Executive Summary

The concept of *Health Literacy*, as defined by the World Health Organization (WHO), encompasses not only the knowledge of health-related information, but also individuals' motivation and ability to access, understand, evaluate, and apply that information in order to make informed decisions throughout their lives regarding healthcare, prevention, and health promotion—thus maintaining or improving their quality of life.

As efforts to enhance health literacy increase, it becomes equally essential to ensure that such empowerment also encompasses knowledge and understanding of patients' rights within the context of healthcare provision. In this regard, healthcare regulation plays a crucial role in guaranteeing that patients' rights are both respected and effectively upheld. Therefore, literacy concerning patients' rights emerges as a key component of overall health literacy—reflected in individuals' ability not only to know their rights, but also to understand, value, and exercise them in an informed and assertive manner.

In line with the responsibilities and legal remit of the Portuguese Health Regulatory Authority (ERS), this study aims to assess the level of literacy among patients, healthcare professionals, and administrative staff regarding patients' rights, while also identifying ongoing challenges. The findings will enable ERS to define targeted regulatory actions, particularly in the promotion of literacy. This analysis follows a previous study conducted by ERS in 2017, which revealed inadequate levels of literacy on patients' rights and demonstrated the need for a new assessment to monitor progress on this issue.

For this study, healthcare professionals and administrative staff were analysed as distinct groups, to provide a more accurate and segmented understanding of literacy levels concerning patients' rights. This differentiation allows for greater insight into the specific roles and needs of each group and supports the identification of more effective intervention areas. Administrative staff, often the first point of contact for patients, play a critical role in facilitating access and providing information—thus influencing patients' understanding of their rights. In contrast, healthcare professionals, given the technical and clinical nature of their roles, interact with patients differently and assume other responsibilities. By analysing these groups, the study seeks to inform the development of targeted measures and more effective strategies for promoting literacy on patients' rights across the healthcare sector.

To assess literacy on patients' rights, two tailored questionnaires were developed—one for patients and one for healthcare professionals and administrative staff.

Data collection was conducted through two distinct methods, adapted to the target audiences. For healthcare professionals and administrative staff, an online questionnaire was administered via the LimeSurvey platform and distributed by email to all public, private, and social healthcare providers registered in the ERS Regulated Establishments Registry (SRER). For patients, data was collected in person by trained interviewers at a random and scientifically validated sample of healthcare establishments (both public and private) across mainland Portugal.

The questionnaire covered 11 thematic areas:

- Knowledge of ERS;
- Right to health protection;
- Right of access to healthcare;
- Right to quality healthcare;
- Right to make decisions;
- Right to access clinical information and right to personal data protection;
- Right to spiritual and religious assistance;
- Right to accompaniment;
- Rights of individuals in advanced illness or end-of-life situations;
- Right to be represented or to form associations defending patients' rights;
- Right to submit complaints and grievances.

The study sample comprised 1.010 valid patient responses and 4.623 responses from healthcare professionals and administrative staff, across public, private, cooperative, and social sector establishments in all regions of mainland Portugal.

The results showed that 20,3% of patients had *inadequate* overall literacy, 58,2% demonstrated *problematic* literacy, 21,2% achieved a *sufficient* level, and 0,3% reached an *excellent* level. This classification is based on an index defining four levels of health literacy: *inadequate* (0-50%), *problematic* (51-66%), *sufficient* (67-84%), and *excellent* (85-100%). Compared to the 2017 study, overall results improved: the percentage of patients with inadequate or problematic literacy declined from 94,7% to 78,5%. Furthermore, the literacy level was influenced by factors such as age, education, and employment status, with better results among individuals with higher education, self-employed professionals, and private health insurance holders.

Healthcare professionals demonstrated higher levels of overall literacy, with more than 80.0% showing *sufficient* (54,7%) or *excellent* (25,9%) literacy. Among administrative staff, this proportion was lower, at under 70,0%. Conversely, 19,4% of healthcare professionals and 32,1% of administrative staff displayed *problematic* or *inadequate* literacy levels. Compared with 2017, significant improvements were observed in both groups, with a notable reduction in low literacy levels. Healthcare professionals showed the greatest progress, rising from 46,4% to over 80,0% achieving *sufficient* or *excellent* literacy. Although administrative staff also improved, further progress is still needed, increasing from 26,6% to 67,9% in overall literacy.

Despite these improvements since 2017, the study reveals that most patients, healthcare professionals, and administrative staff continue to face significant challenges in understanding patients' rights.

Considering these findings, ERS emphasises the need to:

- Intensify awareness campaigns and capacity-building initiatives regarding patients' rights;

- Develop clear and accessible information materials tailored to different socio-demographic profiles;

- Strengthen the training of healthcare professionals for more effective communication on patients' rights;

- Foster strategic partnerships with key entities within the healthcare system to broaden the reach of literacy promotion initiatives.

In this context, ERS will continue to pursue specific regulatory interventions, as set out in its statutory remit, with the goal of empowering patients, healthcare providers, and other key stakeholders within the healthcare system. It will also continue to invest in the dissemination of high-quality information and in the development of strategies to promote literacy on patients' rights, thereby enhancing informed access to information and encouraging active participation by all individuals in managing their health.