

**IMPACT
HUB**

Cluster for Patient
Empowerment

C4PE

Cluster for Patient Empowerment



**IMPACT
HUB** Madrid



PHILIPS

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CLUSTER FOR PATIENT EMPOWERMENT

Today's healthcare system faces very complex challenges like ageing, chronicity and the sustainability of the system itself.

At the same time, the world is currently undergoing a large-scale digital transformation at breakneck speed, what is often referred to as the "fourth industrial revolution." Physical, digital and biological limits are becoming blurred and interrelated, significantly impacting our lives and how both the sick and the healthy manage their health.

Given this complexity, and the wealth of opportunities it holds in store, we need to rethink how we prevent, identify, resolve and treat health problems. Ongoing technological advances can help us design a sustainable and proactive health system focused on maintaining health, and preventing disease and acute episodes, while preserving universality, fairness and quality. But it is not a matter of technology alone. Despite there being widespread consensus on what the new health system can and should be, we will have to join forces to manage the transition to this new system.

The new 21st century health system therefore extends beyond the borders of the current healthcare system, making it necessary to

C4PE

The Cluster for Patient Empowerment is a multidisciplinary, flexible, and participatory organizational partnership launched by Impact Hub Madrid in September 2016. Its mission is to accelerate the empowerment of patients by experimenting with new ways of working at different levels, generating knowledge and experience to help improve patients' quality of life and to become an engine of transformation in healthcare.

It is an innovative space where organizations, people, institutions and communities work together to develop innovative approaches to health products and services with improved quality and efficiency, and that are an engine for economic and social development nationwide.

evolve towards a participatory health system involving citizens, healthcare professionals, industry, and the social arena, as well as new non-traditional healthcare players like companies, schools, neighbourhoods and cities, forging partnerships to tackle major health challenges.

In this new environment, citizens will have to take a much more active role in maintaining and caring for their health. At the same time, patient experience, opinion and knowledge can and must become a key factor in determining objectives and priorities, and in innovation, product development, service provision and research.

The Cluster for Patient Empowerment is a participatory partnership that brings together individuals and organisations with a shared vision and a mission to affect change in the world.

Carolina Rubio Miner.
C4PE Coordinator.

Since its launch in 2010 **Impact Hub Madrid** has hosted numerous activities and programmes related to innovation in health. A very diverse ecosystem of agents directly and indirectly related to health has evolved over the intervening years, committed to working together to tackle the 21st century's health challenges. In April 2016, on the sixth anniversary of **Impact Hub de Madrid**, a series of co-creation workshops were organized involving individuals from the across the health ecosystem. It was during these sessions that the idea to create a cluster to work on patient empowerment arose.

Impact Hub de Madrid is a neutral space and the ideal home for a multi-agent initiative like a cluster focused

on developing co-creation processes; sharing the latest trends, activities and practices in patient empowerment; generating greater community knowledge of the main issues linked to patient empowerment through studies, position papers and practical solutions; and collaborating with opinion leaders and the entire healthcare field to make positive impacts in Spain.

Antonio González.
Director of Impact Hub Madrid.



Impact Hub is an international movement launched 11 years ago in London, and currently present in over 80 cities worldwide with over 15,000 members. We focus on promoting innovation and social entrepreneurship by inspiring, connecting and driving collaborative and entrepreneurial projects with impact.





Takeda is an innovative pharmaceutical company with over 230 years of history and tradition. Today it mainly works in the fields of oncology, inflammatory bowel disease and pain management.

Grounded in our experience but with our sights set firmly on the future, we have seen an opportunity in the Cluster for Patient Empowerment from its onset, to work as a pioneering company with Impact Hub to build a space for generating knowledge, establishing partnerships, creating work networks, and sharing health experiences in an environment conducive to growing ideas.

Thanks to our work developing innovative, effective and

sustainable drugs that add value to health systems, innovation is part of our DNA and is the main reason we support this project.

We understand that behind research lie the hopes of many people that their diseases will be cured, or at least their symptoms alleviated, so that they can resume their daily lives and return to working, studying, enjoying free time or caring for their families.

At Takeda, we hope that the day will come when we will be able to say that diseases like cancer or inflammatory bowel disease can be cured or converted into chronic illnesses, and that pain will cause increasingly less suffering.

In this future that we imagine for ourselves it will be essential to work together to support innovation in the healthcare system, not only in what we do but in how we do it.

Today's new world needs inspirational people to contribute their knowledge and experience to tackling major healthcare challenges; leading influential organisations to cover outstanding needs in health; and of course patient associations, NGOs, companies, innovative start-ups, scientific societies, universities, and others.

In this sense, Takeda's collaboration with Impact Hub transcends our everyday routine to become a strategic

partnership in health with an openness to change.

Happy first anniversary and we look forward to celebrating many more years together.

Margarita Morais.

Strategic Planning & Commercial Operations Director.



At **Philips** we have set an ambitious goal for 2025: to improve the lives of 3 billion people worldwide each year. We make lives better by helping people stay healthy, live well and enjoy life. We work together with our clients and partners. We help doctors care for patients and their families. We help people take better care of their health. We integrate technology, data and individuals to help people stay healthy and recover quickly from illness.

At the end of the day, our mission is to break down barriers on the path to becoming a patient-centric health and healthcare organisation, with the goal of achieving better results. One of

the keys to this is collaboration. The concept of “patient-centric healthcare” seems to have finally shaken off the remnants of the paternalistic system. The key to progress and transformation is undoubtedly to move towards collaborative healthcare in which patient experience is integrated into the design of processes, procedures and technology.

That is why we consider an initiative like the Cluster for Patient Empowerment to be so important, and why we have decided to support it from the onset. Because only through a constructive dialogue among all stakeholders, based on patient experience, will it be possible to transform healthcare. And because we believe that any

initiative in this field must go beyond the mere exchange of ideas to include actions to break down barriers and overcome organisational, cultural, technological and economic limits.

By supporting the C4PE we reaffirm our conviction that

there is always a better way to improve people’s lives, through innovation and collaboration

Ángeles Barrios.

Brand, Communications and Digital Director at Philips Ibérica.



CLUSTER FOR PATIENT EMPOWERMENT

AREAS OF WORK

We work in the following areas:

Generating co-creation processes related to patient empowerment, with the help of patients, health professionals and other agents in the system.

Sharing the latest trends, activities and practices in the area of patient empowerment with Cluster members.

Helping to generate greater community knowledge on key issues related to patient empowerment through studies, position papers and practical solutions.

Working with opinion leaders and public administrations to affect positive change around this issue throughout Spain.

Positioning companies and other agents on the issue of patient empowerment.

CLUSTER MEETINGS

“INSPIRATION-ACTION” MEETINGS

Cluster meetings are “inspiration-action” sessions held approximately every two months. Facilitated by experts, these sessions aim to share initiatives, practices and activities that inspire attendees to then work together on solving a series of challenges.

The meetings are attended by around 40 individuals from the health ecosystem, including representatives from the health system (professionals and managers), industry (large companies and start-ups), the pharma and healthtech field, patients’ families and social networks (patients and associations), and other agents directly or indirectly related to the sector (research, medical and pharmaceutical associations, universities, etc.).



PUBLICITY AND COMMUNICATION

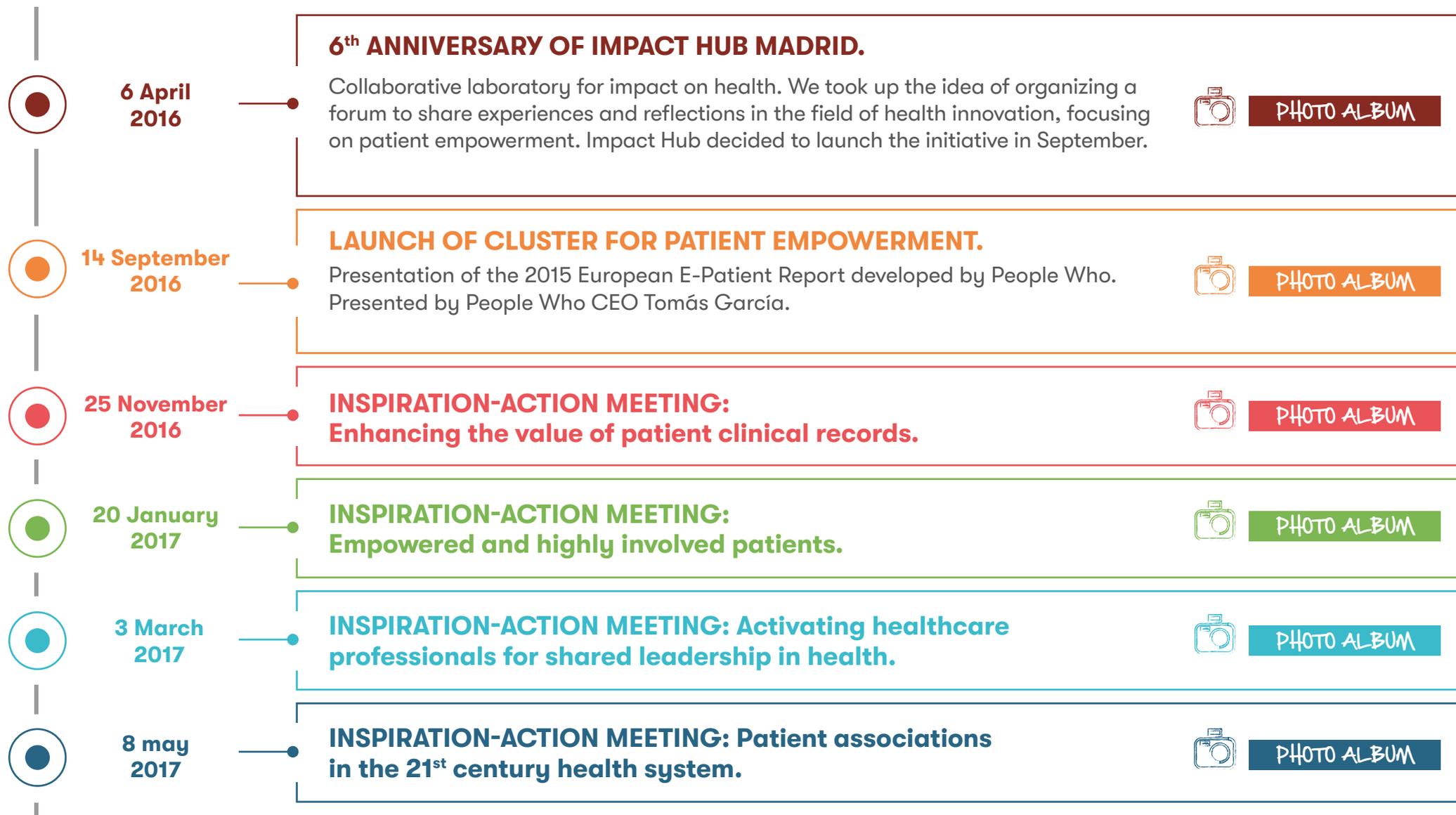
The lessons learned and conclusions reached in each meeting are shared with all members of the Cluster and beyond through an online guide that is open to the public:

➔ <https://guides.co/g/cluster-for-patient-empowerment/63407>

The goal is for the information to be shared with the greatest possible number of people and organisations, in order to generate reflections, knowledge and experience aimed at transforming the health system.



ONE YEAR OF C4PE





CLUSTER MEETINGS



Enhancing the value of patient clinical records

25 November 2016



“I want a health record where I can store and process the data I want, on the app or device I want, and share them with whomever I want... Can anybody help me?”

This is a common request from many patients worldwide. But what is the situation in Spain? How would patients benefit? Do we understand the potential of unified clinical records? How would this improve how the healthcare system is managed? What about treatments and diagnoses? What possibilities does it offer for research? These questions and many more were raised at this Cluster meeting.

TESTIMONIES



“We need a plan for training patients to manage their clinical records and to truly take charge of them, deciding how, when and with whom to share them.”

María Gálvez. Director of Patient Organisations Platform.



“Clinical records are going to go from belonging to doctors to belonging to us, as citizens. We have no greater capital than our own health, and our clinical records will be a basic instrument to advocate for it, maintain it and take better care of it.”

Olga Rivera. Chair of the University of Deusto. Former Deputy Minister of Healthcare Quality, Research and Innovation of the Basque Government.



“At Savana we extract information buried in electronic medical records and make it available for all possible uses – like supporting research and generating science – with innumerable benefits for patients.”

Jorge Tello. Savana Founder and CTO.

Enhancing the value of patient clinical records

25 November 2016

INSIGHTS

- In Spain it is unusual for citizens to request their clinical records: they don't realize they can, they don't know how and where to do so, they wouldn't know what to do with them, and they don't perceive the value in it.
- We must promote a movement towards universal vital health records. We must inform and educate citizens about the importance of vital health records and their value to patients, to healthcare professionals and organisations, to the research field, and to the health of all citizens. We must call for legislation addressing the ownership and custody of data, and their processing, transfer, security, and other related issues.
- The lack of interoperability standards makes it difficult for data from different sources to be quickly integrated and displayed on a single platform and transferred to third parties.
- Patient-centric business models and solutions do not exist. Current solutions deliver much greater value to the paying entity that manages the application and the data (insurance companies, healthcare system, employers, etc.) than to citizens themselves, and these entities are not motivated to enrich the data and keep it updated.

VISION

Develop interoperable platforms with a critical mass of users in order to make the "vital health record" a tool of collective intelligence that can translate data into information that is valuable to citizens, helping them stay healthy and inspiring healthy behaviour, and becoming something that is truly powerful for patients, healthcare professionals/ organisations, the health research field, and all of humanity



➔ Conclusions summarized at the following link:

<https://www.slideshare.net/ImpactHubMAD/cluster-for-patient-empowerment-conclusiones-del-encuentro-del-25-de-noviembre>

Empowered and highly involved patients

20 January 2017



“Patients aren’t experts in diagnosing and treating illnesses, but they are experts in experiencing them”

Patients are an essential source of information and education for other patients. By participating in workshops, blogs, social media and other activities, they are helping other patients in many ways: to understand and better manage their illness, to learn about the latest technological and pharmaceutical advancements for diagnosis and treatment, to manage their emotions and/or those of their family members regarding their disease, to internalise their health status and reduce its impact on their lives, to name just a few.

What impact do these patients have on the healthcare/health system? What is their role in 21st century health? What efforts are needed to maintain this dedication? Is their knowledge and dedication being recognised? Should their work be professionalised? Who could support their economic sustainability and how, while maintaining impartiality?

TESTIMONIES



“Diabetes requires you to be an expert in YOUR diabetes. The Internet is key to learning how. Patients could begin to help transform the healthcare system in a very obvious, simple and clear way starting tomorrow, if they were just given a voice and a channel to do so.”

Óscar López de Briñas. communication specialist and author of the blog “Reflexiones de un Jedi Azucarado”.



“We can use blogs and social media to interact with other patients, share experiences, and together learn how to better manage our diseases; in short, to learn more about multiple sclerosis.”

Paula Bornachea. computer specialist, professor and author of the blog “Una de cada mil”.

Empowered and highly involved patients

20 January 2017

INSIGHTS

- The benefits that come from patient empowerment/activation are widely recognised. But there is increasing evidence of the benefits of **inter-patient support**.
- Empowered/active patients contribute to prevention, quality of life and self-healing. **Highly involved patients** ALSO contribute to improving the health of other patients.
- Empowered and highly involved patients could carry out different health actions/initiatives aimed at other patients, healthcare service providers, the health industry, health research and healthcare administration.
- Inter-patient support at the different stages of disease is something that the healthcare system should include in its services.

VISION

Patients will play an increasingly active role in the new 21st century social-healthcare model. Patient experience and opinion are of key importance and have the potential to contribute to the health of other patients, to the formulation of new products and services, and to research; in short, to the transformation and sustainability of the social-healthcare system. It is therefore essential to channel patient participation and convert their opinions and experience into knowledge and **VALUE**, to develop network capabilities and solutions to respond to **TODAY'S** real social-healthcare problems, and to identify future capacities and requirements to develop solutions for **TOMORROW**.



➔ Conclusions summarized at the following link:

<https://www.slideshare.net/ImpactHubMAD/cluster-for-patient-empowerment-conclusiones-del-encuentro-del-2-de-enero-2017>

Activating healthcare professionals for shared leadership in health

3 March 2017

One of the main goals of patient empowerment is to enable people to actively participate and achieve shared leadership in health management (healthcare professional-patient). This requires patients to be properly trained and motivated to do so. But is this enough?

Educational initiatives have thus far mainly focused on patients, but to achieve shared leadership is it also necessary to activate or motivate healthcare professionals? What preparation do healthcare professionals require in order to treat empowered and digitized patients? How can we build trusting relationships that foster positive health results and better experiences for both parties?

TESTIMONIES



“It is a programme that rests on two pillars. One is the methodology of business schools, which attempts to tackle programs from the inside out, breaking them down in order to solve them. The other pillar is experiential learning, using simulation environments with state-of-the-art mannequins, actors and even real patients.”

Joaquín Casariego. MD, EMBA Fundación Aldebarán – Simulation-based experiential training method.



“There are several means of empowerment: transmitting knowledge to healthcare professionals and patients through training programmes; relational empowerment in which healthcare professionals, patients and other stakeholders work together to build technology, protocols, etc. to level out relationships; and emotional empowerment, which can reduce the anxiety and stress levels of patients and professionals alike.”

Carlos Bezos. Patient Experience Institute – Training methods for patient empowerment.

Activating healthcare professionals for shared leadership in health

3 March 2017

INSIGHTS

- The main ingredients of trust are sincerity, empathy and a feeling of safety. A good trusting relationship also requires approachability, respect and effective communication. We must promote active listening, transparency and horizontality as well as a process of constant evolution.
- Constantly evolving towards putting patients at the centre is also necessary.
- Although the digital world plays an essential role, human contact remains a key element. Technology is not an ends but a means to promote two-way relationships that are proactive and based on the sharing of large amounts of quality information.
- Generating spaces where patients can interact with the healthcare ecosystem in a friendly human environment, where information is always available and where patients take active roles within the healthcare system, becoming involved in assisting and supporting new patients.

VISION

Healthcare professionals and patients must work together to establish a new relationship paradigm of shared leadership in health backed by other agents from the social and business spheres in order to contribute to the transformation and sustainability of the 21st century healthcare system. Trust, active listening, transparency, horizontality, knowledge and two-way communication are key factors to achieving this shared leadership.



Patient associations in the 21st century health system

8th may 2017

The 21st century healthcare system faces very complex challenges, making it necessary to rethink how we prevent, resolve and treat health problems. We must join forces around a great common challenge: the transformation and sustainability of the healthcare system.

How can patient associations contribute to the transformation and sustainability of the healthcare system? How can we join forces to help them? What is the role of patient associations in the 21st century healthcare system? – Patient empowerment – Self-care – Digitization – Prevention – Quality of life – Interdependence - Collaboration.



Patient associations in the 21st century health system

8 may 2017

TESTIMONIES



“It is essential that all citizens get involved in dignifying and humanizing the patient experience. At Dos Abrazos we want to be here supporting this initiative and share a bit of optimism.”

Carlos Hernández.
Dos Abrazos.



“Health schools have an essential aim: to boost the empowerment of patients-people-citizens. We therefore want to support all initiatives related to training people in life skills.”

Juana Mateos.
Madrid School of Health.



“I created the foundation with a key project: to offer self-care programmes to patients and to create a mobile educator network of healthcare professionals, from inside and outside the healthcare system, to assist and support patients in their self-care.”

Shane Fitch.
Fundación Lovexair.



“Events like this one are essential for bringing together groups of patients, caregivers and professionals from the healthcare sector. We can listen to each other and learn from each other, identify shortcomings, and determine how together we can do a bit better and help more people.”

Pablo Barredo.
Fundación Diario de un Cuidador.

Patient associations in the 21st century health system

8 may 2017

INSIGHTS

- New POP UP communities are aimed at designing campaigns or generating opinion for a limited time. They are born with a clear objective and die once the objective has been met or when members no longer see the value in belonging.
- POP UP communities are having an impact on association membership in general, based on long-term commitment. This is a major opportunity for their campaigns to reach a larger audience and to **work with other associations** on achieving common goals.
- Patient associations can carry out important joint efforts, both in health maintenance and disease prevention, in patient empowerment, and in influencing research agendas and promoting unified clinical records that are accessible to patients.

VISION

The 21st century health system faces very complex challenges, and it is essential to evolve towards a participatory health system involving various agents of the health ecosystem, especially citizens themselves. Patient associations can and must work together to contribute to the co-creation of solutions to shared problems and those not directly linked to disease. There is an opportunity for substantial collaboration and innovation that, if realised, would have a very positive impact on the health system, benefiting society at large.



CONCLUSIONS FROM THE FIRST YEAR OF C4PE

Together, individual actions have the potential to affect major social changes

With that in mind, during this first year of C4PE we have come together with the main stakeholders in the Spanish health ecosystem to emphasize the importance of patient empowerment for maintaining and improving health, and as an engine for transforming healthcare. Through inspiration sessions and co-creation processes, and by sharing all the knowledge generated with Cluster members and the general public, we have helped raise awareness about the main issues related to patient empowerment. We have generated transformational experiences for participants, trusting them to pass them on to organizations, and to be able to contribute to the transformation necessary for facing the challenges of the new 21st century health system.

We would like to thank all the participants who made this first edition possible – patients, healthcare professionals, industry, start-ups, patient and professional associations – for your participation in the meetings and for your help in publicizing the conclusions.

During the 2017-2018 year we will continue to hold inspiration-action meetings, but we want to go a step further through collaborative projects, putting into practice some of the actions that come out of these meetings.

At **Impact Hub** we are therefore creating a new area dedicated exclusively to health programmes. The IHM Health Programmes area will promote and host different projects and initiatives related to health innovation and entrepreneurship. We will provide our space, know-how, and methodology/facilitation to help different organizations in the health ecosystem drive forward projects/activities with the support of our community, team and space.

It is shaping up to be a year full of excitement, projects and fun. We look forward to working with all of you!

Carolina Rubio Miner.

C4PE Coordinator.

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