

Editorial

Kidney health literacy in the digital era: The experience of the *Salud Renal Siempre* platform



Alfabetización en salud renal en la era digital: la experiencia de la plataforma Salud Renal Siempre

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What is health literacy?

The World Health Organization (WHO) defines health literacy HL as “the ability of people to access, understand, evaluate and use health-related information to make decisions that improve their quality of life”.¹ This definition goes beyond the mere ability to read or write. It involves a complex set of cognitive, social and functional skills that allow effective interaction with the health system, understanding the risks and benefits of different therapeutic options and active participation in clinical decisions.²

The *Healthy People 2030* initiative of the Department of Health and Human Services of the United States expands this approach by considering HL as not only an individual responsibility but also an organizational responsibility. In accordance with this vision, health institutions should design accessible and understandable environments to support people in their health decisions.³

As a social determinant of health, literacy directly influences the equity, sustainability and humanization of care.^{4,5} Limited levels of HL are related to difficulties in interpreting analytical results, following prescriptions or identifying warning signs. In contrast, a high level of literacy favors empowerment, self-management and active participation, with a positive impact on quality of life.

Importance of literacy in kidney health

Chronic kidney disease (CKD) represents one of the greatest health challenges worldwide because of its high incidence, relationship with cardiovascular and metabolic comorbidities, and high cost of care.^{6–8} Its course is insidious, with late symptoms and little knowledge among the general population, which leads to diagnoses at advanced stages.^{9,10} The lack of knowledge about kidney health and risk factors is of particular concern, even among people with a university-level education.^{11–13}

In this context, kidney health literacy emerges as a strategic component for the prevention, early detection and comprehensive management of CKD. It involves adapting health education to the stage of the disease and the sociocultural profile of the patient and integrating the information into routine clinical practice to increase participation and improve self-care.

Renal health literacy according to disease stage

Renal health literacy should be understood as an evolutionary process that adjusts to the progression of the disease and the needs of each person:

- In *advanced chronic kidney disease* (ACKD), the priority is that the patient understands the course of their disease, knows how to interpret the results of his/her health tests and knows the options for renal replacement therapy (RRT). Factors such as age, educational level or comorbidities can influence the level of HL.¹⁴ Patients with greater literacy at this stage tend to opt for an arteriovenous fistula instead of a catheter, improving clinical results.¹⁵ In contrast, limited literacy is associated with less access to kidney transplantation, even independently of other factors.¹⁶
- In *replacement therapy* (dialysis), literacy should allow patients to manage the complex aspects of treatment, from diet and medication to vascular access control, interpretation of results and detection of complications. Low levels of HL in this phase are associated with a higher rate of avoidable hospitalizations and worse health indicators.¹⁷
- In *postrenal transplantation*, health literacy is essential for monitoring immunosuppressive therapy, infection prevention, clinical control and social reintegration.¹⁸ High HL is related to better graft function and greater therapeutic adherence, whereas low levels compromise both access to transplantation and postoperative survival.¹⁹

The data show a higher prevalence of limited literacy among incident dialysis patients (20%) compared with patients on waiting

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lists (15%) and recent transplant patients (12%).¹⁴ In addition, patients receiving home hemodialysis and peritoneal dialysis have better levels of literacy than those who receive hemodialysis in a center or predialysis.²⁰ These differences suggest that environments that favor autonomy and coresponsibility also increase literacy.

Factors such as low socioeconomic status, language barriers or the presence of comorbidities are associated with limited HL,¹⁴ whereas being on the waiting list or having received an early transplant or from a living donor is related to better levels.

Levels and consequences of limited health literacy

Muscat et al.²¹ describe three progressive levels of health literacy:

- **Functional:** basic reading, writing and comprehension skills to follow instructions.
- **Interactive:** cognitive and social skills to actively participate in clinical decisions.
- **Critical:** ability to analyze, evaluate and act on the determinants of health.

For patients with chronic diseases such as CKD, moving toward interactive and critical levels is crucial. Limited literacy is associated with increased morbidity and mortality, decreased therapeutic adherence, increased avoidable hospitalizations and low participation in prevention programs.^{22–24} For renal transplant patients, low HL is associated with higher creatinine levels, a lower likelihood of inclusion on a waiting list and worse prognosis.^{25,26}

Digital literacy in renal health

The digital environment has become the main source of information for many people. The internet and social networks offer an abundance of resources that can be accessed immediately, but they also present challenges in terms of quality, reliability and comprehension. Given the large amount of inaccurate information available online, individuals can easily become misinformed, which can prompt anxiety, self-medication or misdiagnosis.²⁷ Therefore, digital literacy in health has become a new frontier.

In the field of CKD, having the skills to discriminate reliable sources, interpret content and make appropriate decisions is essential. Digital interventions with regard to HL remain scarce and heterogeneous. Some such interventions include training, educational portals, monitoring tools or interactive resources, but higher-quality studies are needed to measure their impact.²⁸

Table 1
Contents of the renal health platform.

Profile/Stage	Literacy objectives	Main contents	Formats	Literacy level
Population at risk/initial CKD	Prevent kidney damage, identify risk factors, promote healthy habits	Basic information on renal function and risk factors; warning signs; Self-assessment tools	Infographics, short videos, frequently asked questions, calculators	Functional
Conservative treatment/predialysis	Understand the evolution of the disease, tests and treatment modalities; advanced self-care	Explanation of diagnostic tests; control of comorbidities; comparison of therapies; forums with professionals	Videos and podcasts with experts, practical guides, moderated forums	Interactive
Dialysis (hemodialysis and peritoneal)	Daily treatment management, interpretation of parameters, prevention of complications	Step-by-step guides by modality; analysis reading; prevention of vascular access problems; patient rights	Explanatory audiovisual material, testimonies, parameter graphs	Critical
Posttransplant	Autonomous management of immunosuppressive therapy, infection prevention, healthy lifestyle	Medication reminders; clinical control; physical activity and nutrition; signs of rejection	Self-care guides, educational videos, practical advice	Interactive + Critical
Family members and caregivers	Active support for the patient, understanding of the process, self-care of the caregiver	Guides to accompany in consultation; administration of medication; emotional support; self-care resources	Explanatory videos, written guides, forums	Functional + Interactive
Transversal resources	Adapt content to the user and encourage active participation	Assistant that suggests options; thematic specials; wellness and leisure resources; travel tools	Multiformat: text, audio, video, infographics	All levels

The always renal health experience: from evidence to action

On the basis of a bibliographic review, the voice of patients and experts, and a pedagogical design focused on the user experience, the Spanish Renal Foundation launched the digital platform Renal Health Always (<https://saludrenalsiempre.org/>) in February 2024. This multiformat and free access resource is being developed by more than 60 professionals (nephrologists, nurses, psychologists, nutritionists, and social workers), patients and caregivers, with the support of entities such as SEN, SEDEN, and ALCER, among others, ensuring scientific accuracy, practical relevance and a direct connection with the life experience of the people affected.

The platform seeks to create a digital community that promotes patient empowerment, shared decision-making and comprehensive care. It addresses the three levels of literacy described by Muscat et al.²¹:

- **Functional:** basic and accessible content for the general population and risk groups.
- **Interactive:** interactive resources and spaces to ask questions.
- **Critique:** testimonies, real cases, guides, interpretation of parameters, patient rights.

Structure and resources

The platform is organized into four main thematic blocks that respond to the specific needs of each situation (Table 1, Fig. 1a, b).

- 1 **Prevention and kidney health:** explains how the kidneys work, risk factors, and warning signs and includes calculators, videos, self-assessments, and more than 150 frequently asked questions.
- 2 **Kidney disease:** covers causes, diagnosis, therapeutic options, and topics such as nutrition, emotional health or sex perspective, with explanatory videos.
- 3 **Dialysis:** describes the different modalities, practical guidelines, interpretation of analyses, vascular access care and patient testimonials.
- 4 **Transplantation:** covers everything from the process of inclusion on the waiting list to post-transplant follow-up, including topics such as medication, infections, social reintegration, pregnancy, leisure and real experiences.

A. Ejemplos de contenido de la plataforma de salud renal siempre



B. QR de acceso a la plataforma



Figure 1. A) Examples of content from the Always Renal Health platform. B) QR for platform access.

In addition, there are other sections, such as the following:

- “Facts you should know”: key statistics on CKD.
- “Surely you wonder”: frequently asked questions answered in clear language.
- “In the first person”: Patient testimonies.
- “Experts speak” or “The figure of the cultural mediator in health”: videos and explanations of professionals on topics such as emotional impact, nutrition, sex and control of risk factors. A trained professional or volunteer should be incorporated to act as a liaison between the health team and the community, facilitating communication and trust.

Visitantes por mes de Salud Renal Siempre

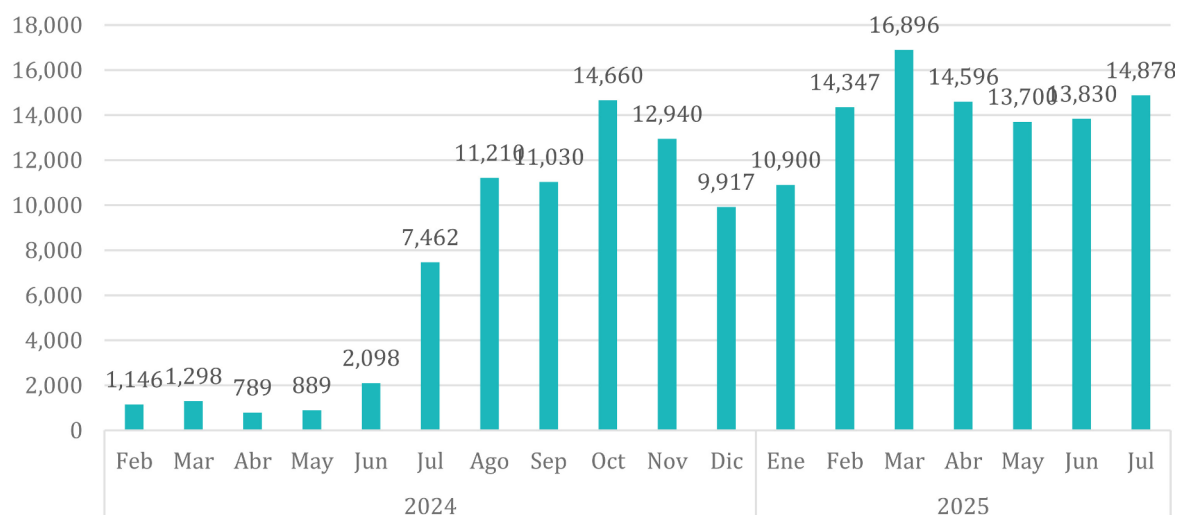


Figure 2. Number of visits to the Always Renal Health platform since its launch on February 19, 2024.

- “Practical guides”: information on daily treatment, complications and self-care.
- Resources for nutritional, physical, social and emotional well-being.
- Thematic specials (World Kidney Day, sports, equity in treatment).
- Calculators, recommendations for travel and social assistance.

Technological innovations and accessibility

The differential elements are as follows:

- System of personalized recommendations, a tool that proposes the recommendations that are the most appropriate for the user.
- Multimodal formats (text, audio, videos, and infographics).
- Clear language and no technical terms.
- Deep cultural and linguistic adaptation.
- Inclusion of expert cultural mediators.
- Feedback mechanisms to improve content.
- A sex-specific focus that highlights the barriers and specific needs of women with CKD.

The platform also offers space for family members and caregivers, with materials aimed at supporting the patient, accompanying them in consultations, managing medication and caring for themselves.

Implementation and results

Since its launch, Renal Health Always has had a considerable impact. The website was published in March 2025, on World Kidney Day, and received more than 16,000 visitors in a single month (Fig. 2). A large amount of visitors are from Argentina (25.3% of the total number of visitors as of July 2025). Mexico (19.4%) and Spain (13.4%), in addition to other Latin American countries and the United States. The long duration of visits to the website and the user interaction with the website contents reflect the value perceived by the users.

The success of Renal Health Always lies in translating scientific evidence into practical tools adapted to the real context of people with CKD. The platform has shown that it is possible to improve adherence, promote self-care and build communities of digital support.

Future projection

Future work includes integrating this type of intervention into routine clinical practice in nephrology, including the evaluation of kidney health literacy in chronicity plans, the development of intelligent digital resources and the strengthening of coordination between scientific societies, administrations and patient associations.

In short, kidney health literacy is not a complement but rather a strategic pillar for preventing, diagnosing and managing CKD. Initiatives such as Renal Health Always demonstrate that it is possible to transform information into practical competency, but the sustainability of providing this information requires that it be incorporated into a coherent health policy and not depend on isolated efforts.^{29,30}

Conclusion

Renal health literacy is a strategic investment in public health that directly affects the prevention, control and prognosis of chronic kidney disease. It not only involves informing people but also providing people with the necessary skills to actively participate in their care, make shared decisions and exercise effective self-control throughout all stages of the disease.

The experience of the Renal Health Always platform shows that, with a design adapted to the different profiles of patients and caregivers, it is possible to translate scientific evidence into accessible, useful and culturally relevant tools. Its initial impact confirms that the combination of organized content, multimodal digital resources and an inclusive approach can create support communities across geographical borders.

The current challenge is to ensure that initiatives like this do not depend on the isolated will of organizations or professionals but are integrated into national and international strategic plans for CKD care, guaranteeing their continuity, updating and scope. Only then can we establish kidney health literacy as a structural element of the health system and transform an epidemic.

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Declaration of competing interest

The authors declare that they have no conflicts of interest.

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