

Patient Mediated Research - What is That?



[Vincent Keunen](#)

*****@***andaman7.com

Founder and CEO - Andaman 7
Digital Influencer - HIMSS
Patient Advocate

Patients have long been left out of the loop when it comes to controlling their medical information. Accordingly, Andaman7 intends to help patients regain control over their health data and enable secure interactions between patients and health actors (hospitals, doctors and public and private researchers). With its innovative patient-centric approach, it also allows to conduct patient-mediated research.

Patients' Right to Control Their Own Medical Information

In the age of digitalisation, the collection and use of medical data have become an essential part of healthcare management as well as a key component of care integration. However, patients have long been left out of the loop when it comes to controlling their medical information. In recent years, there has been a growing recognition of the need for patients to understand, control and access their medical data.

Why do patients need to control their medical information?

- **Patients have the right to access and control their medical information** . They have a fundamental right to their personal medical information, which includes medical history, treatment plans, diagnostic test results, medication lists and more. Many countries have regulations in that sense, and more are developing them. Besides regulations, it's also ethical in accordance with Article 25 of the universal declaration of human rights: "Everyone has the right to good health and well-being of himself and his family".
- **Patients who control their medical information are more likely to engage in their care process and willing to play an active role** , which can lead to better health outcomes. Andaman7 helps patients gather and manage their personal health data in a secure manner with its unique "security by design and privacy by default" architecture, and in this way, contributes to developing patient empowerment.
- **Patients are the primary beneficiaries of their medical information**. Patients who have access to their medical information are better equipped to manage their health in an autonomous manner. They can understand their medical conditions, medications, and treatments better. They can also share their medical information with their doctors and caregivers, which can help improve their care. This is exactly what this app proposes as a tool that allows them to share their medical information with their circle of trust directly inside the app.
- **Patients in control of their health data can also contribute to research**. Research is complex and takes a lot of time - especially for doctors that are already overworked. Engaging patients directly in research with sponsors can help. Patients are also highly motivated to contribute to research that could directly improve their personal situation or their loved ones.

To sum up, patients have the right to access, understand and control their medical information. This is a prerequisite to help them play a more active role in their care pathways, manage their health effectively, contribute to clinical research and make them empowered patients.

[Vincent Keunen](#), the CEO of Andaman7, started with a personal story to create a revolutionary platform. In 2007, he was diagnosed with leukaemia which he survived thanks to the very efficient Gleevec drug. Three months later, his son Pierre, only 10 years old, was diagnosed with bone cancer. He decided to devote himself entirely to innovative software for the medical field. This is how Andaman7 was born, to develop a collaborative health record on smartphones and tablets.

Andaman7 is a mobile application for patients and a secure medical data exchange platform which allows - at last - a real interaction between patients and health actors (hospitals, doctors and public and private researchers). One of its key features is its focus on patient-centred care. It also supports collaboration between healthcare providers. Andaman7 is an innovative platform that drives positive changes in the way health

data is managed and shared with the ultimate purpose of enhancing the overall health outcomes for patients. By empowering individuals and enabling secure collaboration between healthcare providers, the platform intends to improve continuity and quality of care, as well as help develop integrated care all around the globe in accordance with the global trends promoted by the WHO.

The Future of Data Sharing: Privacy and Security as a Top Priority

Since reliable/verified data has become increasingly important in the healthcare industry, it's clear that data-sharing practices need to evolve to meet changing requirements and expectations.

A major trend worldwide is the increasing importance of data governance and compliance. As data becomes more valuable and ubiquitous, there is a greater need for organisations to manage and protect it effectively. But, as said earlier, returning the control of data to individuals is also a right and a necessity.

We, therefore, need new platforms to reach these objectives. Andaman7, developed by patients for patients, does not store any health data in the cloud: all the health information is stored on the patient's phone - and only there (with backups in case the phone is lost). This guarantees a high level of privacy and data security. Then, only if patients consent can they be part of clinical trials and decide to share some of their health data with researchers. This is, in our opinion, the only win-win situation.

The Role of the Patient in Data Sharing

The patient plays a critical role in data sharing. Andaman7 is designed with an innovative patient-centric approach, which means that the patient is at the centre of the data-sharing process. The patient has full control over their health data and can choose who they want to share it with (circle of trust). This means that the patient can decide which healthcare providers, family members, caregivers, or researchers can receive their health information.

The patient can also choose which specific pieces of information to share, such as lab results, medications, or allergies. By giving patients greater control over their health data, we are empowering them to take a more active role in their own healthcare. Patients can use the platform to keep track of their health information over time, monitor their progress, and share their data with healthcare providers to facilitate more personalised care.

In addition, Andaman7 is opening the path to a new way of carrying out medical research, which is called patient-mediated research. This makes it easier to run DCT, RWE, HEOR studies or, more broadly, next-generation clinical research studies. Concretely, patients who would wish to contribute to the advancement of science can use the platform to participate in clinical research studies or to donate their data for scientific purposes. This can help to advance medical research and ultimately lead to better treatments and outcomes for patients. Obviously, patients always consent before contributing to medical research in accordance with GDPR and HIPAA regulations. Besides privacy regulations, tools for clinical research must also be validated for FDA 21 CFR part 11 and EU Annex 11.

Overall, the patient's role in data sharing is crucial. By giving patients greater control over their health data and enabling them to participate in the sharing process, such advanced platforms are helping to foster a more collaborative and patient-centric healthcare system.

Complex Profitability due to the Patient, HCP and Payer Triangle

The triangle of patient-consumer, HCP-provider and payer creates distortions in the supply and demand of health services, making profitability complex. Indeed, the relationship between supply and demand is indirect due to the presence of social security in Europe or insurers/payers in the United States, who play the role of intermediaries. This intricate nature of healthcare profitability arises from the interaction between patients as users of healthcare services, healthcare providers acting as service suppliers, and payers (like insurance companies or social security) serving as the financial backbone, or often a brake, of the service. This dynamic creates a three-party relationship that may result in supply and demand distortions.

The Andaman7 platform aims to improve the patient experience while providing value for healthcare providers and payers. To navigate this complex triangle, it must balance the financial viability of its platform with its goal of improving healthcare outcomes and patient satisfaction - without any additional cost to patients. That's the social goal of the project, which is a critical part of this approach.

Conflict of Interest Between High Profitability and the Social and Non-Economic Aspects of Personal Care

When it comes to healthcare, tension can be noticed between profitability and accessibility, a sort of double bind. On the one hand, profitability is needed to ensure the sustainability of health systems and health organisations, but on the other hand, healthcare and health services should also remain financially accessible for patients, regardless of their financial situation. Indeed, accessibility of care is also one of the key components of integrated care, which might be difficult to balance with the above-mentioned profitability constraint. As a result, in a healthcare system focused on high profitability, there can be a conflict of interest between seeking economic profit and providing socially responsible care.

This is not unlike the components of the well-known Triple Aim model, a framework developed by the Institute for Healthcare Improvement, which consists of a combination of three interdependent objectives: “improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for populations”. Healthcare organisations use this framework to create a more sustainable and effective healthcare system that delivers high-quality care, improves population health, and reduces costs.

Andaman7 and the Triple Aim framework share a commitment to improving healthcare outcomes by focusing on patient-centred care, improving population health, and reducing healthcare costs.

Conclusion

In the era of digitalisation, care integration, patient empowerment and new needs for research, the development of tools that allow patients to regain power over their health data in a secure manner has become a top priority. In this context, a key challenge is to create tools that are accessible to patients and healthcare professionals while maintaining the balance between cost effectiveness, quality and accessibility. Integrating clinical research with patients and care providers is also becoming critical.

Andaman7, a project by patients for patients, was born in this context, trying to deal with those different constraints. The platform combines, in an innovative manner, an advanced PHR and a medical research platform in order to achieve a threefold goal:

- empowering patients by helping them better manage their health data.
- enhancing collaboration between healthcare providers with a tool that supports disease management for hospitals and doctors.
- improving clinical research by enabling outcome measurement for pharma and research.

Published on : Tue, 1 Aug 2023