### ESC Advocacy Industry Forum

**10th January 2020 – 10:00-14:00 – Renaissance Brussels Hotel**

Executive Summary & Action points

#### ESC Participants
- Laurence Alliot – Partnership Policy Committee member
- Elisabetta Zanon – Advocacy Director
- Aoife Delmas – Industry Director
- Christina Dimopoulou – European Project Manager
- Patricia Munoz – EU Policy & Advocacy Coordinator
- Inga Drossart – Patient Officer
- Laurie-Anne Pereira – Account Manager

#### Industry Partners
- Abbott – Lucia Osoro, Hindrik W.J. Robbe
- Abbott Vascular International – Marie-Laure Schenck
- Amgen – Andras Fehervary
- AstraZeneca AB – Karina Morley
- Bayer AG – Pamela Cohen
- Bristol-Myers Squibb – Dimitri Pouradier-Duteil, Emmanuel Chantelot
- Boehringer Ingelheim – Andreas Preising
- Daiichi Sankyo Europe – Hans Lanz
- Edwards Lifesciences – Fanny van der Loo
- Ferrer Internacional – Alfredo Gracia
- GE Healthcare – Felix Uedelhoven
- Medtronic International – Virginie Delage, Anja Strootker, Jasmin Lennartz
- Myokardia – Birgit Roy
- Novartis Pharma – Lena Lymperopoulou
- Novo Nordisk A/S – Morgane Cuisenier
- Philips Healthcare – Jan-Willem Scheijgrond
- Roche Diagnostics International – Markus Ott
- Siemens Healthcare – Carolin Hehr
- Stereotaxis – Steffen Wuttke
- Vifor – Thierry Schulmann
- WeHealth Digital Medicine – Sophie Nisse-Durgeat
Summary & Feedback

1. Introduction & rationale for an ESC Advocacy Industry Forum
Laurence Alliot, ESC Partnership Policy Committee member, introduced the first ever Advocacy Industry Forum meeting organized by the ESC and set-up the rationale for such an event. ESC is entitled to act in areas where Industry Partners cannot and can dialogue with decision-makers in a way which is different and complementary to the way industry act to place CVD on the political radar.
She pointed out the connection between this Forum and the Cardiovascular Round Table (CRT) where ESC leadership and Industry Partners interact on high-stake topics to shape the future of cardiovascular health in Europe.
This Forum meeting is probably the first one of a long series and it therefore be important to keep the same interlocutors to ensure a continuity in our discussions. Industry Partners feedback will be important to define how to shape the Forum going forward.

2. Perception and reality of cardiovascular disease (CVD) – why we need to advocate for CVD
Prof. Lina Badimon, ESC Advocacy Chair was unfortunately unable to attend and Elisabetta Zanon, ESC Advocacy Director, replaced her to share the reasons to advocate for CVD. We are actually facing a gap between the perception of CVD (lifestyle disease that can be cured) and the reality – CVD also hits many people with healthy lifestyles and can be highly debilitating. The ESC Atlas of Cardiology demonstrates the huge differences between countries in terms of CVD mortality, treatments and procedures. The analysis is clear, CVD is the leading cause of death and the situation won't unfortunately improve in the coming years. More action by policymakers is urgently needed to tackle the increasing burden of CVD.

Feedback: Industry Partners wanted to be involved in ESC advocacy activities – there is a urgent need to convince political and official bodies but also to inform people about economic and societal burden of CVD. They all observe an important discrepancy between oncolgy or HIV patients, where patient organisations are very active and informed (events, social media, rallying of lay public, screening awareness etc…) and CVD, where we failed to raise awareness for the time being. Patients groups in Europe are not as well organized as it could be in the US for instance. When talking about CVD, there is a lack of clarity on what needs to be screened & there is a need for wider general public awareness. Industry partners were thankful for the compelling report that has been presented but also suggested to look at the trend over the past 10 years and to plan research work to understand the reasons for such differences on CVD mortality between countries (access to procedures, infrastructure, reimbursement etc…). Another suggestion would also be to breakdown the the topic CVD which is considered too large and target only some some specific CVD diseases to act more efficiently.Consensus to get clarification on how Industry Partners can collaborate with ESC on this topic and what are the priorities.

3. ESC Advocacy – an overview
Elisabetta Zanon, ESC Advocacy Director, presented the ESC advocacy activities. ESC Advocacy is a relatively new area of work in the ESC. It was a strategic decision to have offices in Brussels, close to the European institutions. She underlined the lack of registries and data in Europe compared to the US, where it is one single healthcare system, compared to Europe where each country has a different system and different approaches in collecting data. ESC produced in 2019 "ESC CV realities 2019", its first advocacy document. The booklet includes a Call to Action, addressing policymakers. A joint document with the European Heart Network (EHN) is also being finalized with 20 recommendations for actions at EU level to address the burden of CVD. It is mainly focused on prevention, research and innovation (better regulatory framework around RCT to improve research and innovations) and improving diagnosis, treatment and rehabilitation.
It is necessary to have politicians as advocates and ESC is planning to dialogue with Members of the European Parliament (MEP). As a first step, letters were sent to each MEP, highlighting the burden of CVD and proposing the re-establishment of the MEP Heart Group for the European Parliament 2019-24 mandate. ESC also aims to interact with EU presidencies to influence the health agenda and get in contact with Health Ministers on a country basis. A task force has been established with National Cardiac Societies (NCS) representatives to that effect.
Feedback: Industry Partners mentioned the importance of advocacy coalitions and suggested that ESC should work with other partners on the topic of comorbidities. As a matter of fact, ESC is a founding member of the European Chronic Disease Alliance and the Biomedical Alliance in Europe. It has also been expressed by partners present that the MEP Heart Group was not particularly effective and active in the past. ESC will try to re-energise the group and move from prevention only to multi-faced reasons of CVD and point out research. Regarding the joint document with EHN, discussion was held on how to measure ESC’s impact after the publication. ESC considers that if one, or more, of the suggested actions is implemented, it will already be a proof of success.

Suggestions have been shared such as:
- to involve famous people in addition to MEP, as they do so in the US e.g. AHA to draw public attention to CVD
- to change the name of “MEP Heart Group” to include “CVD” dimension instead of “heart”, to be more impactful
- to agree on key messages on the topic of advocacy, to communicate efficiently with stakeholders and share them with Industry Partners, to have a unique line of communication.
- to involve Industry Partners in ESC advocacy activities when feasible.

Overall congratulations for the ongoing work. Industry Partners confirmed their considerable interest to support ESC in the advocacy field and are willing to get more information.

4. **Horizon Europe – making the case for CVD research & innovation**

Christina Dimopoulou, ESC European Project Manager, focused on the importance of increasing research and innovations in the CVD area.

ESC is actively pushing for more EU Research Funding for CVD and has contributed (member of the Advisory Board) to the development of the ERA-CVD Strategic Research Agenda (SRA). The SRA is an advocacy document which makes a strong case on why more CVD Research is needed, requiring actions both on a European and national level.

ESC is constantly striving to involve the political sphere in its action and during the first Digital Health Summit in October 2019, the Prime Minister of Estonia made a speech.

The ESC is currently involved in 12 EU projects, including CATCH ME project started in 2015, BigData@Heart and Coro prevention project (coming up with EAPC involvement).

Feedback: Industry Partners would be interested to know about the ongoing projects, including CATCH ME and CoroPrevention. When speaking about Digital Health, the lack of incentives has also been raised.

5. **ESC shaping the regulatory framework for health technologies**

Patricia Munoz, ESC EU Policy & Advocacy Coordinator, explained the work that the ESC has undertaken to influence the regulatory framework for health technologies. She provided highlights on ESC activities to shape regulation on medical devices, clinical trials, and health technology assessment (HTA).

In terms of clinical trials, we have observed a significant drop in the development and authorization of new CVD medicines. CVD trial costs are 3 times higher than for oncology and 6 times than for usual medicines. ESC has been advocating for a more flexible international standard for clinical trials.

ESC also advocated for a stronger European collaboration on HTA as a way of helping to adopt evidence-based decisions and bridging gaps between countries.

Feedback: Some Industry Partners highlighted that medical devices and pharmaceuticals are different and that as single HTA system would not be appropriate. It can be challenging to address this topic as HTA as different importance depending on Industry focus. There are other topics above HTA such as dialogue between payers and regulators and ESC could be a voice for pragmatic solutions.

6. **The ESC Patient Forum – patients as advocates**

Inga Drossart, ESC Patient Officer, presented why patient engagement is important.
The first step has been the creation of the ESC Patient Forum, comprising of 24 patients from 12 EU countries and with different heart conditions. None of them are currently representative of a patient organisation to ensure an unbiased position. The plan is to involve caregivers into that forum too. Patient involvement in the ESC is an ongoing process, which only started one year and a half ago, with different implications and activities. For instance, patients are currently part of two Guidelines Task Forces. Other patients are involved in the Task Force for the revision of the core curriculum, as well as in activities of the ESC associations, including the update of patient information websites. Patients can be very powerful advocates and the ESC plans to make patients speak at advocacy events. Each patient has his/her own experience and personal story, which is a powerful added value and allow them to bring in a different perspective for projects and for advocacy. Patients groups in CVD are not so active in Europe compared to the US, as having a cardiovascular disease or simply wearing a pacemaker can be a taboo. It is crucial to change this perception.

**Feedback:** Patient engagement topic has raised many comments and the group agreed on the importance to work with patients, to share their voice, their story, to be more impactful. The fact that ESC is working with individual patients rather than patients organisations (sometimes funded by the Industry) led to questioning. If Industry partners want to become more patient centric, how can they collaborate or be involved in ESC patient engagement? The ESC is open to work with patient organisations and to collaborate with industry as part of a multi-stakeholder coalition which could be established to raise the profile of CVD. When dealing with patient engagement, language can sometimes be an important barrier. The patients selected for the Forum all speak fluent English.

It has been noticed that patients are looking for more information. With this in mind, it is crucial to develop more patient educational materials from a neutral organisation (sometimes people don’t trust information coming from the Industry). British Heart Foundation has fantastic online brochures and ESC could do something along similar lines. ESC will follow-up on this suggestion but capacity is limited, it is important to act step by step. ESC is very proud of what has been done during one year and a half only and plan to continue strategy & resource investment. Industry partners also suggested:

- to use more social media, make storytelling and create a blog on ESC website with regular content. Smart strategy to couple data with stories.
- Industry could potentially share the name of patients they work with in case the ESC wanted to establish contact with them to collaborate.
- to centralize and maybe use information from Industry Partners – they are probably all increasingly involving patients on different levels, asking the same questions to the same patients organisations.
- to increase patient engagement in events/congresses. ESC needs to find the best way to involve patients. During ESC Congress, in Munich, they were only observers, in Paris they had their first session and in 2020 this will probably increase. Patients are also part of subspecialties congresses like EHRA. Important to act step by step.
- to provide more general educational material/patient website. For now, it is focused either on HF, AF or Prevention and an “umbrella” approach would be recommended.

**Conclusion**

Aoife Delmas concluded and thanked all participants for their presence and contribution to this important Forum. Industry Partners feedback was appreciated and will be helpful to move forward on advocacy matters.

**Feedback:** The first Industry Advocacy Forum meeting has been fantastic to foster exchange and develop consultation. It is an important starting point to join forces to place CVD on the agenda of decision-makers. ESC pointed out that actions need to be done step by step. As of today, ESC doesn’t have a collaborative model in place for advocacy and will have to work on it. Participants finally expressed their interest to have this type of Forum renewed. ESC needs to work on how collaboration can look like and another Forum meeting will be probably organised when the new ESC Advocacy Committee is in place, following the change in ESC leadership at the next ESC Congress. For the next meeting, it has been suggested to invite trade associations from different sectors, such as MedTech & EFPIA.
Action points/next steps

- Call for volunteers from the group to advise on work by the ESC to develop a partnership framework model for Advocacy activities with practical examples; Patient Group Initiatives, Disease Awareness Campaigns, Lobbying Campaigns
- Continue the Forum annually as an important information exchange platform