

# PATIENT INNOVATION

Sharing solutions, improving life

#### INNOVATION AND ENTREPRENEURSHIP IN HEALTH

Solutions developed by citizens (user-innovation)

Helena Canhão, MD PhD

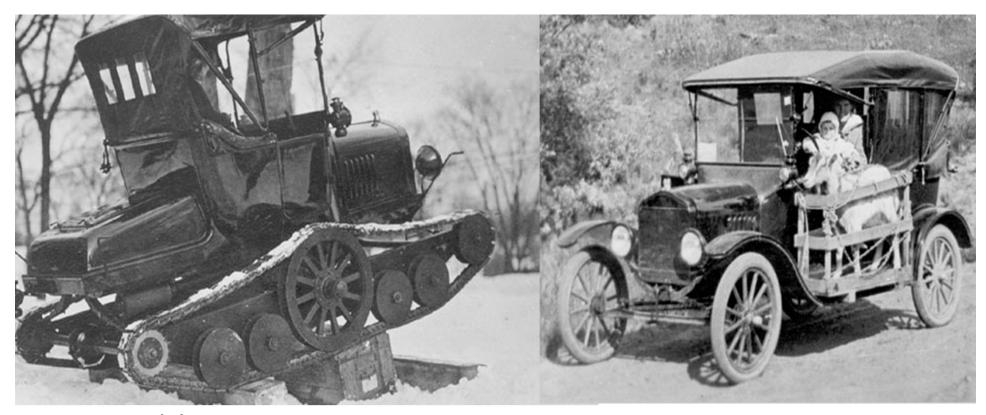
CHRC, NOVA Medical School & Patient Innovation





FORD T Model





FORD T Model Converted by users into snowmobiles, trucks and tractors







Why transport the bag... if the bag can transport you?







### To what extent is this phenomena relevant in healthcare?



RESEARCH

**Open Access** 

#### Innovation by patients with rare diseases and chronic needs

Pedro Oliveira<sup>1\*</sup>, Leid Zejnilovic<sup>1,2</sup>, Helena Canhão<sup>3</sup> and Eric von Hippel<sup>4</sup>

Abstract: We provide the first empirical exploration of disease-related innovation by patients and their caregivers. Our aims were to explore to what degree do patients develop innovative solutions; how many of these are unique developments; and do these solutions have positive perceived impact on the patients' overall quality of life? In addition, we explored the factors associated with patient innovation development, and sharing of the solutions that the patients developed.

#### REVOLUTIONISING HEALTHCARE BY **EMPOWERING PATIENTS TO INNOVATE**

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Disclosure: The authors have declared no conflicts of interest Received: 07.03.16 Accepted: 04.04.16

Citation: EMJ Innov. 2017;1[1]:31-34.

#### INTRODUCING A NEW PARADIGM OF HEALTHCARE INNOVATION

delivery, namely in:

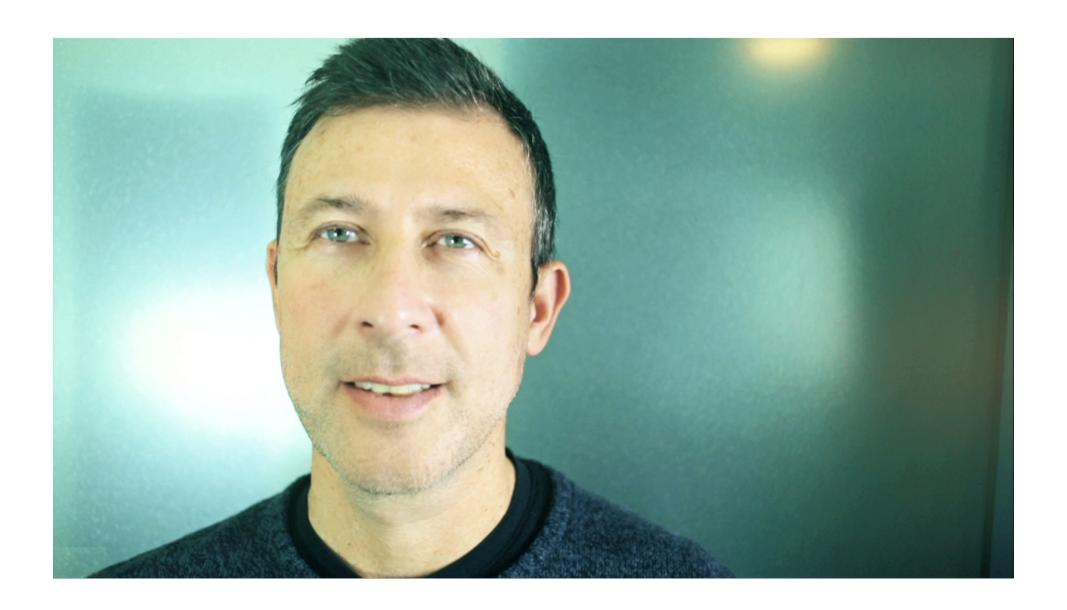
or health condition. We found that patients and caregivers have significant innovative capabilities and have developed various solutions, treatments, A growing stream of literature argues for a more and medical aid devices for themselves (e.g. active role for patients and caregivers in healthcare about 50% of the solutions for cystic fibrosis were developed by the patients). These solutions span





Michael Seres, Crohn's Disease with ileostomy, UK







# David Day, father of Cystic Fibrosis patient Computer games







**Debby Elnatan** the Upsee – a mobility device for children





Ivan Owen, USA







# Nuno, 3D printed prosthetic hand, Portugal



#### Project

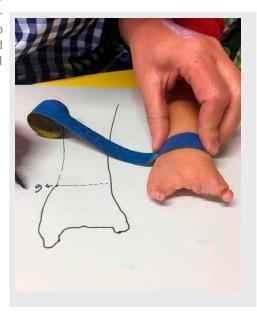
### Offer ahand

"Offer a hand" is a project that consists of designing, printing and giving, for free, 3D printed hands and arms to kids from all over Portugal who need a prosthesis.

The project "Offer a hand" was one of the winners of the Santa Casa da a 3D printed prosthesis under this Misericórdia Challenge and the Fide- project. lidade Comunidade prizes that reward social inclusion and healthcare promotion projects. This award allows us to contribute to the development and production of low-cost 3D printed prosthesis for up to 20 children.

Measurement and sketch of plaster cast for

Rodrigo was the first child to receive





Plaster cast of the hand that will receive the prosthesis.



Rodrigo, first child to receive a prosthesis in this project.



# **OFFER YOUR HAND**

Promoted by:



Awards winning project:









RESEARCH Open Access

# Innovation by patients with rare diseases and chronic needs

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**Abstract:** We provide the first empirical exploration of disease-related innovation by patients and their caregivers. Our aims were to explore to what degree do patients develop innovative solutions; how many of these are unique developments; and do these solutions have positive perceived impact on the patients' overall quality of life? In addition, we explored the factors associated with patient innovation development, and sharing of the solutions that the patients developed.

**Methods:** We administered a questionnaire via telephone interviewing to a sample of 500 rare disease patients and caregivers. The solutions reported were pre-screened by the authors for their fit with the self-developed innovation aim of the study. All the reported solutions were then validated for their novelty by two medical professionals. Logistic regression models were used to test the relationships between our key variables, patient innovation and solution sharing.

**Results:** 263 (53%) of our survey respondents reported developing and using a solution to improve management of their diseases. An initial screening removed 81 (16%) solutions for being an obvious misfit to the self-developed innovation aim of the study. This lowered the sample of potentially innovative solutions to 182 (36%). Assessment of novelty and usefulness of the solutions, conducted by two medical evaluators, confirmed that 40 solutions (8%) were indeed novel, while the remaining 142 (28%) were already known to medicine. The likelihood of patient

# The solutions significantly improve their quality of life...



But they rarely diffuse (e.g. only 5% are show to medical professionals)

Quality of life differences Scale 1-5

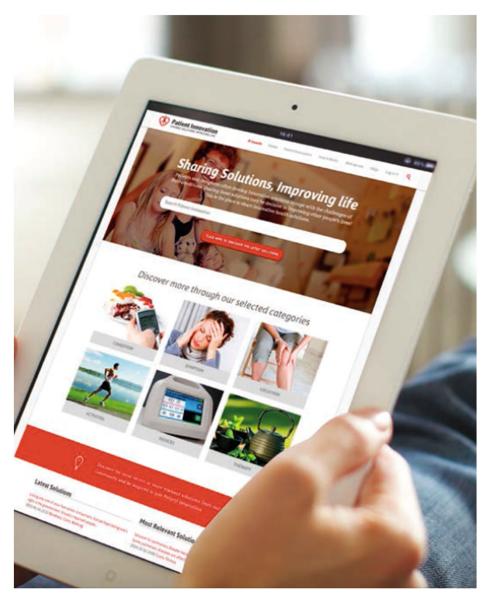
	Patients mean (SD)	Caregivers mean (SD)
Products	2.2 (1.5)	1.7 (1.4)
Services	1.8 (1.4)	2 (1.7)
Total	2 (1.4)	1.9 (1.6)

	New to	New to the
	the world	patient
Shown it locally to other patients	89%	92%
Shown it to medical		
professionals	5%	2%
Shared the info on a		
website/blog/social network	37%	28%
Shared it through media	16%	8%
other	25%	13%



Oliveira, Zejnilovic, Canhão and von Hippel (2015)

# http://www.patient-innovation.com



PATIENT INNOVATION platform



# 1,5 innovations/day

- Out of 2000 submissions; about half are rejected at medical "screening"
- From over 70 countries from US to South Korea



2020

# Platform Evolution

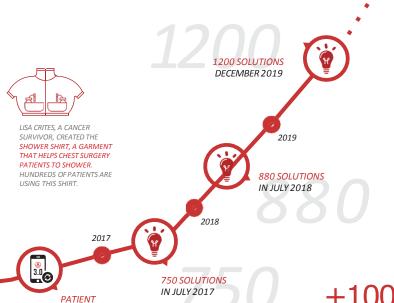
Patient Innovation has made some significant changes to its platform since its launch, back in 2014.

What started as an academic repository of medical innovations developed by patients, caregivers and collaborators has grown into a multilingual platform that encourages people from all around the world to post, share, discuss and evaluate solutions, tips and adaptations that can make life more comfortable and happier for the community.

It became a centralized place for the posting and sharing of innovative solutions that help improve people's lives. Patient Innovation recently unveiled its new homepage and the whole website in German.

The team is always working to improve the platform's design, content and usability.

In December 2019, Patient Innovation achieved another milestone: 1200 live solutions developed by members of the community and curated by the Patient Innovation medical team. With the help of our community, the Patient Innovation database is growing every day.



2016 **PATIENT INNOVATION** PLATFORM VERSION 2.0 RELEASED ON NOVEMBER 2014 600 SOLUTIONS IN APRIL 2016 **500 SOLUTIONS** FEBRUARY, 2014 2015 IN DECEMBER 2015 100 SOLUTIONS IN JULY 2014

PATIENT INNOVATION PLATFORM LAUNCHED IN FEBRUARY 2014

FREQUENCER, A SOLUTION BY LOUIS PLANTE FOR CYSTIC FIBROSIS, WAS SHARED ON NOVEMBER 16, 2014.



FLATWARE FOR DISABLED PEOPLE WAS ONE OF THE FIRST SOLUTIONS OF 2016. SHARED IN THE PATIENT INNOVATION PLATFORM ON JANUARY 11, 2016.

**INNOVATION** 

**PLATFORM** 

**VERSION 3.0 RELEASED IN** 

NOVEMBER 2016

Share your solutions now at www.natient-inovation.com

solutions related

to 3D printing

technology

## **Our Vision**

THE PATIENT INNOVATION PLATFORM

Each patient, caregiver or collaborator is a potential innovator.



We are driven to work, everyday, on a non-profit platform that connects patients, caregivers and collaborators and enables the sharing of solutions, devices and knowledge, otherwise unknown to others.



Doctors make the worst patients. Maybe in the future patients will make the best doctors.

#### Carlos Moedas

Former European Comissioner for Research, Science and

THE PLATFORM PATIENT INNOVATION HAS MORE THAN **1200 SOLUTIONS** ONLINE.

## How does it work?

The Patient Innovation Platform is an international, multilingual, totally free-of-charge venue for patients, caregivers and collaborators of any disease to share their innovations within the community with the community w



The platform allows searches by disease, symptom, location, type of activity, device and therapy. It is available online at:

patientinnovation.com



# Research and management team

The Patient Innovation Project has resulted from the joint research and international cooperation of scholars (in the health sciences, management, engineering and law), healthcare practitioners and institutions that are committed to help promote knowledge and solutions that can improve patients' well being.

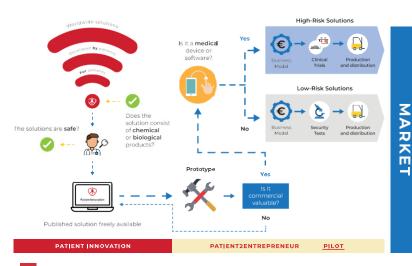
#### **Projects**

### Patient 2 Entrepreneur (P2E)

P2E is a consortium which envolves Católica Lisbon School of Business and Economics, Nova Medical School, Nova School of Business and Economics, Luz Saúde and Orange Bird.

This project, relying on the Patient Innovation platform and on all partners, aims to empower patients by valuing innovation and promoting entrepreneurship.

Here's how it works:



#### **Projects**

### Releasing the power of users

Patient Innovation is part of the "Releasing the power of users - articulating user interest to accelerate new and welfare sector".

Norwegian Research Council and aims to understanding of and expectations of users related to welfare technology.

The project is currently being lead consortium for the research project by Tatiana Iakovleva, professor of entrepreneurship at the University of Stavanger UiS Business School, and innovative pathways in digital health includes international partners such as Norwegian Smart Care Cluster, This project is funded by the Copen- hagen Business School, University of Twente, University of develop a greater Manchester, University of Michigan, the users by University of Southern California, identifying the attitudes, concerns Western Norway University of Applied Science and Queensland University of Technology.





# **Patient Innovation Bootcamp**



Potenciar o empreendedorismo entre doentes e

cuidadores informais

Lisbon - Barcelona - Copenhaga

Esta é a primeira série de **bootcamps com o objetivo de ajudar doentes e cuidadores** informais a implementar e levar para o mercado soluções inovadores desenvolvidas pelos próprios.



**Pedro Oliveira CBS** 



Helena Canhão **Patient Innovation** Patient Innovation Nova Medical School



Biocat

**Judit Valero** 



Luca Venza **IESE Business School** 



**Rudi Westendorp** U. of Copenhagen



**James Barlow** Imperial College



**Thomas Unt** Smile Incubator



Filipa Fixe Glintt



Lisa Pape Walk with Path











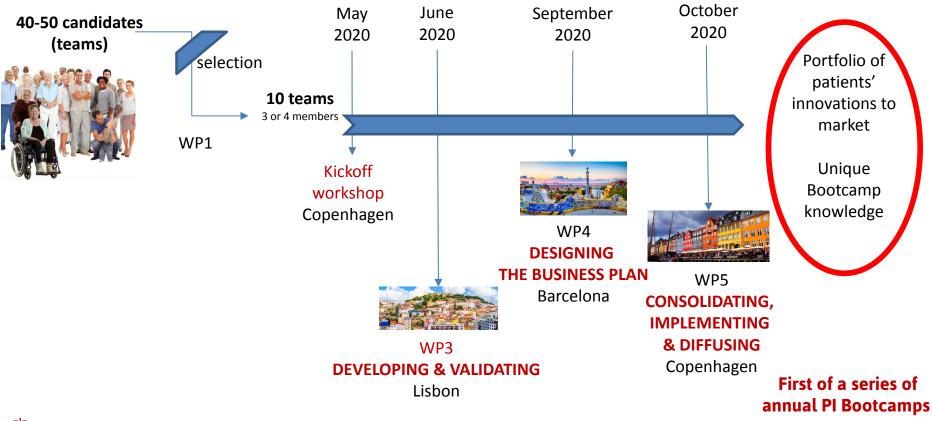








### The plan







# PATIENT INNOVATION AWARDS

#### 1st Edition Calouste Gulbenkian Foundation

#### 2nd Edition Web Summit 2016 Europe's largest and most important technology market place



Carlos Moedas, **European Commissioner for** Research, Science and Innovation





#### **3rd Edition Calouste Gulbenkian Foundation**





Research, Science and Innovation; Marianne Thyssen, European Commissioner for **Employment, Social Affairs;** The President of the Portuguese Republic,

Professor Marcelo Rebelo de Sousa.





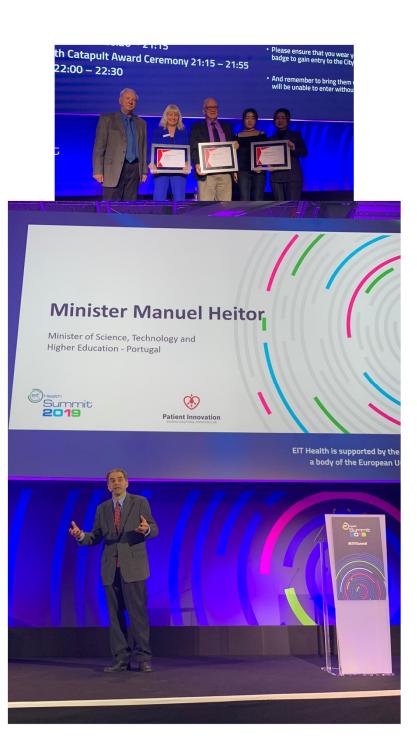


Palais Brongniart, Paris, France Dec 2nd 2019, 6pm











# Awards & recognitions























### Recognition by United Nations Secretary General Ban Ki-moon

For its contribution to the UN's SDGs

- Good health and Well-Being & Industry
  - · Innovation and Infrastructure

## In the media

BBC

sky news

Austria: LT1, Neues Volskblatt; Reader Digest

Belgium: Horizon Magazine;

Brazil: El Pais (Brazil); Reader Digest

Canada: Canoe; Cyprus: CYBC;

the France: Reader Digest guardian **Germany**: Reader Digest Italy: Il Sole 24 Ore;

Kenya: Business Daily Africa;

Luxemburg: Luxemburger Wort, Tageblatt;

Paraguay: Reader Digest

Poland: Wyborcza, Human, National Geographic Polska;

Portugal: RTP 1/2/3/Internacional, RDP Internacional, SIC, SIC-N, TVI, Expresso, Público, DN, JN, Observador, Sol, Sábado, Visão, Diário Económico, Jornal de Negócios, Exame,

Dinheiro Vivo, Antena 1/2, Radio Renascença, TSF;

Russia: Clip;

Spain: El Pais, El Independiente de Granada; Selecciones

Slovenia: VAL 2020 Radio Slovenija:

Switzerland: World Economic Forum, Neue Zürcher Zeitung;

**UAE**: Akbar El Emarat, MBC;

UK: BBC, Sky News, The Guardian, The Independent, Time Out London, Virgin, E&T

Magazine; Reader Digest

USA: Huffington Post, NEJM Catalyst, Florida Today, Miami Herald, Medgaget, MGH

Proto Magazine, Business Insider, Reader Digest, among other.



INDEPENDENT







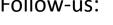






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## www.patient-innovation.com

### **THANKS!**



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