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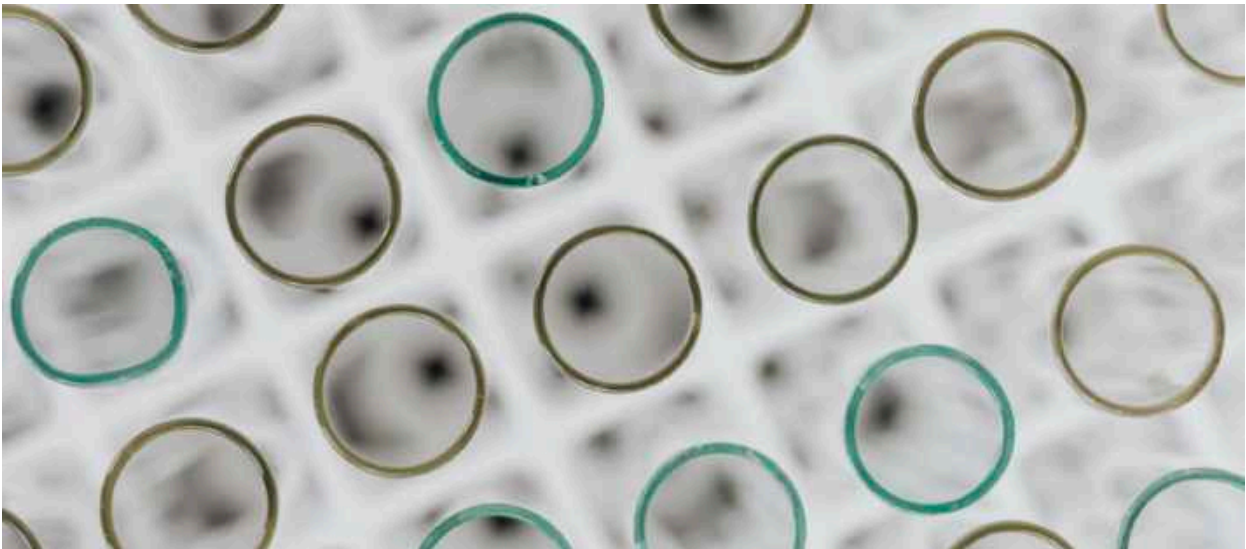


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THE EFFECTIVE COMBINATION OF VALUE-BASED HEALTHCARE AND HUMAN-CENTERED DESIGN

The successful example of Project Copernico on a rare disease conducted by the Maugeri Scientific Clinical Institutes with the support of Takeda and Your Business Partner.

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THE ITALIAN HEALTHCARE LANDSCAPE has been facing a growing challenge for some time: the management of chronic rare diseases. These conditions require specialized and long-term care, putting a strain on the National Health System (SSN) and its sustainability. The Value-Based Healthcare (VBHC) approach, devised by Michael Porter, a professor at Harvard Business School, emerges as a beacon of hope by offering the possibility to improve clinical outcomes and patient experience at significantly lower costs.

In the United States and in Northern European countries, including the Netherlands, Denmark, and Sweden, this approach is already widely used and has led to

Project Copernico: The Case of Hereditary Angioedema

The Maugeri Scientific Clinical Institutes, also thanks to the unconditional sponsorship of Takeda, have decided to apply the Value-Based Healthcare approach combined with

Human-Centered Design to a patient pathway, in order to conduct a pilot project and measure its results. In fact, with Project Copernico, the clinical team at Maugeri, supported by Your Business Partner (YBP), a consulting company specialising in strategy and innovation, has worked on redesigning the pathway dedicated to Hereditary Angioedema (HAE). Copernico has allowed the development of an effective model that ensures process standardisation, personalised care, and high-quality services for patients and caregivers. Given the sustainability of the model, ICS Maugeri is now structuring its scalability for other patient pathways.

To address the challenging issues present in a context like that of HAE, Project Copernico adopts the methodology of Value-Based Healthcare and the tools of Human-Centered Design to identify the unmet needs of key stakeholders, design innovative and disruptive solutions, and, above all, communicate empathetically the complexity of the lives and experiences of these patients and caregivers.

To achieve this, Project Copernico worked with a multidisciplinary team led by clinicians, including two HAE specialists, an allergist/immunologist, a psychologist, and a dedicated nurse. The medical team was supported by consultants from Your Business Partner with expertise in project management, disruptive innovation, business analysis, and service design.

A rare hereditary disease

Hereditary Angioedema (HAE) is a rare hereditary disease that affects approximately 15,000 people in Europe and about 1,200 in Italy. Patients with this condition suffer from unpredictable episodes of severe swelling that can last from 2 to 5 days. The severity varies depending on the affected area, and if not adequately treated, the condition can become life-threatening. HAE patients require on-demand medications during attacks and, depending on the severity of the condition, long-term prophylactic treatment. The lack of awareness among emergency room physicians and the various symptomatic manifestations of the condition often lead to misdiagnoses. Studies have shown that the average delay in diagnosing HAE patients in Europe is about 10 years, and affected individuals typically visit an average of 4.4 doctors before receiving an HAE diagnosis. In Italy, in 2018, the average annual cost for an HAE patient to the National Health Service (SSN) was approximately €11,912. However, misdiagnosed or inadequately treated HAE attacks can lead to increased hospitalizations and even unnecessary surgical procedures, further raising costs for the SSN.

Furthermore, individuals with HAE face specific challenges related to the disease, influencing their physical and mental health and limiting their ability to perform daily activities. 42.5% of patients may exhibit symptoms of depression and anxiety, often related to the severity of the chronic illness or associated pathophysiological characteristics. Patients with more frequent and severe attacks may encounter significant barriers to education and productivity at work, creating an additional economic burden. This underscores the need for a change in the care pathway to increase value for patients and all stakeholders involved.

Achieved Results

Project Copernico has achieved numerous significant results that have particularly improved the patient experience along the care pathway and the organisational effectiveness of the process. In the pre-diagnosis and diagnosis phase, there are two

main results, both aimed at reducing diagnostic delays and facilitating the patient in reaching a diagnosis:

1. Utilisation of SEO to direct search engines toward the scientific society, patient association, and the operational unit for HAE care.
2. Streamlining the laboratory testing process to provide patients with a clear diagnosis in a timely manner.

In the post-diagnosis phase, which involves treatment and monitoring, three impactful results have been achieved:

1. The establishment of a drug management pathway that includes the adoption of a bundled payment contract for drug supply based on the requests and needs of patients. This new drug management pathway ensures a reduction in waiting times for patients and a significant decrease in warehouse waste and inefficiencies, leading to a consequent reduction in costs for the healthcare system.
2. Introduction of dedicated psychological support. Alongside the Clinical Psychologist, now an integral part of the multidisciplinary team for HAE patient care, an integrated mental health pathway has been developed. Recent studies have shown that anxiety and depression can be triggering factors for HAE attacks, and conversations conducted with patients during the project have once again confirmed this connection. The structured psychological support pathway with Project Copernico can be individual or group-based, depending on the preferences and different situations in which patients find themselves.
3. Remote monitoring through a digital platform. To measure the outcomes of the new care pathway, the team has designed a completely new tool in the context of HAE, the Ecological Momentary Assessment (EMA). EMA is a tool that observes the moods and behaviours of patients in their daily lives, specifically focusing on mental health factors and psychosocial stress indicators. This method provides more accurate results compared to data collection methods that require people to recall symptoms, moods, and events over an extended period.

The Different Phases in Detail

Project Copernico has been divided into two phases: understanding the needs of patients and caregivers, and redesigning the patient pathway.

Phase 1: Understanding the needs of patients and caregivers. The Your Business Partner team conducted 17 conversations with patients, caregivers, and individuals who are both patients and caregivers. The conversations took the form of semi-structured interviews to maintain a common structure for comparative analysis while allowing the interviewees the freedom to express themselves and share their experiences and needs.

These conversations resulted in a total of 6 Personas, including 4 patients, 1 patient-caregiver, and 1 caregiver not affected by HAE. Personas are archetypes representing the real stories, experiences, and needs of specific segments of patients with common characteristics. This Human-Centered Design tool allows for empathetic communication of the lived experiences of the interviewees and the insights gathered while maintaining the absolute anonymity of the interviewees and presenting the results in an aggregated manner.

The team used specialised software for textual analysis to conduct a thematic analysis of the conversations and objectively identify the most important themes for patients. Additionally, thanks to the same software, the team could associate emotions such as

anxiety or relief with each of the emerging themes, beginning to structure an organisation of topics by identifying elements of difficulty and facilitators that emerged.

Figure 1. Example of a Personas: HAE-affected patient

LUCA
 • 40-49 anni
 • Emilia-Romagna
 • Lavora a tempo pieno
 • Senza figli

La nostra malattia è difficile da far capire perché ti vedono così [senza sintomi esterni], "questa qui si sta sognando" [pensano], e magari internamente stiamo morendo.

BACKGROUND
 Luca è la prima persona ad essere stata diagnosticata nella sua famiglia. La famiglia aveva forti gonfiori, ma a suo tempo nessuno sapeva nulla di HAE. Sospetta che sua nonna possa essere morta da giovane a causa di HAE.

Luca ha avuto i suoi primi attacchi quando era un bambino. Gli altri bambini lo prendevano in giro a scuola a causa della sua faccia gonfia e preferiva nascondersi a casa. All'inizio dei suoi 20 anni, ha avuto un forte attacco che lo ha mandato al pronto soccorso. Non riuscivano a capire cosa avesse. Dopo svariate consultazioni un allergologo decise di controllare i suoi inibitori C1/C4 e lo mandò da uno specialista che finalmente fu in grado di diagnosticarlo. Di conseguenza, i suoi familiari vennero testati e diagnosticati a loro volta.

Ad oggi i suoi familiari si supportano a vicenda nella gestione di HAE: visite al primo soccorso, raccolta e condivisione dei farmaci, viaggi a Milano.

Luca è un membro dell'associazione pazienti e frequenta regolarmente gli incontri. Ritene che sia importante partecipare ai progetti di ricerca che migliorano la vita a coloro che sono affetti da HAE.

ESPERIENZA CON IL CENTRO
 Luca ha seguito gli specialisti HAE in diversi ospedali di Milano (Ospedale San Giuseppe, Ospedale Sacco) e ha partecipato a studi clinici. Quando il Centro HAE ha aperto in Maugeri, ha deciso di spostarsi poiché era più semplice per lui raggiungerlo in macchina e riteneva che il team medico li fosse più empatico e disponibile.

GESTIONE DELL'HAE
 I fattori scatenanti sono lo stress, sforzo fisico, determinate sostanze chimiche, e recentemente il vaccino COVID. Dopo anni di assunzione di Denazol, ha iniziato ad accusare problemi al fegato e ha interrotto la terapia.

Ha avuto una brutta esperienza al pronto soccorso nell'ospedale locale a seguito di un attacco laringeo, il medico non sentendosi sicuro ad effettuare la terapia gli suggerì di spostarsi a Milano, a 75km di distanza da casa sua.

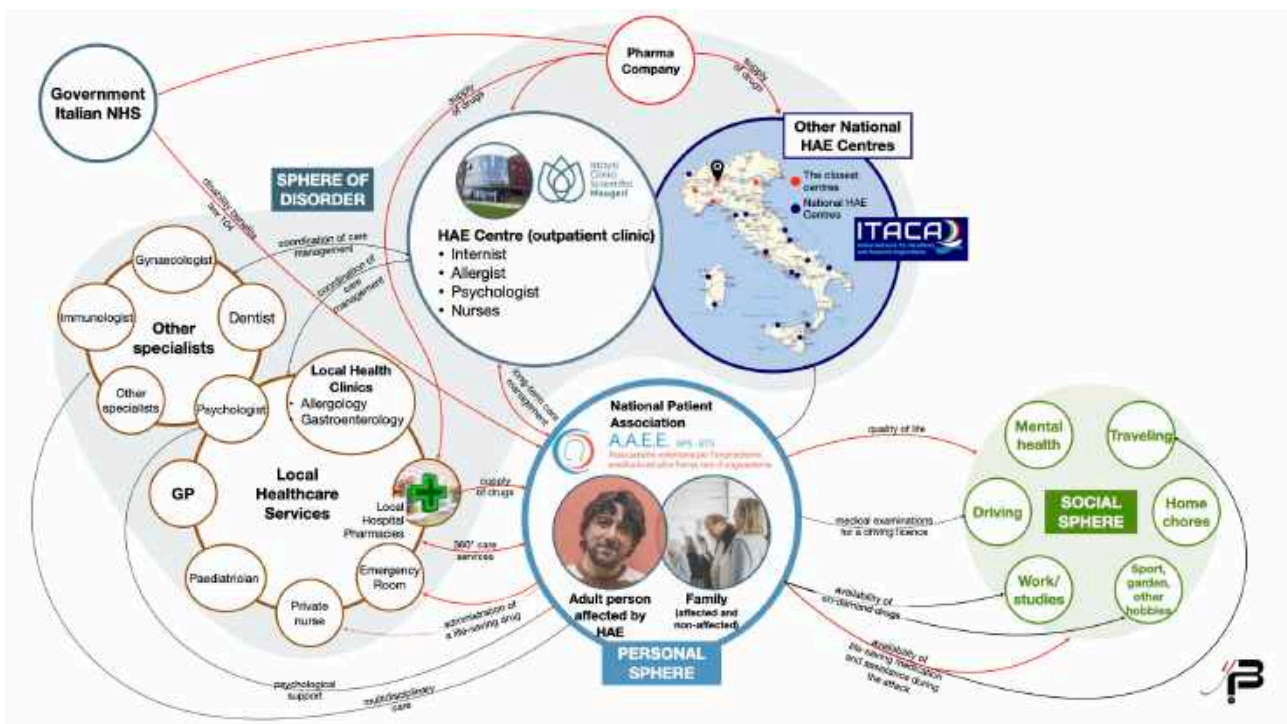
Ora assume farmaci sia per gli attacchi che per la terapia di profilassi. Recentemente un farmaco di profilassi gli ha cambiato drasticamente la vita riducendo gli attacchi. Ha ancora farmaci per gli attacchi a casa e al lavoro, e se li porta con sé quando viaggia. Dopo l'esperienza negativa al pronto soccorso, ha assunto un'infermiera per gestire il farmaco IV per gli attacchi più forti.

BISOGNI

1. **Supporto psicologico:** qualcuno con cui parlare durante i momenti difficili.
2. **Aumentare la sensibilizzazione rispetto all'HAE** tra i professionisti della sanità locali, è stato di dover spiegare cosa sia l'HAE. Ha avuto difficoltà quando ha dovuto rinnovare la sua patente di guida a causa di problematiche legate a agevolazioni per invalidità.
3. **Legge 104:** Luca ha il 70% di agevolazioni per disabilità. Vivere con l'HAE può essere debilitante sia fisicamente che mentalmente. Pertanto, più che un supporto economico, gli piacerebbe avere un permesso di tre giorni con la Legge 104.

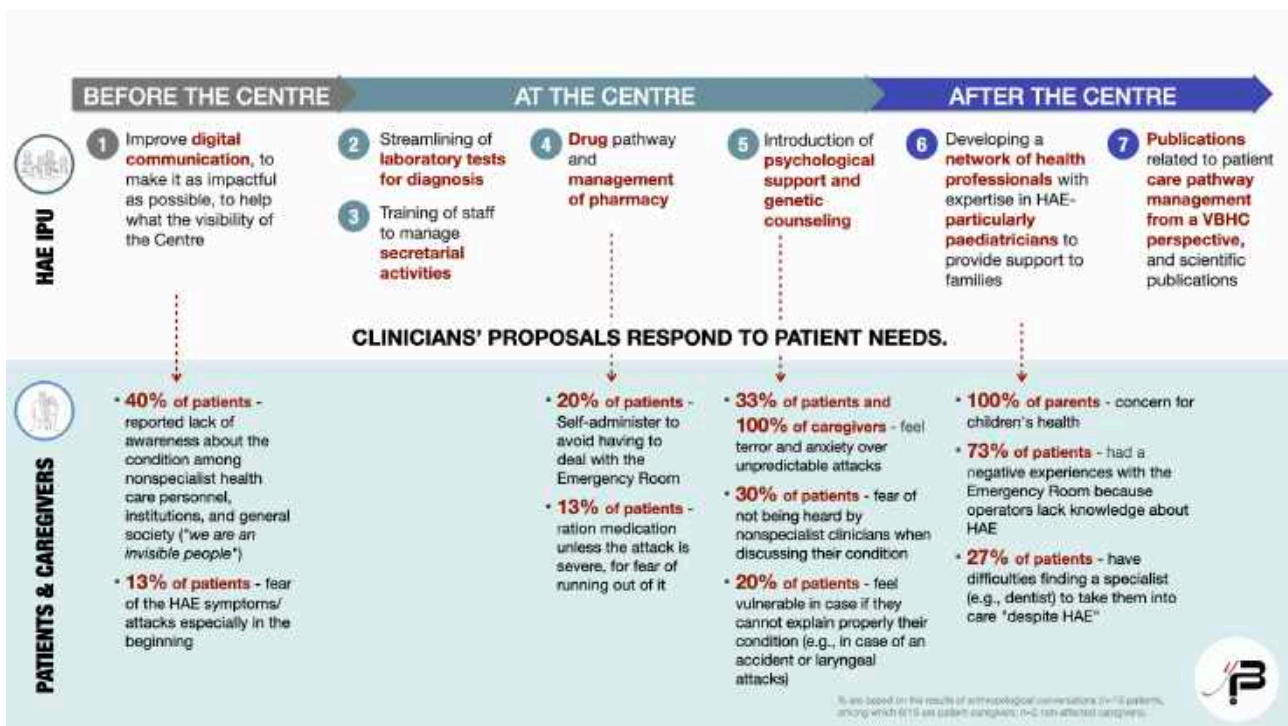
The second output of this initial phase of work was the Relationship Map. This tool consists of an actual mapping of the complex network of social, personal, and clinical interactions that characterise the patient's life from a 360-degree perspective. This tool is crucial for understanding the relationships that provide support to the individual, those that assist them in making important decisions, and the areas necessary for achieving both personal and professional fulfilment. The purpose of this phase of work is to identify services that can enhance the patient's experience even outside the hospital setting.

Figure 2. Example of a Relationship Map for HAE-affected patients



Phase 2. Redesign of the patient pathway. The multidisciplinary team worked intensively in three workshops, each lasting an hour and a half, where they redesigned the entire end-to-end patient pathway, starting from the initial symptoms, through pre-diagnosis, diagnosis, and treatment, and finally to monitoring. The goal of the new pathway was to improve the patient experience, clinical outcomes, and process efficiency. To achieve this, the project's multidisciplinary team began by considering the needs identified in conversations with patients and caregivers. The team noticed how often the needs of patients coincided with the needs of clinicians, which helped structure an even more relevant business case that addressed the needs of multiple stakeholders.

Figure 3. Comparison of Needs Identified by Clinicians and Patients



IN CONCLUSION, the combination of the Value-Based Healthcare approach and Human-Centered Design represents the most effective strategy for understanding the real needs of patients and developing prototypical solutions capable of significantly improving the patient experience, clinical outcomes, and organisational efficiency. Value-Based Healthcare teaches us to focus on outcomes that truly matter to patients, putting their perspective at the forefront. By integrating this approach with Human-Centered Design, we can actively involve patients in the solution development process, using ethnographic research tools and design thinking to thoroughly understand their needs and design services and treatments that specifically address those needs. This synergy between patient value and a user-centred approach ensures that solutions are truly effective, aligned with patient expectations, and capable of optimising organisational resources to provide the maximum benefit possible.