



Reflections on Using Telemonitoring Platforms to Invite Kidney Transplant Recipients to Participate in Research While Ensuring Privacy

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Reflections on Using Telemonitoring Platforms to Invite Kidney Transplant Recipients to Participate in Research While Ensuring Privacy

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Abbreviations

KT: kidney transplantation

KTR: kidney transplant recipient

TEXT

The use of telemonitoring following kidney transplantation (KT), is in the process of rapid development, particularly in the wake of the global pandemic caused by SARS-CoV-2. Hezer *et al.* recently emphasized its potential for improved adherence to treatment, and even for greater patient commitment ^{1,2}. Implementation of telemedicine reduces the incidence of hospitalization and is cost-effective ³. Digital literacy among patients varies ⁴. In France, the 2023 digital barometer published in May 2024 by a private non-profit research organization (CREDOC) found that 87% of French people owned a smartphone and 84% had an internet connection at home ⁵.

Since May 2024, in France, telemonitoring has been governed by common law, and is financially supported by the French Ministry for Health. At Foch Hospital, 400 patients (40% of our KT cohort) have taken advantage of telemonitoring since June 2019. As a team, we wondered whether we could use our telemonitoring platform, designed for care giving and surveillance, to promote the participation of kidney transplant recipients (KTRs) in online survey, to adapt our care protocols, or to help design clinical research protocols.

We have therefore formulated three questions that we felt were important to discuss: 1) What should be the frequency of inquiries to patients that would not cause them discomfort? 2) How should the questions be delineated so as not to compromise a patient's private life? 3) What methodology could be employed to incorporate a patient's opinions or wishes into the routine operations of our clinical practice, as well as into the design of research studies? In response to these queries, a roundtable discussion was convened, comprising nephrologists and an advanced practice nurse engaged in KT, a professor of ethics, two expert patients KTRs (MLA and GR) and two experts on telemonitoring (DL) and qualitative studies promote by patient associations (MLE), respectively. Written consent for audio recording was obtained. A written transcript of this 2-hour meeting was produced. The recurrence of themes was identified afterwards. The study was approved by our institutional ethics committee (IRB00012437).

From this discussion, we concluded that all questions should be theoretically addressed to patients, provided that the patient is informed of the purpose of the questionnaire. It is imperative that a clear distinction is made between clinical practice and clinical research when a patient is approached via a telemonitoring platform. Although the patient's explicit consent is not required for data collection as part of the telemonitoring in France, it is necessary in the case of a study. Patients must be informed they are leaving the telemonitoring platform and give their explicit consent to the collection of data for research purposes. The patient's consent must be collected at each questionnaire. Questionnaires should not be too frequent, and patients can be asked what their personal threshold is.

The methodology must be conducted in accordance with the highest standards of rigor, in compliance with the existing laws, and with the guarantee that personal data will be protected. It is recommended that dedicated platforms be employed, distinct from the telemonitoring platform, although the latter can be used as a bridge to a questionnaire. Questionnaires should be co-constructed with patients. While the use of standardized questionnaires is preferable, the importance of co-construction is even more important when

new tools are contemplated. Patients' associations are a sound resource to identify patients willing to help with this co-construction.

The use of a telemonitoring platform is an extension of the healthcare tool, which helps foster a sense of community among patients and increase their confidence in this technology. A high rate of participation in the questionnaires sent through a telemonitoring platform is important to ensure a proper representation of responses.

Finally, feedback of the results of the questionnaires to patients is essential as a fair recompense for their investment in it. Ideally, the results should be promoted through scientific publications to ensure that patients' voices are clearly heard. The involvement of an institutional ethics committee (Institutional Review Board) is a guarantee of solid methodology, respect for patients' rights and a prerequisite for scientific publication.

A summary of the themes discussed during the roundtable, accompanied by pertinent quotations, is provided in Table 1.

In conclusion, telemonitoring platforms for KTRs appear to be a useful channel for encouraging patients to participate in qualitative studies. A regulatory framework must be established and explicitly defined, and informed consent must be obtained from participants after they have received comprehensive information. Scientific value and result feedback are key steps in building a trust-based relationship between healthcare providers and patients.

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Table 1: Summary of the themes discussed during the roundtable

Theme	Frequency	Quotes
Specialized platform and data protection	10	"We should only collect data that is legitimate according to its purpose." "A telemonitoring platform meets strict regulatory requirements for data protection, ensuring security through audits." "When collecting health data, there is a risk of re-identifying individuals; this is a form of pseudo-anonymization."
Patient consent	9	"While preparing for the roundtable, I wondered if I had been asked for my consent in the telemonitoring platform. I wasn't able to answer or find this information, and I thought that if I had the paper in front of me, I might have remembered this detail." "The patient can request at any time to withdraw their consent for the use of telemonitoring or to have the data deleted." "In France, consent for telemonitoring can simply be given orally." "In the case of research, there is no explicit consent, but the patient will receive information and can object to participating in the research."
Co-construction and tool selection	9	"Qualitative workshops with patients: what questions do we consider? Either we use PREMS or PROMS, international standardised questionnaires, or we create our own questionnaire based on the specific questions we ask, in which case it's a matter of co-construction". "It's important to remember that the telemonitoring platform was itself co-constructed with patients. It's important to point this out to new patients who don't know the history, because they will be all the more involved in telemonitoring." "Co-construction with patients is a guarantee that the research will last."
Patient information	8	"I think it is helpful to place a question within a specific context when we ask it." "Patients participating in studies should know in advance how the study is organized." "Information on data processing and data anonymization is necessary." "Doctors should carefully target their research, their questions, and involve patients, as it is essential to engage patients as much as possible to align them with our inquiry and increase the response rate."

Methods	7	"When there is a desire to collect data, it must be associated with a research project and patients should get access." "Going before an ethics committee will enable the methodology proposed in the research protocol to be verified and improved."
Distinction between clinical research and clinical practice	6	"Care and research are closely connected; improving practices is already a form of research, but it must be distinguished from clinical research." "When I asked a research-oriented question on the telemonitoring platform, I didn't feel intrusive at all. I didn't question whether I was allowed to ask that question or not."
Trust	6	"A patient satisfaction survey showed a response rate of 23% because it is a channel of trust." "I see telemonitoring as an extension of the medical team, which I trust." "To increase trust, it's important to make a community of meaning; horizontal, i.e. the legal aspects; and vertical, i.e. the doctor-patient relationship." "The use of open messaging between the carer and the patient on the telemonitoring platform makes patients actors in their care and encourages their adherence to the platform, and probably plays on the response rate to satisfaction questionnaires, for example."
Patient-researcher channel	6	"Public assistance is developing a platform dedicated to the creation of chronic disease cohorts in order to distribute quality of life questionnaires." "When a patient is asked to answer a questionnaire via a telemonitoring platform, they must be informed that they are leaving the tool for a new platform where the data will be used for research purposes."
Legal framework and Ethics committee	5	"In the context of research, it is in your interest to obtain a favourable opinion from an ethics committee if you wish to publish the results."
Enhancing the scientific value of patients' word	5	
Frequency of questionnaires	4	"We can optimize within the app and set the frequency at which each patient consents to respond to proposed research questionnaires, choosing an appropriate frequency for requests." "Respect the quality of life of patients." "The risk of over-solicitation through connected tools lies in the novelty effect and the eventual burnout of long-term interest."

Taboo	4	"There aren't really any taboo questions, as long as the patient isn't considered as a database to be used for research purpose."
		"If you need to know whether there are implications for a patient's sex life, it's not necessarily taboo as long as you stay within the health framework."
		"There are no taboo subjects. As long as the questionnaire is co-constructed with patients and refers to a research protocol, all questions are allowed."
		"In the context of care, I have no taboo subjects. In a research context, information on the objectives is necessary and there are no limits there either."
Feedback	3	"When you take part in a questionnaire, you'd like to have the results."
Patient experience	3	"Using a living lab can enable a medical device to be tested, unlike a simple online questionnaire."
Representativeness of the panel	2	"On telemonitoring platforms, the response rate to questionnaires is good because this is an application whose purpose is the health of patients, and patients feel concerned about their health."