



Promoting Cardiovascular Health in People Living With, or at Risk of, Type 2 Diabetes:

Priorities for Collaboration between the Diabetes and Cardiovascular Patient Communities

INTRODUCTION

Between April and November 2020, a series of virtual roundtables was convened by the Global Heart Hub, bringing together 33 representatives of the global Diabetes and Cardiovascular Patient communities. The goals of these meetings were to:

- Explore the challenges faced in promoting cardiovascular health in people living with, or at risk of developing, type 2 diabetes.
- Agree measures which could be implemented to help address the key obstacles to progress in this area.
- Establish an action plan for collaboration between the global Diabetes and Cardiovascular Patient communities to improve Cardio-Diabetes care.

This report shares key agreements reached and ideas shared at the roundtables and defines 4 priority areas for action in 2021 and beyond.



Priority Areas for Action:

1. Elevating the patient voice as an equal partner in the Cardio-Diabetes dialogue.
2. Driving the Cardio-Diabetes agenda from a patient perspective and influencing policy decisions.
3. Raising awareness amongst patients and the general public, and empowering patients to take control of their health risks.
4. Highlighting the need for health systems to provide truly integrated patient care.

Roundtable participants are 100% in agreement that Cardiovascular and Diabetes Patient communities must partner and collaborate to drive change in the management of cardiovascular risk in people living with, or at risk of, type 2 diabetes.

Agreed Next Steps:

1. Create a patient-led Cardio-Diabetes Patient Council to facilitate the partnering of Cardiovascular and Diabetes Patient communities to collaboratively advocate for people with, or at risk of developing, these conditions.
2. Via the Cardio-Diabetes Patient Council, develop tools and opportunities to support the Cardio-Diabetes community to drive change, including:
 - » **Multi-stakeholder encounters**, such as debates and roundtables, to elevate the patient voice as an equal partner in the Cardio-Diabetes dialogue.
 - » **Evidence-based position papers**, to drive the Cardio-Diabetes agenda from a Patient perspective and influence policy decisions.
 - » **Patient activation campaigns**, to raise awareness, empower patients to take control of their health risks, and highlight the need for health systems to provide truly integrated patient care

CARDIO-DIABETES

Global Heart Hub responds to a major global health problem

The statistics relating to the cardiovascular complications of diabetes are stark [1]:

- 425 million people worldwide have Type 2 diabetes – this figure is predicted to rise to 629 million by 2045.
- People with diabetes are 2 to 3 times more likely to have CVD, and 2 times as likely to die of CVD or stroke compared to those without diabetes.
- 50% are unaware of their disease.
- 84% of people aged 65 or older, with diabetes, die from heart disease and stroke.
- In 2015, the global economic burden of Type 2 diabetes mellitus was estimated to be \$1.3 trillion, or 1.8% of the global GDP; and it is estimated that this burden will increase to \$2.1 - \$2.5 trillion by 2030.

These statistics point to an urgent need to prevent CVD in those with diabetes, requiring careful attention to CVD risk factors such as tobacco use, hypertension and blood lipids.

However, research conducted by the World Heart Federation and International Diabetes Federation, highlighted the many obstacles to progress towards this goal, including [2]:

- Lack of awareness of the increased CVD risk among those with diabetes.
- Difficulty of changing attitudes and behaviours with regard to a healthy lifestyle.
- Lack of healthcare worker adherence to clinical practice guidelines.
- Lack of an integrated care approach to screening.
- Lack of communication between endocrinologists/diabetologists and non-endocrinologists (e.g. internists and cardiologists).
- Evidence practice gaps in treatment of diabetes and CVD.

The Global Heart Hub, responding to this evidence of a major global health problem, convened 4 virtual roundtables, bringing together representatives of the global Diabetes and Cardiovascular Patient communities, to establish how to best serve people at risk of developing cardiovascular complications of type 2 diabetes.

[1] Reference: Mitchell S, Malanda B, Damasceno A, et al. A Roadmap on the Prevention of Cardiovascular Disease Among People Living With Diabetes. *Glob Heart* 2019;14:215-44

[2] Reference: <https://www.world-heart-federation.org/cvd-roadmaps/wp-content/uploads/sites/6/2019/08/WHF-CVD-and-Diabetes-Roadmap-WEB.pdf>

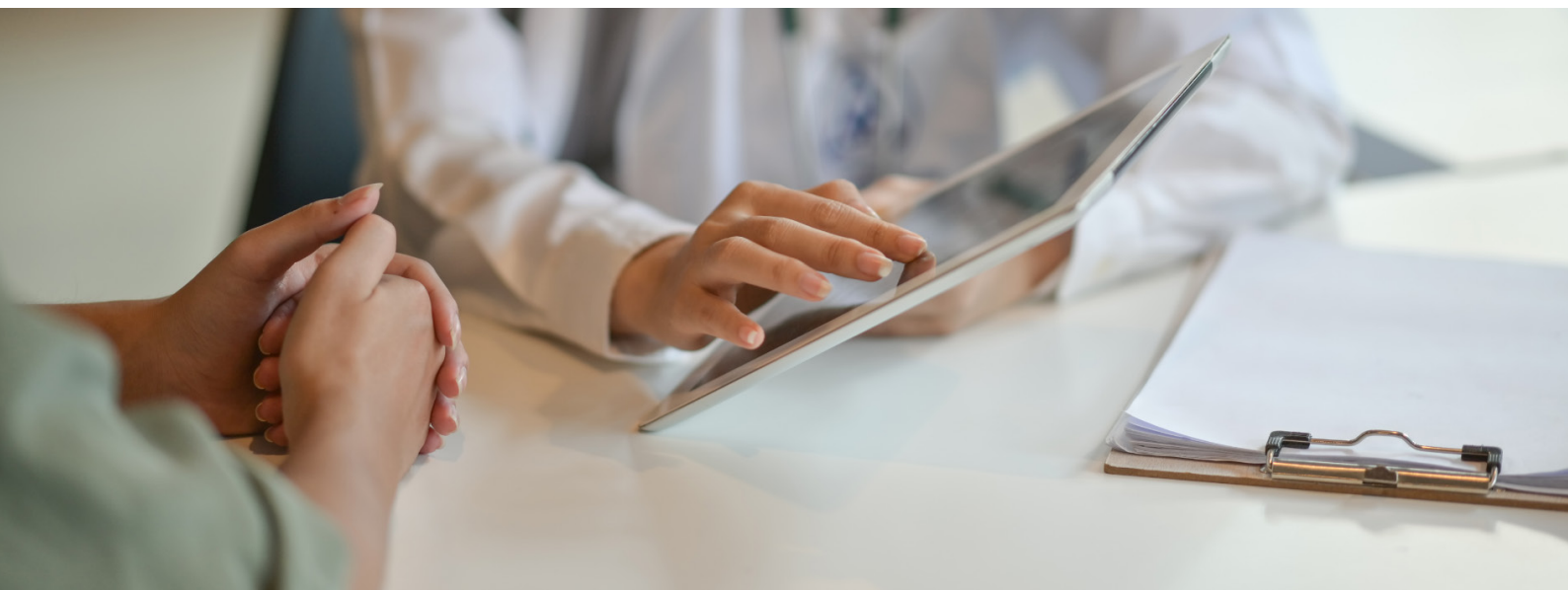


PRIORITY AREA FOR ACTION 1:

Elevating the patient voice as an equal partner in the Cardio-Diabetes dialogue.

Roundtables - Key Agreements:

- Cardiovascular risk is poorly managed in people with type 2 diabetes, leading to poor patient outcomes.
- A key underlying reason for this is that patients are not seen as equal partners in treatment of their condition and its associated risks.
 - » Patients are seldom engaged in decision-making regarding their conditions.
 - » Diabetes patients are at higher risk of cardiovascular disease, but they are often unaware of that risk. This may be due to a lack of communication between different healthcare specialists, who can treat a patient's symptoms but not necessarily put the patient at the centre or their care early enough or often enough.
- The medical community have begun to engage in the Cardio-Diabetes topic, which has featured at recent conferences, such as those of the ESC and EASD.
 - » There is now a need for patient organisations to engage in this discussion and to drive the agenda from a patient's perspective:
 - To gain consensus on needs to be addressed and on how patients can add value.
 - To generate dialogue, influence policy decisions and collaborate with opinion leadership.
- At individual patient level, there is a real need for increased knowledge and understanding about their disease and the associated cardiovascular risks, to enable them to participate as equal partners in the Cardio-Diabetes dialogue. *(see Priority for Action 3)*
- Systems must be put in place to ensure that the patient voice is truly heard by:
 - » Policymakers *(see Priority for Action 2)*
 - » HCPs *(see Priority for Action 4)*



PRIORITY AREA FOR ACTION 2:

Driving the Cardio-Diabetes agenda from a patient perspective and influencing policy decisions.

Roundtables - Key Agreements:

- The failure to categorise type 2 diabetes as a health policy priority is a contributing factor to the poor management of cardiovascular risk in these patients.
 - » Policy makers are aware of the risks associated with type 1 diabetes, thus type 1 diabetes gains political support.
 - » There is an incorrect perception that type 2 diabetes carries lower risk than type 1 diabetes overall, therefore the associated cardiovascular health risk message is not heard.
 - » Type 2 diabetes must not be ignored, since treatment of the condition and its associated complications is costly, putting huge pressure on health systems.
- Globally, health systems are not designed to address NCDs adequately.
 - » Prevention is not a priority.
 - » There is a lack of screening which would support earlier detection and intervention, allowing for better patient health outcomes and quality aging.
 - » Evidence-based guidelines exist to guide the management of type 2 diabetes and associated cardiovascular risks, however, adherence is inconsistent, and auditing to establish levels of implementation is rare.
- It is important to engage with policy makers in addressing the barriers to adequate management of the cardiovascular risks of type 2 diabetes.
 - » There is much to be learned from countries where risks have been identified via cross-working collaborations. For example, in Portugal, heart and diabetes organisations work together, and produce an annual report identifying the Cardio-Diabetes burden at local, regional and national levels, as a tool to engage and influence policy makers.
 - » COVID-19 has exposed the disproportionate vulnerability of individuals with underlying conditions and co-morbidities, particularly in disadvantaged areas where risk factors are compounded.
 - » A patient-centric approach to policy-making is essential.
- Diabetes and Cardiovascular patient organisations can unify as one voice, via the Global Heart Hub and IDF, to have an impactful effect on international policy makers.
 - » Collective, joint action allows the prospect of developing an international position paper or patient charter.
 - » The COVID-19 pandemic creates an opportunity to galvanize action in prevention strategies.



PRIORITY AREA FOR ACTION 3:

Raising awareness amongst patients and the general public, and empowering patients to take control of their health risks.

Roundtables - Key Agreements:

- One of the most important factors contributing to the poor management of cardiovascular risk in people with type 2 diabetes is the very low levels of awareness of the link between these two conditions, not only amongst the general public, but also amongst the cardiovascular and diabetic patient communities.
 - » There is also a disconnect between the high levels of awareness of the risks amongst HCPs and the low levels amongst patients, highlighting problems with communication.
 - » There is a lack of resources available to help people with type 2 diabetes manage their risk of developing cardiovascular disease.
- Awareness campaigns initiated by patient organisations have historically focused on disease specifics and not on co-morbidity.
 - » There is insufficient exchange of information between the cardiovascular and diabetes patient communities.
 - » Relying on HCPs as a primary source of information is problematic, since access is usually limited, thus awareness-raising must involve the community.
 - » Patients should be supported, beyond their integrated healthcare team, by advocacy organisations and community support systems.
- There is a need to build on existing knowledge to create collaborative, structured education to generate greater awareness of type 2 diabetes and associated cardiovascular disease risk factors.
 - » Mass public awareness campaign to raise awareness, thus:
 - Empowering and equipping patients to ask specific questions relating to their condition and discuss their risk profile with their HCP.
 - Helping to identify those who are as yet undiagnosed.
 - » Use emotional messaging to reinforce the prevention message.
- Diabetes and Cardiovascular organisations can leverage world heart and diabetes days to drive messaging.
 - » There is an urgent need to take action and work together on agreed initiatives and primary prevention priorities.



PRIORITY AREA FOR ACTION 4:

Highlighting the need for health systems to provide truly integrated patient care.

Roundtables - Key Agreements:

- One of the most important factors contributing to the poor management of the cardiovascular complications of type 2 diabetes is the lack of collaboration between heart and diabetes health professionals.
 - » The inter-related conditions of type 2 diabetes and cardiovascular disease are regularly managed in silos, with no communication between patients' HCPs.
 - » A patient-centric approach is essential, focusing on the patient and not on the condition, to allow synergistic management of their health across conditions and co-morbidities.
 - » Patients' care should be managed by an integrated and collaborative team - primary care physicians, nurses, specialist physicians, lifestyle specialists, etc.
- Diabetes patients are rarely made aware of their risk of developing cardiovascular disease.
 - » The medical community is aware of the risk relationship, however this is inadequately communicated to patients.
 - » There is a need for better communication between HCPs and patients to increase their awareness of risk.
 - » Primary care physicians are the key interface for patients with type 2 diabetes, so their knowledge of the correct standards of care and their ability to communicate risks to their patients has a significant impact on these patients' health outcomes.
- There is a clear need to engage with HCPs in developing solutions to the current barriers to adequate cardiovascular risk management.
 - » There is also a need for greater collaboration between HCPs and patient organisations.



PLAN AGREED TO ADDRESS PRIORITY AREAS FOR ACTION:

Action 1: Create a patient-led Cardio-Diabetes Patient Council

The creation of a Cardio-Diabetes Patient Council would facilitate the partnering of Cardiovascular and Diabetes Patient communities to collaboratively advocate for people with, or at risk of developing, these conditions.

The Council Affiliates would work in partnership to develop tools and opportunities which would support the Cardio-Diabetes community to drive change.



Action 2: Arrange multi-stakeholder encounters

Multi-stakeholder encounters, such as debates and roundtables, would assist in elevating the patient voice as an equal partner in the Cardio-Diabetes dialogue.

These meetings would facilitate shared understanding of different perspectives, enable cross-fertilisation of ideas, and foster collective action and accountability.



Action 3: Produce evidence-based position papers

Evidence-based position papers would help to drive the Cardio-Diabetes agenda from a patient perspective and influence policy decisions.

Such documents would provide a means to connect the dots in prevention and management of Cardio-Diabetes, bringing different experts to the table to engage in identifying and proposing solutions to the challenges faced globally and locally.

They would also create opportunities to generate awareness via media campaigns.



Action 4: Implement patient activation campaigns

Patient activation campaigns would raise awareness, empower patients to take control of their health risks, and highlight to HCPs their responsibility in providing truly integrated patient care.

Such campaigns would activate and mobilise patients, allowing them to become advocates for themselves and others with, or at risk of developing cardiovascular complications of type 2 diabetes.



ROUNDTABLE PARTICIPANTS

Organisation	Country/ Region	Participants
ECPO	Europe	Vicky Mooney
IDF Europe	Europe	Elisabeth Dupont Sabine Dupont
Beyond Type 2 Diabetes	USA	Tara Smith
Diabetes Sisters	USA	Anna Norton
Mended Hearts	USA	Andrea Bare
Diabetes Canada	Canada	Kimberley Hanson Mario Miceli
Heart and Stroke Canada	Canada	Ellen Ross
Instituto Lado a Lado	Brazil	Fernanda Carvalho
Asociación Ale	Mexico	Carlos Castro
DeDoc Labs	Germany	Bastian Hauck
Croí Heart & Stroke Foundation	Ireland	Neil Johnson
Diabetes Ireland	Ireland	Clair Naughton Valarie Humphries Cormac Gollogly
ICPO	Ireland	Susie Birney Maura Murphy
Patient Representative	Ireland	Enda Folan
Italian Society for Cardiovascular Prevention (SIPREC)	Italy	Dr. Roberto Volpe
Biedrības "ParSirdi.lv" cilmes šūna	Latvia	Inese Mauriņa
Cardiovascular Disease Prevention Group	Lithuania	Rasa Semiotiene
EcoSecre	Poland	Agnieszka Wolczenko
Fundacja Diabeciaki	Poland	Barbara Kucharska
Polish Association for People with Heart Failure	Poland	Dr. Marta Kaluzna Dr. Magdalena
Polish Diabetes Association	Poland	Anna Sliwinska
Associação Protectora dos Diabéticos de Portugal	Portugal	Prof Joao Filipe Raposo
Diabetes UK	UK	Emma Elvin
Patient Representative	UK	Richard Cordell
Patient Representative	UK	Paul McGreavy
Patient Representative	UK	Sheila Winters
Global Heart Hub	Global	Maeve O'Sullivan





The Global Heart Hub (GHH) is the first global non-profit organisation established to provide a voice for those affected by cardiovascular disease. We are an alliance of heart patient organisations, aiming to create a unified global voice for those living with, or affected by, heart disease.

Established in January 2020, the GHH is rapidly expanding, with over 70 Affiliate patient organisations globally, across 3 Patient Councils - Heart Failure, Heart Valve Disease, Cardiomyopathy – in addition to multiple Working Groups (including Cardio-Diabetes).





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