Global Heart Hub

The Health Policy Partnership

Cardio-Diabetes Think Tank: Call To Action

Advancing action through patient collaboration

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Foreword

This call to action aims to galvanise the cardiovascular disease (CVD) and diabetes communities to advocate for increased attention and new strategies addressing a very important health issue – namely the interrelationship between heart disease and diabetes. The prevalence of these conditions, the critical links between them, ongoing advances in the management of diabetes and CVD, and the underutilisation of appropriate lifesaving therapies require new collaborative approaches.

Together, CVD and diabetes affect hundreds of millions of people across the world, cause millions of needless deaths – and their burden is predicted to grow in the following decades, including increasingly in younger people.[1-3] CVD is a major driver of mortality among people living with type 2 diabetes, who are twice as likely to experience a life-changing cardiovascular event, such as a stroke, heart attack or CVD-related sudden death in high-income countries, compared with individuals without diabetes.[4 5] Such risks can be even greater in middle and low-income countries.[6 7] Furthermore, treating CVD has a substantial impact on healthcare costs for type 2 diabetes, accounting for up to half of its expenditure.[5]

To date, this important issue has been advanced by global organisations such as the World Heart Federation and the International Diabetes Federation. While there has been significant progress in improving cardio-diabetes care in some countries, moving national and local health systems towards concrete change remains a challenging task. This call to action lends it new urgency from a patient perspective by presenting a consensus as to the immediate actions advocates wish to take.
As ever, we do not lack scientific evidence or clinical best-practice guidelines for the management of CVD, diabetes or their intersection; we do, however, lack implementation. The relationship between diabetes and CVD is still incompletely understood, despite the linkages between diabetes and cardiovascular risk being consolidated in joint clinical guidelines as far back as 2007. This interrelationship remains challenging for systems of healthcare delivery, education and scientific discovery, which are typically built around disease siloes, with decision-makers often focused on short-term, cost-containment objectives.

The Global Heart Hub wishes to put a spotlight on a vital missing piece of the advocacy struggle – a patient-led call to action that speaks to immediate patient and system needs across the globe, and puts patients at the heart of care for type 2 diabetes and CVD.

This document lays a foundation for future work, based on a clear consensus with colleagues across different sectors and both disease areas, including patient advocates and healthcare professionals. I would like to express my gratitude to everyone who has contributed to the discussions upon which this call to action is based.

We hope that advocates across the diabetes and CVD communities take these actions forward to transform cardio-diabetes care and improve the lives of patients.

Neil Johnson
Executive Director, Global Heart Hub

1. Why have we developed this call to action?

We need the patient voice to drive real action in cardio-diabetes

> We need more unity, we have to fight against the inertia regarding CVD and diabetes. If we find common ground, we can prevail in putting patients at the centre of these conversations and the health system.

Carlos Castro
Patient and CEO, Pacientes de Corazón

From a clinical perspective, we understand the linkages between diabetes and CVD better than ever before. In recent years the growing scientific understanding of shared risk factors and populations has driven the clinical community to come together to clarify best practice, raise awareness and find strategies to address these conditions. The European Society of Cardiology and the European Association for the Study of Diabetes jointly developed the first cardio-diabetes clinical guidelines in 2007, and since then, several education programmes and conferences have been dedicated to this topic.

In 2019, these efforts culminated with the development of A Roadmap on the Prevention of Cardiovascular Disease Among People Living with Diabetes by the World Heart Federation and the International Diabetes Federation, which outlined the main challenges and potential solutions to improve care along the patient pathway.

However, system transformation is challenging, and the development of stronger, united patient advocacy for both diabetes and CVD has been a much needed factor. Between April and November 2020, the Global Heart Hub (GHH) engaged patient organisations in a series of virtual round tables. Bringing together representatives of the global diabetes and cardiovascular patient communities, the meetings resulted in the development of the report Promoting Cardiovascular Health in People Living With, or at Risk of, Type 2 Diabetes, identifying four overarching unmet needs that must be addressed across countries.

These initial conversations have generated much-needed momentum, but now we must move into concrete action. It is time for the patient community to play its part in driving the policy agenda forward by clarifying our expectations of decision-makers and the advocacy community, and taking direct action where possible.

2. How have we developed this call to action?

Building on the 2020 round tables, the Global Heart Hub organised a think tank in May 2022 to establish specific tangible actions that are needed to improve care and elevate policymakers' responses. The think tank brought together representatives of global and regional organisations, including five patient groups, three umbrella organisations and healthcare professionals in nursing, primary and secondary care.

Following a discussion on the unmet needs identified during the round tables, the think tank split into several focus groups. By the end of the discussion, each group presented their proposed recommendations and actions to help resolve these unmet needs. Based on this meeting, this call to action provides specific recommendations that the diabetes and CVD communities can take forward.

Participants at the GHH Cardio-Diabetes Think Tank

- **Carlos Castro**, patient, CEO Pacientes de Corazón, Mexico
- **Jean-Luc Eiselé**, CEO, World Heart Federation
- **Emma Elvin**, Senior Clinical Advisor, Diabetes UK, UK
- **Richard Hobbs**, Chair, European Primary Care Cardiovascular Society; President, International Primary Care Cardiovascular Society; Professor of Primary Care, University of Oxford; Head of Nuffield Department of Primary Care Health Sciences
- **Neil Johnson**, Executive Director, Global Heart Hub; CEO Croi, the Heart & Stroke Charity and National Institute for Prevention and Cardiovascular Health, Ireland
- **Cindy Lamendola**, Board Member, Preventive Cardiovascular Nurses Association; Nurse Practitioner/Clinical Research Nurse Coordinator, Stanford University School of Medicine
- **Inese Maurina**, patient, CEO, ParSirdi.lv, Latvia
- **Anna Norton**, patient, CEO, Diabetes Sisters, USA
- **Jorge Plutzky**, Board Member, Worldwide Cardiodiabetes; Director, Preventive Cardiology, Brigham and Women's Hospital; Principal Investigator and Associate Professor, Harvard Medical School
- **Naveed Sattar**, Board Member, Worldwide Cardiodiabetes; Professor of Metabolic Medicine, University of Glasgow; Honorary Consultant in Metabolic Medicine, Glasgow Royal Infirmary
- **Beatriz Yáñez Jiménez**, Advocacy Lead, International Diabetes Federation

CONTRIBUTOR TO THE GHH CARDIO-DIABETES THINK TANK

- **Anne-Marie Felton**, President, Federation of European Nurses in Diabetes; Honorary Consultant, Queen Mary's Hospital, London

3. What are the unmet needs, barriers and key issues in cardio-diabetes?

Across the world, people with type 2 diabetes often do not have access to diagnosis and treatment of their condition.[1 8] Of serious concern is that, globally, one in two adults with diabetes is unaware of their condition.[1] Even when diagnosed, people with diabetes are often not aware of their CVD risk and common risk factors are often inadequately managed.[9] The lack of optimal intervention leads to delayed diagnoses, poorer outcomes and, ultimately, hospitalisations, morbidity and mortality that could have been prevented.

3.1 MANY GOVERNMENTS DO NOT HAVE FORMAL NATIONAL DIABETES AND CVD STRATEGIES

> It's concerning that – so few countries have formal national cardiovascular prevention strategies. We shouldn't be surprised then, that there is a disconnect between cardiovascular and diabetes prevention and care policies, or that patients commonly report having no awareness of the link between their diabetes and their cardiovascular health until they are admitted to hospital for an acute event.

Neil Johnson
Executive Director, Global Heart Hub

Advocates on both sides consistently report that governments rarely have up-to-date plans on diabetes or CVD. In addition, type 2 diabetes is often incorrectly perceived as lower risk than type 1 diabetes, which along with the stigma attached to type 2 diabetes has contributed to the limited policy focus granted to cardiovascular risk in this population. The lack of national screening programmes for diabetes in many countries also hampers detection and the opportunity for earlier intervention in CVD that would allow better health outcomes and quality of life.

3.2. PUBLIC AWARENESS AND UNDERSTANDING IS LOW OF THE INTERRELATIONSHIP BETWEEN DIABETES AND CVD – THE RISK FACTORS AND HOW TO ADDRESS THEM

> We think that everyone is aware of the link between diabetes and CVD in the US, but many colleagues in primary care, endocrinology and cardiology would actually say they didn't talk to their patients about this link. It's very important that we educate our healthcare community and patients.

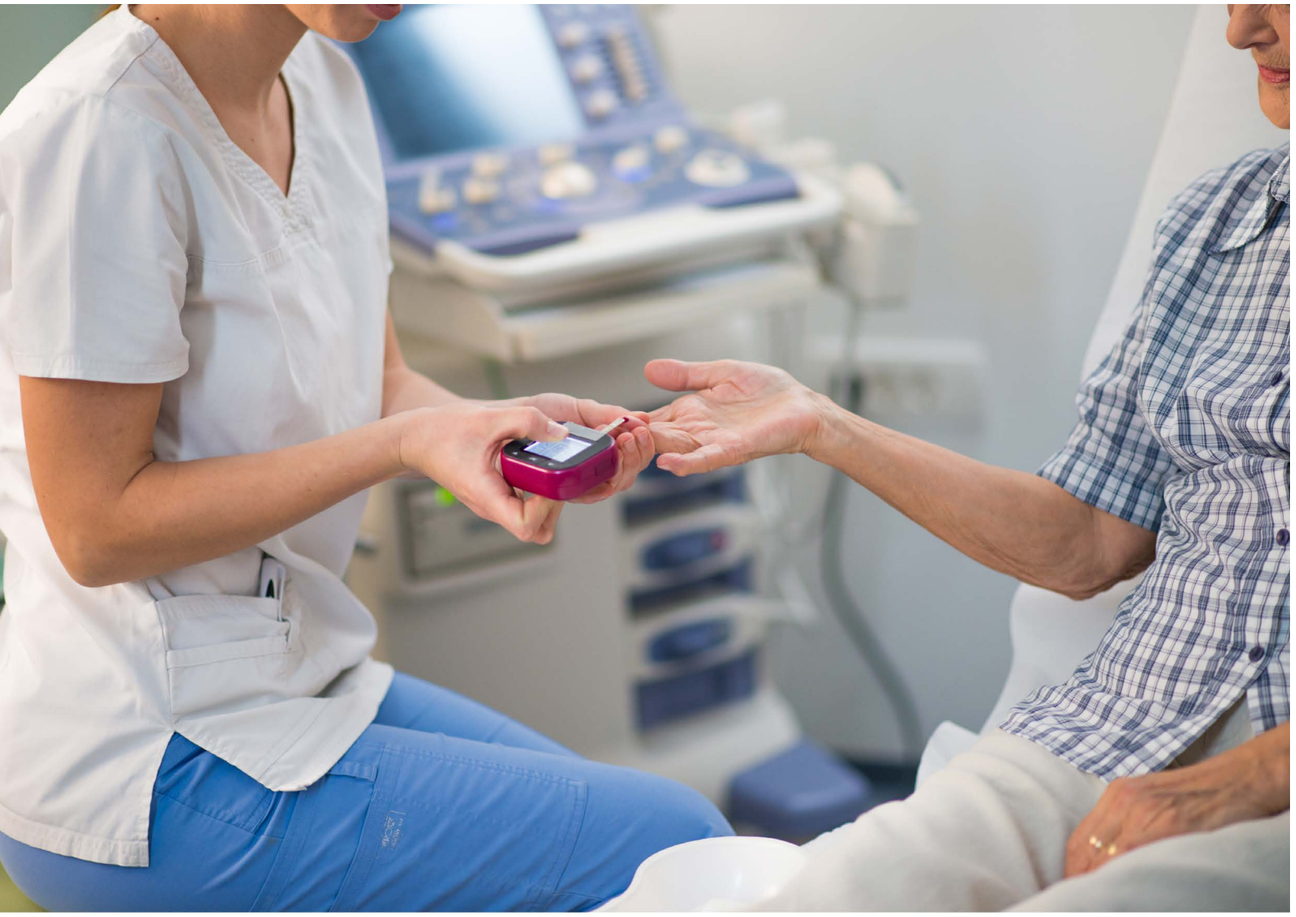
Cindy Lamendola
Board Member, Preventative Cardiovascular Nurses Association

Some healthcare professionals still do not fully understand the relationship between diabetes and CVD, and how to address these conditions jointly. In recent years, there has been a growing body of evidence demonstrating the relationship between CVD, diabetes and their drivers. However, primary and secondary care still lack effective integrated approaches to prevention and management across the two areas. In particular, routine management focuses more on medical risk factors and less on the role of lifestyle and social determinants of health.

People with diabetes are often not aware of their heightened cardiovascular risk. This is likely due to patients having difficulty understanding the full complexity of the message or healthcare professionals not communicating the relationship between diabetes and CVD risk in a way that patients can easily comprehend and address. This highlights the need for training of healthcare professionals regarding how to better communicate the nature of type 2 diabetes and CVD in the time-pressured real-world environment of primary care. Patients need greater education and support on these conditions, as well as an enhanced understanding of what steps they need to take to improve their current and future health status. Such education enables patients and their families to serve as their own advocates in receiving optimal care while also potentially avoiding the development of diabetes among the wider population.

> We speak to patients with diabetes across the world and see a lot of gaps in patient education. Most patients report that they do not have enough time with healthcare professional, which poses a huge challenge for self-care and appropriate risk management.

Beatriz Yáñez Jiménez
Advocacy Lead, International Diabetes Federation



3.3 PATIENTS ARE NOT SEEN AS EQUAL PARTNERS IN THE MANAGEMENT OF THEIR RISK AND TREATMENT OF THEIR CONDITION

Advocates report that patients are often not fully engaged in shared decision-making about their treatment options and health goals. This is possibly caused by cultural perceptions that healthcare professionals exercise their role from a position of authority, but is likely exacerbated by the patients' lack of understanding about their condition and associated risks. Healthcare professionals may also focus their consultations with patients on the control of specific risk factors and signs (e.g. blood sugar, blood pressure, cholesterol, weight, smoking cessation) rather than framing such factors as part of a wider conversation to engage the person in care goals and strategies that relate to their life circumstances and comorbidities as a whole.

> We can help patients understand what are the key questions to ask their physician. For example: "Have you ever screened me for diabetes? Why am I not receiving treatments that help protect my heart, whether diabetes medications or cholesterol-lowering medications with these established benefits?" This can be a very powerful and empowering tool for patients, once directed to their own providers. More could be done by professional organisations and advocacy groups to address this issue.

Jorge Plutzky
Board Member, Worldwide Cardiodiabetes

We know that preventive efforts in diabetes and cardiovascular disease are highly effective, but we need to know more about optimal models of self-care. There is strong evidence of the linkages between diabetes and cardiovascular health, and their impact on quality of life and mortality. There is emerging evidence on the effectiveness of self-care interventions, such as the use of digital health tools. A stronger evidence base will be essential to boost the advocacy efforts of patient organisations and guide investment to the most promising solutions.

3.4 MANY HEALTH SYSTEMS ARE UNABLE TO DELIVER INTEGRATED CARE FROM DIAGNOSIS TO TREATMENT

> A major challenge, especially in the US, is that people with type 2 diabetes are typically not seen by a specialist. They are seen by a general practitioner, a physician's assistant or an internist, who don't always have full grasp of the intricacies and details of diabetes and pre-diabetes. This can make it difficult to have conversations about cardiovascular risk.

Anna Norton
Patient and CEO, Diabetes Sisters

Across the world, people with diabetes have limited access to specialist care. Primary care physicians are often the main point of contact for people with type 2 diabetes. However, general practitioners may not know enough about the relationship between diabetes and CVD to be confident in discussing risk with patients and to provide adequate standard of care. Equally, non-physician community health workers such as pharmacists are typically underused in screening for both diabetes and CVD, and are yet to be effectively engaged in diagnosis and management of basic preventive measures. While specialist-led care is often ideal, each country is different and it may not be realistic for all patients to receive care from a specialist.

Type 2 diabetes and CVD are still typically managed in siloes. Guidelines call for integrated care across a collaborative team that comprises primary care physicians, CVD and diabetes specialists, nurses and other relevant healthcare professionals, yet this happens inconsistently between and within countries. Regardless of the setting, the lack of communication between healthcare professionals is a major factor in the poor management of cardiovascular complications in people with diabetes.

4. What actions are needed to improve cardio-diabetes care?

“We all see that this is a very challenging task, but we have a lot of potential solutions. This is not a sprint, but a marathon, for all of us. I am glad we are doing this from a patient perspective, joining healthcare professionals, academics and others.

Inese Maurina
Patient and CEO, ParSirdi

We recognise that we face persistent systemic barriers, whether explicit or unrecognised, to the optimisation of cardio-diabetes care. However, to date, we have lacked a clear idea of what actions patients want to see, and how to help decision-makers make sense of multiple problems and the best path forward. With this goal, the GHH Cardio-Diabetes Think Tank was able to identify tangible areas of action where we can make real progress.

We call for a coalition across diabetes and CVD organisations for a patient-centred focus in the pursuit of four priorities for action.

PRIORITY ACTION 1: DOCUMENT A CLEAR PICTURE OF THE STATE OF PLAY IN CARDIO-DIABETES

“Type 2 diabetes is a central determinant of heath and needs to be a health policy priority, but we need to craft a careful, simple, clear and positive message.

Jorge Plutzky
Board Member, Worldwide Cardiodiabetes

Establish a new cardio-diabetes coalition that puts patients at the centre and makes the case for change to decision-makers. This might involve activities to:

- Raise awareness of the high prevalence of diabetes and the potential for simple changes to bring huge benefits to patients and health systems.
- Present solutions to decision-makers’ problems, and use evidence-based narratives and storytelling to emphasise the potential return of investment for society and health systems. This may include making the economic case for early identification and guideline-based intervention to gain political recognition and investment for cardio-diabetes (e.g. by highlighting the possibility to reverse type 2 diabetes as well as the important role of socioeconomic determinants of health).

Undertake an analysis of the state of play in cardio-diabetes policy. This could include:

- At country level, map and explain what policies exist, with simple performance statistics on key elements of care, such as the proportion of people with diabetes on statins or specific lipid-modifying therapies.

- At global level, analysis could look at gaps in access to care, both in terms of policy (reimbursement, national plans, care pathways, etc.) and delivery (delays in diagnosis, uptake of treatment, multidisciplinary teams, etc.). Overall, this would help to expose unjustified variation and inefficiency in patient and economic outcomes.

> When talking to policymakers, we should emphasise prevention and joint solutions. We know that risk factors for type 2 diabetes include an unhealthy diet, lack of exercise and smoking. There is a part of personal responsibility, but the socioeconomic environment, the health system and policymakers also have a huge responsibility. To communicate this, we really need to join forces between CVD and diabetes, along with other non-communicable diseases.

Jean-Luc Eiselé
CEO, World Heart Federation

Develop a global position statement on quality of care for cardio-diabetes. This could include:

- Explanations of effective care pathways showing how patients might ideally progress through stages of diagnosis and care, and where fragmentation and gaps in care and management typically manifest. While each system is different, this could inspire more integrated, person-centred local care pathways and improvement programmes.

- Guidance to help decision-makers to understand the potential of quality indicators in allowing countries to assess and compare their health delivery, such as measures of patient, process and economic outcomes, as well as access to services and therapies.

- A mapping and synthesis of leading models of cardio-diabetes interventions across the world, and the value and learning that can be obtained. In diagnosis and basic preventive medications, this may be a useful way to expand opportunistic screening and basic prescriptions outside of specialist care in the community, potentially by non-physicians.

PRIORITY ACTION 2: DEVELOP COMMUNICATION RESOURCES AND CAMPAIGNS TO IMPROVE PUBLIC UNDERSTANDING OF CARDIO-DIABETES RISK AND DISEASE PREVENTION

> There is an opportunity to improve communication across the board. We need to improve education so all healthcare professionals understand what is diabetes, what is cardiovascular risk, their drivers and how to address them. The information we give to patients is often still too complex and not relevant for their lives. We need to translate clinical messages into a journey of achievable changes that patients can make.

Naveed Sattar
Board Member, Worldwide Cardiodiabetes

Develop communication and educational resources to help both healthcare professionals and patients understand and act upon the relationship between diabetes and CVD. For example:

- For healthcare professionals – infographics, leaflets and other materials that outline the best ways to discuss diabetes and cardiovascular risk with patients in real-world settings. This should include ways to make the relationship between cardio-diabetes risk factors easier to understand, and ensure the discussion is as relevant as possible to the perspectives of patients.

- For patients – resources that quickly and effectively make cardio-diabetes risk factors and determinants easier to understand, and are suitable for time-pressured consultations with healthcare professionals. This could also include patient charters and clear statements of care quality that might take a rights-based approach.

> We often fall into a trap of talking about risk factors for individual conditions – we need to join them together and talk about them as risk factors for both conditions, to help people understand the reasons for making difficult lifestyle changes.

Emma Elvin
Senior Clinical Advisor, Diabetes UK

Develop public campaigns to raise awareness of the need for a healthy lifestyle and a supportive environment for the prevention of diabetes and CVD. For example:

- Campaigns that raise awareness of the environment and lifestyle behaviours that can promote health and the prevention of diabetes and CVD. This may include promoting simple messages of habit changes that are realistic and achievable, such as school campaigns promoting a healthy diet and an active lifestyle. It would be important to emphasise that preventing

weight gain is easier than achieving weight loss – a message that could be emphasised among overweight patients by patients themselves.

- Work with disease-specific patient groups to raise awareness that their condition shares risk factors with CVD and other diseases that need similar attention.

PRIORITY ACTION 3: DEVELOP SUPPORT TOOLS TO EMPOWER PATIENTS TO BECOME EQUAL PARTNERS IN THE MANAGEMENT AND TREATMENT OF THEIR CONDITION

> Many people, with suitable training, are able to monitor and even potentially manage hypertension, and that includes patients themselves. There are strong published data showing that patients who are offered involvement in self-monitoring have better disease control, and even that patients with validated devices and fairly simple algorithms can dose-titrate. Self-management won't be for everyone, but many patients could be suitable and in some areas, such as isolated rural areas, it might be more necessary.

Richard Hobbs
President, International Primary Care Cardiovascular Society

Develop resources to help healthcare professionals build stronger partnerships with people living with diabetes. This may include:

- Training that raises awareness of the value of active patient involvement in self-care and shared decision-making, such as improved health outcomes and treatment adherence.

- Guidance and decision-making tools to use during consultations. These might promote collaborative communication with people living with diabetes, such as by avoiding stigmatising language, emphasising the therapeutic partnership between healthcare professional and patient, and supporting patients to set and achieve improved lifestyle goals.

Develop patient-focused resources to raise awareness of the right to shared decision-making and how to assess the quality of care provided. This may include leaflets, media campaigns, webinars, podcasts and other forms of communication that raise awareness of key aspects of person-centred care. These resources can contain explanations on what shared decision-making is and guidance on how patients can be actively involved in medical appointments, such as how to prepare and what questions to ask.

PRIORITY ACTION 4: IMPROVE ACCESS TO AN INTEGRATED CARE PATHWAY FOR CARDIO-DIABETES

> One of the biggest challenges is that we see a lot of siloed healthcare. The cardiologist only treats the heart. The diabetes specialist only treats diabetes. One solution is integrated digital health records, which would be beneficial for all providers to understand what's going on and adopt a team approach.

Anna Norton
Patient and CEO, Diabetes Sisters

Promote a clear vision for continuity of care across settings. Throughout the care pathway, and in particular at discharge, healthcare professionals need to ensure that they provide sufficient information to other healthcare professionals and patients. This can be achieved, for example, by recording detailed notes that facilitate follow-up, and communicating with patients in a way that allows them to engage in their care. Achieving integrated care is usually challenging for any locality, and guidance can be useful. This might include template care pathways and clinician tools at different points of the patient pathway, even if these would likely be verified and adapted at the local level. It could also involve checklists for acute admissions, discharge and routine care, or referral pathways.

Improve access to specialist-coordinated multidisciplinary teams. Ideally, specialist-led multidisciplinary teams would be responsible for coordinating care and acting as the main point of contact. However, this may not be possible in all areas. We must support rapid referrals and prioritisation of specialist involvement for critical points, such as when significant changes in symptoms and risk factors take place.

Support electronic healthcare records, data sharing, digitally enhanced and remote care to facilitate truly integrated care. This is a much broader issue across entire health systems and disease areas. Cardio-diabetes advocates, alongside other non-communicable disease advocates, should play a strong role in highlighting the value of such approaches and demanding investment in this transformation agenda.

5. Conclusion

We thank colleagues from cardiovascular and diabetes organisations across the world for their vital input in taking this issue forward. The actions identified in this report, such as the policy and educational resources described, require significant effort to develop and implement in everyday settings. However, we should be reassured that these are all tangible and achievable approaches whose value has been demonstrated elsewhere. There is nothing to hold us back in delivering on every single action outlined here, except our own determination, readiness to collaborate, and ability to inspire others to support us.

We acknowledge in turn the substantial earlier contributions from other leading global policy commentators, such as the World Heart Federation and the International Diabetes Federation. We at the Global Heart Hub are delighted to play our part in building on this work and providing clear focus on key priorities from the patient perspective.

We believe it falls to us all, in the diabetes and CVD communities, to step into this gap between two major conditions and commit ourselves to transforming health systems to the benefit of patients around the world.

6. Further reading

- A Roadmap on the Prevention of Cardiovascular Disease Among People Living With Diabetes
- Promoting Cardiovascular Health in People Living With, or at Risk of Type 2 Diabetes
- 2019 ESC Guidelines on diabetes, pre-diabetes, and cardiovascular diseases developed in collaboration with the EASD

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ABOUT THE GLOBAL HEART HUB

The Global Heart Hub is the first international 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.

Our aim is to unite patient groups from every country in the world under the umbrella of the Global Heart Hub. Our combined mission is to raise awareness of heart disease and the challenges it presents in everyday life. The Global Heart Hub is a platform for heart patient organisations to share their views, learn from each other's best practice, unite on common advocacy goals, and share resources. We aim to increase awareness and understanding of the many heart conditions that exist, improve patient outcomes, enhance quality of life, and optimise longevity and healthy aging.

ABOUT THE HEALTH POLICY PARTNERSHIP

The Health Policy Partnership is a specialist health policy research organisation. Our work drives policy and system changes to help resolve the most complex issues facing health systems today.

We provide rigorous health policy research and analysis, work closely with different stakeholders, present a multi-partner perspective on key issues and solutions, and focus on actions that deliver impact.

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