Patient Engagement in the ESC

Why is it important to empower and engage Patients?

Prof. Donna Fitzsimons, ESC Lead Patient Engagement
Head of Nursing & Midwifery, Queen’s University Belfast
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

- Drive better patient care
- Achieve better health outcomes
- Lower costs
- Improve patient experience
Co-Production Process

**COMMUNICATION**
- Enhances patient knowledge
- Improves Skills

**SELF MANAGEMENT**
- Adherence improves
- Fewer Complications

**OUTCOMES**
- Improved Patient Experience
- Better Outcomes
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!