

Co-Creating the Future of Slovenian Healthcare

**The Patient as an Equal Partner,
Not Merely a Recipient of Services**

In-Depth Reflection with Patient Organisations:
Assessing the Current Situation, Highlighting Key
Challenges and Proposing Solutions

November 2025

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The Patient as an Equal Partner, Not Merely a Recipient of Services

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Purpose: To present the needs and opportunities for developing the role of patients and patient organisations – from passive recipients of services to active dialogue partners and co-creators – with a vision of strengthening a healthcare system that is inclusive and recognizes health as a key investment in individuals, the economy and society as a whole.

Intended audience: All stakeholders in the healthcare system

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The International Forum of Research-Based Pharmaceutical Companies strives to improve the Slovenian healthcare system by applying global knowledge, best practices, scientific discoveries, technological innovations and extensive experience. With an emphasis on transparency, patient involvement and responsiveness to needs, we can – through joint effort and coordinated action – create an efficient, fair and forward-looking healthcare system for all residents of Slovenia.

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Health is an investment in the future: An appeal for active/effective collaboration across all segments of society

The greatest offering the healthcare industry can provide to patients is to follow their needs.

In modern healthcare systems, the patient is no longer merely a recipient of healthcare services, but an active, informed, and equal partner. Their knowledge, experiences, and insights are indispensable in shaping policies, therapies, data pathways, and support programs that reflect the real needs of people.

Our collective commitment is clear: **when we understand the needs of patients, we can develop solutions that have greater clinical and social value, reach all those who need them faster, and bring about better health outcomes.**

Therefore, we were pleased to support the preparation of the project, which summarized the thoughts of patient associations into a unified document entitled **“The Patient as an Equal Partner, Not Merely a Recipient of Services”**.

In it, we have united key recommendations for a system that: is based on the **real needs of patients**,

- promotes the **ethical, transparent, and structured inclusion of patients**,
- strengthens **trust and partnership dialogue**,

- accelerates **innovation and access to therapies**,
- and strengthens the **sustainability of the healthcare system** and the resilience of society.

We are encouraged by shared successes, such as the legal recognition of the **“Right to be forgotten”** and progress in establishing screening programs for lung and prostate cancer, which provide a good foundation for further fruitful collaborations. This proves that the collaboration of all stakeholders, with the patient at the center, is not only possible but is becoming the new standard.

This document is an invitation to co-create a healthcare system that views the patient as a partner and health as an investment in the future of our society, economy, and a guarantee of further development.

We thank all patient organizations and individuals for their invaluable contribution and valuable time dedicated to the preparation of this document. We look forward to continued cooperation – because only together can we build a system that is just, responsive, and creates added value for patients and society.

mag. Barbara Stegel, Secretary General Farma Forum

Study »The Patient as an Equal Partner«

The study »The Patient as an Equal Partner« offers an in-depth insight into how the Slovenian healthcare system can become more inclusive, transparent, and cooperation-oriented. It stems from the realization that the patient is no longer merely a user of services, but a co-creator of health policy and practice, who significantly contributes with their experiences to understanding people's needs and improving the quality of care.

The central message of the study is the necessity of establishing a partnership between all stakeholders in Slovenian healthcare – patients and their organizations, healthcare professionals, decision-makers, funders, researchers, and the wider society. Such a relationship requires open dialogue, trust, and clearly defined responsibilities, which lead to a more effective and responsive system.

The findings show that patients desire more opportunities for participation in decision-making, better information, and greater transparency in the operation of healthcare institutions. However, for the actual realization of this goal, patient organizations often lack stable support, financial resources, and access to decision-making processes. The study therefore proposes the establishment of a long-term support model that would allow patient associations to

become professionally trained and equal interlocutors of other stakeholders.

An important emphasis is also placed on trust and transparency as two fundamental conditions for the development of a quality and safe healthcare system. Patients must have access to understandable, verified information, and healthcare institutions must operate on the principle of openness and accountability. The essential aspect of stable financing for patient organizations is also highlighted, which will provide the basis for consistent, quality, and sustainable support to the healthcare system. The Patient Organisations Association of Slovenia also pointed this out in our annual Report on the work of NGOs in the health and social care system this year.

The study »The Patient as an Equal Partner« is therefore more than an analysis—it is a call for a change in attitude towards patients, for greater equality, and for understanding healthcare as a joint project of all who participate in it. It represents an important professional and advocacy starting point for the future work of patient organizations and the Patient Organisations Association of Slovenia in building a system based on respect, cooperation, and trust.

Štefanija L. Zlobec, President of the The Patient Organisations Association of Slovenia

Abstract

“One of our interviewees summarized the core message of the patient organisations we spoke with while preparing our reflections on the future of healthcare: *“The system must treat the patient as a partner, not merely as a service recipient.”*”

Bringing these challenges together in one place enhances transparency and responsiveness, creating a strong foundation for dialogue and trust – both essential elements of effective treatment.

We collaborated with eleven patient organisations, carefully selected to represent a diverse sample in terms of size, level of professionalisation and areas of activity. Data were collected from publicly available sources and through eleven in-depth interviews. Our findings were organised thematically and validated in several stages: first by the interviewees themselves, then through questionnaires and finally through a comprehensive review of the entire document.

The discussions revealed four key themes that were consistently interwoven and mutually reinforcing:

- **The importance of user experience, responsibility and influence on service quality:** Participants emphasized perceived system (in)efficiencies and the crucial role of involving healthcare users in improving outcomes.
- **Maintaining users’ trust in the healthcare system:** We explored how patient organisations actively

contribute to strengthening confidence in healthcare delivery.

- **Ensuring equitable access to healthcare:** A recurring concern was safeguarding universal access to healthcare services for all.
- **Viewing healthcare as an investment and promoting stakeholder collaboration:** Healthcare should be regarded as an investment in both individuals and society, not merely as an expense. Achieving this vision requires strong collaboration among all partners.

Addressing these challenges calls for the joint effort of all stakeholders – patient organisations, healthcare professionals, government institutions, academia, industry and others. A collective approach is essential to prepare our healthcare system for the demands of an aging population and the growing needs of society.

Our shared vision is to build an inclusive, data-driven healthcare system that meets people’s needs and recognizes healthcare as an investment in individuals, the economy and society as a whole.

Introduction: Why This Matters?

In our conversations with healthcare professionals, system experts and patient representatives, we often discuss the challenges we all share. Although the experiences are similar, each group views them from its own perspective – and their ideas for solving these issues differ as well. For this reason, we have brought together the experiences of various patient organisations, organised them systematically and outlined a way forward to help align efforts towards shared solutions. Meaningful change will only be possible when all stakeholders are able to contribute their experiences and proposals.

In Slovenia, there is growing consensus that access to high-quality healthcare is essential for the well-being of the population, the economy and society. Now is the right moment to develop mechanisms that allow us to continuously identify the needs of all stakeholders – including service users – and to modernise our healthcare system in an era of rapid technological advancement, increasing life expectancy and an ageing population.

Slovenia is home to top-level experts and outstanding medical excellence. Yet this potential is not fully realized. Users of the healthcare system often point to organisational shortcomings. Healthcare professionals spend a significant portion of their working hours –sometimes up to a third – on administrative tasks. These processes generate vast

amounts of data, but the data often remain inaccessible, unprocessed and poorly structured, limiting their value as feedback and hindering their effective use.

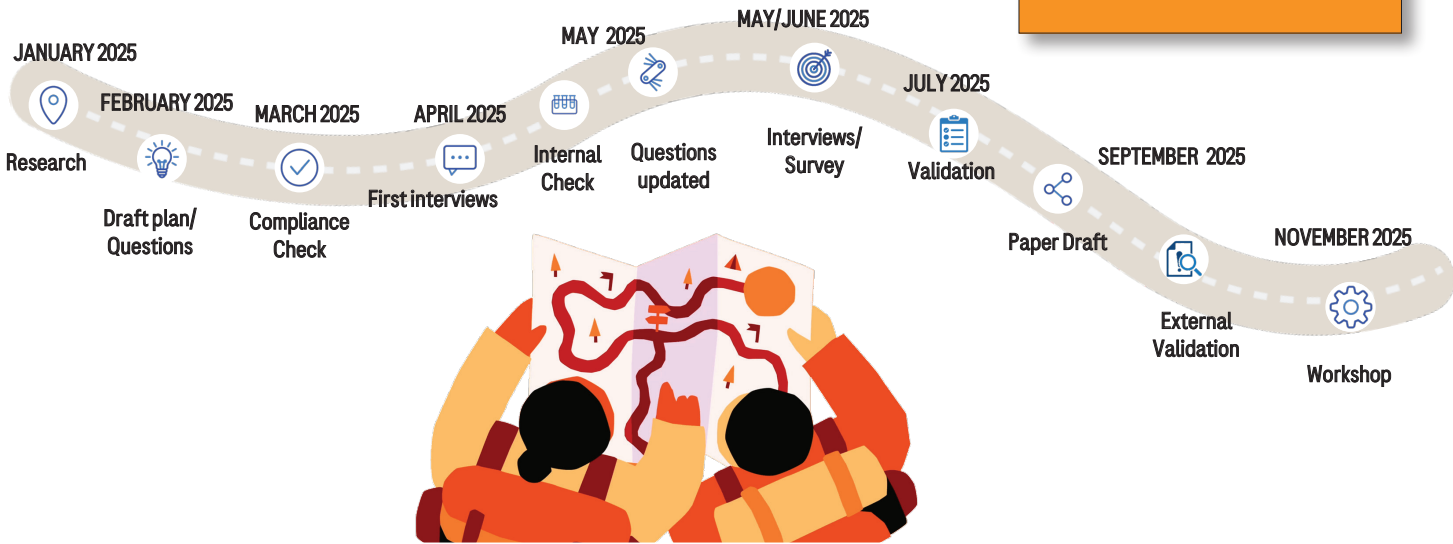
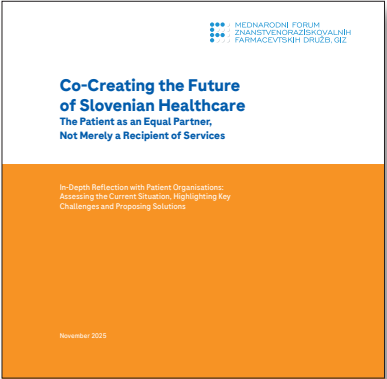
Trust in the healthcare system is crucial. Although the public has confidence in the professionalism of healthcare staff, this trust is eroded by systemic inefficiencies. Both healthcare professionals and patients frequently encounter bureaucratic barriers that seem impossible to overcome, with solutions available only to the most persistent and well-informed. This situation is further complicated by limited health literacy – 48% of adults in Slovenia are considered to have inadequate or problematic health literacy (Source: NIJZ, *Adult Health Literacy in Slovenia*, 2022) – and by the fact that healthcare professionals' duty to inform is often constrained. As a result, patients are left uncertain, lacking understanding of their treatment, the course of their illness, or the functioning of the system itself. In this context, patient organisations play a vital role: they deeply understand patient needs and guide them through the complexities of the healthcare process.

Strong economies are built on healthy populations; health and the economy are therefore inseparably linked. We must recognize healthcare as a strategic investment – a key driver of economic development and societal resilience.

Methodology

In developing this document, we applied a methodology designed to ensure impartial data collection, in-depth analysis and a clear synthesis of information. The process consisted of several key stages, each contributing to a comprehensive understanding of the various dimensions of Slovenia's healthcare ecosystem.

Important steps on our way



Phase 1: Conducting in-depth interviews

In eleven in-depth interviews, we explored questions aimed at understanding the current state and future potential of Slovenia's healthcare system. The interviewees represented a diverse and representative sample of Slovenian patient associations, organisations and federations. Each interview was conducted by two or more interviewers and all responses were returned to participants for verification and additional input. The set of questions was not uniform, as we adapted interactively to the themes and priorities raised during each discussion.

Phase 2: Systematic review of findings and questionnaire

The collected responses were synthesized into fifteen main challenges, which were then validated through an electronic questionnaire sent to all participants. Based on their feedback, we identified seven key challenges whose resolution would have the greatest impact on strengthening and further developing the Slovenian healthcare system.

Phase 3: Review of the draft document with additional external validation

To ensure an independent perspective, we sought the opinion of an experienced external expert, who provided valuable comments that were incorporated into the text. The draft document was also sent back to participating organisations for further review and comment. Their suggestions and corrections were integrated into the final version.

Phase 4: Interactive presentation of findings (November)

The revised version will be shared during an interactive workshop with a broader group of patient representatives. Through active participation in the discussion, they will further contribute to a shared understanding of the challenges and opportunities within Slovenia's healthcare system.

Through this methodology, we ensured an inclusive, accurate and comprehensive representation of the diverse perspectives within the Slovenian healthcare ecosystem. The views presented in this document reflect exclusively the positions of the participating patient organisations and do not necessarily represent the opinions or personal experiences of individual patients — a distinction also highlighted by the external expert reviewer:

Results and Findings: What Are the Key Challenges?

Theme 1: The importance of user experience, responsibility and the ability to influence service quality

Key findings:

- Patient organisations are often overlooked and insufficiently involved in the co-creation of the health-care system.
- The lack of systematic funding prevents long-term and effective operation of patient organisations; however, financing should not rely on a single source, as this increases dependency.
- Patients often fail to recognize the importance of active engagement in maintaining and developing their rights.

Consequences:

- Underutilized potential of patient organisations, which possess deep knowledge of users' needs.
- Less effective patient support and increased strain on the healthcare system.
- Patients may take their rights for granted, which can lead to a gradual erosion of those rights.
- Patients who are not actively involved in their treatment often experience poorer outcomes and consequently place a heavier burden on the healthcare system.

Theme 2: Maintaining users' trust in the healthcare system

Key findings:

- Service users often fail to understand systemic challenges and instead attribute the consequences to healthcare professionals, which undermines mutual trust.
- Preventive activities are neglected both by individuals and the system itself, while their effectiveness is underestimated by the public and by patients.
- Some patients deliberately avoid care or fail to follow prescribed treatment.
- Building mutual trust between patients and healthcare professionals remains a challenge that can be addressed through better, two-way communication and greater transparency.
- Financial constraints limit access to modern therapies.

Consequences:

- Increased complications and higher treatment costs.
- Loss of trust in healthcare professionals undermines patient relationships, directly hindering partnership building and reducing active patient participation in treatment.
- Negative impacts on public health, workforce productivity and public finance.
- Increased demand for additional assistance and, over time, higher overall costs.

Theme 3: Ensuring accessibility of healthcare

Key findings:

- Systemic barriers, bureaucracy and fragmented systems make it difficult for patients to navigate the healthcare environment.
- Limited access to primary care and longer waiting times for secondary and tertiary services.
- Insufficient oversight allows the advertising and sale of harmful products and services.
- Political influence and a lack of knowledge among key decision-makers can lead to inefficient organisation of the healthcare system.

Consequences:

- Rising levels of sickness absence as a result of limited access to healthcare services and extended waiting times.
- An increase in complications and higher costs arising from delayed diagnosis and treatment.
- Harmful products and misleading services that claim to improve health can cause irreversible harm, place additional pressure on the healthcare system and undermine trust between patients and healthcare professionals.
- Reduced efficiency and poor organisation across the healthcare system.

Theme 4: Viewing healthcare as an investment and promoting stakeholder collaboration

Key findings:

- Healthcare is still perceived primarily as a cost, rather than an investment in people, the economy and society.
- Insufficient cooperation among key stakeholders (policy makers, the Health Insurance Institute of Slovenia, patients, healthcare organisations and industry)* slows or prevents necessary reforms.

Consequences:

- Inadequate investment and lengthy procedures that harm both individuals and society in the long run.
- Delayed or hindered implementation of essential systemic changes in healthcare.

* The interviewees emphasised that there is no consistent understanding of who the key stakeholders are

Through in-depth interviews with representatives of patient organisations, we identified essential insights that are critical to understanding the changes and expectations of healthcare users. The analysis of interviews revealed 15 key challenges currently faced by the system, as perceived by patient organisations. To determine priorities, interviewees were asked – through an additional questionnaire – to rank the most significant challenges based on their impact on Slovenia's healthcare system, or to suggest new ones.

The selected key challenges are presented first and are highlighted in bold.

1. **Systemic barriers, bureaucracy and fragmented structures make it difficult for patients to navigate the healthcare system.**
2. **Insufficient cooperation among key stakeholders (policy makers, the Health Insurance Institute of Slovenia, patients, healthcare organisations, industry and others) hinders essential reforms in the healthcare system.**
3. **Limited access to primary care prevents early treatment, leading to complications and higher costs.**
4. **The lack of systemic funding for patient organisations prevents their long-term, strategic, specialized and proactive work, which could otherwise effectively support the healthcare system.***
5. **Patient organisations are often overlooked and involved too late or too little in the co-creation of the healthcare system, despite their deep understanding of patients' needs and their daily role in supporting patients and relieving the burden on the system.**
6. **Healthcare is perceived primarily as a cost rather than an investment in people, the economy and society.**
7. **Service users often misunderstand systemic issues in healthcare and attribute their consequences to healthcare professionals, even though professionals themselves face systemic challenges.**
8. Increasing sick leave rates are linked to poor access to healthcare services, long waiting times and insufficient oversight of service utilisation.

9. Patients often fail to recognize the importance of active involvement in maintaining and developing their rights, frequently taking them for granted.
10. Limited access to modern therapies fuels the spread of unproven and unsafe practices, leading to the use of illegal or inappropriate substances and unsafe treatments.
11. A share of patients deliberately avoid care or do not follow prescribed treatment, resulting in complications and higher healthcare costs.
12. Insufficient regulation enables the advertising and sale of harmful products and treatments, leaving the healthcare system to deal with the consequences.
13. Poor accessibility to innovative therapies and diagnostics can increase the need for additional support and long-term costs.
14. Neglect of preventive activities harms public health, workforce productivity and the national budget.
15. Political influence and a lack of knowledge among key decision-makers can lead to inefficient organisation of the healthcare system.

Focusing on these areas, according to patient organisations, would most rapidly lead to a more effective, collaborative and patient-centered model of healthcare in Slovenia — one that recognizes health as a vital investment in society and individuals, rather than merely a cost.

* In this context, patient organisations emphasise that they seek support in securing funding from diverse sources, not just government ones, in order to maintain their independence.

Conclusion

Involving patients in the treatment process improves outcomes. When patients feel heard and valued, they are more likely to follow medical advice and actively participate in their recovery. The same principle applies to their involvement in shaping the healthcare system.

This approach emphasizes the humanisation of healthcare – placing the patient experience, with its rights, responsibilities and needs, at the heart of every process.

The document “Co-Creating the Future of Slovenian Healthcare: The Patient as an Equal Partner, Not Merely a Service Recipient” highlights the urgent need to redefine the role of patients in the Slovenian healthcare system – from often passive recipients of services to active partners and co-creators. The findings gathered through in-depth interviews with eleven patient organisations reveal four key themes and fifteen interconnected challenges. These challenges – including the insufficient and delayed involvement of patients and their organisations, systemic barriers, lack of funding, limited understanding of healthcare as an investment and low awareness of patient responsibility – hinder the effectiveness and sustainability of healthcare delivery.

The vision for the future of Slovenian healthcare is a data-driven system that integrates patient perspectives into decision-making and fosters an

environment that views healthcare as a strategic investment in individuals, their well-being and productivity –and, consequently, in the economy and society as a whole. This vision focuses on a shift from a reactive to a proactive approach to health, emphasizing prevention, early diagnosis and personalized care tailored to each individual’s specific needs.

Achieving this ambitious vision requires close and transparent collaboration among all key stakeholders. Among them, patient organisations play an invaluable role, as their knowledge and experience contribute to developing policies and services that are truly patient-centered. Such collaboration enables earlier disease detection, fewer therapies, reduced absenteeism and lower costs. Healthcare professionals – doctors, nurses, pharmacists and others – form the backbone of the system; therefore, investment in their education, training and optimal working conditions is crucial. Government authorities and policymakers must establish a stable regulatory and financial framework that supports innovation and sustainable development. Academic and research institutions drive fundamental research for the development of new therapies, while industry contributes innovative solutions and resources for implementing advanced health technologies. A Call to Action:

A Framework for Collaboration Between Patient Organisations and Partners

To effectively address the identified challenges and realize this vision, a coordinated and multi-layered approach based on the active cooperation of patient organisations and partners is essential.

1. Involving Patients and Their Organisations in the Healthcare System:

We recommend that patient organisations develop a strategy for active advocacy and for representing their needs and proposals at all levels of decision-making. They should design and implement programmes to raise patients' awareness of the importance of active involvement in maintaining and developing their rights and establish transparent mechanisms for collecting and sharing patient feedback. Government authorities should systematically and promptly include patient organisations in working groups, committees and policymaking processes; ensure long-term and independent funding; and create platforms for regular, structured dialogue between national and local decision-makers, payers, healthcare institutions, industry representatives and patient organisations.

Healthcare institutions should encourage patient organisation involvement in local quality improvement processes and educate healthcare staff about the importance and role of these organisations.

Industry partners should support patient-led initiatives that enhance patient engagement and collaborate on developing solutions aligned with patient needs.

2. Systemic Barriers and Access to Healthcare:

We recommend that patient organisations collect and document examples of systemic barriers, bureaucracy and fragmented systems encountered by patients, put forward concrete proposals to simplify procedures and improve navigation within the system and promote the digitalisation and integration of healthcare information systems. Government authorities should simplify administrative procedures and reduce bureaucracy. They must establish a comprehensive and integrated information system that allows patients to easily navigate and access necessary information. Expanding access to primary care and reducing waiting times for secondary and tertiary services is essential.

Additionally, stricter control over the advertising and sale of harmful products that falsely promise health improvements is needed, as such practices can cause irreversible harm and erode trust in the healthcare system. Healthcare organisations should improve internal organisation and communication and adopt unified information systems and protocols. Industry should develop and provide technological solutions that support digitalisation and streamline healthcare processes.

3. Recognizing Healthcare as an Investment and Fostering Stakeholder Collaboration:

We recommend that patient organisations engage in active communication about the value of health and healthcare as an investment in society and the economy and collaborate with the media to raise public awareness of this issue. Government authorities should shift the perception of healthcare from a cost to a strategic investment at all levels of decision-making, promote cross-sectoral cooperation and establish transparent dialogue among all stakeholders for joint planning and implementation of reforms. Healthcare institutions should emphasize prevention and early detection as essential investments in public health. Industry partners should share examples of best practices and actively participate in joint projects and initiatives.

4. Responsibility and Awareness Among Service Users:

We recommend that patient organisations develop educational programmes and communication campaigns aimed at informing patients about their role and responsibility in maintaining their health. They should promote preventive activities and healthy lifestyles and provide patients with support and information to help them adhere to prescribed treatment. Training for healthcare professionals on their duty to explain and communicate with patients should also be actively implemented. Government bodies should invest in prevention programmes and public awareness initiatives and ensure appropriate access to modern and innovative therapies. Healthcare organisations should explicitly emphasise and consistently uphold the doctor's duty to consult and inform patients, improve communication with them and encourage active participation in their treatment. They should also offer a holistic approach to care that includes preventive education. The healthcare industry should develop innovative therapies, and solutions that improve patients' quality of life and support research and development in the field of prevention.

Through collective effort and coordinated action, patient organisations, government authorities, healthcare institutions and industry can transform Slovenian healthcare into an effective, patient-friendly and sustainable system that recognizes the health of its people as the most important investment in the nation's future.

