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LIVING WITH END STAGE KIDNEY DISEASE IN IRELAND

Patient Satisfaction with ESKD Services in Ireland

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We would also like to thank the policy director of Kidney Care UK, Ms. Fiona Loud, who authorised the use and modification of questions from the Patient Reported Experience Measure (PREM) Survey[1] to meet our study objectives. We thank the patient reviewers for their contribution to this report.

Lastly, to all of the renal patients that participated in this study, your participation and enthusiasm towards this research is what promotes change to how renal care is experienced in Ireland.

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[1] https://kidneycareuk.org/get-involved/kidney-patient-reported-experience-measure-prem/

"Nurses, doctors, all health professionals are amazing and have changed my life. When I started dialysis 9 years ago, I didn't want to live, they changed my life, they saved me."

"I can contact the renal team any time I have a question or are worried about something. Always one of the team there to speak to and reassure me."

"I believe I am getting the best care I need – I can talk to people any time."

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FOREWORD

This is the first time the experiences of renal patients have been researched in a national, systematic survey. The focus of this report is on patient opinions of the services they receive, rather than clinical results. As a national patient led organisation, the patient voice is critical to how we work, and we hope this report initiated by us, thanks to an educational funding grant from CSL Vifor (who were not involved in any aspect of this research) will be used to improve service delivery to patients. In this regard, we were delighted to partner with the HSE 's National Renal Office to ensure the findings can be used by healthcare professionals.

Unlike most diseases, which are often lived at home, patients on dialysis require visits to hospitals or satellite units three or four times a week. Patients who may be on dialysis for many years get to know their healthcare professionals very well. So, it is very encouraging to see such positive results, which are higher than international rankings. They reflect a high degree of patient satisfaction with the services they receive. Our thanks to all the healthcare professionals involved, who look after our community so well.

As is common though, there is room for improvement. The major issues raised by patients relate to food quality and limited privacy when discussing sensitive issues.

Access to allied health professionals such as dieticians, physiotherapists and counsellors could be improved. While the IKA provides counselling, the study shows only 62% of patients were made aware of the supports available from the IKA. Given that mental health issues are common amongst patients, providing mental health care in one setting would reduce the obstacles to patients receiving services.

Access to supports was particularly an issue for patients on home dialysis, who also requested more financial and services support. More recently, the water and electricity outages caused by Storm Éowyn in January 2025 resulted in substantial difficulties for many patients and their families. Given the cost savings on delivering home dialysis versus centre-based dialysis, this is an area worth focusing on to encourage more patients to choose home dialysis. It could also support reducing the 46% of patients who must travel more than an hour to their nearest dialysis unit.

Patients talked about understaffing in dialysis units and some patients raised concerns about a lack of access to out of area dialysis in Ireland. Given the pattern of increasing demand for dialysis treatments year on year this is a serious concern.

Patients also expressed worry about the lack of communication between healthcare providers and the lack of an electronic health record. In this regard, the proposed HSE new patient App is a positive development.

Overall, we welcome this report and thank all who designed or participated in this important research. It clearly shows the patients' value and appreciation towards the care being provided to them. It is also a very useful resource to guide our advocacy and campaigning on behalf of patients and ensure their voices are heard.

Carol Moore
CEO, Irish Kidney Association

FOREWORD

Chronic Kidney Disease (CKD) is the medical term for persistent irreversible damage to the kidney. CKD is a disease that tends to progress, especially if not detected and treated. Patients with chronic kidney disease are at increased risk of cardiac events and premature cardiovascular death. For some patients, CKD results in complete kidney failure with associated symptoms known as uraemia. These patients are said to have End Stage Kidney Disease (ESKD) and require treatment including dialysis and/or kidney transplantation. Patients with end-stage kidney disease are particularly vulnerable. They have significant healthcare needs in addition to the provision of dialysis or a kidney transplant, as most have some underlying medical diseases. In addition to direct healthcare costs, ESKD places a financial burden on patients and their carers through lost working days and increased morbidity. In addition, many patients with ESKD are unable to work and require additional supports both financial and healthcare supports.

The National Renal Office is tasked with the strategic development of renal services in Ireland. In line with trends worldwide, the number of patients treated by dialysis or kidney transplantation in Ireland has more than doubled over the past 20 years.

The delivery of treatment of ESKD has been primarily hospital-based, particularly in terms of delivery of dialysis which occurs in a hospital or clinic setting in almost 90% of cases. The HSE provides over 340,000 in-centre haemodialysis treatments annually which is the largest day case activity of the HSE. In addition, patients carry out hundred thousand home dialysis treatments per year. Delivering this amount of clinical care requires significant support from a variety of healthcare professionals including nursing staff, medical staff, dieticians, social workers and others.

It is important for healthcare professionals to fully understand the needs of their patients and the NRO welcomes this in-depth survey of the kidney disease patient experience in the Irish healthcare system.

This survey will help guide the HSE and the NRO into addressing the needs of our patients.

Professor George Mellotte
National Clinical Lead for Renal Services, HSE

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ABBREVIATIONS

Acronym	Definition
CKD	Chronic Kidney Disease
ED	Emergency Department
EHR	Electronic Health Record
ESKD	End Stage Kidney Disease
GMS	General Medical Services
GP	General Practitioner
HD	Haemodialysis
HHD	Home Haemodialysis
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IKA	Irish Kidney Association
MDT	Multidisciplinary Team
KDCPMS	Kidney Disease Clinical Patient Management System
NKTS	National Kidney Transplant Service
NRO	National Renal Office
PD	Peritoneal Dialysis
PPI	Public and Patient Involvement
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
RCSI	Royal College of Surgeons in Ireland
RRT	Renal Replacement Therapy

EXECUTIVE SUMMARY

This is the first national report to explore how renal patients in Ireland experience the Irish healthcare system. This research provided people living on Renal Replacement Therapy (RRT) and with a functioning kidney transplant an opportunity to share their experiences as recipients of care, highlight areas that matter most to them, and where they feel their patient experience could be improved.

A survey was developed through consultation with the Patient Reported Experience Measures (PREM) UK research group, the National Renal Office (NRO) and patient representatives from the Irish Kidney Association (IKA), and distributed from June to August 2023. 1006 renal patients provided their experiences; 58% were Haemodialysis patients (HD), 31% had a functioning kidney transplant, 8% were on home Peritoneal Dialysis (PD) and 2% were on Home Haemodialysis (HHD).

Findings overall found a high level of satisfaction with the delivery of care for ESKD by renal staff. Cleanliness of renal facilities, supportive staff, participation in shared care and the capacity to interact with other patients were perceived to be positives among in-centre HD patients. Home dialysis patients reported a high level of satisfaction with the freedom and autonomy associated with their treatment type. Transplant recipients experienced largely positive renal care in Ireland, as receiving a kidney transplant gave them a new lease of life. Supportive staff, satisfaction with out-patient care and provision of clear information were also perceived to be positives among transplant patients. Some aspects of care were highlighted by patients as matters important to them which need to be addressed for future progression of service delivery, including hospital catering for haemodialysis patients, privacy for discussion of sensitive issues, and the need for a national patient EHR to facilitate better interdisciplinary communication. Improved governmental support for financial hardship caused by reduced economic earning potential was also highlighted as needing attention, including increased governmental support for GMS card eligibility for dialysis and transplant patients, financial supports for home dialysis therapies, inclusion of ESKD on the Long-Term Illness Scheme, and reinstatement of support with the cost of sunscreen use on the Primary Care Reimbursement Scheme.

The overarching conclusion from this report is that service developments implemented by the NRO to date, and patient support initiatives delivered by the IKA, have had a significant impact in providing a positive patient experience for all treatment groups, both in clinical and community settings. Findings provide a roadmap for targeting aspects of clinical care where future service developments may be required, and provide a benchmark against the impact to which future service developments can be measured.

As defined by the HSE:

- The **Primary Care Reimbursement Scheme** supports the delivery of primary healthcare by providing reimbursement services to primary care contractors for the provision of health services to members of the public in their own community.
- The **Long-Term Illness Scheme** provides free drugs, medicine, and medical and surgical appliances for the treatment of certain medical conditions.

KEY FINDINGS

DIALYSIS CARE:

- **80%** of all dialysis participants report that their treatment is "the best it can be"
- **93%** of dialysis patients report that they are treated with respect and kindness
- **95%** of haemodialysis participants report that the environments they attend for haemodialysis are always clean and tidy
- **97%** report that healthcare professionals that come into contact with them always wash their hands
- **87%** of haemodialysis patients availing of the HSE non-emergency patient transport report that the vehicle is suitable to them. 85% of haemodialysis patients report that pick-up waiting times are suitable to them
- Food and catering received the lowest rating across all areas examined in the survey. A total of **32%** of hospital / satellite haemodialysis patients regard catering and food provided during treatment hours as excellent. **29%** rated catering and food very good, **22%** good, **11%** fair and **6%** poor. Sandwich choice is reported as often suboptimal, and only **63%** reported that dietary needs were met for most patients with comorbid conditions (diabetes or coeliac disease)
- **80%** feel supported by their renal team, and **75%** report good communication with their renal team
- **11%** of in-centre dialysis patients saw a renal dietician in the last 12 months, and report the need for more dietician input in their care
- **10%** of in-centre dialysis patients saw a counsellor or psychologist for support with mental health conditions in the last 12 months, and report the need for better mental health support
- **58%** partook in shared care, participating in some or all aspects of their dialysis care
- **43%** of dialysis patients are aware of the process for providing feedback/complaints to the renal team
- **75%** of HHD and PD patients are aware of available financial assistance measures for home dialysis
- **72%** of all dialysis patients held a GMS card. Those without a GMS card report the need for improved governmental support, particularly the inclusion of ESKD in the Long-Term Illness Scheme given the complex level of care required for dialysis patients.

POST-TRANSPLANT CARE:

- **79%** of transplant recipients stated that their treatment is "the best it can be"
- **89%** of transplant recipients report having good access to their renal team, and **87%** report good communication with their renal team
- **81%** of transplant recipients report feeling supported by their renal team
- **79%** of transplant recipients are satisfied with the scheduling of out-patient appointments
- **92%** of transplant recipients report that their dignity is respected in out-patient appointments
- **66%** of transplant recipients report that are they engaged in shared decision making related to their care
- **47%** report that they are satisfied with the communication between their renal team and their GP
- **74%** report wearing sunscreen every day
- **5%** of transplant recipients saw a counsellor or psychologist for support with mental health conditions and report the need for better mental health support
- **63%** of transplant recipients held a GMS card. Those without a GMS card report the need for improved governmental support, including removal of means testing for a GMS card, given the complex life-long medical needs post-transplant. Support with sunscreen costs was also identified as a need.

Chapter 1
Introduction

CHAPTER 1: INTRODUCTION

1.1 Living with End Stage Kidney Disease

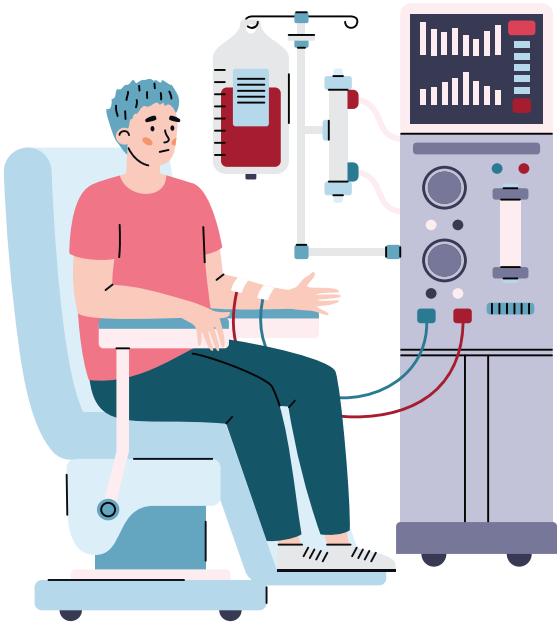
End Stage Kidney Disease (ESKD) affects up to 800 million people worldwide[1], with diabetes mellitus and hypertension being major risk factors for this condition[2]. The Irish Longitudinal Study on Ageing (TILDA) found that Chronic Kidney Disease (CKD) is increasing in Ireland, particularly among women, and affects more than 1 in 7 people over the age of 50[3]. Although women are more affected by ESKD than men within the Irish healthcare system, mortality rates and Renal Replacement Therapy (RRT) rates have shown to be considerably higher in men[4]. Uncontrolled hypertension is more common in males with ESKD compared to females which can worsen the onset of the disease over time[5]. Diabetes, hypertension, obesity and aging are conditions largely attributed to the global increase in ESKD[6].

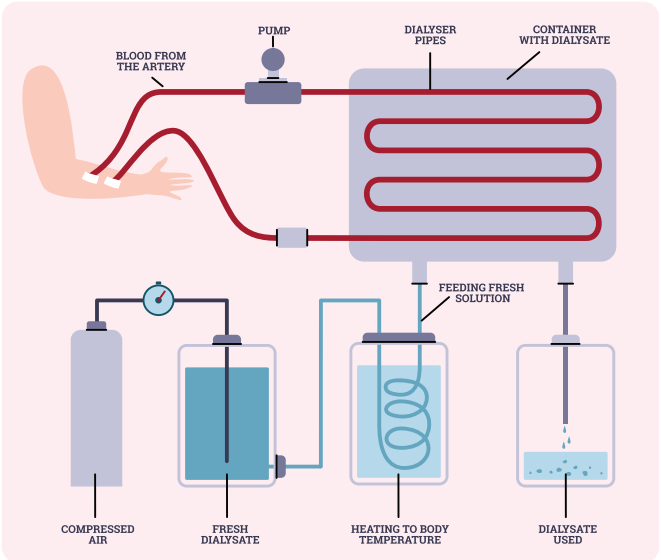
1.2 Treatment for End Stage Kidney Disease

There are three types of treatment for ESKD: **Haemodialysis (HD)** (in-centre or at home), **Home Peritoneal Dialysis (PD)** and **Kidney Transplantation**[7]. Fifty-two percent of the Irish ESKD population have a functioning kidney transplant.

Dialysis is a renal replacement treatment for ESKD. It ensures proper internal functioning in those experiencing loss of kidney function and is required when one's kidneys are unable to clear waste and fluid from the blood[8]. The types of dialysis treatment are described below:

HAEMODIALYSIS



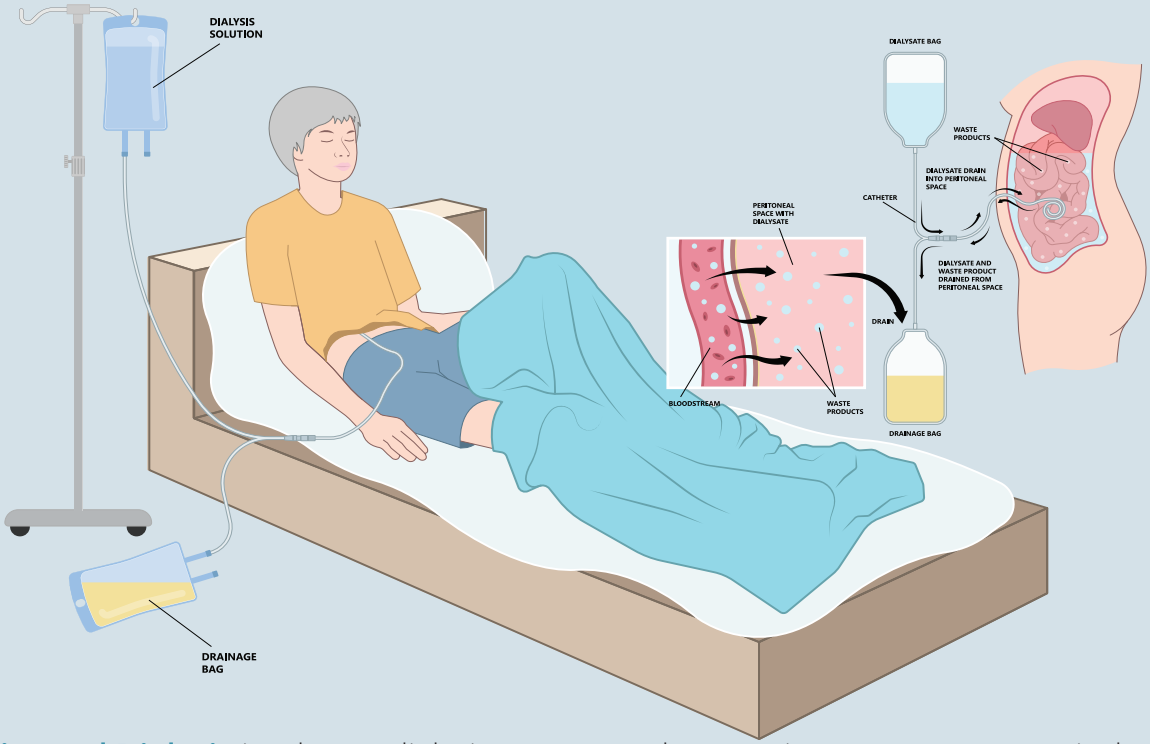


Haemodialysis is a procedure whereby a dialysis machine features an artificial kidney (dialyser) to clean the blood. A renal nurse performs this at a hospital or satellite unit by accessing blood vessels through the arm (arteriovenous fistula) or neck / groin (central venous catheter) of the patient, connecting them to the dialysis machine for treatment for approximately four hour sessions 3-4 times weekly[9].

HOME HAEMODIALYSIS

Home Haemodialysis is treatment similar to in-centre haemodialysis where the patient has been professionally trained to carry out haemodialysis by themselves at home, 4-6 times a week for 3-4 hours daily[10]. To be eligible, the patient must have the ability to self-needle (if applicable to them) and have a functioning arteriovenous fistula. A home assessment is carried out prior to set-up and necessary equipment is provided[11].

PERITONEAL DIALYSIS



Peritoneal Dialysis is a home dialysis treatment that requires permanent surgical insertion of a soft tube into the patient's abdomen, this tube then allows dialysis fluid to enter into the peritoneal membrane to clear excess water and waste from the blood. This is known as an 'exchange process' – the fluid can be changed four times during the day (Continuous Ambulatory Peritoneal Dialysis) or using a machine at night as the patient sleeps (Automated Peritoneal Dialysis)[12].

KIDNEY TRANSPLANTATION

Kidney Transplantation is the preferred option for ESKD. The patient must have generally good health apart from kidney disease and will undergo a thorough medical assessment to be considered eligible for a kidney transplant. If test results are satisfactory, a patient will be placed on a transplant waiting list and must be contactable at any time in case a transplant from a deceased donor becomes available[13]. Patients can also receive a living-donor transplant, in which the donor is a family member or emotionally related to them (e.g. spouse) as part of a paired-organ exchange programme or altruistic donation[14]. Statistics from the National Kidney Transplant Service (NKTS) at Beaumont Hospital report a 10-year transplant survival rate of 65% for a kidney transplant from a deceased donor and 77% for a kidney transplant from a deceased donor. In 2023, the NKTS performed 189 transplants[15].

1.3 ESKD in Ireland

National surveillance data published by the national Kidney Disease Clinical Patient Management System (KDCPMS) has highlighted that treatment for ESKD accounts for 5% of the HSE Acute Hospital Budget in Ireland[16,27]. This cost is expected to rise as numbers of patients needing to avail of treatment services for ESKD increase, with a 2.1% increase in patient numbers observed from 2022 – 2023.

Currently, there are 2,755 people living with a kidney transplant in Ireland[16], and 2,502 people receiving dialysis treatment either in a haemodialysis centre or their own home; 88% of these treatments were delivered in a haemodialysis centre, and 12% at home.

Haemodialysis for adults is provided in three types of centres in Ireland across 24 units; 13 HSE public hospital renal units, 2 HSE public hospital satellite units and 9 HSE contracted satellite units. Children receive dialysis in the National Paediatric Dialysis Centre at Children's Health Ireland, Temple Street[16].

1.4 Delivering patient-centred care

The HSE National Renal Office (NRO) and the Irish Kidney Association (IKA) share the objective of delivering patient-centred care. To do so, there is a need to hear from patients themselves to identify issues in their care that may contribute to treatment difficulties and poor health-related quality of life.

Emerging international research guidelines recommend using a Patient Reported Outcome Measure (PROM), a measure of a person's health which is reported directly by the patient, without interpretation by a healthcare professional[17]. PROMs can describe specific physical and psychological symptoms, treatment preferences or aspects of overall health that provide insights into the patient's wellbeing that are not captured through routine clinical care alone[18].

Patient Reported Outcome Measure

PROMs-based surveys provide outcome information typically not available via traditional clinical measures such as biochemical indices, and morbidity and mortality statistics[17-19]. PROMs data can provide feedback to Healthcare Professionals on aspects of care most important to patients, and where improvements can be introduced to improve patient outcomes[20].

Awareness and integration of information gathered from PROMs can have a significant impact on clinical care, and research studies in the US and UK have demonstrated improved shared decision making, improved communication between physicians and patients, improved facilitation of patient self-monitoring, reduced emergency department utilisation, and allows more nuanced predictions of disease trajectory[19].

ESKD patients face several obstacles in different facets of their renal care, and it is crucial that healthcare professionals play an active role in helping ESKD patients understand and self-manage their condition.

Dialysis patients in particular experience a high physical and psychological symptom burden, in addition to dialysis-specific challenges such as fluid, diet and lifestyle restrictions, employment and financial challenges, side effects of medications and complications arising from dialysis treatment.

Kidney transplant recipients experience fewer but significant challenges within their care. As part of their post-transplant care, transplant recipients must manage their lifestyle, adhere to immunosuppressant medications which can have significant side effects, and attend life-long follow-up medical care.[21-23]

1.5 Report objectives

The objective of this report is to give ESKD patients in Ireland a voice by providing information and feedback on aspects of their treatment and care that matter to them. The clinical research team in the RCSI School of Population Health, the Health Service Executive National Renal Office and the Irish Kidney Association gathered the views and experiences of dialysis patients and transplant recipients in Ireland using a PROMs-based survey.

Chapter 2 of this report describes the research methodology and Chapter 3 describes the findings generated from patient responses to the PROMs survey.
The final chapter concludes the findings and provides recommendations for future clinical care and research.

Findings are aimed for use by healthcare professionals, hospitals, patient advocacy organisations, policy makers, researchers, and patients and their carers.

Chapter 2
Methodology

CHAPTER 2: METHODLOGY

2.1 Ethics

Ethical approval to conduct this research was granted by the Research Ethics Committee at the Royal College of Surgeons in Ireland (REC202301021). The Irish Kidney Association and National Renal Office did not require ethical exemption as neither organisation were direct recipients of the data collected from participants.

2.2 Study design and survey development

This cross-sectional quantitative survey evaluated the quality of care for transplant and dialysis patients nationally based on specific aspects of patient care.

The purpose of the survey was to capture information on individual perspectives from a large cohort of renal patients in Ireland[24]. Two validated surveys were modified and combined for this research – the Patient Reported Experience Measure (PREM) Survey from The UK Kidney Association[25] and the National Renal Office Patient Survey from the Health Service Executive in Ireland (HSE).

Questions were specific to the Irish ESKD population and examined numerous themes of patient care, with several free text options to invite expression of personal opinions and experiences. The first section of the survey included 8 demographic questions before being divided by treatment modality (Dialysis and Transplantation).

2.2.1 Dialysis patients completed questions related to:

- Healthcare professionals involved in patient care
- Decision-making and participation in shared haemodialysis care
- Fistula Care
- Environment
- Transport
- Fluid and diet
- Access to the renal team
- Communication
- Supports for home dialysis (peritoneal and haemodialysis)
- Overall satisfaction with care
- Patient comments on overall experience of care for ESKD
- Uremic Pruritus (*reported separately)

2.2.2 Transplant patients completed questions related to:

- Healthcare professionals involved in patient care
- Access to the renal team
- Outpatient care – tests, appointment scheduling and planning
- Decision making and participation in shared care
- Communication
- Overall satisfaction with care
- Patient comments on overall experience of care for ESKD.

2.3 Public and patient involvement

As part of survey development, a consensus meeting was held with the IKA Patient Support Manager, Ms Fiona Aherne, and patient peer support volunteers leading the IKA Peer Support Service. The purpose of this meeting was to pilot and review the survey for relevance to patient needs and appropriateness of survey questions.

2.4 Participants and procedure

The inclusion criteria for study participation were individuals aged 18 years or over who were receiving in-centre or at-home dialysis treatment or living with a functioning kidney transplant. Purposive sampling was used to recruit participants through the IKA and through in-centre HD units in the Republic of Ireland.

The option to complete the survey in paper and online formats was implemented to encourage a high response rate[26]. The survey was emailed to 1,208 IKA patient members by an IKA staff member, and 924 members without email addresses received a free-return paper survey by post.

Recruitment for both aspects of the study was also advertised in the 2023 spring edition of the IKA *SUPPORT* magazine which patient members received by post, and via social media on the IKA Facebook and Twitter pages.

2,231 paper surveys were also distributed to all hospital and satellite HD units nationally accompanied by poster advertisements that featured a QR code directing users to the online survey when scanned.

2.5 Data collection

Data Collection for the survey lasted 8 weeks from June to August 2023. Survey responses were anonymous. At the time of survey completion, participants were given the option to provide informed consent to participate in a separate qualitative study including focus groups examining the patient experience of ESKD care.

2.6 Data analysis

Data analysis was conducted using STATA® Version 18 (StataCorp LLC). Findings for quantitative data are presented using descriptive statistical tests for continuous and categorical variables. Qualitative data from open-ended free-text comments were analysed using thematic content analysis to identify emerging trends from the data.

Chapter 3
Results
– Survey Findings –

CHAPTER 3: RESULTS – SURVEY FINDINGS

3.1 Profile of participants

A total of 4363 surveys were distributed to Irish Kidney Association patient members (n=2132; 1208 email, 924 post) and to patients in in-centre haemodialysis units (n=2231). Sixty-two completed surveys were excluded as they failed to meet the study's inclusion criteria. A total of 1006 eligible participants, 609 males (61%), 395 females (39%) and 2 non-binary individuals, completed the survey. This returned a survey response rate of 23%.

All dialysis units in the Republic of Ireland were represented, including hospital and satellite units. A total of 1004 patients reported their treatment type: 58% in-centre HD; 2% HHD; 8% PD; 31% transplant recipients. Of the sample on in-centre haemodialysis, 62% reported attending a hospital dialysis unit, 33% reported attending a satellite dialysis unit, and 5% did not report dialysis location.

3.2 Representativeness of survey sample

The National Renal Office end of 2023 statistics Overview[16] reports national patient data from the Kidney Disease Clinical Patient Management System (KDCPMS). Based on end-of-year 2023 statistics, there were 5190 patients receiving treatment for ESKD by dialysis or transplantation in Ireland; therefore, our survey sample represented 19.3% of the 2023 total Irish ESKD population. Table 1 outlines the percentage of survey respondents per treatment type as compared with the total Irish ESKD population per treatment type according to National Renal Office KDCPMS 2024 statistics.

Table 1. *Representativeness of survey sample as compared to 2023 national statistics*

	Total ESKD Population	In-centre haemodialysis	Home dialysis		Living with a functioning kidney transplant
			Peritoneal dialysis	Home haemodialysis	
KDCPMS 2023 National statistics	5190	2191	237	57	2705
Proportion of the Irish ESKD population included in survey sample	1004 (19.3%)	584 (26.7%)	83 (35%)	22 (38.6%)	315 (11.6%)

Most participants who completed the survey were between the age of 59-69 (26%), followed by the 70-80 age group (25%). The least common age bracket were 18-25 years old (1%). Table 2 outlines the demographic characteristics of the patient survey sample.

Table 2. *Demographic characteristics of all patient survey respondents by treatment modality*

	Total Sample (n=1004)	Haemodialysis – Hospital Unit (n=413)	Haemodialysis – Satellite Unit (n=171)	Home Haemodialysis (n=22)	Home Peritoneal dialysis (n=83)	Living with a functioning kidney transplant (n=315)
AGE						
18–25	13 (1%)	5 (38%)	1 (8%)	1 (8%)	1 (8%)	5 (38%)
26–26	41 (4%)	16 (39%)	7 (17%)	1 (2%)	5 (12%)	12 (29%)
37–47	136 (14%)	39 (29%)	17 (13%)	2 (1%)	14 (10%)	64 (47%)
48–58	205 (20%)	71 (35%)	23 (11%)	6 (3%)	16 (8%)	89 (43%)
59–69	266 (26%)	104 (39%)	39 (15%)	11 (4%)	23 (9%)	89 (33%)
70–80	253 (25%)	127 (51%)	59 (24%)	1 (<1%)	17 (7%)	47 (19%)
81+	92 (9%)	51 (55%)	25 (27%)	0 (0%)	7 (8%)	9 (10%)
GENDER						
Male	609 (61%)	256 (42%)	121 (20%)	11 (2%)	58 (10%)	162 (27%)
Female	395 (39%)	155 (39%)	50 (13%)	11 (3%)	25 (6%)	153 (39%)
Non-binary	2 (<1%)	2 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
ETHNICITY						
White Irish	911 (90%)	367 (40%)	151 (17%)	18 (2%)	69 (8%)	304 (33%)
White Irish Traveller	5 (1%)	3 (60%)	2 (40%)	0 (0%)	0 (0%)	0 (0%)
Any other white background	38 (4%)	23 (61%)	4 (11%)	2 (5%)	4 (11%)	5 (13%)
Black or Black Irish	17 (2%)	8 (47%)	6 (35%)	1 (6%)	1 (6%)	1 (6%)
Asian or Asian Chinese	5 (1%)	3 (60%)	0 (0%)	0 (0%)	1 (20%)	1 (20%)
Asian or Asian Irish Any other background	20 (2%)	5 (25%)	6 (30%)	0 (0%)	7 (35%)	2 (10%)
Other – including mixed background	9 (1%)	4 (44%)	2 (22%)	1 (11%)	1 (11%)	1 (11%)

3.3 Access to free health services schemes

A total of 982 patients reported the supports they avail of and overall, participants reported good access to free health service schemes. Collectively, 72% of dialysis patients and 63% of kidney transplant recipients were in receipt of a GMS Card, as compared to 37% of the general population.

Table 3. *Access to free health services schemes by treatment modality*

	Haemodialysis – Hospital Unit (n=403)	Haemodialysis – Satellite Unit (n=165)	Home Haemodialysis (n=20)	Home Peritoneal Dialysis (n=83)	Living with a functioning kidney transplant (n=311)
General Medicine Services Card	306 (76%)	126 (76%)	17 (85%)	48 (58%)	195 (63%)
GP Visit Card	54 (13%)	29 (18%)	1 (5%)	17 (20%)	33 (11%)
Drug Payment Scheme Card	104 (26%)	45 (27%)	3 (15%)	31 (37%)	22 (39%)

SECTION 1:

THE DIALYSIS PATIENT EXPERIENCE

A total of 689 dialysis participants completed the survey (68%) and 14% of people on dialysis reported receiving a kidney transplant previously. The mean length of time transplanted before returning to dialysis was 11 years, ranging from 24 hours to 29 years. For current dialysis patients, 34% of participants reported receiving dialysis for less than 2 years, 25% were 2-4 years, 15% were 5-7 years and 27% were receiving dialysis for eight years or more.

A number of specific aspects of care related to the patient experience for patients on all forms of dialysis were examined. Survey findings and summarised free-text comments for each domain of care are presented in the following sections.

1. HEALTHCARE PROFESSIONALS INVOLVED IN PATIENT CARE

A multidisciplinary approach to the management of ESKD is associated with reduced morbidity, hospitalisations, and ESKD complications[28-29]. An ESKD Multidisciplinary Team (MDT) typically includes a nephrologist, nurse, dietician, social worker and pharmacist, with input from additional allied health professionals depending on patient needs[28].

In Ireland, significant expansion in staffing for renal services has occurred to support a 30% increase in dialysis activity, including an approximate 25% increase in the number of consultant nephrologists in the past five years[27].

Table 4 presents the various healthcare professionals that participants reported were involved in their care in the previous 12 months, with consultant nephrologist / renal team doctor reported as the most frequent across all dialysis types, followed by a General Practitioner (GP) and a Clinical Nurse Manager. Least frequent involvement was reported for a Renal Dietician, Psychologist/Counsellor, Social worker and Physiotherapist. HHD patients reported the highest frequency of interactions with core MDT professionals, with 100% seeing a Nephrologist, 86% seeing a GP, and 73% seeing a Pharmacist. Interaction with a renal dietician was also highest for HHD patients (27%).

Table 4. *Healthcare professionals involved in dialysis patient care in previous 12 months by treatment modality*

	Haemodialysis – Hospital Unit (n=404)	Haemodialysis – Satellite Unit (n=168)	Home Haemodialysis (n=22)	Home Peritoneal Dialysis (n=83)
Consultant Nephrologist/ Renal Team Doctor	371 (92%)	160 (95%)	22 (100%)	80 (96%)
GP (General Practitioner)	230 (57%)	107 (64%)	13 (59%)	49 (59%)
Clinical Nurse Manager	224 (55%)	96 (57%)	19 (86%)	53 (64%)
Renal Nutritionist / Dietician	39 (10%)	18 (11%)	6 (27%)	15 (18%)
Physiotherapist	6 (1%)	3 (2%)	2 (9%)	0 (0%)
Pharmacist	198 (49%)	97 (58%)	16 (73%)	41 (49%)
Social worker	39 (10%)	6 (4%)	1 (5%)	6 (7%)
Diabetes specialist	72 (18%)	26 (15%)	3 (14%)	13 (16%)
Psychologist / Counsellor	49 (12%)	15 (9%)	1 (5%)	6 (7%)
None of the above	6 (1%)	1 (1%)	0 (0%)	0 (0%)

Participants were asked to provide an open-ended response about what other services they thought should be made available to them, and analysis of free-text comments revealed that dialysis participants would like to access a psychologist / counsellor on a regular basis:

> *"Counselling and psychological support. The Renal clinic is very much focused on physical health."*

> *"Counselling should be readily available and not limited to 6 sessions."*

Findings show that 10% of patients accessed a psychologist or counsellor in the past 12 months. When discussing aspects of patient care that can be overlooked by healthcare professionals, the majority of participants said that the mental health and wellbeing of patients is not always considered and participants must emotionally tackle different facets of their renal journey without immediate professional support.

Patients reported the benefit of access to mental health professionals trained to work with ESKD patients to reduce mental health problems. Previous research with Irish haemodialysis patients has highlighted the prevalence of mental health problems amongst dialysis patients, with 51% and 35% of patients having clinically significant depression and anxiety, and 26% of patients having experienced suicidal ideation[30]. Together, these findings indicate that patients would benefit from accessing treatment for mental health problems as part of routine care for ESKD patients. The IKA provide free counselling for patients and family members, and access to peer support groups for all ESKD patient IKA members, yet patients reported that this isn't signposted by healthcare professionals to patients when initially diagnosed, or when experiencing significant psychological distress.

2. DECISION-MAKING AND PARTICIPATION IN SHARED HAEMODIALYSIS CARE

Shared haemodialysis care in ESKD involves the patient taking more control over their disease by taking an active role in their dialysis treatment[31]. A shared care model includes 14 tasks - patients start by engaging in simple tasks such as measuring own blood pressure, pulse, and weight. With staff support to develop confidence and skill, patients progress to more complex tasks including machine set-up and monitoring, needle self-insertion / removal, and machine strip-down[32]. Shared care is associated with greater patient independence, a more positive experience of care, fewer Emergency Department (ED) admissions and improved quality of life[33-36]. It can also empower centre-based haemodialysis patients to switch to home haemodialysis[32,37,38]. Currently in Ireland, a shared care model is in a trial phase, with nursing staff receiving training to support patients in active shared care[38]. Findings below outline the patient experience of engaging in shared decision making and shared dialysis care.

3.4 Decision-making for initiating treatment

Eighty-nine percent of participants reported that they were informed about all of the different dialysis treatment options (in-centre HD; HHD; PD) prior to starting dialysis therapy. Participants were asked to provide a free-text response of their experience in the treatment decision-making process, with varying experiences reported. Some participants stated that they complied with the recommendations of their renal team, whilst some patients led the decision-making process by gathering information about the different types of dialysis treatment, discussing their options with family and considering their lifestyle before making a considered decision:

> *"I received lots of reading material which I brought home and discussed my options with family before making an informed decision."*

The majority of patients who chose home based therapies, particularly PD, needed to integrate work commitments and family responsibilities:

> *"I have a young family so it was the best way to not have a major impact on my life."*

> *"I decided to choose PD because I am full-time working and wanted to continue my normal routine and PD is perfect for me."*

For some, in-centre haemodialysis provided a sense of security and access to renal staff in medical crises:

> *"Having been advised of the options, I chose hospital-based dialysis as I did not want to convert my home into a hospital facility. Also, I wanted professionals on hand to deal with any issues arising."*

A number of personal, clinical and system factors also impacted on the type of treatment that patients could access. For example, medical complications and/or comorbid conditions precluded some patients from choosing home therapies. Some patients reported that they chose in-centre dialysis as they perceived that their opportunities for a transplant would be higher if they were more visible to renal staff. Staffing shortages in supporting home dialysis therapies were also highlighted as a barrier, as were lack of financial and carer supports for choosing home dialysis:

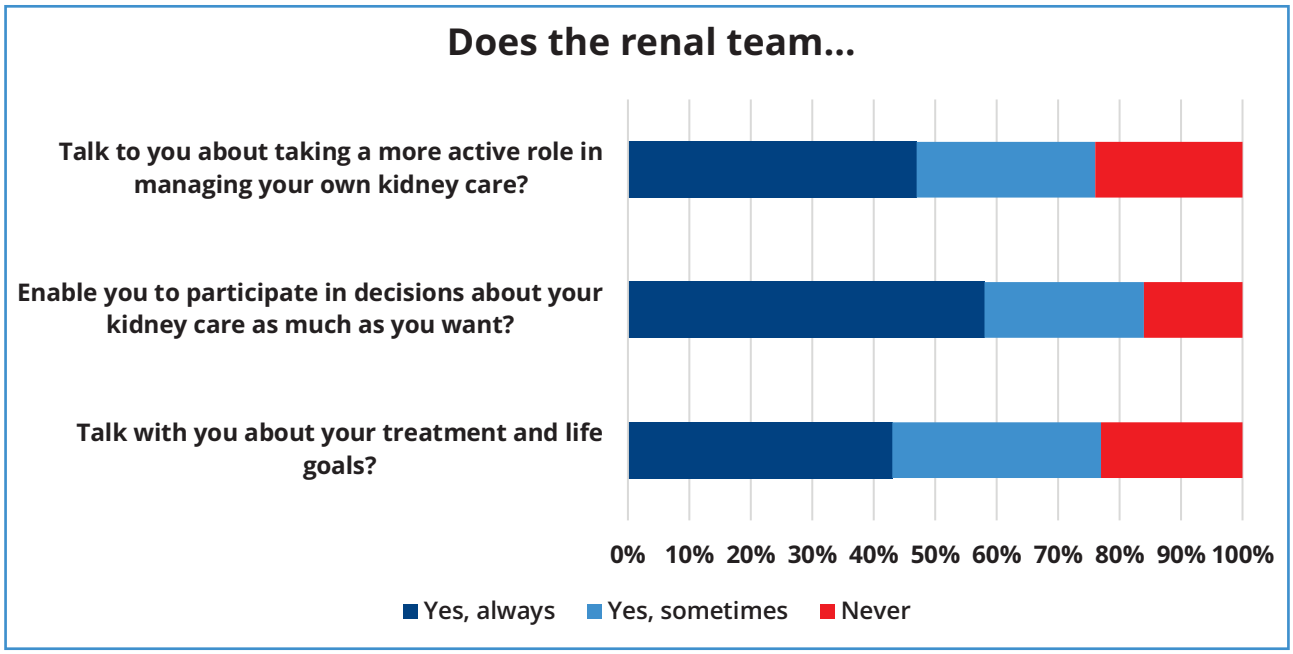
> *"Wanted to do home dialysis because of the convenience, but wasn't able to consider as I couldn't get home support from the HSE.."*

3.5 Participation in shared care

Figure 1 highlights that shared care happens to some extent nationally. Following its introduction in Ireland in 2022, 58% of dialysis participants reported that their renal team always enables them to participate in decisions about their renal care, and 47% said their renal team always talks to them about taking a more active role in self-managing their care. Discussions regarding treatment and life goals is an area of shared care that was reportedly least common, with 43% reporting that this is a regular conversation with their renal team.

Six percent reported that they had been invited and were currently participating in shared care, including self-insertion of needles for haemodialysis. Fourteen percent were invited but declined to participate, and 71% were not invited to participate in shared care. Eight percent did not know if shared care was offered to them. Shared care participation was highest amongst 48-58yrs (9%), and lowest among 70-80yrs (1%).

Figure 1. *Promoting self-management among dialysis patients*



Findings show a growing inclusion of shared care opportunities following the introduction of staff training in some units nationally. From a service delivery perspective in haemodialysis units, implementation of shared care affords nursing staff more time to allocate to patients with complex needs if a percentage of patients require less supervision by self-dialysing. Irish data from the National Patient Experience Survey identified that whilst experiences of shared care are largely positive amongst the general patient population in Ireland not specific to ESKD, opportunities to clarify information and inclusion of caregivers / family members could improve the delivery of shared care across different chronic conditions[39].

Furthermore, international experiences of shared care implementation specific to haemodialysis highlight that supportive organisational policies and the culture within the dialysis unit foster expansion of this initiative. Further rollout of staff training on a national level in Ireland and the inclusion of caregivers / family members may increase uptake of shared haemodialysis care to foster patient independence, and encourage patients to consider home haemodialysis as a treatment option.

3. FISTULA CARE

Haemodialysis participants were asked about their experiences of pain when the renal team insert needles. Overall, the experience of pain was low. Thirty-nine percent reported that their renal team always insert their needles with as little pain possible, while 18% reported that they sometimes experienced pain upon insertion and 5% said the renal team never insert the needle with as little pain possible. In relation to their fistula care, patients were asked to provide a free-text response on their experience with needle insertion. It was reported that the ability to insert a needle is a *"variable skill"* among staff and that whilst most staff can successfully perform the task, others are less competent and suggested that in-depth training is vital to ensure that nurses can effectively insert needles to prevent or reduce pain and potential damage to the patient's fistula:

> *"I am a long time on dialysis, so it is very important that the nurses putting in the needle are competent and well trained in doing this task. I have the same fistula service for a long time, so I need to mind it very carefully. I'm sorry to say that a large percentage of nurses are rather poor at putting in needles, because of this my fistula gets damaged and sore from time to time. I am not squeamish or afraid of needles but I know when damage is being done to the fistula. Some nurses are excellent, no pain and you know it was done very well, but a large percentage just do not do this vital part properly."*

Patients who reported positive experiences with regards to needle insertion, acknowledged the skillset that some nurses possess to do this task pain-free:

> *"Staff in unit are amazing. The staff can insert the needles with no pain, they chat away and before you realise, you're on."*

4. ENVIRONMENT

Infection control is a cornerstone of patient and staff safety in the dialysis unit. Dialysis patients are at increased risk of infection due to their immunocompromised health status, prolonged vascular access during dialysis, close proximity to other patients and frequent staff contact during treatment[40]. Infection is the most common reason for hospitalisation for dialysis patients, in addition to being the second most common cause of mortality, accounting for 8% of all deaths[41]. Thus, adherence to infection control procedures is paramount for the safe delivery of care.

In-centre haemodialysis patients undergo approximately 156 dialysis treatments per year, leading to a high level of interaction with staff and dialysis unit facilities. Environmental considerations within the dialysis unit can have a significant impact on patient's quality of life. In particular, patient trust in the staff, receiving gentle and supportive care, and patient privacy when discussing confidential matters are highlighted internationally as enhancing the patient experience[42,43]. Findings presented below outline the patient experience of the dialysis unit environment.

3.6 Infection control

Overall, participants reported satisfaction with the dialysis environment, particularly for cleanliness of dialysis facilities (95%) and personal hygiene among health care professionals (97%).

3.7 Patient-staff interaction

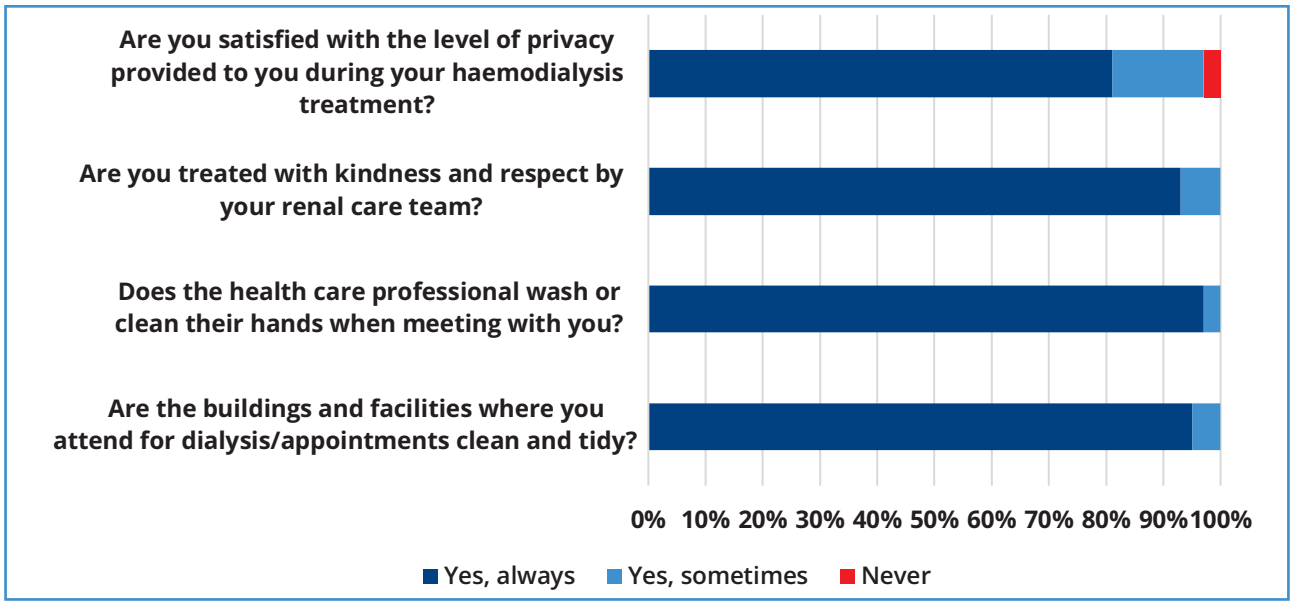
Ninety-three percent of patients reported that they were always treated with respect and kindness by their renal team.

3.8 Physical environment

Privacy scored lowest on participant ratings and was identified as an issue for some participants, with 16% reporting that they are only sometimes satisfied with the level of privacy provided and 3% reporting that they are never satisfied with the level of privacy provided during haemodialysis:

> *"Our unit needs (a) small office place to meet privately with professionals. People / patients can hear one's conversation, we have no privacy."*

Figure 2. *Environment and patient respect in dialysis units*



Findings regarding satisfaction with dialysis unit environment were overall positive. There was almost 100% satisfaction with cleanliness and personal hygiene. Notably, this reflects the strict adherence to infection control policies by dialysis unit staff and patients. Further, positive experiences of patient-staff interaction have been highlighted as central to enhancing a patient's sense of control and emotional regulation during dialysis treatment[44,45]. Thus, findings here support the excellent level of clinical skill and care delivery against the backdrop of the current climate of health workforce shortages and resourcing pressures.

International in-centre dialysis guidelines suggest that there is a contradictory requirement for staff visibility of patients while maintaining patient privacy[46]. Privacy is a documented concern amongst haemodialysis patients internationally[46], with confidentiality of personal discussions and visibility and dignity during invasive procedures highlighted as key concerns. This may prompt patients to avoid disclosing sensitive yet important issues with their renal team, particularly mental health issues.

Such findings support previous research conducted with renal patients and renal nurses which reported that patients are reluctant to voice their problems, especially mental health issues, in front of fellow patients with whom they have built relationships[47,48].

Whilst new, purpose-built dialysis units in Ireland have the capacity to plan appropriate spaces to facilitate patient confidentiality and dignity, the majority of dialysis units were historically generic spaces allocated within existing hospital buildings with little room for private spaces after patient bed capacity was maximised. Moving forward, the NRO will endeavour to provide guidance and input into the design and environmental considerations for upgrades of existing units. Of particular focus is the provision of adequate private examination rooms, space considerations for patients with special needs, television systems and related equipment, and comfortable patient waiting lounges:

"The TVs in unit only have one remote, which is often lost!!!"

"Have more wheelchair accessible facilities."

5. TRANSPORT TO HAEMODIALYSIS TREATMENT

The 2019 NRO patient transport guidance policy outlines that the majority of haemodialysis patients cannot drive to treatment, and therefore effective and timely transport to the dialysis unit is a fundamental part of their care[49]. The "on time, every time" model of service delivery is imperative to ensure patients not only receive the full duration of their treatment, but also that the dialysis schedule for all patients is not disrupted. Furthermore, if patients experience problems with service-provided transport, this can cause unnecessary distress and can have clinical consequences. A HSE non-emergency patient transport service which may include shared or individual journeys, is provided by the HSE at no cost to the renal patient. In addition, reimbursement of motor expenses is provided to patients who drive themselves to dialysis treatment. The provision of free travel to dialysis varies between countries. For example, in Australia, Canada and the Netherlands[50-52] free travel is not obligatory. However there is increasing recognition that the cost of travel can be an impediment to receiving treatment with many countries now examining how to improve their support for travel to dialysis costs.

Table 5 presents the variation in travel modalities to haemodialysis, with 'HSE provided' reported as the most common modality – 78% for hospital haemodialysis patients and 71% for satellite haemodialysis patients. Fifty-three percent of all haemodialysis participants had a round-trip treatment travel time of less than 1 hour, and 12% had a round-trip travel time of more than 3 hours. Four percent of patients reported that the travel time was not acceptable to them. When asked if they had any comments on travel, the majority of participants offered positive remarks about the patient transport drivers and an overall appreciation for the service provided by the HSE:

> *"It's very good to get transport and a very much appreciated service. I am thankful for it. I have no way in without it!"*

Table 5. *Travel methods and travel duration among Haemodialysis participants*

TRAVEL DURATION (return journey)	Haemodialysis – Hospital Unit (n=407)	Haemodialysis – Satellite Unit (n=169)
Less than 1 hour	217 (53%)	89 (53%)
1–2 hours	119 (29%)	61 (36%)
2–3 hours	36 (9%)	12 (7%)
More than 3 hours	31 (8%)	6 (4%)
Not applicable	4 (1%)	1 (<1%)
TRAVEL METHOD (return journey)	**Haemodialysis – Hospital Unit (n=403)**	**Haemodialysis – Satellite Unit (n=168)**
HSE provide me with transplant service e.g. HSE non-emergency patient transport	315 (78%)	120 (71%)
Public transport e.g. bus or train	2 (<1%)	3 (2%)
I drive / family member / friend drives me	86 (21%)	45 (27%)

For participants whose transport was arranged for them by the HSE, 87% reported that the vehicle provided was always suitable for them, 11% reported that it was sometimes suitable, and 2% reported that it was not suitable. Participants were also asked if the time it takes to travel from their home and the renal unit was acceptable to them; 85% reported that it always is. Participants identified pick-up and collection times to and from their dialysis sessions and sharing the patient non-emergency transport service with other participants as their main concern regarding the transport service. When asked if they had any additional comments on travel, some participants stated that patient transport are sometimes late to pick them up due to collecting other patients for a shared journey, and some patients must wait up to an hour after their dialysis treatment ends to be collected with another patient. This is time-consuming and tiring for patients and has caused worries surrounding infection-control in some cases:

> *"Problems arise when one has to share transport. May have to spend up to 4 hours travelling and have to travel around the county. Higher risk of picking up infections. I'm prone to chest infections."*

> *"After dialysis, I really don't like waiting for other patients, especially for 45 minutes to an hour before I can go home."*

Findings show that overall, the transport service provided by the HSE is acceptable and meets the needs of patients. Waiting times after dialysis treatment and sharing patient transport with other patients were identified as key concerns, however it is unknown from this data if these concerns are localised to specific dialysis units. The NRO and the IKA will continue to advocate for continuity of governmental financial support for patients who choose to drive to haemodialysis treatments, and ensure adherence to the NRO transport guidance policy related to delivery of high quality non-emergency patient transport for patients unable to drive to treatment.

6. FLUID AND DIET

Fluid intake and management of diet is a central part of dialysis self-management[53], and non-adherence to prescribed fluid and dietary intake can cause significant clinical complications, including electrolyte imbalances, fluid overload, exacerbation of symptoms, reduced quality of life, increased hospital admissions, higher health care costs and higher mortality. Globally, non-adherence to fluid restrictions is estimated as 47%-73%, and 50%-71% for dietary restrictions[54]. Findings presented below outline the patient experience of fluid and dietary advice and food experiences in the dialysis unit.

Overall, 79% of participants reported always receiving clear advice on fluid intake. Advice for diet was slightly lower, with 77% reporting that they had received clear dietary advice. Food and catering received the lowest rating across all areas examined in the survey. Thirty-two percent of hospital / satellite haemodialysis patients regard catering and food provided during treatment hours as excellent. Twenty-nine percent rated catering and food very good, 22% good, 11% fair and 6% poor.

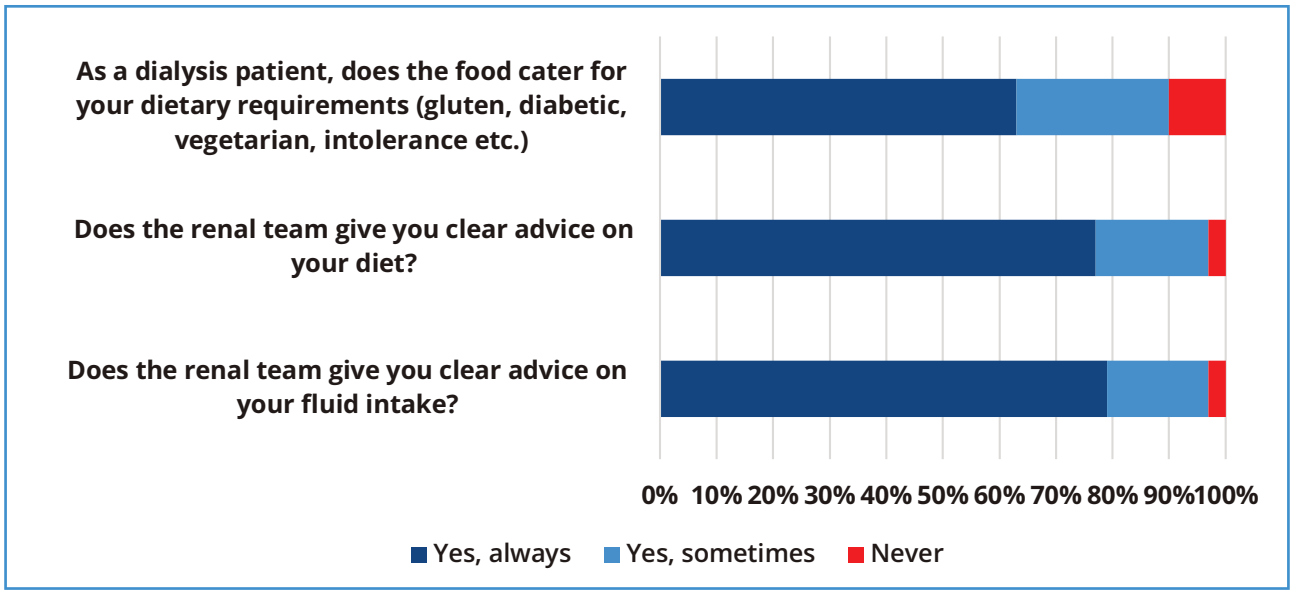
Sixty-three percent reported that food provided during haemodialysis was suitable for their specific dietary requirements, such as diabetes or coeliac disease, and 10% stated that the food provided during their dialysis treatment was not suitable for their specific dietary requirements (Figure 3):

> *"They serve white bread sandwiches only to all patients. It is a big deal to receive brown wholegrain bread. The Dietitian thinks brown wholegrain bread is better for diabetics and renal patients. Although, brown wholegrain bread contains more phosphates, you tend to eat less of it than white bread as it is more filling and the digestive system only absorbs about half the phosphates from it."*

Some patients commented on the limited selection of kidney-friendly sandwiches and suggested providing "less salty sandwiches" and offer more options to patients:

> *"Nothing to eat at treatment centre – only sandwiches which I cannot eat (no variety or kidney friendly options)."*

Figure 3. *Fluid and diet requirements*



While eating during treatment has been associated with dialysis complications and has led to strict in-centre nutrition policies across global dialysis centres[55], poor food intake among haemodialysis patients on treatment days can be a problem for patients if not provided a meal during treatment hours[56]. Provision of hot meals for patients with lengthy travel times was also suggested.

These findings are unsurprising and reflect catering experiences in the wider hospital environment nationally. Findings from the National Patient Experience Survey targeted patients across 40 hospitals and found that the quality of meals and catering services was reported to be a major determinant of care experience in hospitals, and concerns with poor quality meals and limited menus were highlighted[57]. Health Information and Quality Authority (HIQA) recommendations to improve catering services within the general hospital environment are outlined as expanding menu options, inclusion of vegetarian options and healthier vending machine options[57]. Whilst improvement of hospital catering services is outside of the remit of the NRO, the NRO will continue to advocate for an expanded menu for sandwich options and greater consideration of renal dietary requirements. The provision of hot meals is currently not a catering option due to precise regulation and policies regarding hot food preparation in individual hospitals.

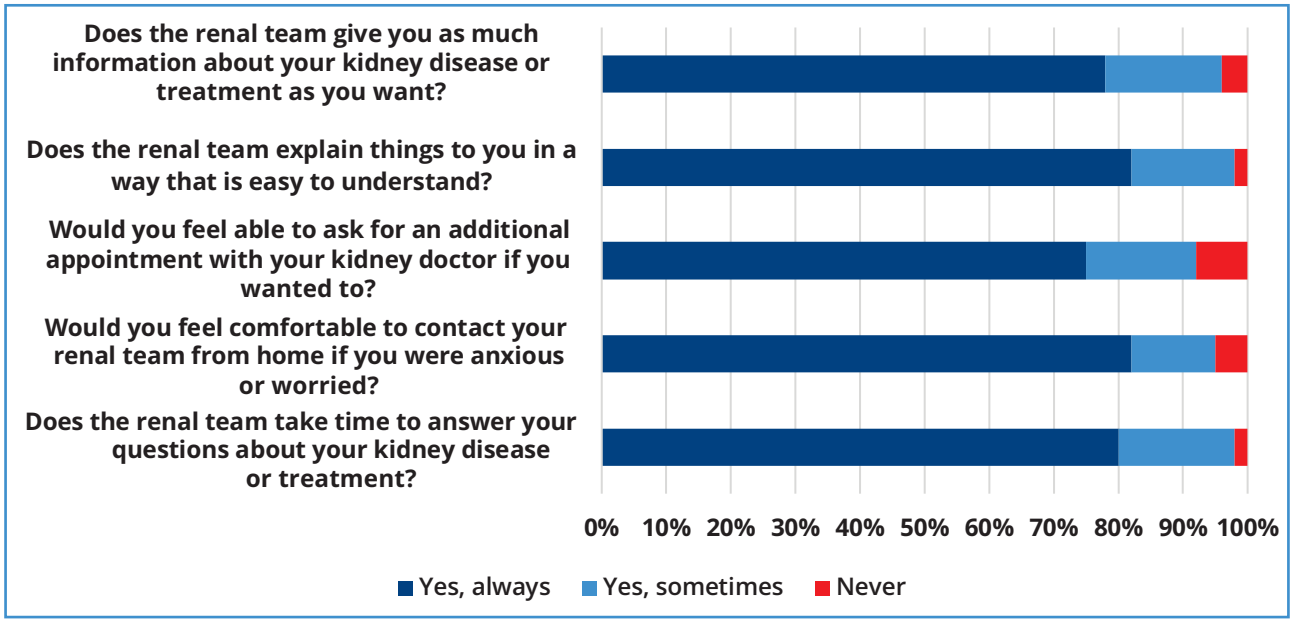
Findings related to provision of advice on fluid and diet management show that nearly a quarter of patients did not receive clear advice related to fluid and dietary restrictions. Further, findings from Section 1 indicated that approximately 11% of haemodialysis patients reported seeing a dietician in the past 12 months. Recent international evidence has suggested that education materials provided by healthcare staff may not increase fluid and diet adherence due over-medicalised language, and the presentation of general guidelines that are not specific to individual patient circumstances[58]. Peer-to-peer education on fluid and dietary restrictions can potentially improve adherence through sharing the lived experience, and provision of strategies to manage fluid and diet challenges[59]. The recently established IKA Peer Support programme, which is delivered by patient volunteers, may have capacity to incorporate fluid and diet mentoring as part of its remit for patient support with living with ESKD[60].

7. ACCESS TO THE RENAL TEAM

Ability to access the renal team was largely positive. 80% of dialysis participants stated that their renal team takes time to answer their questions about their kidney disease or treatment, and 82% of participants reported that the renal team explain things in a way that is easily understood, and would feel comfortable to contact their renal team remotely if they felt anxious or worried about their condition (Figure 4).

Most participants (78%) also reported that the renal team gives them as much information about their kidney disease as they want, and 75% confirmed that they always feel able to request an additional appointment with their doctor if desired.

Figure 4. *Access to the renal team for dialysis patients*



Participants were asked about the aspects of access to care that were most important to them, and 80% rated having a renal unit close to their home and being able to contact their renal team about their care (80%) as very important (Figure 5).

Figure 5. *Important aspects of dialysis care*

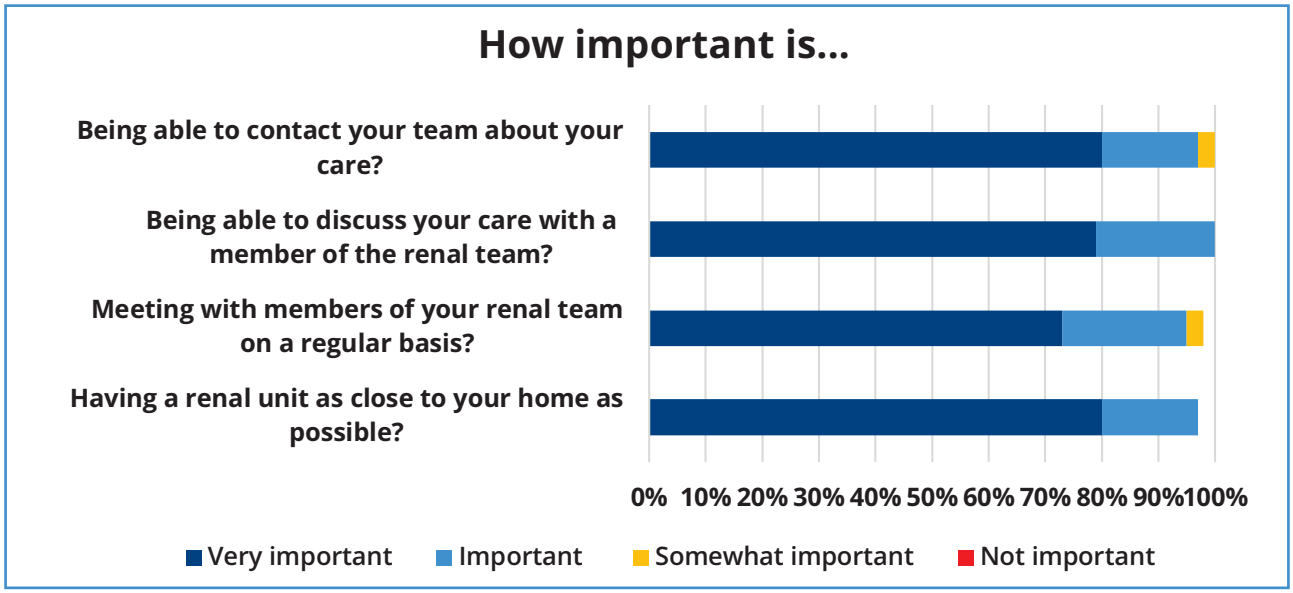
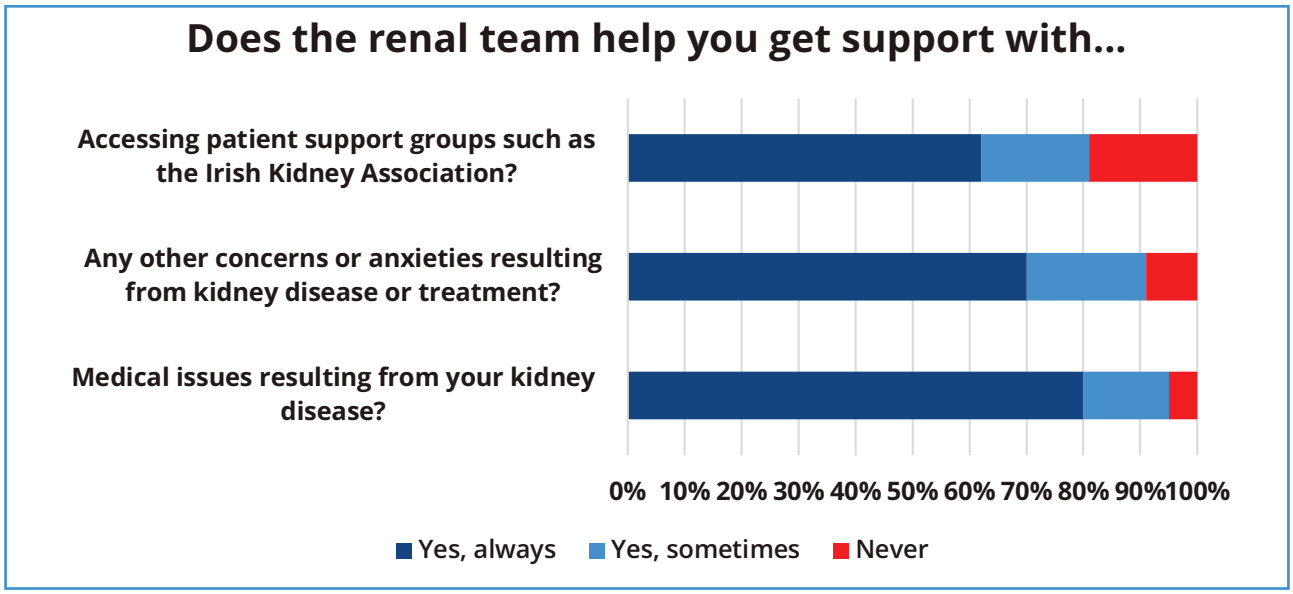
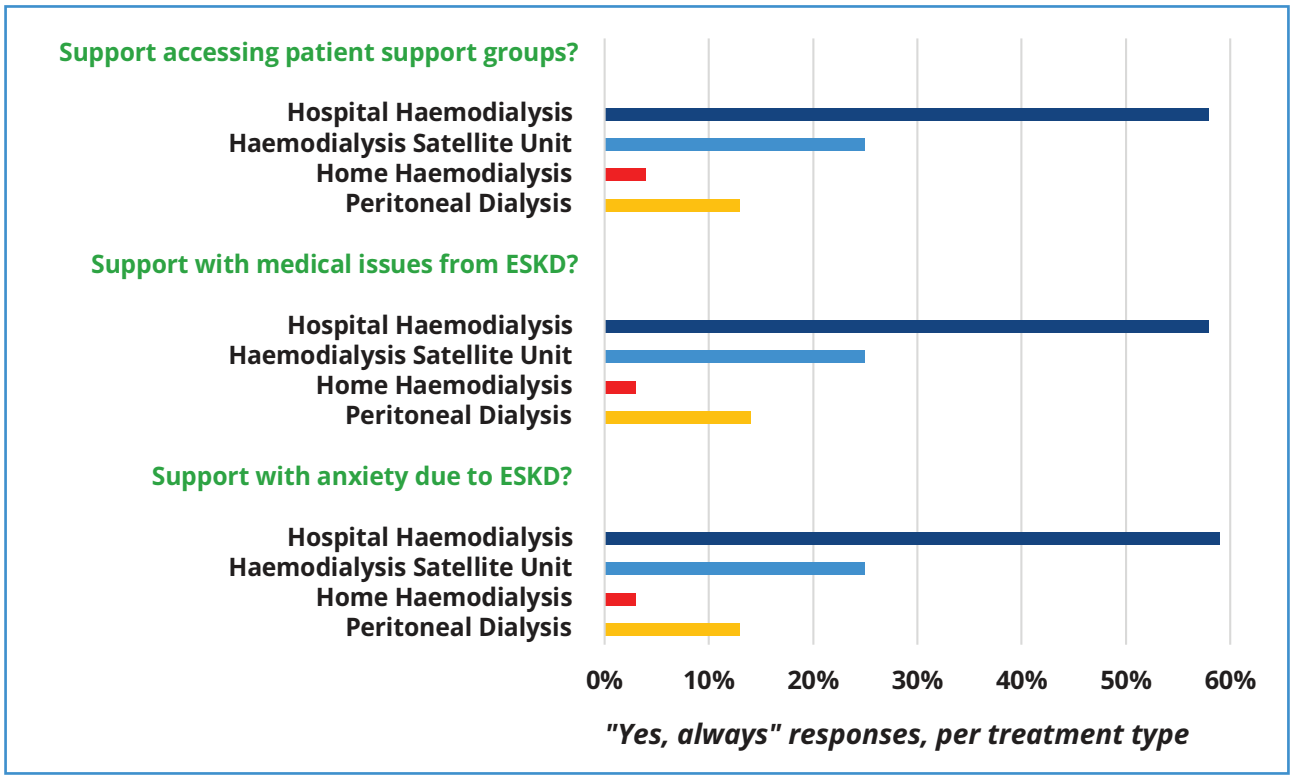


Figure 6. *Provision of support from the renal team for dialysis patients*



Provision of support from the renal team was rated highest for helping patients get support with medical issues resulting from their kidney disease (80%). Support for accessing patient support groups was rated lowest for participants, with 62% reporting that they always receive support with this (Figure 6). Hospital HD patients reportedly received the most support across all dialysis treatment modalities, with HHD receiving the least support (Figure 7).

Figure 7. *Variations in support across different dialysis treatments*

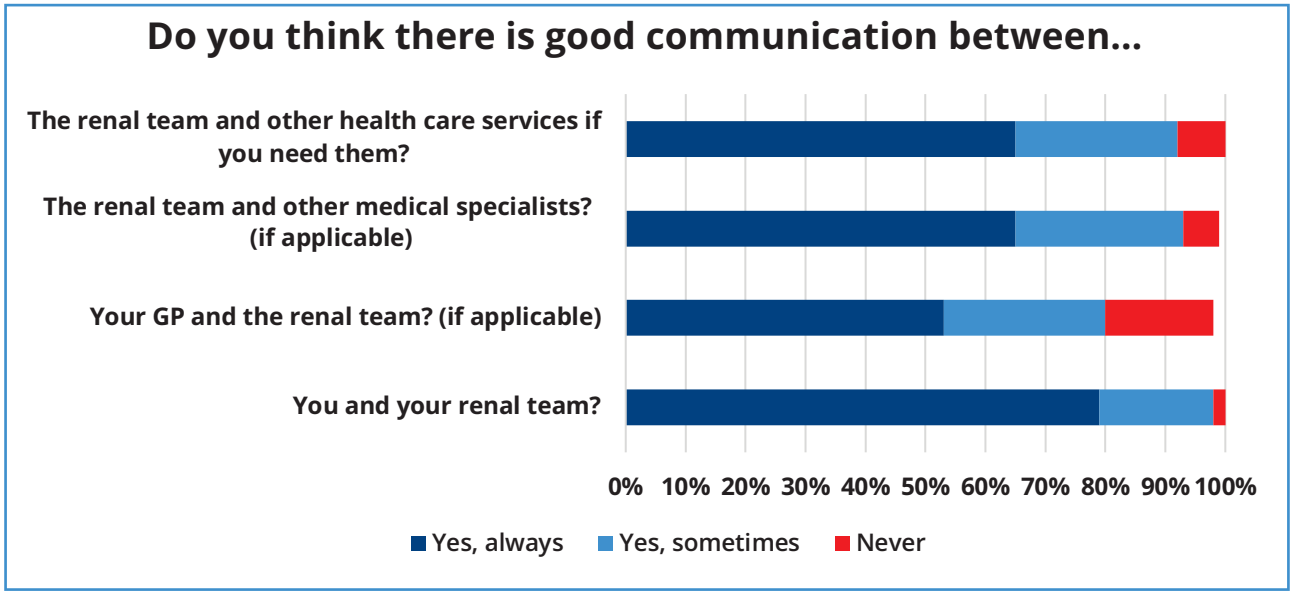


8. COMMUNICATION

Renal patients have complex healthcare needs, and interact with a number of healthcare professionals in differing specialties across primary, secondary and tertiary care. Coordinated collaborative care is required for most patients, and prompt and accurate communication of patient information is a central part of an integrated care pathway[61]. In ESKD treatment internationally, inefficient communication between healthcare providers can be a risk factor for patient safety errors[62]. Findings presented below outline the patient experience of staff-patient and interdisciplinary communication related to the management of their care.

Figure 8 outlines that 79% participants reported that overall they had good communication with their renal team. Sixty-five percent reported good interdisciplinary communication; regular communication between the GP and the renal team was reported as least satisfactory (53%).

Figure 8. *Communication in dialysis care*



Given the central importance of accurate and timely transfer of patient information, findings show that overall, communication between the renal team and other medical specialties / GPs was often suboptimal. Currently in Ireland, a national integrated patient EHR is not available within the wider health system, and thus fragmented communication between healthcare professionals across different specialties is common[63]. Patients expressed the need for an integrated patient EHR that can be accessed by all healthcare professionals involved in their care across specialties, hospital sites and primary care and secondary care.

This systemic failure in the Irish health data landscape has been identified as an area of significant weakness in the Irish health information infrastructure[64], which can negatively impact on quality and safety of healthcare delivery[65].

The ten-year health reform plan, Sláintecare[66], proposes an EHR as a core element of its eHealth pillar[67,68]. However, delays in delivery of this pillar have been documented with no clear timeline for delivery as yet established[69].

Whilst the establishment of an integrated EHR nationally is beyond the jurisdiction of the NRO, accurate, real-time patient data capture is identified as a priority in ESKD care by the NRO, and this is reflected by the NRO management of the national Kidney Disease Clinical Patient Management System (KDCPMS), which provides up-to-date surveillance data from each of the 24 renal units across all Health Regions, and helps to guide service planning by the NRO and HSE.

9. SUPPORTS FOR HOME DIALYSIS (PERITONEAL AND HAEMODIALYSIS)

PD is the second most common form of treatment for ESKD in Ireland, with 237 patients (6% of the total ESKD population) undergoing PD in 2023. HHD is the newest and least common type of treatment for ESKD in Ireland, with 57 patients (1%) receiving haemodialysis at home in 2023. In Ireland, HHD and PD patients can avail of tax relief for financial assistance with providing treatment at home, including reimbursement for electricity, laundry, protective clothing and telephone expenses. Additionally, they can register their household as a vulnerable customer with energy / water providers.

Eight percent of survey respondents were on PD, and 2% were on HHD. Participants were asked if they were aware of these financial assistance measures. Not all patients knew of their right to financial assistance, with 75% aware that they could register their household as a vulnerable customer with energy and water providers.

Findings indicate that when discussing treatment options with HHD and PD patients, there is a need for staff to clarify all available financial supports, and refer patients to appropriate services if necessary, e.g. social work, for additional support with application procedures:

> *"We [wife and I] are not able to get any help on our extremely high bills, I could not manage my dialysis without my wife being there to assist me. My point is whereas, we are doing the hospital's work here at home. We are saving the hospital hundreds of euros. My wife has got carers' allowance, which is a bonus, she was only allowed half an allowance, even though she does almost the nurses job here. This might be a problem with other home dialysis patients, but I haven't spoken to anyone else about this matter. Maybe having a social worker to be the someone to talk on behalf of the patient, would be a good thing."*

HHD and PD offer improved quality of life and reduced hospital attendance to suitable patients[70,71], however globally, financial and reimbursement issues are the most important non-medical factors in deciding to choose home dialysis treatment (HD and PD)[71–74]. Discrepancies also exist for the level of governmental financial support and tax relief available to patients in some form of employment, versus the unwaged / retired patients. International variations have been detected with regards to reimbursement for out-of-pocket costs for home dialysis patients. For example, Denmark provides full coverage for out-of-pocket expenses for home dialysis patients, the United States offers very little[75]. Given the growing prevalence of ESKD in Ireland and the consequent capacity strain on in-centre haemodialysis infrastructure, the promotion of uptake of home dialysis is a key priority for the NRO and IKA in future service planning. Therefore, it is imperative to ensure that financial considerations are not a deterrent. The NRO and IKA will continue to advocate for improved governmental financial assistance, equity of allocation of financial assistance, and equity of access to clinical support for patients choosing home dialysis therapies.

10. OVERALL SATISFACTION WITH CARE

Patient satisfaction with care is an essential measure of quality of care that supports healthcare providers in service assessment and implementation of quality improvement processes. A number of factors contribute to patients' satisfaction with care, including staff-patient factors (e.g. communication skills and responsiveness), service factors (e.g. nutrition, transport, location, parking, safety, environment, equipment, and treatment factors (e.g. mode of treatment, availability, frequency, duration)[76].

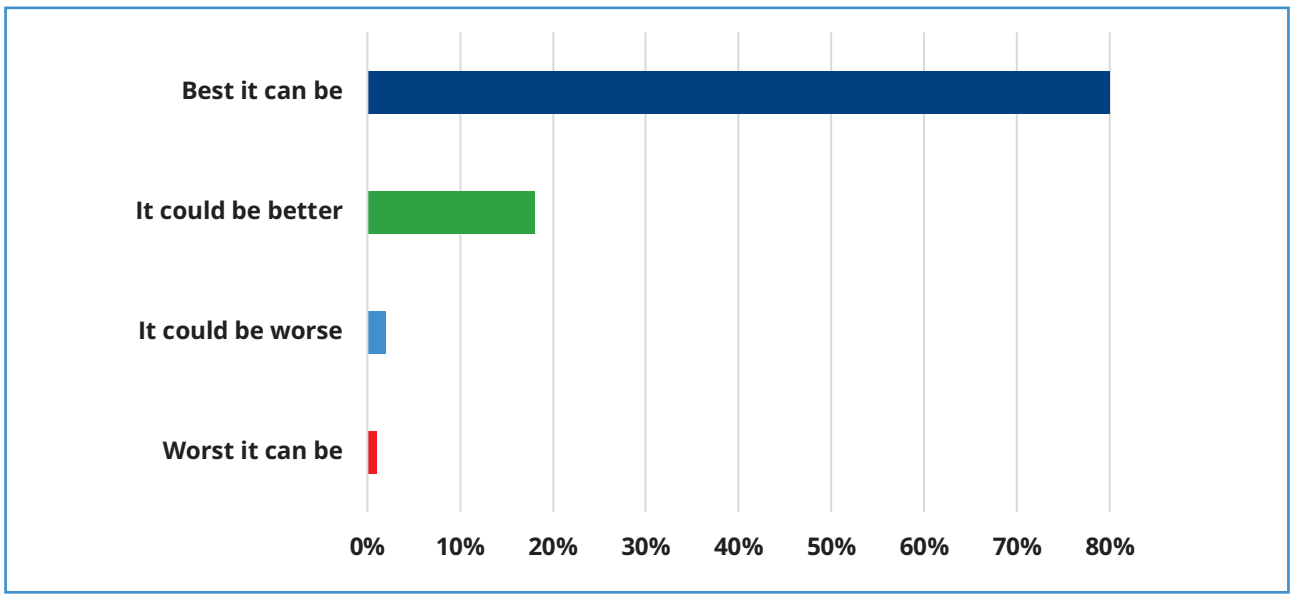
Satisfaction with care can be measured through survey procedures[77], however a common proxy indicator of general patient satisfaction may be provision of feedback and/or complaints from patients. To provide this feedback, patients may either be asked for feedback from unit staff, or be aware of the formal feedback procedure in their dialysis unit.

Findings presented below outline the patient satisfaction rating and awareness of mechanisms for providing feedback on quality of care (Figure 9).

3.9 Satisfaction with overall care

Participants were asked to grade their overall experience of the services provided by their renal unit. Positively, 80% of patients reported that their experience was the best it can be, with only 1% stating that it was the worst it can be.

Figure 9. *Overall rating of care for dialysis patients*



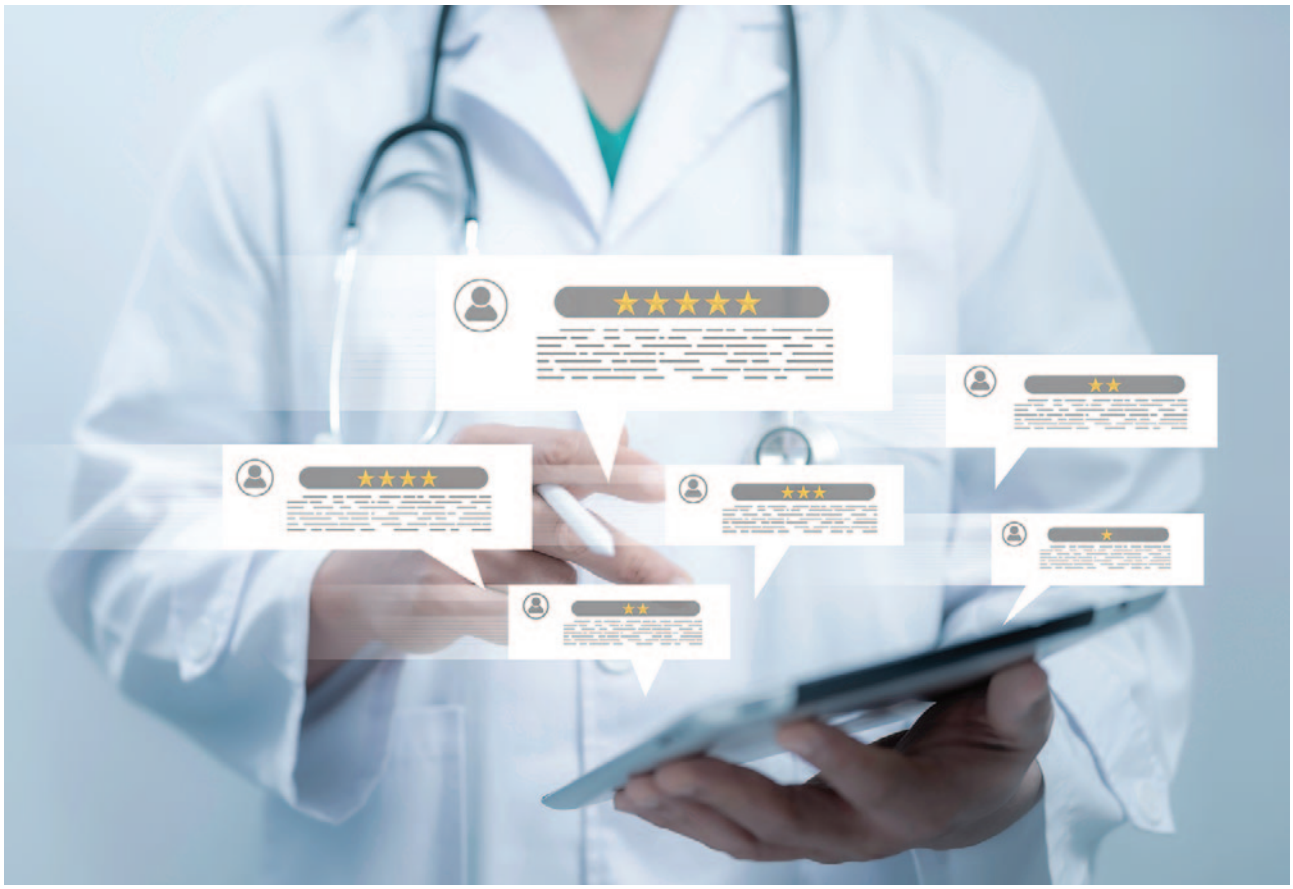
3.10 Provision of feedback

Twenty-seven percent reported that their renal team always asked for feedback regarding their care and treatment. Twenty-eight percent reported that they were sometimes asked for feedback, 20% reported that they were rarely asked for feedback and 25% said they were never asked for feedback.

Forty-three percent of participants were aware of the process for submitting complaints, compliments or general feedback to their dialysis unit and renal team.

The 2022 National Patient Experience Survey reports that 82% of Irish hospital in-patients reported their overall experience as good or very good[78]. Findings here indicate that satisfaction with care provided in the dialysis unit is on par with the national average. Considering that each haemodialysis patient spends approximately 620 hours on haemodialysis yearly, findings show that this standard of care is consistently high over the course of the patient's treatment journey. Additionally, this satisfaction rating is higher than globally reported ratings, with international data from Europe and South America identifying an overall high satisfaction rating of 46.5%[79].

Circulation of regular patient satisfaction surveys at unit and/or national level has logistic and financial challenges, therefore on-site, local provision of feedback is key to understanding the patients' needs and implementing local and national improvement procedures accordingly. Findings here indicate that staff requests for feedback and patient awareness of formal feedback procedures was low. Importantly whilst low, this rating is higher than the national average reported in the 2022 National Patient Experience Survey (26%)[78]. Moving forward, future change management processes by the NRO and IKA can address the need for staff to invite patients to provide feedback, and also signpost patients towards formal feedback procedures.



11. PATIENT COMMENTS ON OVERALL EXPERIENCE OF CARE FOR ESKD

Patients were asked a series of open-ended questions in which they could provide more detail of their individual experiences related to positive aspects of dialysis care, concerning aspects of dialysis care, and suggested improvements to dialysis care. Findings below represent a thematic summary of responses, and largely support the quantitative findings presented in the previous sections of this report. Of note, surveys were anonymous and concerns raised may be localised in some cases, and not representative of the national standard.

3.11 Standard of nursing care

Comments indicated that overall, patients reported that staff, particularly nurses, are highly attentive and caring towards patients. Despite the physical and emotional challenges associated with their dialysis treatment, patients stated that staff do their best to create a positive atmosphere in the unit and make patients feel comfortable during their treatment sessions:

> *"Nurses, Doctors, all health professionals are amazing and have changed my life. When I started dialysis 9 years ago, I didn't want to live, they changed my life, they saved me."*

3.12 Clean dialysis facilities

In conjunction with supportive staff in the units, comments indicated that overall a large proportion of dialysis patients appreciated the cleanliness and general maintenance of the dialysis facilities they attend and how staff remember to wash their hands regularly, when coming into contact with patients:

> *"The place is kept clean to a high standard. The nurses wash their hands before every / any patient contact."*

3.13 Remaining in control for home dialysis patients

Comments indicated that Home PD and HHD patients consider the autonomy they have gained from doing home dialysis as the most positive aspect of their care. Although they must adhere to a treatment schedule, they reported that they can choose their own treatment hours which enables them to continue with their daily lives, hence promoting a sense of control over their treatment:

> *"Home haemodialysis lets you organise dialysis around your life. E.g. if you have a morning appointment you can do dialysis in the evening and vice versa."*

3.14 Areas of most concern for dialysis care

Lack of privacy in dialysis units

Comments indicated that privacy in dialysis units could be improved as there are *"confined spaces between each patient."* Some participants felt that their sense of dignity is diminished when the renal team discuss their private matters in front of fellow patients:

> *"It's crowded leading to lack of privacy. You can overhear other patients discussing their problems."*

Catering provided in dialysis units

Comments indicated that there is a need for better catering services offered in renal units. When offering sandwiches to dialysis patients, a better variety could be provided to patients who must attend dialysis sessions 3 times weekly:

> *"Better choices of food supplied (not just egg or ham - why not tuna or turkey?)"*

> *"Always gluten free egg – never any changes, 3 times every week, I'm starting to get fed up of egg, egg, egg."*

Understaffing in dialysis units

Comments indicated that participants noticed a lack of staff present in dialysis units, commented on high staff turnover rates and the expectation for relief staff to monitor dialysis patients during their treatment sessions:

> *"Staff changes, too many - not trained. Fully relief staff."*

Waiting times and waiting areas

Comments indicated that some dialysis patients regarded waiting areas, waiting times to start treatment and patient transport collection times as aspects of their care in need of improvement.

> *"People being put on before other people when it's not their time. If someone is ill, it's fine but if it happens because people are pushing to get on first, it's annoying!"*

> *"I wish to highlight the waiting area for patients is totally unsuitable, not fit for purpose."*

Poor access to renal doctors during treatment hours

Comments indicated that patients were often dissatisfied with the lack of communication between patients and consultant nephrologists / renal doctors during their treatment sessions. Participants acknowledged the pressures that renal units are under, but commented on the lack of communication between them and their main consultant:

> *"Staff and consultants that forget about you and just let the machine do its thing! Haven't spoken to my consultant in 5 months."*

Similarly, consistent interaction between consultants from different hospital departments or external medical facilities (involved in a patient's care) is also essential according to some patients:

> *"Lack of communication between team and me as a patient as well as between team and my other consultants in both same and other hospitals."*

Increase in electricity use and utility bills due to home dialysis treatments

Comments indicated that governmental financial assistance measures for home dialysis patients are suboptimal, with patients detailing increased household costs associated with their treatment as a compromised component of their care. Despite the freedom they have from being a home dialysis patient, they acknowledged that there are increased costs in their electricity and utility bills (e.g. recycling waste bin) as a result of their home treatment:

> *"Set up time at home. Increased waste (recycling, etc.) no additional supports provided for non-clinical waste."*

> *"Cost of energy - more money should be allocated to home dialysis patients."*

3.15 Suggestions for improving the patient experience of dialysis care

Regular access to a renal doctor during treatment hours

Comments indicated that patients felt that they had limited interaction with their renal team and little to no access to their renal consultant or doctor with renal training when faced with renal-related health concerns whilst on dialysis. It was suggested that patients should have necessary one-to-one access to their renal team while receiving dialysis treatment, ideally in a private and respectable setting when discussing private matters:

> *"An area to be made available where you can discuss your treatment etc. with the renal staff. I think to be sitting on a seat opposite to staff, instead of lying down discussing things with staff standing over you. It can be off-putting."*

3.16 Overall feedback on experience of dialysis care

Overall, dialysis patients portrayed satisfaction towards dialysis care in Ireland and appreciation for the health care professionals who make their renal journey as easy as possible. Gratitude was extended to renal staff in the closing comments and both satellite and hospital units across Ireland were credited for their ability to take care of renal patients:

> *"The staff are very friendly and supportive. Having the same staff on means you can build trust. I always feel safe with them."*

When summarising participant feedback, participants collectively reiterated that improving communication between the patient and their renal team, as well as general communication among medical specialists involved in patient care, could make a positive difference to their healthcare experiences:

> *"Overall I'm well looked after but there is a definite lack of communication between consultants."*

Participants also emphasised that understaffing and under-resourced dialysis units warrant urgent attention, as it is an ongoing issue that can lead to long-term negative effects on the Irish health care system and patient wellbeing:

> *"There is a shortage of renal nurses which puts undue pressure on those who work in the service. An under-served system working constantly at capacity – it is only a matter of time before something goes terribly wrong. A viable recruitment plan is needed."*

A minority of dialysis patients reported difficulty accessing support for holiday arrangements within Ireland and abroad, concluding that they would like the option of booking a holiday, permitted they can get dialysis organised before travelling:

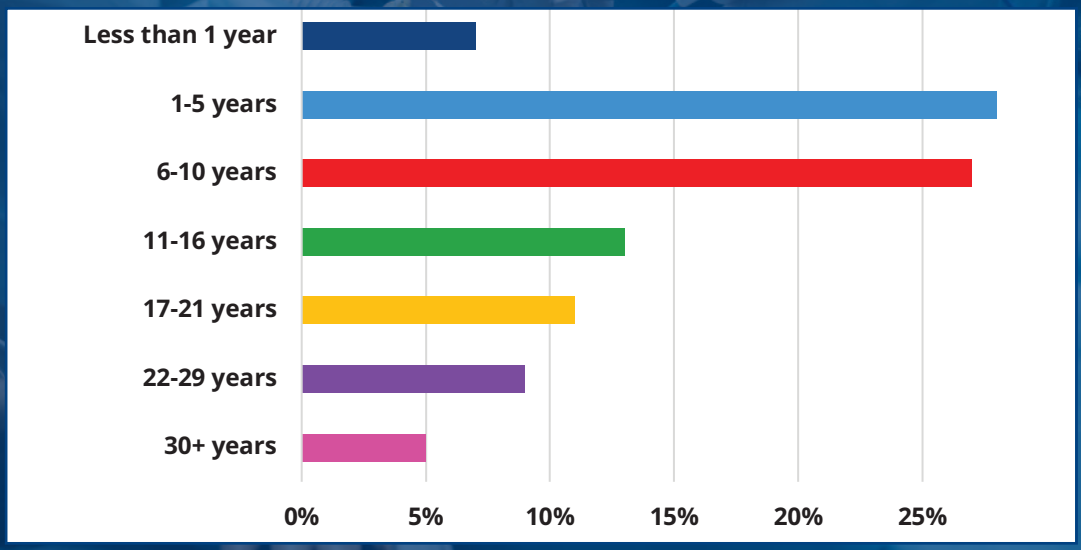
> *"At home dialysis works well. In centre dialysis is totally broken and needs new ideas, life and flexibility injected into it to try to improve the lives of patients in centre. Holiday dialysis is a joke and something major needs to be done so that patients can get a holiday. The stress of dialysis is enormous and in centre support / for light activities while on the machines needs to be supported as well as a holiday."*

SECTION 2:

THE TRANSPLANT PATIENT EXPERIENCE

Thirty-one percent of the total survey participants were patients with a functioning kidney transplant, representing 19% of the total ESKD transplant population in Ireland in 2023. Mean length of time since transplant was 3.42 years. Twenty-eight percent of transplant participants had their transplant for 1-5 years, followed by 6-10 years for 27% of transplant participants.

Figure10.*Transplant duration of transplant recipients*



Participants were asked about their experiences of post-transplant care in the transplant clinic across a number of specific domains. Results for each domain and comparisons with dialysis patients are presented in the following sections.

1. HEALTHCARE PROFESSIONALS INVOLVED IN PATIENT CARE

As with dialysis patients, multidisciplinary healthcare post-transplant is required to ensure optimal recovery and preservation of organ function[80]. Table 6 presents data from 309 transplant recipients relating to the various healthcare professionals that patients reported were involved in their care in the previous 12 months, with Consultant Nephrologist / Renal Team Doctor reported as the most frequent (99%), followed by GP (75%) and Pharmacist (65%). Least frequent involvement was reported for Physiotherapist, Social worker and Psychologist / Counsellor.

Table 6. *Healthcare professionals involved in transplant patient care in previous 12 months*

	N	%
Consultant Nephrologist/Renal Team Doctor	305	99%
GP (General Practitioner)	233	75%
Clinical Nurse Manager	130	42%
Renal Nutritionist/Dietician	66	21%
Dermatologist	125	40%
Physiotherapist	40	13%
Pharmacist	202	65%
Social worker	4	1%
Diabetes specialist	38	12%
Phychologist/Counsellor	14	5%
None of the above	0	0%

There was a difference in healthcare professional involvement between dialysis and transplant patients. Unsurprisingly, transplant patients had 15% higher involvement with their GP, as post-transplant care has significant primary care involvement. Pharmacy involvement was 13% higher for transplant patients (65%) as compared to dialysis patients (52%), which reflects the importance of correct medication adherence to immunosuppressants to prevent organ rejection[22]. Use of dermatology services was suboptimal among transplant recipients (40%), considering patients have an increased skin cancer risk post-transplant[81,82].

Involvement from allied health professionals was reported as higher than dialysis patients, however was still low. Twenty-one percent of transplant recipients received support from a renal nutritionist / dietician as part of their post-transplant care as compared to 11% of dialysis participants. Similarly, 13% of transplant recipients availed of a physiotherapist in the last 12 months compared to 2% of dialysis patients. Involvement of a social worker was lower for transplant recipients (1%), as compared to 8% of dialysis participants. Involvement from a psychologist / counsellor remained relatively low among both transplant and dialysis patients, 5% and 10% respectively.

Participants were asked about what other services they thought should be made available to them, and analysis of free-text comments identified the following services:

continued...

3.17 Access to psychological support post-transplant

Patients felt that psychological / counselling services should be offered to transplant recipients as there can be an excessive focus on physical health. Patients reported that there is poor awareness of both the psychological impact of living with kidney failure and the significance of transitioning from dialysis to transplantation, especially for those who have spent several years on dialysis and adhering to dialysis-related restrictions before receiving a transplant and living a dialysis-free life:

> *"I think therapy or counselling would be really beneficial to those on dialysis or post-transplant or anywhere along the journey of kidney disease. I think it's important to talk to someone about every aspect of the kidney transplant, especially at a younger age."*

Underlying mental health disorders do not change following kidney transplantation, and further mental health difficulties may arise if the transplant is not working well, or patients face the possibility of returning to dialysis. Additionally, emotional and/or psychological problems reportedly have the biggest impact on quality of life post-transplant[83]. Internationally, it is recommended that standardised mental health assessments are completed post-transplant in order to identify mental health challenges, promote patient autonomy, and help patients to manage adherence to medication and the adoption of more appropriate lifestyles post-transplant[84–86].

3.18 Exercise programmes post-transplant

Following a healthy lifestyle, including exercise, proper diet and weight reduction is a central part of post-transplant care[86]. In this survey, transplant recipients also reported an interest in accessing renal-friendly exercise programmes / classes as well as a desire to have frequent interaction with a physiotherapist. Participants outlined that from their time on dialysis, they lost muscle mass and since being transplanted would like improve their mobility and build strength. However, more support is needed to help transplant recipients achieve this goal:

> *"I think that in the immediate aftermath of a transplant patients should be offered a plan to regain fitness. Much physical fitness is lost during end stage renal disease and patients are often nervous and unsure about exercise as they recover."*

3.19 Financial support with post-transplant care

Transplant patients currently without a GMS card suggested that they should be granted a GMS card without means testing to manage their complex lifelong condition. It is imperative that ESKD patients, including kidney transplant patients are recognised to be living with a long-term illness and this remains an ongoing problem for kidney transplant patients. Currently, ESKD is not listed as part of the Long Term Illness Scheme and this can cause significant financial hardship for post-transplant patients given lifelong medication costs and costs of healthcare use:

> *"The lack of recognition that kidney disease / transplant is not recognised as a long-term illness by the government and all the costs associated with being ill."*

Long-term immunosuppressant medication use substantially increases the risk of skin cancers post-transplant. Transplant patients have up to a 100-fold[87] increased risk of several types of skin cancers[88–90], and up to 50% of patients have recurrent skin cancers[81], thus a crucial part of the self-management process requires the use of daily high-quality sunscreen. Although 100% of transplant patients were aware of the importance of daily sunscreen use post-transplant, 25% of patients sometimes or never wore sunscreen, with cost highlighted as a barrier to daily use. Participants requested that the cost of high quality sunscreen should be covered on the Primary Care Reimbursement Scheme similar to post-cancer patients[91], as financial cost has been identified as a significant deterrent to post-transplant sunscreen compliance:

> *"Sunscreen should be on the GMS card as it is a critical part of our on-going care and management of kidney transplant."*

3.20 Access to post-transplant dietary advice

International clinical practice guidelines for post-transplant care advise that patients follow a healthy diet which minimises the intake of saturated fat, sugar and salt[85,86], and suggest that patients should have access to dietary advice post-transplant. Not all transplant patients have access to a renal dietician if needed, and they suggest that for patients who are anxious about their diet and/or weight management, referral to a dietician would be prudent.

> *"I think I should have seen a dietician to explain diet after transplant and given proper instructions. I wasn't and I was eating the wrong food ended up back in hospital with very high potassium."*

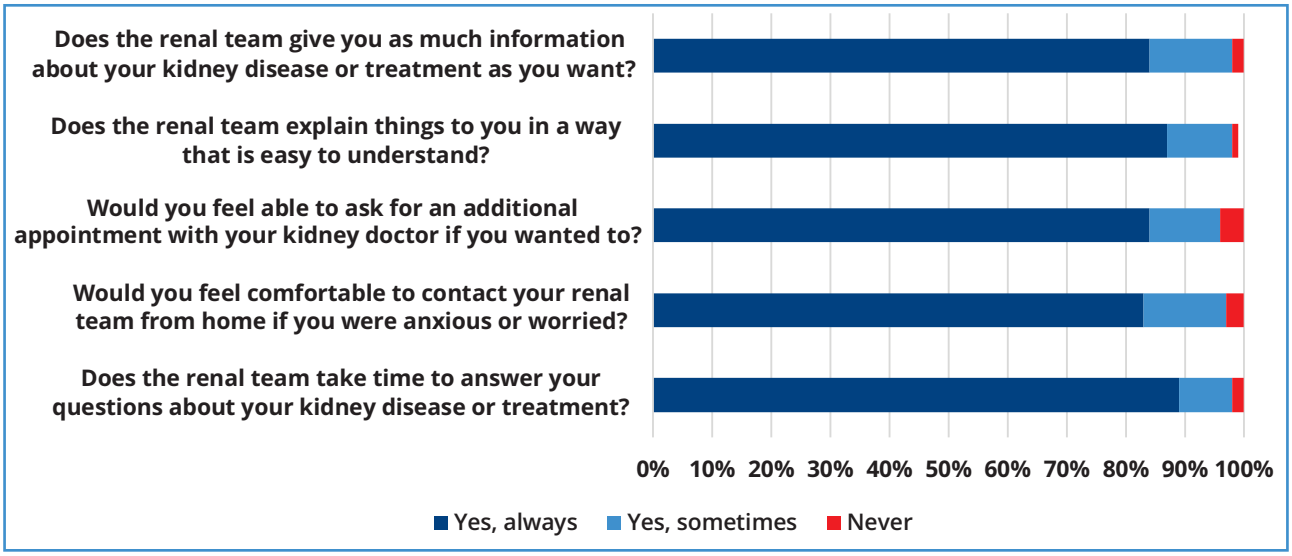
2. ACCESS TO RENAL TEAM

International guidelines for post-operative and long-term care for transplant patients outline that a patient-centred model of care should be facilitated, and patients ideally should have open access to an established point of contact within the renal service[85,86]. Guidelines also state that patient education is a crucial element of care. Transplant patients do not have the same frequency of interaction with renal staff as dialysis patients, therefore appropriate expertise on correct self-management is necessary. Findings below outline the patient experience of ease of access to their renal team post-transplant.

Over 89% of participants reported good access to their renal team overall for post-transplant care (Figure 11). Results for access to the renal team were similar among dialysis and transplant recipients. Transplant patients reported that the renal team take time to answer their questions about their kidney disease and 83% would feel comfortable to contact their renal team remotely if anxious or worried.

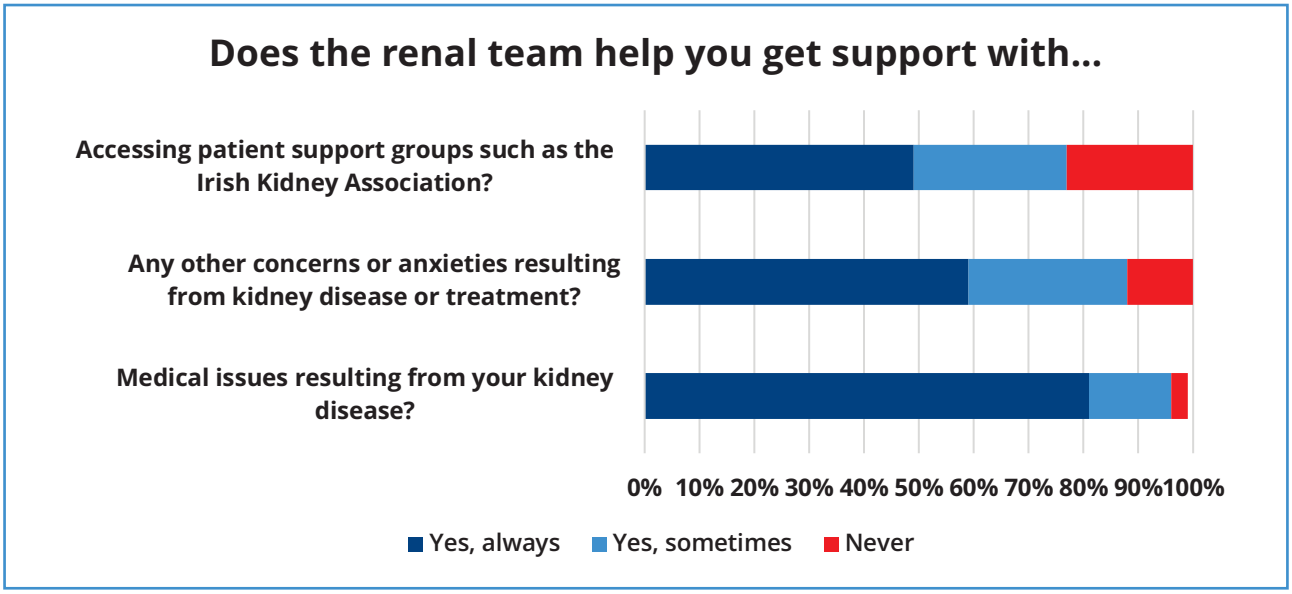
Participants were asked about the provision of information to them related to their care. Overall, 87% of transplant participants reported that the information provided was explained in a way that is easy to understand for participants and 84% reported that their renal team give them as much information about their kidney disease treatment as they want. These findings were similar to the dialysis cohort.

Figure 11. *Access to the renal team for transplant patients*



Provision of support from the renal team was rated highest for medical issues resulting from kidney disease (81%). Support from renal staff with accessing patient groups, such as the IKA, was rated lowest for participants, with 49% reporting that they were signposted to appropriate patient support groups (Figure 12). These findings were slightly different to the dialysis cohort where almost two thirds reported that they get help accessing patient support groups (62%).

Figure 12. *Provision of support from the renal team for transplant patients*

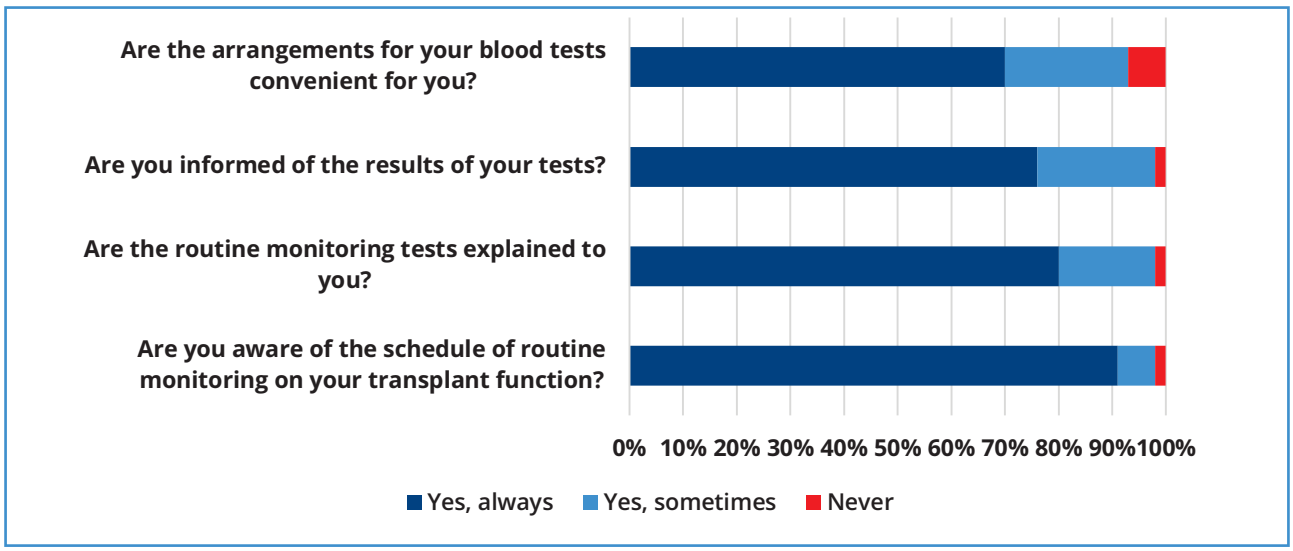


3. OUTPATIENT CARE – TESTS, APPOINTMENT SCHEDULING AND PLANNING

Post-transplant care involves lifelong attendance at transplant clinics, with frequency dependent on length of time since transplant and overall health and transplant function. International guidelines outline that patients should have ready access to their test results, in either written or electronic format (or both)[85]. This promotes patient-centred care and gives patients autonomy to successfully manage their conditions and make appropriate lifestyle adaptations.

Figure 13 shows that overall, participants reported satisfaction with routine monitoring tests as part of their post-transplant care. Participants' awareness of the schedule of routine monitoring for their transplant function was rated highest (91%), and rated the convenience of arrangements for blood tests as lowest in terms of overall satisfaction (70%).

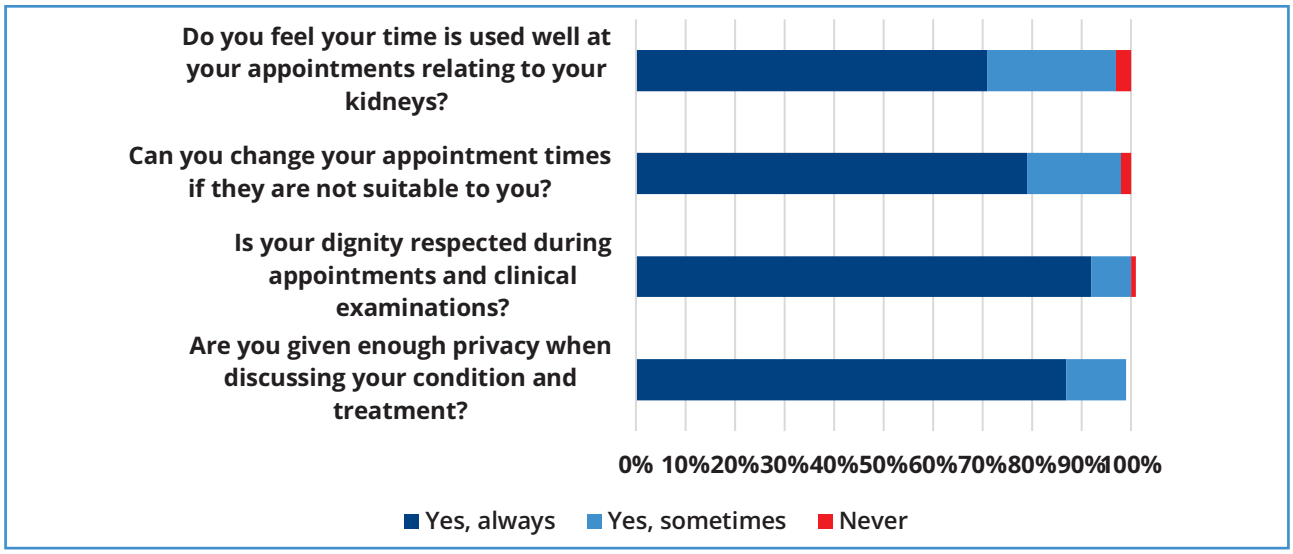
Figure 13. *Blood test arrangements for transplant recipients*



Currently in Ireland, a novel self-monitoring mobile phone app supported by an Advanced Nurse Practitioner in Beaumont hospital is available to newly transplanted patients. This app facilitates access to updated test results, allows patients to record their weight and blood pressure, and receive tailored, individualised same-day feedback on blood test results and medication dose alterations. Currently, this app is offered to all patients with an approximate 80% uptake rate, and has significantly reduced the number of out-patient clinic appointments during the acute post-transplant period.

Seventy-nine percent of participants reported satisfaction with the appointment re-scheduling process, and overall, felt that the time was well used at their outpatient appointment (Figure 14). In the out-patient clinic environment, participants reported satisfaction with the level of privacy given to them during appointments (87%). Importantly, they reported that they felt their dignity was respected when attending an out-patient clinic (92%).

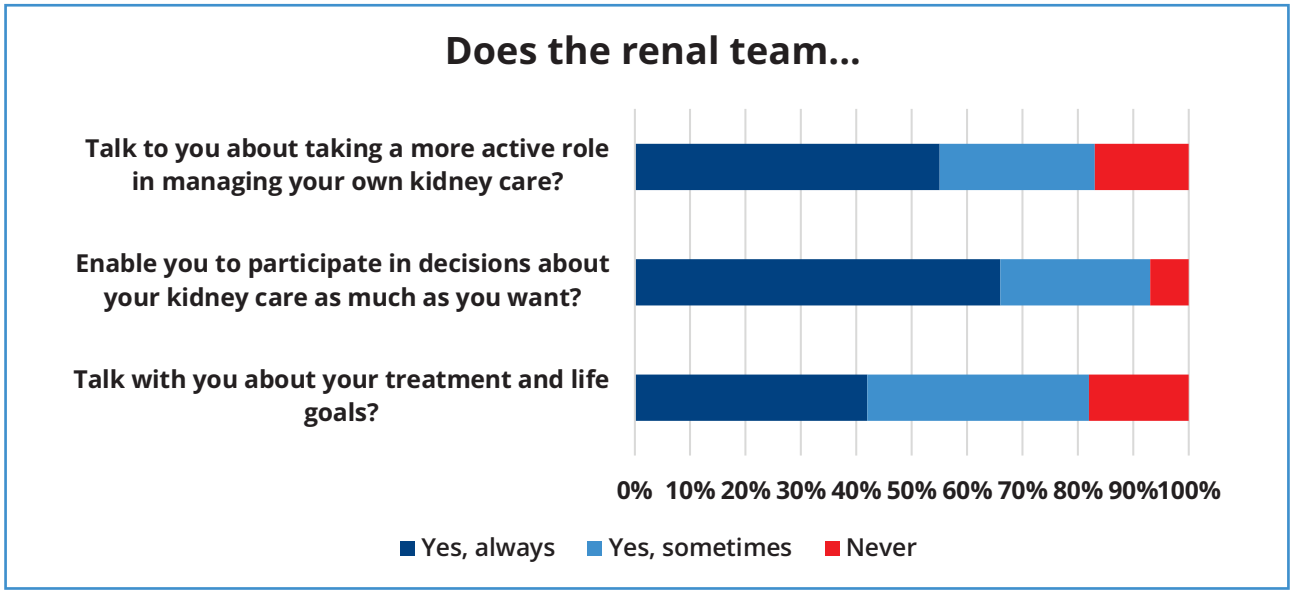
Figure 14. *Privacy, dignity and appointment scheduling for transplant patients*



4. DECISION-MAKING AND PARTICIPATION IN SHARED CARE

As outlined in sections above, patient-centred care and promotion of patient autonomy through shared decision making is imperative for long-term prevention of organ rejection[92], and is associated with improved patient outcomes and increased quality of life[85,93]. Participant responses were positive overall in relation to engagement in shared decision making for their post-transplant care, particularly for their renal team enabling them to participate in decisions about their kidney care as much as they want (66%). Talking to transplant recipients about their treatment and life goals and taking a more active role in managing their own kidney care was rated lowest as 18% reported that their renal team never speak about this (Figure 15).

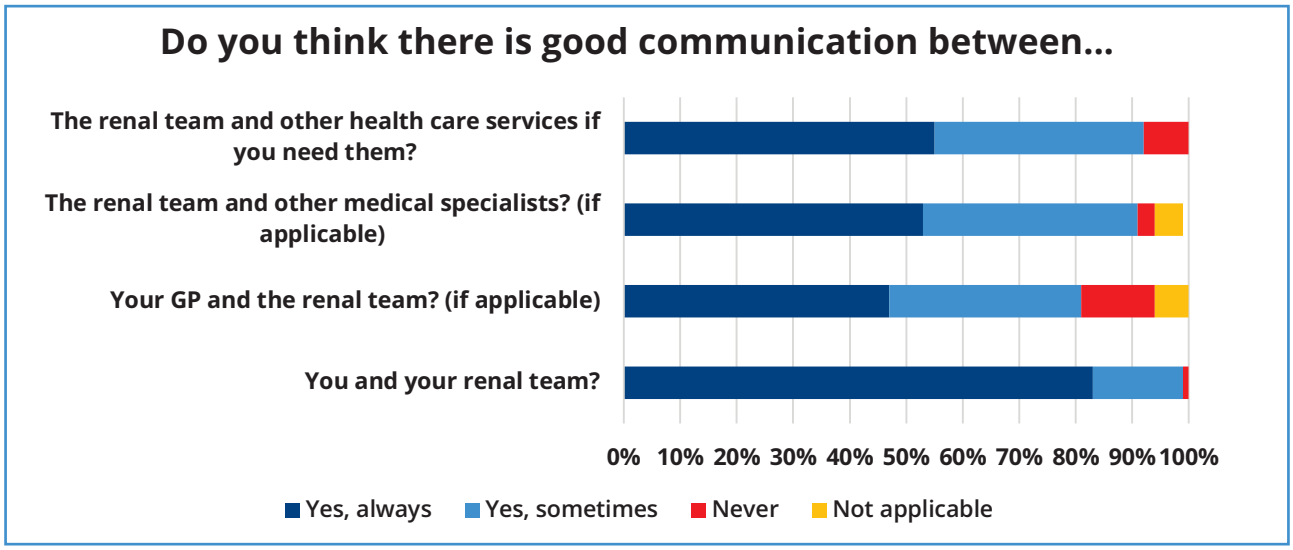
Figure 15. *Promoting self-management among transplant patients*



5. COMMUNICATION

As with dialysis patients, post-transplant status is considered a complex chronic condition, and involves multidisciplinary, coordinated collaborative care across primary, secondary and tertiary care, in addition to communication between the transplant patient and their healthcare provider (Figure 16). Overall, 83% participants reported that they had good communication with their renal team. Regular communication between the GP and the renal team was reported as least satisfactory (47%).

Figure 16. *Communication in transplant care*



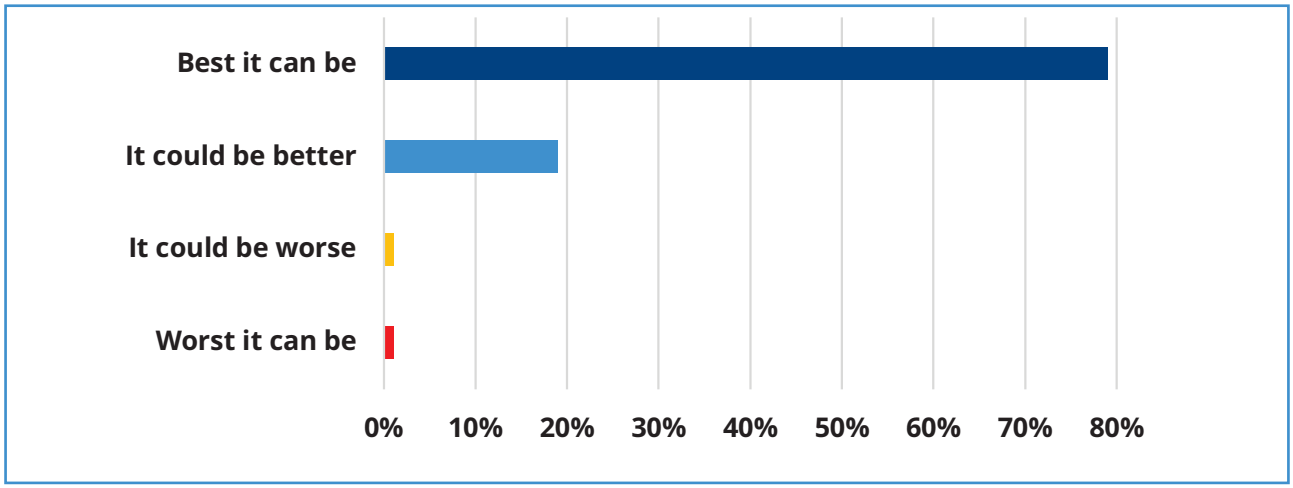
6. OVERALL SATISFACTION WITH CARE

3.21 Satisfaction with overall care

Similar to patient satisfaction with dialysis care, the measurement of patient satisfaction for individuals with a kidney transplant serves as an indicator of the quality of clinical care, and can guide implementation of future service changes. Internationally, transplant patients report higher levels of health-related quality of life as compared to dialysis patients[94,95], chiefly related to the ability to be more active and return to a sense of normality in life[96].

Participants were asked to grade their overall experience of the post-transplant service. Positively, 79% of patients reported that their experience is the best it can be, which is similar to 'best it can be' ratings for the dialysis cohort (80%).

Figure 17. *Overall rating of care for transplant recipients*



Similar to the overall rating of care by the dialysis cohort, the overall rating of care by transplant patients matches the national average of 82% for the Irish inpatient population, as reported in the 2022 National Inpatient Experience Survey[78].

7. PATIENT COMMENTS ON OVERALL EXPERIENCE OF POST-TRANSPLANT CARE

Patients were asked a series of open-ended questions in which they could provide further detail on their individual experiences related to positive aspects of post-transplant care, concerning aspects of post-transplant care, and suggested improvements to post-transplant care. Findings below represent a thematic summary of responses, and largely support the quantitative findings in the previous sections.

3.22 Positive aspects of post-transplant care

Having a supportive renal team

In comments provided, transplant participants reported positive feedback regarding their post-transplant care. Several participants mentioned that they feel listened to and supported by their renal team:

> *"I receive fantastic renal care from my renal team. Depending on the doctor, I am always heard and listened to and or if I have any concerns. I feel they don't get the credit they deserve. There is never a service that is perfect but they are compassionate and supportive of their patients. They listen and understand and are very accommodating towards their patients."*

Having access to the renal team

Recently transplanted participants in particular, stated that they have easy access to their renal team which brings comfort to them when they feel worried or uncertain about their health:

> *"There is always someone at the other end of a phone call if I am worried, even at weekends."*

Comments indicated that transplant recipients felt that they are kept informed about their renal health and updated on any test results. When changes occur, the renal team liaise with them and refer them to other medical specialists if necessary:

> *"I am always informed of how my blood results and overall health of my kidney are going. And any changes that may benefit me would be discussed."*

3.23 Areas of most concern for post-transplant care

Lack of communication on post-transplant medication side-effects

Comments highlighted that some transplant participants stated that they were not informed about the possible medication side-effects that they dealt with post-transplant, which significantly impacted their quality of life:

> *"No mention of other side effects that are not as common. i.e. itch and hair loss."*

Fewer appointments post-transplant

Comments highlighted that the decrease in clinical visits post-transplant was a concern for some transplant recipients as they would like more contact with their renal team to discuss their progress:

> *"After the initial clinics post-transplant, the clinics move out to 6 months and during which time anything can happen, I'd prefer the clinics were more frequent."*

Engaging with new doctors and difficulty arranging blood tests

Comments indicated that for some transplant recipients, the reduced frequency of appointments means that they can often see doctors with varying renal knowledge and experience with transplant patients:

> *"I see a different doctor every time... sometimes the new doctors have very little renal knowledge."*

> *"Choose preferred consultant and not given any doctor or someone from team. That way it limits the time having to reintroducing yourself and your history to new people."*

Additionally, arranging blood tests and receiving results in a timely manner can be a cumbersome experience for longer-term kidney transplant recipients:

> *"The most thing I would change is the system for taking bloods. There can be a lot of queueing and waiting and confusion over who is next in line etc. Also, blood results come back a couple of days after the appointment. It would be great to be able to discuss today's blood tests at today's appointment. I think it would offer more peace of mind leaving the clinic."*

3.24 Suggestions for improving the patient experience of post-transplant care

Easier access to test results

To improve the patient experience of post-transplant care, longer-term transplant participants suggested that healthcare providers permit blood samples to be taken by their GP as they must attend over-occupied clinics and wait a long time to see a consultant. Furthermore, it could be made easier for them to access their test results either through a mobile app / online similar to newly transplanted patients, or by receiving feedback from their consultants within a swifter timeframe, as they reported that attending the post-transplant clinic and waiting for their test results is disorganised and onerous:

> *"Waiting around all morning in the renal day ward for blood results and to see the team is distressing."*

Online consultations and education sessions

Transplant recipients suggested that some of their appointments could be done online or over the phone, as was facilitated during the COVID-19 pandemic. This would save them time travelling and reduce the number of hours they spend waiting in clinics / hospitals:

> *"It would be great if the hospitals did some online appointments on zoom / MS teams for long-term transplants. After all they did manage to do phone appointments during the pandemic. I find it hard as a working transplant patient to juggle the appointments in person."*

After receiving a transplant and adjusting to their new way of life, transplant participants suggested providing more information to them on different aspects of their care, including details on post-transplant medications. Transplant participants also proposed that education sessions could be held to educate them and their families about post-transplant care:

> *"Family education groups. Even online education sessions."*

Promoting access to psychological support services

Transplant participants suggested that renal staff promote the use of psychological / counselling services. Receiving a kidney transplant is a major milestone for transplant recipients, therefore the need to discuss the psychological impact of adapting to new lifestyle changes may be prominent among this cohort:

> *"I would like to see more support around mental health and support on getting the right balance in relation to work, family and being a transplant recipient. As a transplant patient we do get more fatigue and I often feel that this is disregarded and not spoken about."*

3.25 Overall feedback of post-transplant care

Comments indicated that transplant recipients reported largely positive feedback on their experience of post-transplant care in Ireland. Many transplant participants said that they felt well looked after by their renal team over the years:

> *"Everyone was perfect to me and very helpful. All those people in hospital were so nice to me every time and they are all the best people I've ever met."*

Chapter 4
Conclusion

This was the first national survey of ESKD patients in Ireland and provides the patient perspective on aspects of treatment that are important to them, and where future service advancements may be targeted in order to further expand the delivery of care. Findings also provide a benchmark for measuring the impact of future service developments.

Overall, findings reflect a high degree of patient satisfaction with the majority of important aspects of their care. Patients report an excellent experience of clinical care, cleanliness, communication and overall are treated with dignity, respect and compassion. Patients also highlighted aspects of care that may require attention for further service development. Areas of concern for dialysis patients related to the impact of wider systemic organisational factors, including understaffing and under-resourcing in haemodialysis units and inadequate electronic information system infrastructure. Aspects of concern relating to delivery of patient care in dialysis units include greater access to dietician support and mental health support, privacy in haemodialysis units, and improved variation in catering services. Transplant patients additionally identified the removal of means-testing for free access to care for transplant patients, reinstating the inclusion of the cost of high-quality sunscreens on the Primacy Care Reimbursement Scheme, and improved psychological support as important matters in strengthening post-transplant care.

4.1 Strengths of this research

This is the first national survey of the Irish ESKD population, with participation from all in-centre and satellite haemodialysis units, and representation from the kidney transplant population. This collaboration between the NRO and the IKA enhanced access to both dialysis and transplant cohorts on a national level. Survey development was based on an existing well-established UK PREM survey of kidney patients[25]. The survey was also developed in consultation with patient representatives from the IKA which ensured questions were relevant to Irish patients, and by using PROMs, focused on outcomes important to Irish patients.

4.2 Limitations and recommendations for future research

This baseline national survey was developed to examine aspects of care that the NRO, IKA and patient representatives felt were currently most pertinent to patients, and therefore focused on a limited number of PROMs related to delivery of care for ESKD. Recent best practice guidelines advise the use of extended PROMs to capture the complete picture of the patient experience[17]. Additional survey questions related to social aspects of health, a measure of physical and cognitive function, treatment side effects and health related quality of life are recommended for future waves of this survey[17]. Further, this baseline survey was a cross-sectional, and patient experiences, symptoms, and priorities may evolve throughout the illness trajectory. Capturing PROMs data longitudinally can capture a patient's personal ESKD trajectory[17,31]. As this was the first national survey of ESKD patients in Ireland, data were anonymous and therefore participants cannot be followed longitudinally at this stage of the research programme. It is recommended that future waves of this survey could consider a longitudinal design, to track changes to a patient's experience of care and disease progression over time, which could better guide treatment decisions and continuity of care[97].

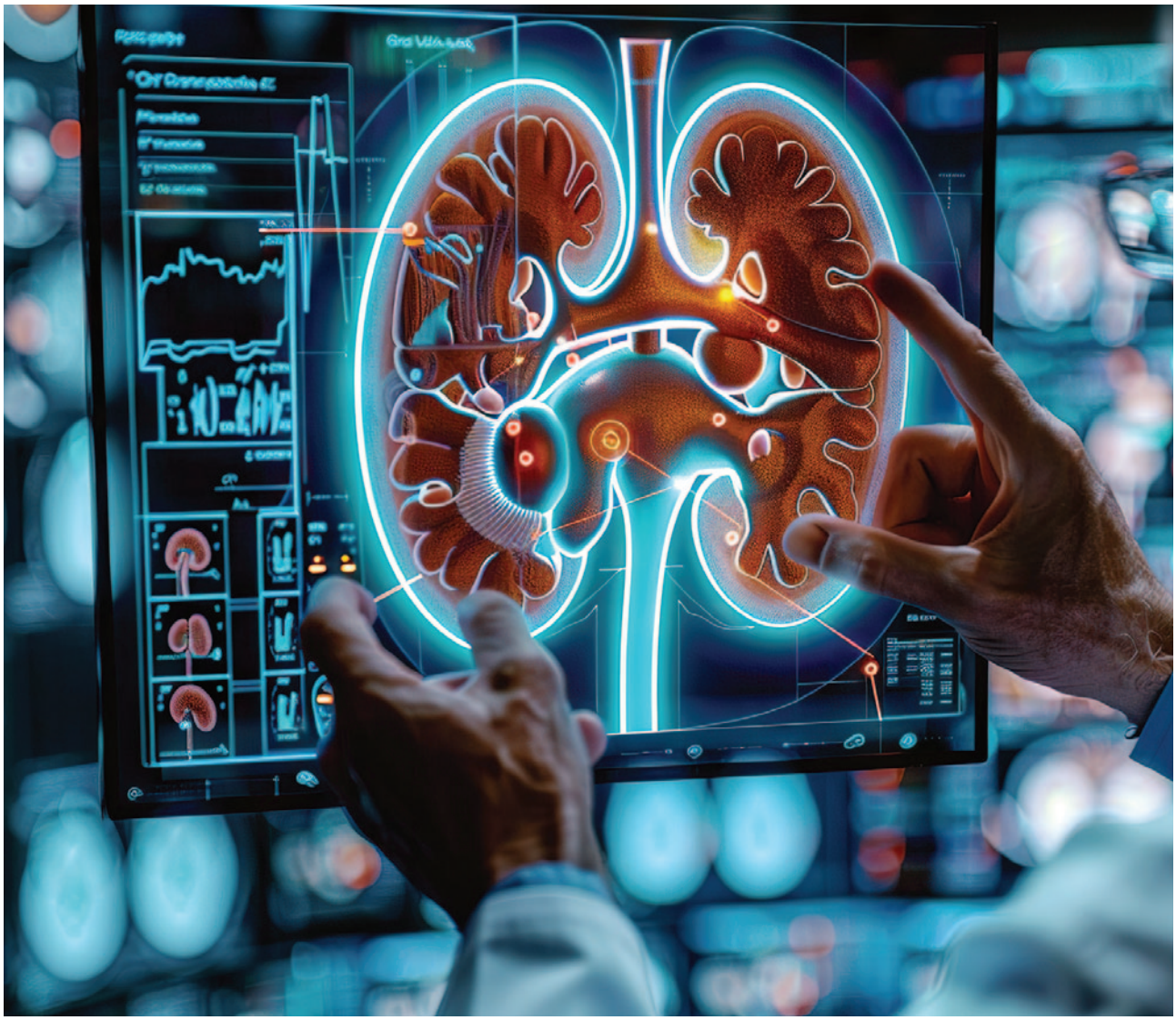
It is also suggested that future research should include focus groups and / or semi-structured interviews with healthcare professionals to gather their opinions on patient-reported experiences. Throughout the findings reported here, renal patients detailed their interactions with healthcare professionals and hospital systems, which could be affirmed or explained by renal specialists who frequently engage with patients.

continued...

4.3 Summary

The NRO and IKA's shared priority is to continually develop the delivery of patient-centred care for persons living with ESKD. This report enabled the identification of areas of excellence and areas of some concern from the patient perspective, and findings should be considered when planning future developments in the delivery of ESKD care. Implementation of recommendations outlined in this report would lead to further improvements in the patient journey, with significant impact on patient outcomes and satisfaction with care.

In addition to guiding service improvements, it is hoped that findings may prompt dialogue between patients and their healthcare professionals to address the psychological and social challenges associated with dialysis treatment and kidney transplantation, and any arising burdens from living with ESKD. By prioritising the patient experience in the delivery of care, healthcare professionals can offer holistic support that addresses the multifaceted needs of those living with ESKD.



References

References

1. Jager KJ, Kovesdy C, Langham R, Rosenberg M, Jha V, Zoccali C. A single number for advocacy and communication-worldwide more than 850 million individuals have kidney diseases. Kidney Int. 2019;1;34(11):1803–5.
2. Kovesdy CP. Epidemiology of chronic kidney disease: an update 2022 (2011). Kidney Int Suppl. 2022;2(1):7–11.
3. Chronic Kidney Disease in community-dwelling adults aged 50+ years in Ireland: A report from TILDA and the National Renal Office: Trinity College Dublin; 2023. Available from:https://www.tcd.ie/search/q/?tcdsearchq=chronic+kidney&tcdsearchcollection=site&tcdsearchsitetitle=The+Irish+Longitudinal+Study+on+Ageing+%28TILDA%29&tcdsearchsitesearch=http%3A%2F%2Ftilda.tcd.ie
4. Stack A, Laird M, Glynn L, Walsh C, Galvin R, Shah S, et al. Mortality differences between men and women with chronic kidney disease in the Irish health system: The National Kidney Disease Surveillance Programme. Nephrol Dial Transplant. 2022;37(Supplement_3):gfac071.046.
5. Hecking M, Hödlmoser S, Ahmed SB, Carrero JJ. The other way around: Living with chronic kidney disease from the perspective of men. Semin Nephrol. 2022;42(2):122–8.
6. Fiseha T, Osborne NJ. Burden of end-stage renal disease of undetermined etiology in Africa. Ren Replace Ther. 2023 Sep 5;9(1):44.
7. Morton JI, Liew D, McDonald SP, Shaw JE, Magliano DJ. The association between age of onset of type 2 diabetes and the long-term risk of End-Stage Kidney Disease: A national registry study. Diabetes Care. 2020;43(8):1788-1795
8. McIntyre CW, Burton JO. Dialysis. BMJ. 2014;348:g2.
9. Ellis P. An overview of haemodialysis. Br J Nurs. 2023;32(8):456-462.
10. Connaughton DM, Jamal A, McWilliams J, O'Kelly P, Ormond J, Butler A, et al. Home haemodialysis in Ireland. Ir J Med Sci. 2013;182(1):91–6.
11. Kennedy C, Connaughton DM, Murray S, Ormond J, Butler A, Phelan E, et al. Home haemodialysis in Ireland. QJM. 2018;111(4):225–9.
12. Andreoli MCC, Totoli C. Peritoneal dialysis. Rev Assoc Med Bras (1992). 2020;66Suppl 1(Suppl 1):s37–44.
13. Augustine J. Kidney transplant: New opportunities and challenges. Cleve Clin J Med. 2018 ;85(2):138–44.
14. Mahendran AO, Veitch PS. Paired exchange programmes can expand the live kidney donor pool. Br J Surg. 2007;94(6):657–64.
15. Organ Donation Transplant Ireland. 2023 annual report. Dublin: Organ Donation Transplant Ireland; 2024. Available from: https://www.hse.ie/eng/about/who/acute-hospitals-division/organ-donation-transplant-ireland/publications/organ-donation-transplant-ireland-annual-report-2023.pdf
16. National Renal Office. Renal Service Report 2024. Dublin: National Renal Office; 2024. Available from: https://www.hse.ie/eng/about/who/cspd/ncps/renal/resources/nro-report-epidemiology-of-eskd-in-ireland-2024.pdf
17. Tang E, Yantsis A, Ho M, Hussain J, Dano S, Aiyegbusi OL, et al. Patient-reported outcome measures for patients with CKD: The case for patient-reported outcomes measurement information system (PROMIS) tools. Am J Kidney Dis. 2024;83(4):508–18.
18. Nair D, Wilson FP. Patient-reported outcome measures for adults with kidney disease: Current measures, ongoing initiatives, and future opportunities for incorporation into patient-centered kidney care. Am J Kidney Dis. 2019;74(6):791–802.

19. Anderson NE, Calvert M, Cockwell P, Dutton M, Aiyegbusi OL, Kyte D. Using patient-reported outcome measures (PROMs) to promote quality of care in the management of patients with established kidney disease requiring treatment with haemodialysis in the UK (PROM-HD): a qualitative study protocol. BMJ Open. 2018;8(10):e021532.
20. Costal Tirado A, McDermott AM, Thomas C, Ferrick D, Harris J, Edwards A, et al. Using patient-reported outcome measures for quality improvement in clinical genetics: an exploratory study. J Genet Couns. 2017;26(5):1017–28.
21. Wheless L, Jacks S, Mooneyham KA, Leach BC, Cook J. Skin cancer in organ transplant recipients: more than the immune system. J Am Acad Dermatol. 2014;71(2):359–65.
22. Mellon L, Doyle F, Hickey A, Ward KD, Freitas DG de, McCormick PA, et al. Interventions for increasing immunosuppressant medication adherence in solid organ transplant recipients. Cochrane Database Syst Rev. 2022; 2022;9:CD012854.
23. Chen T, Wang Y, Tian D, Zhang J, Xu Q, Lv Q, et al. Follow-up factors contribute to immunosuppressant adherence in kidney transplant recipients. Patient Prefer Adherence. 2022;16:2811–9.
24. Jones T, Baxter M, Khanduja V. A quick guide to survey research. Ann R Coll Surg Engl. 2013;95(1):5–7.
25. UK Kidney Association. Kidney Patient Reported Experience Measure (PREM). United Kingdom: UK Kidney Association; 2024. Available from: https://www.ukkidney.org/sites/default/files/106695%20PREM%20report%202023%20FINAL-compressed.pdf
26. Wu MJ, Zhao K, Fils-Aime F. Response rates of online surveys in published research: A meta-analysis. Computers in Human Behavior Reports. 202;7:100206.
27. National Renal Office. Epidemiology of ESKD in Ireland 2023: Provision of kidney replacement therapy in Ireland - 2022 update - prevalence and growth. Dublin: National Renal Office; 2023. Available from: https://www.hse.ie/eng/about/who/cspd/ncps/renal/resources/nro-report-epidemiology-of-eskd-in-ireland-2023.pdf
28. Collister D, Pyne L, Cunningham J, Donald M, Molnar A, Beaulieu M, et al. Multidisciplinary chronic kidney disease clinic practices: A scoping review. Can J Kidney Health Dis. 2019;6:2054358119882667.
29. Abe M, Hatta T, Imamura Y, Sakurada T, Kaname S. Inpatient multidisciplinary care can prevent deterioration of renal function in patients with chronic kidney disease: a nationwide cohort study. Front Endocrinol. 2023;14:1180477.
30. Cogley C, Bramham J, Bramham K, Smith A, Holian J, O'Riordan A, et al. High rates of psychological distress, mental health diagnoses and suicide attempts in people with chronic kidney disease in Ireland. Nephrol Dial Transplant. 2023;38(10):2152–9.
31. Hussein WF, Bennett PN, Abra G, Watson E, Schiller B. Integrating patient activation into dialysis care. Am J Kidney Dis. 2022;79(1):105–12.
32. Wilkie M, Barnes T. Shared hemodialysis care. Clin J Am Soc Nephrol. 2019;14(9):1402–4.
33. Fotheringham J, Barnes T, Dunn L, Lee S, Ariss S, Young T, et al. Rationale and design for SHAREHD: a quality improvement collaborative to scale up Shared Haemodialysis Care for patients on centre based haemodialysis. BMC Nephrol. 2017;18(1):335.
34. Fotheringham J, Barnes T, Dunn L, Lee S, Ariss S, Young T, et al. A breakthrough series collaborative to increase patient participation with hemodialysis tasks: A stepped wedge cluster randomised controlled trial. PLoS One. 2021;16(7):e0253966.
35. Begum N, Donald M, Ozolins IZ, Dower J. Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes. Diabetes Res Clin Pract. 2011;93(2):260–7.

36. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. Health Aff. 2015;34(3):431–7.
37. Lockridge R, Weinhandl E, Kraus M, Schreiber M, Spry L, Tailor P, et al. A Systematic approach to promoting home hemodialysis during End Stage Kidney Disease. Kidney360. 2020;1(9):993–1001.
38. Irish Kidney Association. Shared Haemodialysis Care - Can it help you? Available from: https://ika.ie/2022/10/shared-haemodialysis-care-can-it-help-you/ [Accessed 26 Jul 2024]
39. Drummond L, Guiney S, Connolly D, Foley C, O'Connor L, O'Carroll T, et al. Experiences of shared decision making in acute hospitals: A mixed methods secondary analysis of the Irish ational Inpatient Experience Survey. Patient Educ Couns. 2023;113:107755.
40. Karkar A. Infection control guidelines in hemodialysis facilities. Kidney Res Clin Pract. 2018;37(1):1–3.
41. United states Renal Data System. 2016 Annual data report volume 1: Chronic Kidney Disease - chapter 3: Morbidity and mortality in patients with CKD. USA: National Institute of Diabetes and Digestive and Kidney Diseases; 2017. Available from: https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/usrds/prior-data-reports/2016
42. Wood AF, Tocher J, Rodgers S. Delivering direct patient care in the haemodialysis unit: a focused ethnographic study of care delivery. J Res Nurs. 2019;24(8):712–25.
43. Bonner A, Lloyd A. What information counts at the moment of practice? Information practices of renal nurses. J Adv Nurs. 2011 Jun;67(6):1213–21.
44. Chenitz KB, Fernando M, Shea JA. In-center hemodialysis attendance: patient perceptions of risks, barriers, and recommendations. Hemodial Int. 2014;18(2):364–73.
45. Glyde M, Keane D, Dye L, Sutherland E. Patients' perceptions of their experience, control and knowledge of fluid management when receiving haemodialysis. J Ren Care. 2019;45(2):83–92.
46. International Health Facility Guidelines. Part B - Health Facility Briefing & Design: 270 Renal Dialysis Unit. Available from: https://www.healthfacilityguidelines.com/ViewPDF/ViewIndexPDF/iHFG_part_b_renal_dialysis_unit [Accessed 2 Aug 2024
47. Schick-Makaroff K, Wozniak LA, Short H, Davison SN, Klarenbach S, Buzinski R, et al. Burden of mental health symptoms and perceptions of their management in in-centre hemodialysis care: a mixed methods study. J Patient Rep Outcomes. 2021;28;5(1):111.
48. van der Borg WE, Verdonk P, de Jong-Camerik J, Abma TA. How to relate to dialysis patients' fatigue - perspectives of dialysis nurses and renal health professionals: A qualitative study. Int J Nurs Stud. 2021;117:103884.
49. National Renal Office. Guidance for non-emergency haemodialysis patient transport. Dublin: National Renal Office. 2019.
50. McDonald SP, Ullah S, Dansie K, Duncanson E, Gulyani A, Davies CE, et al. The burden of travel-time and distance traveled for hemodialysis patients in Australian major city areas. Kidney Int Rep. 2023;8(5):1105–8.
51. Lewis RA, Bohm C, Fraser F, Fraser R, Woytkiw L, Jurgutis S, et al. Transportation burden associated With hemodialysis in Canada: A qualitative study of stakeholders. Kidney Med. 2022;5(2):100571.
52. de Vries EF, Los J, de Wit GA, Hakkaart-van Roijen L. Patient, family and productivity costs of end-stage renal disease in the Netherlands; exposing non-healthcare related costs. BMC Nephrol. 2021;22(1):341.
53. Mardiyah A, Maktum U, Julianti E, Zulkifli. Self-care of patients undergoing hemodialysis in compliance with diet, nutrition, and fluids. J Appl Nurs Health. 2024;6(1):45-56.

54. Vr V, Kaur Kang H. The Worldwide Prevalence of nonadherence to diet and fluid restrictions among hemodialysis patients: A systematic review and meta-analysis. J Ren Nutr. 2022;32(6):658–69.
55. Fotiadou E, Georgianos PI, Chourdakis M, Zebekakis PE, Liakopoulos V. Eating during the hemodialysis session: A practice improving nutritional status or a risk factor for intradialytic hypotension and reduced dialysis adequacy? Nutrients. 2020;12(6):1703.
56. Kalantar-Zadeh K, Alp Ikizler T. Let them eat during dialysis: An overlooked opportunity to improve outcomes in maintenance hemodialysis patients. J Ren Nutr. 2013;23(3):157–63.
57. Health Information and Quality Authority. Patient-Centred Service Improvement: Final Summary Report on Secondary Analysis of 2017 & 2018 Qualitative Survey Responses. Available from: https://yourexperience.ie/wp-content/uploads/2021/02/PACSI-Final-Report.pdf [Accessed 6 Aug 2024]
58. Chen X, Hua L, Zhang C, Xu Z, Cao X, Cai Y. Effect of peer support on improving self-management ability in peritoneal dialysis patients-a randomized controlled trial. Ann Palliat Med. 2021;10(3):3028–38.
59. Irajpour A, Hashemi MS, Abazari P, Shahidi S. The effects of peer education on treatment adherence among patients receiving hemodialysis: A randomized controlled trial. Iran J Nurs Midwifery Res. 2024;29(1):46–55.
60. Irish Kidney Association. Peer Support. Real Stories, Real Impact. https://ika.ie/peersupport/ [Accessed 17 Oct 2024]
61. Johns TS, Prudhvi K, Motechin RA, Sedaliu K, Estrella MM, Stark A, et al. Interdisciplinary care and preparedness for kidney failure management in a high-risk population. Kidney Med. 2022;4(5):100450.
62. Duronville JV, Diamantidis CJ. Medical safety in the care of the person with End Stage Kidney Disease. Semin Dial. 2018;31(2):140–8.
63. Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med. 2006;144(10):742-52.
64. Ivanković D, Jansen T, Barbazza E, Fernandes ÓB, Klazinga N, Kringos D. Status of the health information system in Ireland and its fitness to support health system performance assessment: a multimethod assessment based on stakeholder involvement. Health Res Policy Syst. 2022;21:1.
65. Bowman S. Impact of electronic health record systems on information integrity: Quality and safety implications. Perspect Health Inf Manag. 2013;10(Fall):1c.
66. Burke S, Barry S, Siersbaek R, Johnston B, Ní Fhallúin M, Thomas S. Sláintecare - A ten-year plan to achieve universal healthcare in Ireland. Health Policy. 2018;122(12):1278–82.
67. Health Information and Quality Authority. Safer Better Care, Annual Report 2021. Available from: https://www.hiqa.ie/sites/default/files/2022-06/HIQA-Annual-Report-2021.pdf [Accessed 17 Oct 2024].
68. Health Information and Quality Authority. The Need to Reform Ireland's Health Information System to support the delivery of health and social care services. Available from: https://www.hiqa.ie/sites/default/files/2021-10/The-need-for-reform-of-the-health-information-system.pdf [Accessed 8 Oct 2024].
69. Sláintecare Action Plan 2023. Sláintecare Implementation Strategy & Action Plan 2021-2023. Available from: https://assets.gov.ie/251347/e0cc4c23-ce8a-49f0-9ffc-d9220000bbcb.pdf [Accessed 4 Nov 2024]
70. Rostoker G, Issad B, Fessi H, Massy ZA. Why and how should we promote home dialysis for patients with end-stage kidney disease during and after the coronavirus 2019 disease pandemic? A French perspective. J Nephrol. 2021;34(4):985–9.

71. Just PM, de Charro FTh, Tschosik EA, Noe LL, Bhattacharyya SK, Riella MC. Reimbursement and economic factors influencing dialysis modality choice around the world. Nephrol Dial Transplant. 2008;23(7):2365–73.
72. National Institute for Health and Care Excellence. Renal replacement therapy and conservative management: NICE guideline. Report No.: [NG107]. Available from: https://www.nice.org.uk/guidance/ng107 [Accessed 2 Aug 2024].
73. Correa-Rotter R. The cost barrier to renal replacement therapy and peritoneal dialysis in the developing world. Perit Dial Int. 2001;21 Suppl 3:S314-317.
74. Lameire N, Peeters P, Vanholder R, Van Biesen W. Peritoneal dialysis in Europe: an analysis of its rise and fall. Blood Purif. 2006;24(1):107–14.
75. Walker RC, Howard K, Tong A, Palmer SC, Marshall MR, Morton RL. The economic considerations of patients and caregivers in choice of dialysis modality. Hemodial Int. 2016 Oct;20(4):634–42.
76. Al Nuairi A, Bermamet H, Abdulla H, Simsekler MCE, Anwar S, Lentine KL. Identifying patient satisfaction determinants in hemodialysis settings: A systematic review. Risk Manag Healthc Policy. 2022;15:1843–57.
77. RAND Health Care. Dialysis Patient Satisfaction Survey (DPSS). Available from: https://www.rand.org/health-care/surveys_tools/dpss.html [Accessed 2 Aug 2024].
78. National Inpatient Experience Survey. Findings of the 2022 Inpatient Survey. Available from: https://yourexperience.ie/wp-content/uploads/2022/12/2022-National-Inpatient-Experience-Survey-Report.pdf [Accessed 2 Aug 2024].
79. Palmer SC, Berardis G de, Craig JC, Tong A, Tonelli M, Pellegrini F, et al. Patient satisfaction with in-centre haemodialysis care: an international survey. BMJ Open. 2014;4(5):e005020.
80. Taber DJ, Pilch NA, McGillicuddy JW, Bratton CF, Chavin KD, Baliga PK. Improved patient safety and outcomes with a comprehensive interdisciplinary improvement Initiative in Kidney Transplant Recipients. Am J Med Qual. 2013 Mar 1;28(2):103–12.
81. Wehner MR, Niu J, Wheless L, Baker LX, Cohen OG, Margolis DJ, et al. Risks of multiple skin cancers in organ transplant recipients: A cohort study in 2 administrative data sets. JAMA Dermatology. 2021;157(12):1447–55.
82. Granata S, Tessari G, Stallone G, Zaza G. Skin cancer in solid organ transplant recipients: still an open problem. Front Med. 2023;10:1189680.
83. De Pasquale C, Pistorio ML, Veroux M, Indelicato L, Biffa G, Bennardi N, et al. Psychological and psychopathological aspects of kidney transplantation: A systematic review. Front Psychiatry. 2020;11:106.
84. De Pasquale C, Veroux M, Indelicato L, Sinagra N, Giaquinta A, Fornaro M, et al. Psychopathological aspects of kidney transplantation: Efficacy of a multidisciplinary team. World J Transplant. 2014;4(4):267–75.
85. Baker RJ, Mark PB, Patel RK, Stevens KK, Palmer N. Renal association clinical practice guideline in post-operative care in the kidney transplant recipient. BMC Nephrology. 2017;18(1):174.
86. Kidney Disease: Improving Global Outcomes (KDIGO) Transplant Work Group. KDIGO Clinical Practice Guideline for the Care of Kidney Transplant Recipients. 2009;Suppl3:S1-S55
87. Krynitz B, Edgren G, Lindelöf B, et al. Risk of skin cancer and other malignancies in kidney, liver, heart, and lung transplant recipients 1970 to 2008—a Swedish population-based study. Int J Cancer. 2013;132(6):1429-1438
88. Greenberg JN, Zwald FO. Management of skin cancer in solid-organ transplant recipients: A multidisciplinary approach. Dermatol Clin. 2011 Apr;29(2):231–41, ix.
89. Euvrard S, Kanitakis J, Claudy A. Skin cancers after organ transplantation. N Engl J Med. 2003;348(17):1681–91.

90. University of California San Francisco. Transplant Skin Cancer Network. For Transplant Patients. Available from: https://skincancer.ucsf.edu/transplant-patients [Accessed 2 Aug 2024].
91. Medicines Management Programme. Reimbursement of sunscreen. Dublin: Health Services Executive; 2017. Available from: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/mmp-reimbursement-review-sunscreen.pdf
92. Engels N, de Graav GN, van der Nat P, van den Dorpel M, Stiggelbout AM, Bos WJ. Shared decision-making in advanced kidney disease: a scoping review. BMJ Open. 2022;12(9):e055248.
93. Hole B, Scanlon M, Tomson C. Shared decision making: a personal view from two kidney doctors and a patient. Clin Kidney J. 2023;16(Supplement_1):i12–9.
94. Yildirim A. The importance of patient satisfaction and health-related quality of life after renal transplantation. Transplant Proc. 2006;38(9):2831–4.
95. Sarhan AL, Jarareh RH, Shraim M. Quality of life for kidney transplant recipients and hemodialysis patients in Palestine: a cross-sectional study. BMC Nephrol. 2021;22:210.
96. Muehrer RJ, Becker BN. Life after transplantation: new transitions in quality of life and psychological distress. Semin Dial. 2005;18(2):124–31.
97. Tang E, Bansal A, Novak M, Mucsi I. Patient-reported outcomes in patients with chronic kidney disease and kidney transplant-Part 1. Front Med. 2017;4:254.

Appendix 1:
Poster advertisement for the National Renal Office

Feidhmeannacht Na Seirbhise Sláinte
Health Service Executive

UNIVERSITY OF MEDICINE AND HEALTH SCIENCES
RCSI

HEALTH SERVICE EXECUTIVE (HSE)

National Kidney Care Programme Patient Survey

Tell us about **YOUR** renal care experiences by asking the unit nurse for a paper copy of the survey or scan the QR code using your mobile phone!

HAVE MORE TO SAY?

The Health Psychology Research team at RCSI are holding focus group interviews with renal patients.

To take part contact **Cheyenne Downey** at **cheyennedowney@rcsi.ie** or by phone: **+353 (0)86 0302408**

Have a question?
Contact Cheyenne using the details above for assistance.

Appendix 2: Patient Survey

Chronic Kidney Disease Patients' Experiences of the Irish Health Care System with respect to Renal Services

Background

This survey invites people living with chronic kidney disease to voice their views around the care they are receiving as they manage their condition. The purpose of this survey is to help the Irish Kidney Association and HSE's National Renal Office understand how patients feel about their renal care and treatment within the Irish health care system. **We want to hear what YOU have to say about your experiences in order to make positive changes that are patient-driven. Your feedback can give patients a voice and influence how renal care is experienced in the future.**

The survey is anonymous and your name or any identifiable information will not appear in the final report. **If you would prefer to complete this survey online, please contact Cheyenne Downey (cheyennedowney@rcsi.ie)**

COMPLETING THE SURVEY

ALL PARTICIPANTS PLEASE COMPLETE THE INTRODUCTORY SECTION (PAGE 2 AND 3).

IF YOU ARE CURRENTLY RECEIVING DIALYSIS, PLEASE COMPLETE THE INTRODUCTION AND SECTIONS 1 AND 2 ONLY (PAGE 2 – 14)

IF YOU HAVE A FUNCTIONING KIDNEY TRANSPLANT, PLEASE COMPLETE THE INTRODUCTION AND SECTION 3 ONLY. (PAGE 2 AND 3, THEN PAGES 15 – 20).

The survey should take approximately 20 minutes to complete. Please only tick one box for each question or statement, unless instructed otherwise. The survey is in English and includes 'free text' boxes for you to write about your renal care experience(s). We encourage you to answer the questions honestly. Please note that by completing this survey you are consenting to your anonymous data being used by RCSI and the research team in the Department of Health Psychology at RCSI for research purposes only.

AFTER COMPLETION

If you completed the survey online, you are not expected to return this form. Participants who completed a paper copy, please put the survey into the FREE POST envelope provided and send it back to us via post.

INTRODUCTION - ABOUT YOU

ALL PARTICIPANTS ARE ASKED TO COMPLETE THIS SECTION.

1. Do you consent for us to collect this data?

Yes ☐
No ☐

2. Country of origin

Ireland ☐ United Kingdom ☐ EU ☐ Other ☐

If other, which country? _____

3. Age

- 18-25 ☐
- 26-36 ☐
- 37-47 ☐
- 48-58 ☐
- 59-69 ☐
- 70-80 ☐
- 81+ ☐

4. Gender

- Male ☐
- Female ☐
- Non-binary ☐
- Prefer not to say ☐

5. Ethnicity

- White Irish ☐
- White Irish traveller ☐
- Any other White background ☐
- Black or Black Irish ☐
- Asian or Asian Irish – Chinese ☐
- Asian or Asian Irish – any other background ☐
- Other - (including mixed background) ☐

Please state: _____

6. Which type of treatment are you receiving?

- Haemodialysis - Hospital Unit ☐
- Haemodialysis Satellite Unit ☐
  (e.g. Beacon renal, Fresenius Medical Care, B Braun)
- Home haemodialysis ☐
- Home Peritoneal dialysis ☐

Please name the unit you attend: _____

I have received a transplant
(please complete the introduction, then move to section 3)

7. How long have you been receiving dialysis or living with a kidney transplant?

Less than 2 years ☐ 2-4 years ☐ 5-7 years ☐ 8+ years ☐

8. Do you hold any of the following cards? *(✓tick any that apply to you)*

	Tick (✓)
• GMS card	☐
• Drug Payment Scheme Card	☐
• GP Visit Card	☐
• Long-term Illness Card	☐
• Health Amendment Act Card	☐
• European Health Insurance Card	☐
• None of the above	☐

Other, please state: _____

SECTION 1 – YOUR DIALYSIS JOURNEY

THIS SECTION IS FOR DIALYSIS PATIENTS.
IF YOU ARE NOT A DIALYSIS PATIENT, COMPLETE SECTION 3.

9. Have you ever had a kidney transplant and returned to dialysis?

Yes ☐
No ☐

10. If yes, how many years did your transplant last before returning to dialysis?

Please state:

11. For current haemo and peritoneal dialysis patients only - How long have you been a dialysis patient?

Less than 2 years ☐ 2-4 years ☐ 5-7 years ☐ 8+ years ☐

12. Were you informed about the types of dialysis treatment available to you (i.e. hospital haemodialysis, home haemodialysis or home peritoneal dialysis)?

Yes ☐
No ☐

13. Can you describe your part in the decision-making process? Please detail:

_____

_____

_____

14. If you currently receive haemodialysis in-satellite or in-hospital, have you been invited to participate in any tasks (i.e. shared care such as inserting your own needles for haemodialysis?)

- Yes, invited and participating ☐
- Yes, invited and declined ☐
- No, I have not been invited to participate ☐
- I don't know ☐

15. How do you generally travel to your haemodialysis treatment?

- I drive / family member / friend drives me ☐
- Public Transport – e.g. bus or train ☐
- HSE provide me with transport Service e.g. taxi ☐
- Other (home haemodialysis / home peritoneal dialysis) ☐

16. How much time do you usually spend travelling to your haemodialysis treatment? (total journey including return journey)?

< 1 hour ☐ 1-2 hours ☐ 2-3 hours ☐ > 3 hours ☐ Not applicable ☐

Any comments on travel: _____

_____

_____

YOUR VISIT

17. In the last 6-12 months, what type of health care professionals have been involved in your care? (✓tick any that apply to you)

	Tick (✓)
• Consultant Nephrologist / Renal Team Doctor	☐
• GP (General Practitioner)	☐
• Clinical Nurse Manager	☐
• Renal Nutritionist / Dietician	☐
• Dermatologist	☐
• Physiotherapist	☐
• Pharmacist	☐
• Social worker	☐
• Diabetes specialist	☐
• Cardiologist	☐
• Psychologist / Counsellor	☐
• None of the above	☐

18. Are there any OTHER support services that you have availed of in the last 6 months? If yes, please list:

_____

_____

_____

19. Are there any OTHER services that you think should be made available to you? If yes, please list:

_____

_____

_____

20. Please tell us about how important the following are to you? (please ✓tick your answers)

	Very Important	Important	Somewhat Important	Not Important
Having a renal unit as close to your home as possible?				
Meeting with members of your renal team on a regular basis?				
Being able to discuss your care with a member of the renal team?				
Being able to contact your team about your care?				

21. Please ✓tick your answer to the question below:

	Always	Sometimes	Never	Not applicable
How often do the renal team insert your needles with as little pain as possible? (if applicable)				

22. Do you have comments regarding needle insertion (if applicable):

23. please ✓tick your answer to the question below:

	Yes, always	Yes, sometimes	Never
As a dialysis patient, does the food cater for your dietary requirements (gluten, diabetic, vegetarian, intolerance etc.)			

24. Please ✓tick your answer to the question below:

	Excellent	Very good	Good	Fair	Poor
How would you rate the refreshments/catering you are provided during your dialysis appointment?					

25. Please answer the following questions (please ✓tick your answers)

	Yes, always	Yes, sometimes	Never
Are the buildings and facilities where you attend for dialysis/appointments clean and tidy?			
Does the healthcare professional wash or clean their hands when meeting with you?			
Are you treated with kindness and respect by your renal care team?			
Are you satisfied with the level of privacy provided to you during your haemodialysis treatment?			

26. Please answer the following questions (please ✓tick your answers)

	Yes	No	Not applicable
Is the advice or information provided by the renal team or nurse *easy to understand?*			
Is the advice or information provided by the renal team or nurse *helpful to you?*			

27. Please answer the following questions (please ✓tick your answers)

	Yes, always	Yes, sometimes	Never
Does the renal team take time to answer your questions about your kidney disease or treatment?			
Would you feel comfortable to contact your renal team from home if you were anxious or worried?			
Would you feel able to ask for an additional appointment with your kidney doctor if you wanted to?			

28. Does the renal team help you to get the support you want with the following? (please ✓tick your answer)

	Yes, always	Yes, sometimes	Never
Medical issues resulting from your kidney disease?			
Any other concerns or anxieties resulting from kidney disease or treatment?			
Accessing patient support groups such as the Irish Kidney Association?			

29. Do you think there is good communication between:

	Yes, always	Yes, sometimes	Never
You and your renal team?			
Your GP and the renal team? (if applicable)			
The renal team and other medical specialists? (if applicable)			
The renal team and other healthcare services if you need them?			

30. Does the renal team:

	Yes, always	Yes, sometimes	Never
Explain things to you in a way that is easy to understand?			
Give you as much information about your kidney disease or treatment as you want?			

31. Thinking about the advice you are given about fluid intake and diet...

	Yes, always	Yes, sometimes	Never
Does the renal team give you clear advice on *your fluid intake?*			
Does the renal team give you clear advice on *your diet?*			

32. Does the renal team do the following... (please ✓tick your answers)

	Yes, always	Yes, sometimes	Never
Talk with you about your treatment and life goals?			
Enable you to participate in decisions about your kidney care as much as you want?			
Talk to you about taking a more active role in managing your own kidney care?			

33. If your renal team arrange your transport, please answer these questions. If the unit does not arrange your transport, then please move onto QUESTION 34.

	Yes, always	Yes, sometimes	Never
Is the vehicle provided suitable for you?			
Is the time it takes to travel between your home and the renal unit acceptable to you?			

34. Please ✓tick your answer to the question below:

	Worst it can be	It could be worse	It could be better	Best it can be
How well would you grade your overall experience of the service provided by your renal unit?				

35. Are you a home haemodialysis / home peritoneal dialysis patient?

Yes, I am a home haemodialysis patient ☐
Yes, I am a home peritoneal dialysis patient ☐
No *(please skip to Q.37)* ☐

36. As a home dialysis patient, are you aware that you can register your household as vulnerable customer with energy/water providers?

Yes ☐
No ☐
Rather not say ☐

Registering as a vulnerable customer will keep you informed of any power outages / water supply issues in your local area which may affect your treatment.

SECTION 2 – UREMIC PRURITUS (ITCHING)

THIS SECTION IS FOR DIALYSIS PATIENTS WHO ARE EXPERIENCING ITCHING.
IF YOU ARE NOT A DIALYSIS PATIENT, COMPLETE SECTION 3.

Dialysis patients often report that itching ("uremic pruritus") is a common and distressing symptom of being on dialysis. The following questions relate to your experience of itching, and any other symptoms you experience.

37. During the last 2 weeks, how many hours a day have you been itching?

- Less than 6 hours a day ☐
- 6-12 hours a day ☐
- 13-18 hours a day ☐
- 19-24 hours a day ☐

38. Please rate the intensity of your itching over the past 2 weeks

- Not present ☐
- Mild ☐
- Moderate ☐
- Severe ☐
- Unbearable ☐

39. Over the past 2 weeks has your itching got better or worse compared to the previous month?

- Completely resolved ☐
- Much better but still present ☐
- Slightly better but still present ☐
- Unchanged ☐
- Getting worse ☐

40. Rate the impact of your itching on the following activities over the last 2 weeks (please ✓tick your answer)

	Always affects this activity	Frequently affects this activity	Rarely affects this activity	Never affects this activity
Sleep				
Leisure				
Household work/errands				
Work/School				

41. Has itching been present in the following part of your body over the last 2 weeks? If a body part is not listed, choose the one that is closest anatomically (please ✓tick all that apply to you)

	Tick (✓)
• Abdomen	☐
• Back	☐
• Buttocks	☐
• Chest	☐
• Face	☐
• Forearms	☐
• Groin	☐
• Head/Scalp	☐
• Lower legs	☐
• Palms	☐
• Point of contact with clothing (e.g. waistband, undergarment)	☐
• Soles	☐
• Thighs	☐
• Top of feet/toes	☐
• Top of hands/fingers	☐
• Upper arms	☐

42. Please comment below on your experience of uremic pruritus (itching) and any other symptoms you experience from being on dialysis:

SECTION 3 – NON-DIALYSIS RENAL CARE

THIS SECTION IS FOR PEOPLE WHO HAVE A FUNCTIONING KIDNEY TRANSPLANT ONLY.

PART 1: ACCESS TO THE RENAL TEAM

43. How long have you had your kidney transplant? Please state:

44. The following questions in these sections ask you about your experience with your transplant clinic, your kidney disease and treatment (please ✓tick your answers)

	Yes, always	Yes, sometimes	Never
Does the renal team take time to answer your questions about your kidney disease or treatment?			
Would you feel comfortable to contact your renal team from home if you were anxious or worried?			
Would you feel able to ask for an additional appointment with your kidney doctor if you wanted to?			

PART 2: SUPPORT

45. Does the renal team help you to get the support you want with the following? (please ✓tick your answer)

	Yes, always	Yes, sometimes	Never
Medical issues resulting from your kidney disease?			
Any other concerns or anxieties resulting from kidney disease or treatment?			
Accessing patient support groups such as the Irish Kidney Association?			

46. In the last 6-12 months, what type of healthcare professionals have been involved in your care? (✓tick any that apply to you)

	Tick (✓)
• Consultant Nephrologist/Renal Team Doctor	☐
• GP (General Practitioner)	☐
• Clinical Nurse Manager	☐
• Renal Nutritionist/Dietician	☐
• Dermatologist	☐
• Physiotherapist	☐
• Pharmacist	☐
• Social worker	☐
• Diabetes specialist	☐
• Cardiologist	☐
• Psychologist/Counsellor	☐
• None of the above	☐

47. Are there any OTHER support services that you have availed of in the last 6 months? If yes, please list:

48. Are there any OTHER services that you think should be made available to you? If yes, please list:

PART 3: COMMUNICATION

49. Do you think there is good communication between:

	Yes, always	Yes, sometimes	Never
You and your renal team?			
Your GP and the renal team? (if applicable)			
The renal team and other medical specialists? (if applicable)			
The renal team and other health care services if you need them?			

PART 4: PATIENT INFORMATION

50. Does the renal team

	Yes, always	Yes, sometimes	Never
Explain things to you in a way that is easy to understand?			
Give you as much information about your kidney disease or treatment as you want?			

PART 5: TESTS

51. Please ✓tick your answers to the following questions

	Yes, always	Yes, sometimes	Never
Are you aware of the schedule of routine monitoring on your transplant function?			
Are the routine monitoring tests explained to you?			
Are you informed of the results of your tests?			
Are the arrangements for your blood tests convenient for you?			

PART 6: SHARING DECISIONS ABOUT YOUR CARE

52. Does the renal team do the following... (please ✓tick your answers)

	Yes, always	Yes, sometimes	Never
Talk with you about your treatment and life goals?			
Enable you to participate in decisions about your kidney care as much as you want?			
Talk to you about taking a more active role in managing your own kidney care?			

PART 7: PRIVACY AND DIGNITY

53. Please ✓tick your answers to the following questions

	Yes, always	Yes, sometimes	Never
Are you given enough privacy when discussing your condition and treatment?			
Is your dignity respected during appointments and clinical examinations?			

PART 8: SCHEDULING AND PLANNING

54. Please ✓tick your answers to the following questions

	Yes, always	Yes, sometimes	Never
Can you change your appointment times if they are not suitable to you?			
Do you feel your time is used well at your appointments relating to your kidneys?			

PART 9: OVERALL EXPERIENCE

55. Please ✓tick your answers to the following questions

	Worst it can be	It could be worse	It could be better	Best it can be
How well would you grade your overall experience of the service provided by your renal unit?				

56. Please list any suggestions that would improve your experience of your renal care. Please detail:

57. As a transplant recipient, please list positive aspects associated with your renal care:

58. As a transplant recipient, please list negative aspects associated with your renal care:

59. Are you aware that as a transplant recipient, you have an increased risks of skin cancer compared to the general population due to the immunosuppressive medications taken to protect transplanted organs?

Yes, I am aware ☐
No, I am not aware ☐

60. Do you wear sunscreen?

Yes, always ☐
Yes, sometimes ☐
Never ☐

Dermatologists recommend the daily use of water-resistant sunscreen with SPF 30 or higher to provide protection against both UVA and UVB light. This should be used in conjunction with other protective measures such as suitable clothing, avoiding sun exposure and availing of shaded areas.

****SURVEY COMPLETE****

Thank you for completing this survey. By taking part in the survey, you are helping not just us, but also health care professionals to understand what your priorities are and what improvements you would like to see. **If you would like to partake in a focus group interview, please contact Cheyenne Downey either by phone call / text message: [Researcher's Ph. Number inserted] or email: cheyennedowney@rcsi.ie**

NOTES

NOTES

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