



# Personalised Medicine Conference 2016

1-2 June 2016, Brussels

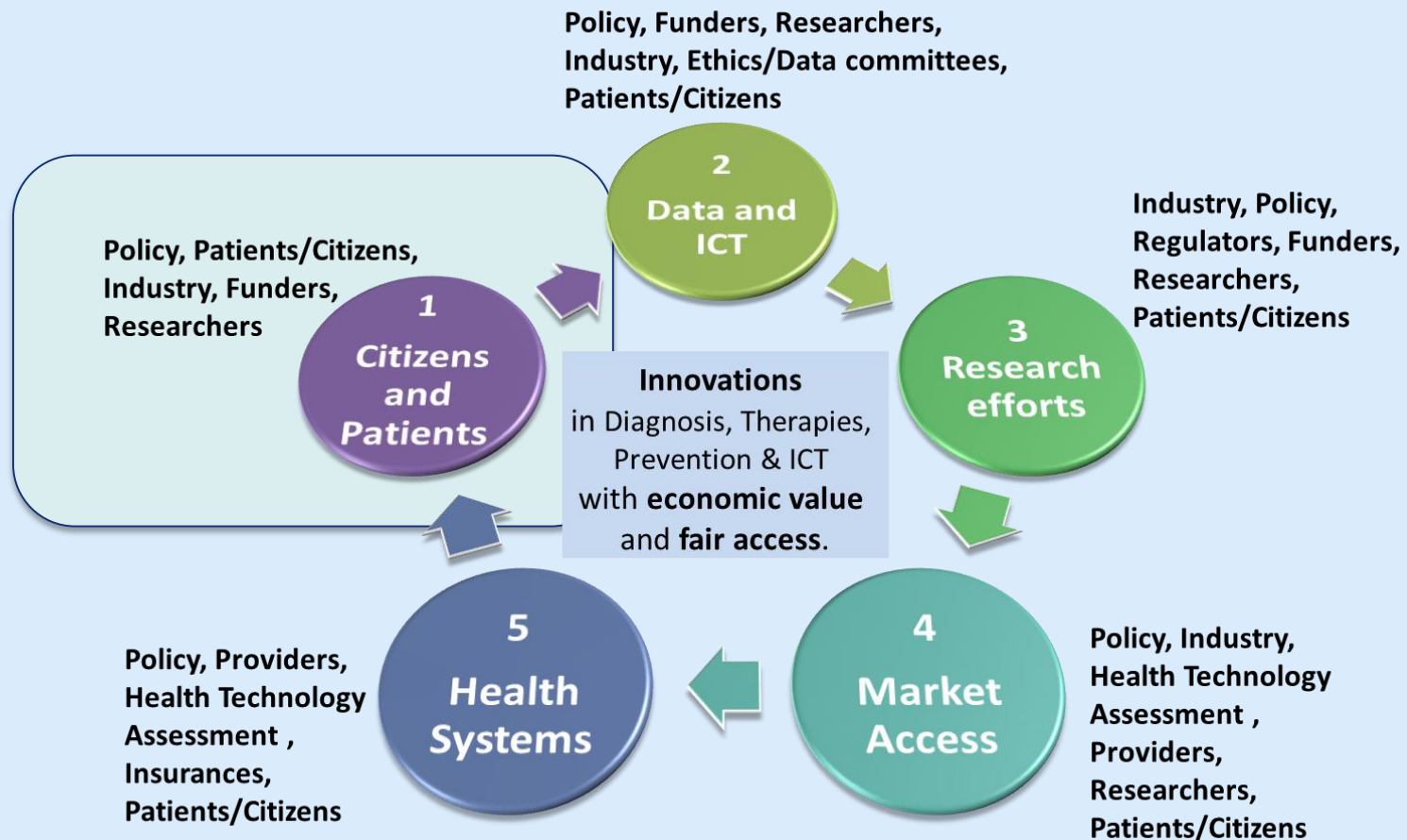
Challenge Group 1.

Facilitator: Prof. Maria Judit Molnar MD,



Research and  
Innovation

# Circle of the five Challenges



# Empowerment and awareness?



Eva's father was positive for the BRCA gene mutation. It was suggested to her by the fathers' oncologist to be tested for BRCA mutation.

Her father had non-Hodgkin's lymphoma. She wondered why he was he tested for BRCA mutation. Her aunt had breast cancer and was positive for the BRCA1 mutation



She decided to speak with a genetic counselor.

She found out that if she is positive for BRCA1 she had a 70% risk of developing breast cancer and 50% risk of developing ovarian cancer

## The shocking genetic test

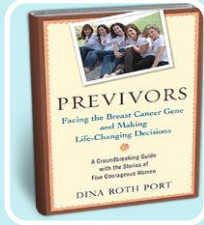


She had positive test for BRCA1 and her life was forever changed.

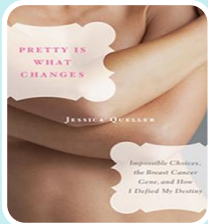
The genetic counselor spoke for 2 hours about family history, statistics, genetics, treatment options and she remembers back

*„I don't think I heard a thing she said. I only remember what she discussed, because she gave me a copy of what she spoke about. **None of it really did until I went to see a breast specialist and gynecologist.** The wake-up call came when he told within the first 10 minutes of my appointment - we need to discuss the removal of your ovaries. - I was shocked by his bold and unvarnished statement“.*

# She began read books, to do research online about having the BRCA gene mutation



“Previvors” by Dina Roth Port: stories of five women living with the BRCA mutation and the choices they make.



“Pretty is What Changes: Tough Choices, the breast cancer gene, and learning how to live in the DNA age” by Jessica Queller.



„Webicina” Browse the best, curated news, advice and tips about cancer in social media resources from blogs and communities to podcasts and Twitter channels.

- She attended the FORCE conference – helped to move forward and provided hope and truly empowered her:
- ***„I discovered myself, my depth of strength and my ability to try to not take life too seriously; it only makes things more difficult. BRCA cannot overcome me; I am empowered“.***

**The engaged citizens**  
**Well trained healthcare professionals**  
**Access to accurate and actionable health information**  
**Person-centered services with informed decisions**





# The main areas influencing the future healthcare in PM



## Change the medical model, create a new model for care with patients

- **Cultural changes:** patient centric model vs physician centric
- **Curricula reform**
- **Improve the citizens' health and digital literacy** to enhance informed decisions, share the responsibility, improve self management

## New technologies, better relationships are increasing citizens engagement

- **IT driven health monitoring** (eHealth, mHealth, eHRs etc.)
- **New type of communications** (ePatients, social media, etc.)
- **Artificial intelligence** in the everyday clinical practice

## Paradigm change in the science

- Thomas Kuhn: The structure of the scientific revolutions
- Patient science – DIY biology, genetics, biotechnology
- Patient centric clinical trials





## **Roadmap clusters of Challenge Group 1**

- 1. Build a knowledge network to increase the health and digital literacy of the citizens**
- 2. Curricula development in gradual and postgradual education in order to enhance patient centered care**
- 3. Develop Patient Oriented Research Framework and Network**

Establish a public-private European Alliance to enable responsible sharing genomic and clinical data in collaboration with Challenge Group 2





## **Plenary talks of Challenge Group 1**

### **Patient perspective on PM and how patient organizations empower the community**

Peter KAPITEIN

### **Educational strategies in the era of PM**

Rudi WESTERNDORP

### **The role of patients and healthcare provider in translational medicine**

Jan GEISSLER

### **The health economical impact of increasing patient engagement**

Panos KANAVOS



## **Panel Discussion of Challenge Group 1**

**Moderator:** Andrzej Rys – DG SANTE

### **Panellists:**

- Geissler, Jan (DE) – patient organization
- Hazelzet, Jan (NL) - higher education
- Nemeth, George (HU) - pharma-company, neurology
- O'Driscoll, Mairead (IE) - funding agency
- Poplas, Antonija (SL) - primary health care, health authority