

# Patient Engagement in the ESC

**Why is it important to empower and engage Patients?**

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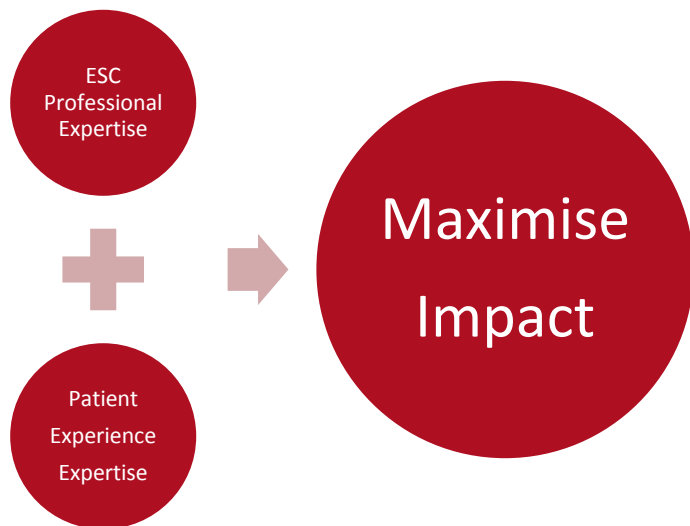
# So what is patient engagement?

- In a nutshell, **patient engagement in healthcare** refers to patients being as informed as possible about their options for treatment, medications, recuperation, and all other aspects of the healthcare system supporting them. Patient engagement involves “**providers and patients working together to improve health**,” noted a report from the Healthcare Information and Management Systems Society (**HIMSS**).

# ESC Mission

**To reduce the burden of cardiovascular disease**

# TOGETHER with patients & their organisations we can increase our clinical and political effectiveness



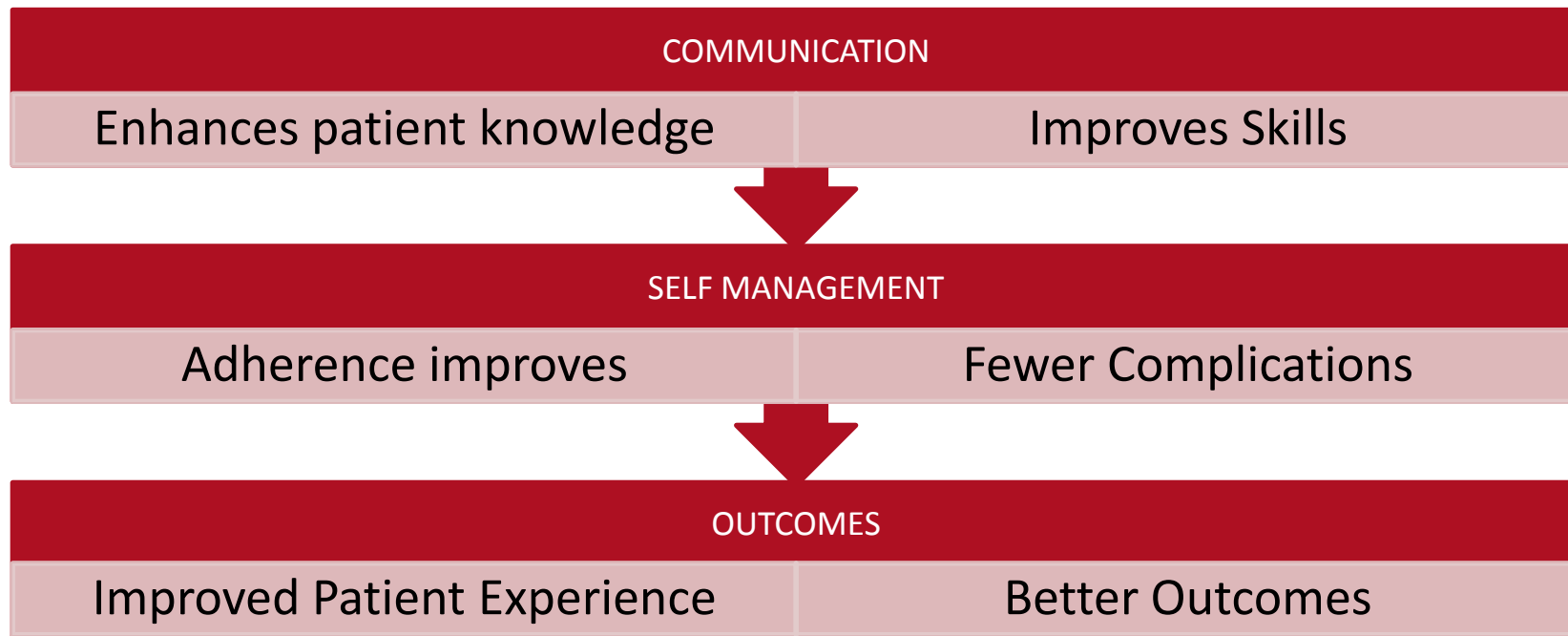
**The ESC is committed to working in partnership with patients and patient organisations to develop initiatives and educational products that aim to reduce the burden of CVD.**

**(ESC Managerial Council May 2017)**

# Patients as Partners



# Co-Production Process



# Patient Engagement – A work in Progress

- **Workshop, Brussels Office March 2016**
- **Consultation with key stakeholders**
- **Adopted as ESC strategic objective, May 2017**
- **Consultation +++++**
- **ESC Patient Ambassadors Identified**
- **Patients Recruited: 25 from 11 countries so far**
- **Patients Forum launch, Brussels June 2018**
- **9 Patients Forum members at the ESC Congress 2018, Munich**

# Launch of the ESC Patients Forum

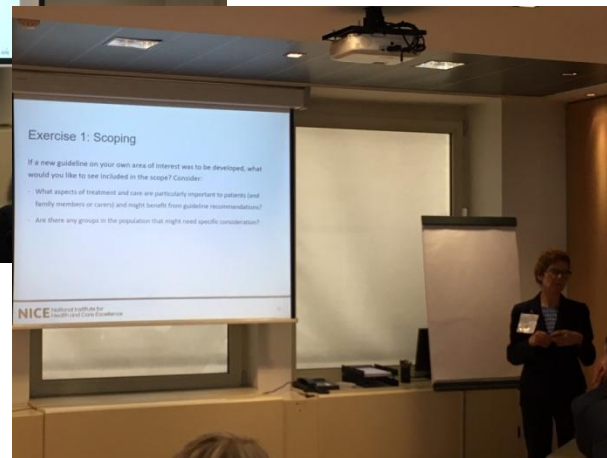
## ESC Brussels Office, June 2018

- **21 CVD Patients** from **11 countries** (Belgium, Croatia, Cyprus, Denmark, Germany, Greece, Hungary, Italy, Poland, Switzerland & UK) joined us for the launch event of the Patient Engagement initiative.

- **Dr Fergus Mac Beth** outlined his experience of patient involvement - from sceptic to convert

- **Jane Cowl** from NICE, delivered successfully a training session to the Patients

- **Corinna Schaefer**, from the German Agency for Quality in Medicine, conducted a separate training for the healthcare Professionals attending the event



# Launch of the ESC Patients Forum

## ESC Brussels Office, June 2018



# Questions, Answers & Thoughtful Deliberation

Launch of the ESC Patients Forum - ESC Brussels Office, June 2018



# The ESC Patients Forum now

- 25 people with experience of different cardiac conditions
- 11 different European countries (Belgium, Croatia, Cyprus, Denmark, Germany, Greece, Hungary, Italy, Poland, Switzerland & UK)
- Range of age (23-81), gender (Males 20/ Females 5) etc
- All speak English
- All willing to participate & consent signed
- Training & induction commenced

# Patients Forum members at the ESC Congress 2018, Munich



# Patients Forum meeting in parallel of the CRT!

- **Patients getting to know ESC better**
- **Understand the strategic importance of Patient Involvement for ESC**
- **Map patient involvement opportunities in ESC activities (Associations, Committees etc)**
- **Provide patient-centered training**
- **Discuss governance issues for the Patient Forum**

# Our vision: A connected process within all ESC Activities (1)



## Education

- Include members of the ESC Patient Forum in Education activities & conferences
- Explore new ways patients' input will benefit Educational Products

## Guidelines

- Invest in training for Patient Forum, TF & Review Chairs
- Co-develop methods to involve patients more closely in the work of CPG

## Advocacy

- Include members of the Patient Forum in various Advocacy activities
- Invite the Patient Forum to voice their experiences of CVD & lobby effectively, pressing for CVD to be higher on the policy makers' agenda

# Our vision: A connected process within all ESC Activities (2)

## ESC Associations

- Involve members of the ESC Patient Forum in the Associations' activities (EAPC, EAPCI, EHRA, HFA, ACCA, EACVI)

## Communication

- Develop a dedicated webpage with patients' testimonials, videos with personal stories & experiences, CVD information for patients
- Cardiopulse Articles, European Heart Journal

## Congresses

- Involving patients and caregivers speakers at Congresses

# New Frontiers Ahead.....

- **Follow up workshop in the new year: additional training and mapping/discussing other area of ESC activity**
- **Collaborative, co-production of the journey**
- **Embrace opportunities**
- **Learn together**
- **Grow together**

**Reduce the burden of CVD together!**