

ESC & Patient Engagement

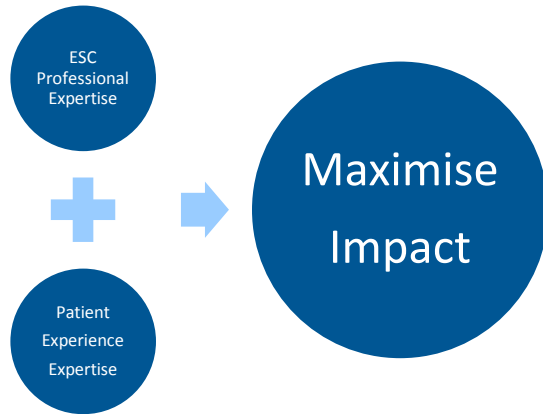
Inga Drossart

ESC Patient Engagement Officer
European Heart Agency, Brussels

EAPC Summit, European Heart House, November 16th, 2019



Why Patient Engagement?



- **“We have much to learn from patients. They are the experts on what it means to experience heart disease.”**

Prof. Barbara Casadei,
ESC President

- **“We have excellent treatments and technology in cardiology, but all too often this is not put into practice or patient adherence is poor. Working more closely with patients can help us understand why, and to find better ways of implementing evidence, supporting self-management, and improving patient outcomes.”**

Prof. Donna Fitzsimons,
ESC Lead on Patient Engagement

The ESC Patient Forum - Governance

“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)

- Established in June 2018 as the **key mechanism to engage patients** across a range of ESC activities
- **ESC Lead on Patient Engagement** (ESC Board Member): Prof. Donna Fitzsimons, Queen’s University Belfast
- **Roadmap 2019/2020** approved in spring 2019
- **Patient Forum Nucleus** elected in July 2019 (7 patients + ESC Lead on Patient Engagement), Chair/Vice-Chair to be elected in Dec. 2019
- **Terms of Reference** entered into force August 2019
- Forum operates through an **online platform** + 3-4 **Patient Forum Workshops** per year



The ESC Patient Forum - Membership

- Patient Forum members are **identified by ESC clinicians**
- Members are **involved in personal capacity**, not as representatives of a patient group or organization
- Currently about **20 members** from 11 European countries → target: around **30 active members** to ensure sufficient capacity and experience in a range of CVD conditions
- Need to improve gender **balance & geographical representation**, include caregivers

- **Basic criteria for membership:**
 - Personal experience with a heart condition
 - Speak English
 - Sufficiently “stable” with their condition to be able to travel internationally
 - Not employed by or receiving remuneration from health industry
 - Committed to contribute to ESC mission



Patient Engagement in ESC activities

We want to develop and enhance patient engagement so that it is embedded like a **golden thread** through all ESC activities.



Patient Engagement in Clinical Practice Guidelines



2019 Guidelines	2020 Guidelines	2021 Guidelines	2022 Guidelines
<ul style="list-style-type: none">Articulate the human story behind the Guidelines - Video TestimoniesDevelop Patient Cards	<ul style="list-style-type: none">Articulate the human story behind the Guidelines - Video Testimonies for all GLsDevelop Patient Cards for all GLsPatients to contribute to the Review process in 2 GLs i.e. AF & NSTEMI	<ul style="list-style-type: none">Articulate the human story behind the Guidelines - Video Testimonies for all GLsDevelopment of Patient Cards for all GLsPatients contribute to the Review Process in all GLsPatients contribute to Scope for all GLsPatients sit on the Guideline Taskforce for Heart Failure	<ul style="list-style-type: none">Articulate the human story behind the Guidelines - Video Testimonies for all GLsDevelopment of Patient Cards for all GLsPatients contribute to the Review Process in all GLsPatients contribute to Scope for all GLsPatients sit on the Guideline Taskforce for all GLs

Patient engagement in the Guidelines will be implemented progressively.

Patient Engagement in Education & Advocacy

- **Education Conference 2019 'Educated healthcare professionals + educated patients = effective shared care':**

9 ESC Patient Forum members actively participated. The overwhelmingly positive feedback had resulted in an invitation to the next Education Conference in 2020.

- **Update of the ESC Core Curriculum for the Cardiologist**

Two patients in the Task Force to provide input on soft skills cardiologists should be equipped with.

- **Advocacy**

- Patients speaking at ESC Advocacy event in the European Parliament – end of 2019
- Patient's voice to be reflected in ESC Advocacy materials – starting Autumn 2019
- Patient's testimonials on GL topics promoted via social media & communications targeting key decision-makers – starting Autumn 2019



Patient Engagement at ESC Congress 2019

- Opening Press Conference with two patients as speakers
- Session “Patient involvement – unleashing the potential for true excellence in cardiovascular care” with two patients as speaker/chair



Patient Engagement in ESC Associations



- **Liaison Officer: Monika Hollander**
- **Patients contributed to development of the new patient webpage launched in August 2019:**
www.healthy-heart.org



- Patient to sit on Board as adviser - ACCA Board to discuss and agree on next steps



- Meeting between Patient Forum and EACVI Liaison Officer to discuss patient engagement - July 2019



- Meeting between Patient Forum and ACNAP Liaison Officer to discuss patient engagement - July 2019

Patient Engagement in ESC Associations



- Patients commented on PREMs & PROMS questionnaires



- Patients contributing to HFA Position Paper on Palliative Care in Heart Failure Management – in progress
- Three patients participated in the HFA Patient Forum meeting - 25 October 2019 (Dubrovnik)
- Patient to comment on the heartfailurematters.org – starts Oct. 2019



- Patients as speakers at the EHRA Congress 2019
- Patient sitting on EHRA & Regulatory Affairs Committee's joint Task Force on CIEDs – in progress
- Patients providing feedback on AF Treatment Burden questionnaire – completed August 2019
- Patients to contribute to paper on “Quality Indicators and Outcomes Measures for Atrial Fibrillation or Atrial Flutter” – starts October 2019



Council of Cardio-Oncology

- Patients to contribute to cardio oncology leaflet explaining the potential cardiovascular side effects/risks of cancer therapy - Leaflet expected to be finalized (English version) in Winter 2019/20



GUCH

- Patients to contribute to policy paper on “Future and advance care planning in grown up congenital heart disease patients” - Kick off meeting of writing committee April 2019, paper tentatively expected in February 2020



eCardiology

- Three Patients contributed as speakers in four roundtable discussions at ESC Digital Summit, Tallinn, October 5th/6th, 2019
- Patients will co-author a section of a Position Paper on Wearables

New Frontiers Ahead ...

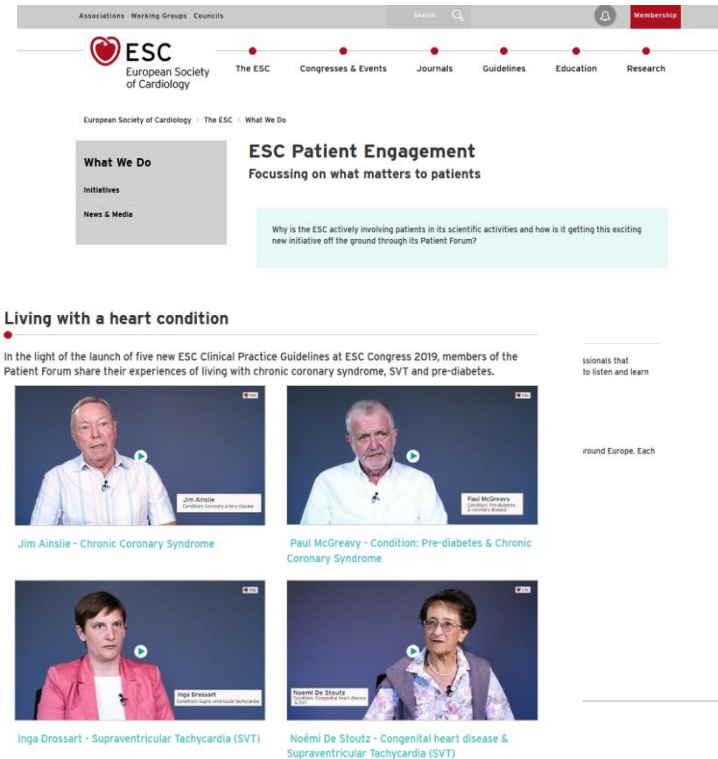
- **Active agenda – much to be done**
- **Collaborative, co-production of the journey**
- **Embracing opportunities**
- **Learning together**
- **Growing together**

Reduce the burden of CVD together!

ESC Patient Forum Webpage

For more information about the ESC Patient Forum & forthcoming activities please visit:

www.escardio.org/patients



The screenshot shows the ESC Patient Engagement webpage. At the top, there is a navigation bar with links for 'Associations', 'Working Groups', 'Councils', a search bar, and a 'Membership' button. Below this is the ESC logo and a horizontal menu with links for 'The ESC', 'Congresses & Events', 'Journals', 'Guidelines', 'Education', and 'Research'. The main content area features a 'What We Do' sidebar with 'Initiatives' and 'News & Media' sections. The main heading is 'ESC Patient Engagement' with the sub-heading 'Focussing on what matters to patients'. A light blue box contains the text: 'Why is the ESC actively involving patients in its scientific activities and how is it getting this exciting new initiative off the ground through its Patient Forum?'. Below this is a section titled 'Living with a heart condition' with a red dot icon. The text reads: 'In the light of the launch of five new ESC Clinical Practice Guidelines at ESC Congress 2019, members of the Patient Forum share their experiences of living with chronic coronary syndrome, SVT and pre-diabetes.' To the right of this text are two columns of text: 'sionals that is listen and learn' and 'round Europe. Each'. Below the text are four video thumbnails, each with a play button icon and a nameplate. The first video is by Jim Ainslie, 'Chronic Coronary Syndrome'. The second is by Paul McGreavy, 'Condition: Pre-diabetes & Chronic Coronary Syndrome'. The third is by Inga Drossart, 'Supraventricular Tachycardia (SVT)'. The fourth is by Noémi De Stoultz, 'Congenital heart disease & Supraventricular Tachycardia (SVT)'.

“The ESC patient engagement initiative will enable the patient voice to be heard, helping health care teams to see things from a different perspective, which could support improvements in the diagnosis and management of heart conditions.”

Luka Vugrač, ESC Patient Forum Member

“You say, you have to MANAGE the patient – I say, no, you have got to COACH the patient!”

Axel Verstrael, ESC Patient Forum Member

“I speak with many patients from all over Europe... But we all have one thing in common, the need to be treated as a human being with emotional as well as physical needs and this requirement is not always met.”

Hywel Jones, ESC Patient Forum Member

Thank you very much!