they do with my information” and “who has access/who will see the data”. Other data and registry related concerns included “if the trial was open to review” and “has this method (of trial recruitment) been used in other areas of research and if so what are the results?”. Ten patients had “no concerns”, e.g., “doesn’t worry me” and “no questions I have total confidence in my consultant”.

### *Time and commitment*

A key piece of information was time and commitment. This was listed by 27.2% (n=18): “how much time would it take”, “how long would it take”, “is there a time requirement”, and commitment - “time and place of meeting”, “where would you have to go”, “when would it be” and “when would it start and finish”.

### *Personal benefit*

Personal benefit was also a key piece of information required (22.7%; n=15): “what is the benefit for me”, and would it be “beneficial to my kidneys”. Three patients wanted to know “if it will help other patients”, “what benefit would it be for my consultant”, “how would it help” and two patients wanted to make sure it would help research if they participated “make sure it is helping research” and “would participation help”.

### *Effect on current treatment*

Effect on current treatment was another piece of information required (15%; n=10): “would my normal treatment be constrained”, patients wanted to know if it would interfere with “my medication”, “my dialysis” or the “times of my dialysis treatment” and “does it reduce dialysis time”.

## **Discussion**

This is an important study that explored patients’ preferences regarding consent to a kidney randomised trial registry. Patients were willing to take steps to participate in clinical trials by consenting to be part of a kRTR. Addressing the barriers such as time and transportation and highlighting the benefits of participation, both personal and altruistic, may improve patient’s willingness to partake. Our findings have relevance for those establishing rRCTs and disease-specific registries but can also be extrapolated to more general consent issues in RCTs and mitigating the risk of ‘losing’ patients before trials begin.

Our findings show more than 80% of patients had an ‘excellent/very good/good’ understanding of ‘informed consent’. This is critical to ensuring that patients’ decision-making is autonomous. This finding contradicts research conducted amongst patients in other medical areas which show a poor understanding of consent for medical procedures (31-33). The finding is also higher than results from a prior meta-analysis, which showed the proportion of patients who understood various components of informed consent ranged from 52.1% to 75.8% (34), though the level of understanding in the meta-analysis is not stated, making direct comparison unreliable. Furthermore, due to the limited number of studies that have been conducted in patients with end-stage renal disease, regarding knowledge and understanding of RCT associated concepts, our findings should be interpreted in context since the research that we compare our findings to, has been conducted among patients in other medical specialities.

Patients had poor understanding of registries but there is limited data to compare it to. However, it informs future researchers establishing registries of the importance of explaining the overall concept of a disease registry for conducting clinical research. Patients’ understanding of ‘randomisation’ was particularly poor. This is not new (35-40). For example, in one trial only 23% of patients were able to explain what randomisation meant (38), similarly only 19.5% of our patients had a ‘excellent/very good’ understanding of ‘randomisation’. We feel this lack of understanding is a reason why most patients are willing to discuss (89.5% strongly agree/agree) and receive (91.7%) information about the kRTR and associated clinical trials. We have gained a valuable insight here on what to focus on when designing informed consent forms for recruiting patients to a registry for subsequent RCT use.

One-third of patients were concerned about the storage of their medical data. There has been an immense amount of progress in this area, e.g., GDPR (General Data Protection Regulation) (41) and the new EU (European Union) clinical trials directive which commenced in 2014 (42). Future research would benefit from further investigating these concerns. It is reassuring that despite these concerns, 80.4% of patients were still 'likely/very likely' to provide consent to participate in a kRTR. Only five patients stated they would be 'not likely/very unlikely' to consent to participate. Some patients did not respond to the question asking them about their concerns about participating in a kidney randomised trial registry. This aspect of the study would benefit from a qualitative investigation, to delve into the nuances of these findings.

Our findings confirm that patients are often altruistic, which is in line with literature based on clinical trial participation (35, 43-45). Two of our four emerging themes dealt with helping others or helping Science; reasons also listed by Swedish haemodialysis patients (46). However, 'personal benefit' was also a key motivator. Patients wanted to improve their health and the quality of care they receive. This theme has been highlighted in previous studies on clinical trial participation (35, 47, 48). However, there is a paradox here: although patients wanted to take part to benefit themselves and improve their health, they were also concerned about the negative effect that trial participation might have on their health. Trialists must ensure that patients are made aware that participation may not always be beneficial, due to the very nature of clinical trials, in order to avoid the issue of therapeutic misconception. This is easily addressed on enrolment to a registry and when providing information to patients. These findings are significant to assist those recruiting to a registry for randomised controlled trials as it facilitates the drafting of the patient information leaflet, so it is targeted and relevant.

Literature shows that individuals are likely to ask for advice on clinical trial participation from their GP or other physicians before consenting to partake (48). In addition, healthcare providers attitude towards clinical trials has been found to be important to patients when making the consent decision (43, 49). Our findings concur, with 51% preferring the GP to be involved in their decision to participate in a kRTR. . GP are not involved in the day-to-day care of dialysis patients and this is likely the reason our finding is slightly lower compared to other literature. For example, in one study 77% of patients stated they wanted to make the decision to participate in a clinical trial with their doctor and only 14% wanted to make it independently (38). Trusting the physician is clearly very important to patients, a finding concomitant with the literature (48, 50) and further evidenced by the fact a third of our patients would like to receive information on the registry from their consultant. Targeting healthcare professionals to ensure they have adequate knowledge and information about clinical trial registries and how to relay this to potential participants may be a worthwhile intervention to improve recruitment to clinical trial registries. The communication triangle between GP, patient and consultant is also critical to patient's ongoing interest in clinical research.

Identifying key pieces of information that patients want when getting involved in a kRTR is essential to successful recruitment. Mitigating any factors that will deter people is also important. Time and travel requirements were common concerns in this study. Many patients in the dialysis unit avail of HSE (Health

Service Executive, (government funded)) provided transport to attend their dialysis sessions. They travel in small groups, therefore arranging transport to participate in any potential research is an issue. However, we anticipate this finding would not be unique to a dialysis cohort and would apply to all rRCTs for patients requiring ongoing regular treatment, e.g., oncology trials. Trialists need to make time and travel requirements very clear and potentially need to be inventive in the design phase of the study, e.g., multiple data collection on the same day, when considering the trial processes to mitigate this, and to improve recruitment especially of those in rural areas with poor transport links. Additionally, this must be budgeted for.

Barriers and concerns in this study are mirrored in other literature based on clinical trial participation. Concerns about medical risks, harms, and side effects (45, 49, 51, 52), time requirement and travel commitment concerns (20, 49, 51, 53-55), data safety concerns (52, 56) are all noted. Lack of understanding of randomisation (35, 36, 57) as well as the research for which they are consenting to (36) was previously noted and is also evident in this study. This is a relatively easy topic to address, and our study suggests that if done well, recruitment should be positive. The question of how to do this well should be investigated separately through further SWATs (Studies Within A Trial).

## Strengths And Limitations

The sample size is relatively modest (n=87) consisting of elderly adults (median age 67yrs) with underlying health conditions, potentially affecting the external validity and generalisability of the findings. However, the unit's demographics were broadly representative of the dialysis population nationally, (Figure 1) and therefore may inform efforts to create a dialysis trial registry that will facilitate rRCTs. Although the sample size was modest, it captured 60% of the available patients. Data were collected in the morning, evening, and some night shifts. This was a strength as younger patients with day-time jobs are more likely to be part of the night shift, therefore we captured a broad age range.

Selection bias was a possibility as participation was voluntary: those who participated in the study may have a greater interest in research and be more willing to partake in further research/clinical trials compared to those who declined to participate. Some very sick patients filled out the questionnaire with assistance, ensuring representation across disease levels. However, assistance may have increased engagement in the research among patients and unintentionally caused response bias, particularly regarding the patients rating their understanding of RCT associated terms, and especially if the researcher was present to help patients fill in the questionnaire. This may have led to the participant positively answering to appease the researcher.

We acknowledge that this small, localised sample has issues of wider representation, and if we were conducting this study again, a national dialysis sample would be beneficial. However, the logistics of this may be difficult as many patients required assistance from the researcher to fill out the questionnaire. Online surveys could be considered for use as patients could fill out the questionnaire when most convenient to them and would facilitate collecting data from patients across the country. However, due to

GDPR it may prove difficult to get an emailing list of renal dialysis patients and since only 9.4% of our sample wished to receive information about the registry via email, it possibly indicates a dislike/lack of understanding of technology, and that more traditional data collection may be more suited to this target population.

## Conclusion

This study shows that the majority of patients are willing to participate in registries for the purpose of conducting clinical trials. Despite being conducted only in a renal population, the findings of this study are important and relevant to trial methodologists as the results contribute to evidence-based decision-making for recruitment strategies to trail registries and more broadly speaking, RCTs. Based on the motivators, barriers and key concerns highlighted by patients, trialists can improve/tailor their participant information leaflets when aiming to recruit participants to registries for randomised controlled trials. This study contributes to trial methodological research by answering a modified PRioRiT<sub>y</sub> study (25) question, no.2, “what information should trialists communicate to members of the public who are being invited to take part in a randomised trial registry in order to improve recruitment to the registry”.

These study findings are relevant and important to stakeholders involved in establishing disease-specific registries for randomised controlled trials, as the results show the importance of gaining patient opinion and guidance regarding the consent of the information that needs to be provided to potential registry participants. Overall, to increase participation in registries for RCTs, the information that is provided to patients needs to be specific and relevant, and they need access to supports to assist making that decision. Education on key registry terms as well as RCT terms is also important .

## List Of Abbreviations

**RCT(s)**– randomised controlled trial(s)

**ESRD** – end-stage renal disease

**GP** – general practitioner

**rRCT(s)** – registry based randomised controlled trial(s)

**KRTR** – kidney randomised trial registry

**GDPR** – General Data Protection Regulation

**EU** – European Union

**HSE** – Health Service Executive

**SWATs** – Studies Within a Trial

# Declarations

## Ethics approval and consent to participate

Ethical approval and consent to conduct this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals in 2019.

## Consent for publication

Not applicable

## Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

## Competing interests

The authors declare that they have no competing interests.

## Funding

This study was funded by the Health Research Board Trials Methodology Research Network (HRB-TMRN). EM was a HRB TMRN summer student scholarship awardee. The views expressed in this paper are those of the author(s). The funder played no part in the design of the study, the collection, analysis or the interpretation of data or in writing the manuscript.

## Authors' contributions

EM designed the questionnaire, collected the data, drafted the manuscript, and approved the final version. FS conceived the study, designed the questionnaire, and contributed to the writing of the manuscript. She contributed to all drafts. JAE facilitated the data collection and reviewed the final version. AOK designed the questionnaire and collected the data. She reviewed the final version. EL facilitated data collection and gave clinical interpretation. She reviewed the final version. NOS facilitated engagement with dialysis unit and data collection. She reviewed the final version. All authors are accountable for this work.

## Acknowledgements

The authors would like to thank all the dialysis patients who completed the questionnaire and the staff at the dialysis centre for facilitating the research.

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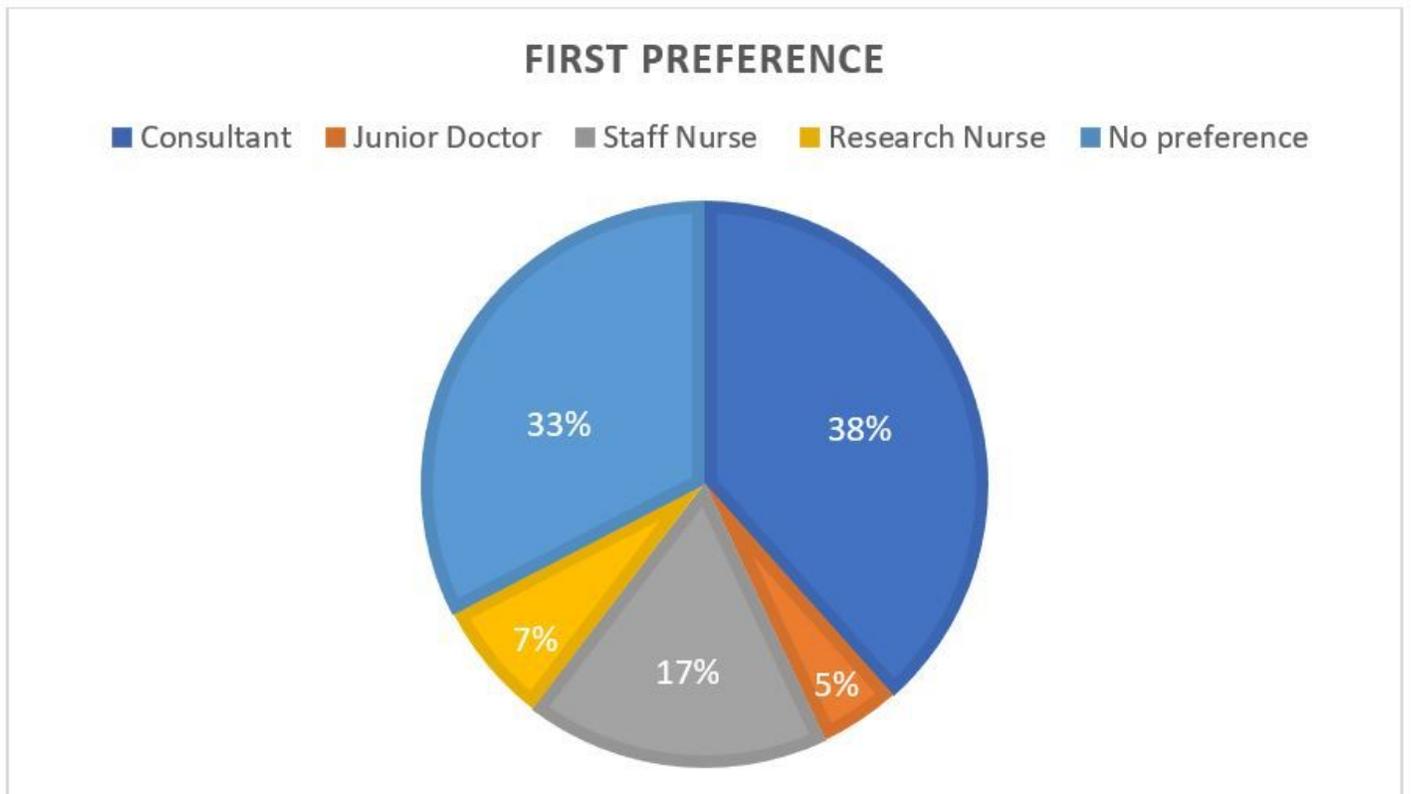
## Figures

# Irish Dialysis Centres



Figure 1

Dialysis centre in Ireland including numbers of patient's dialysed in 2020 Note: The designations employed and the presentation of the material on this map do not imply the expression of any opinion whatsoever on the part of Research Square concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. This map has been provided by the authors.



**Figure 2**

Patients' communicator preferences for receiving/discussing information about kRTR

## Supplementary Files

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- [STROBEcrosssectionalchecklist.docx](#)
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