

The Diabetes Scorecard – Tracking Progress for Action

Informal Advisory Group Terms of Reference

A. Introduction

The International Diabetes Federation has secured funding from the healthcare company, Bupa, for the “Diabetes Scorecard” Project. The Diabetes Scorecard will be a unique advocacy tool through which to measure progress on political commitments for diabetes, most notably the UN Political Declaration on Noncommunicable Diseases (NCD) Prevention and Control, global NCD targets, and other important diabetes priorities.¹ The Scorecard aims to track government progress and build accountability on diabetes and NCD prevention, treatment and care.

The Scorecard will be designed for use by IDF’s 220 Member Associations (MAs) at the national level, enabling MAs to hold national governments accountable for progress on diabetes and NCD prevention, treatment and care. IDF, with the support of Bupa, plan to convene a capacity building workshop for Member Associations at the 2013 World Diabetes Congress in December 2013 to ensure the Scorecard can be effectively used and implemented at the national level.

At the international level, IDF will establish a global monitoring cycle to review MA results, report on progress and drive action. IDF plans to produce biennial (two yearly) global progress reports, that will summarise and analyse results to support national, regional and global diabetes advocacy. This cycle will be aligned to official United Nations (UN) and World Health Organisation (WHO) review processes on the Political Declaration and targets, enabling IDF to monitor and review progress on diabetes at the global level. IDF will also select a number of ‘champion countries’ in which to focus the implementation of the Scorecard and drive government action.

The Diabetes Scorecard is a major IDF project which aims to be both globally relevant and nationally adaptable. The principal beneficiaries are IDF Member Associations (MAs), with indirect beneficiaries including those living with, or at risk of, diabetes and the related NCDs. The governance structure therefore has two components: an IDF Project Team who will coordinate the project from the Executive Office in Brussels, and an Informal Advisory Group (AG) of IDF’s Regional Chairs, additional MA Representatives, and external experts in advocacy and accountability in NCDs, health and development.

As the Scorecard project develops, IDF will consider reforming the IAG into a Review Committee to ensure the sustainability of the Scorecard project in the long term. The Review Committee would be responsible for reviewing the ongoing relevance of the Scorecard and Global Monitoring Cycle and providing qualitative feedback on the impact of the Scorecard at the national level.

Please see Annex 1 for the invited IAG members and Annex 2 for further information on the Project.

B. Purpose

The primary purpose of the IAG is to provide expert input to the IDF Project Team during the development of the Scorecard. National insight and advocacy expertise is needed to ensure the Scorecard is a relevant, useable and effective tool which enables MAs successfully monitor progress on diabetes at the country level. The IAG will provide input on a number of issues within the Scorecard, including the scope and content; usability across different regional and national contexts; and the final content of the Summary Report of the Scorecard. The Report will be launched at a capacity building workshop for MAs at the World Diabetes Congress in Melbourne in December 2013.

¹ A/RES/61/225, World Diabetes Day, Resolution adopted by the UN General Assembly 18th January 2007 ; International Diabetes Federation, International Charter of Rights and Responsibilities of People With Diabetes, 2011; International Diabetes Federation, Global Diabetes Plan 2011-2021, September 2011

The IAG will also serve to ensure that IDF MAs – who are the primary audience of the Scorecard – are involved in the development of the Scorecard throughout the process. Involving IDF MA and regional representatives into the project's governance structure is crucial to achieve one of the principal aims of the Project – mobilising the diabetes community to engage with diabetes monitoring and accountability. Bringing a 'diabetes voice' into the Scorecard project through the IAG will ensure that IDF develops a tool which is usable and valuable in the global diabetes community.

C. Composition

The Scorecard aims to be globally applicable and relevant across national and regional contexts. A global membership will ensure that the Scorecard is valid in all countries – regardless of income category, demographic profile or political organisation. This will be particularly important for developing a methodology (including indicators, data collection methods and data sources) that is globally relevant. The IAG will therefore be international and comprised of IDF Regional Chairs, additional IDF MA representatives, and external representatives in advocacy and accountability from within the NCD, health and wider development communities.

D. Role:

The IAG will be a virtual group and will be consulted at defined stages of the project. These informal consultations will require the IAG to provide input and feedback into different elements of the Scorecard project. Below is an approximate timeline:

PHASE	AIMS	DATE
Methodology and scope	- Initial comments on the proposed scope and methodology of the Scorecard.	March 2013
Indicators and data sources	- Reviewing IDF's proposed indicators, data sources and data collection methods, and providing national and regional insight.	May 2013
Validity Testing	- IAG testing (piloting) scorecard model to test validity, usability and effectiveness.	June 2013
Scorecard summary report	- IAG review final draft of Scorecard summary report	September 2013

The IAG will additionally be invited to provide feedback on IDF's two page summary of the Scorecard project, which will be circulated to key governments – and prospective 'champion countries' – at the World Health Assembly in May 2013.

E. Benefits

Membership of the IAG will be a voluntary position. The IAG's important contribution will be acknowledged in the summary report of the Scorecard and other relevant materials and communications.

F. Working Methods:

The IAG will be a virtual group, consulted at the above stages by the IDF Project Team.

Timeframe: the IAG will be given 2 weeks in which to respond each consultation stage.

Format: the IDF Project Team will supply a template to guide the IAG to respond to each stage of the consultation. The IAG will be asked to submit their response within this template.

Contact: contact will be primarily through email with Lucy Hadley (lucy.hadley@idf.org)

Annex 1: Proposed IAG Members

The IAG will be international and comprised of all IDF Regional Chairs in addition to an IDF Member Association representative, invited to: include a range of country contexts and income levels; for their willingness to develop and test the Scorecard; and on the basis of capacity to engage and share insights with other Member Associations and the wider region.

Africa

1. Regional Chair: Dr Evariste Bouenizabila
2. Ethiopian Diabetes Association and NCD Alliance: Dr. Ahmed Reja Goush

Europe

3. Regional Chair: João Manuel Valente Nabais
4. Diabetesforeningen (Denmark): Charlotte Rulffs Klausen

Middle East and North Africa

5. Regional Chair: Professor Adel El Sayed
6. Qatar Diabetes Association: Dr Abdulla O. Al Hamaq

North America and Caribbean

7. Regional Chair: Serge Langlois
8. Fondation Haïtienne du Diabète et des Maladies Cardiovasculaires (Haïti): Dr Nancy Larco

South and Central America

9. Regional Chair: Dr Edwin Jiminez (Asociacion Nacional Pro Estudio de la diabetes, Endocrinologia)
10. Puerto Rican Association of Diabetes Educators (PRADE): Dr Adolfo Pérez-Comas

South East Asia

11. Regional Chair: Veenoo Basant Rai
12. Diabetic Association of Bangladesh: Professor A K Azad Khan

Western Pacific

13. Regional Chair: Dr Nam Cho
14. Persatuan Diabetes Indonesia: Professor Sidartawan Soegondo

External experts in the NCD, health and development advocacy communities have also been invited for their contribution to the Project:

15. **Dr Fiona Adshead** (Consultant; former Director of Chronic Diseases and Health Promotion at WHO; former Deputy Chief Medical Officer and Director General in the UK Department of Health).
16. **Sir George Alleyne** (Director Emeritus , PAHO; Professor, Bloomberg School of Public Health, Johns Hopkins University; former UN Secretary General's Special Envoy for HIV/AIDS in the Caribbean.)
17. **Dr Gojka Roglic** (Technical Officer, Diabetes in the Department of Chronic Diseases and Health Promotion, WHO)
18. **Katie Dain** (Director of Policy and Campaigns, NCD Alliance)
19. **Rodrigo Garay** (Founder and Executive Director of AIDS Accountability International (AAI) who developed and launched the first global rating for national responses to HIV/AIDS in 2008).

Annex 2: Background Note

The Diabetes Scorecard – Tracking Progress for Action

In September 2011, United Nations (UN) Member States unanimously adopted the Political Declaration of the High Level Meeting on the Prevention and Control of Noncommunicable Diseases (NCDs). The [Political Declaration](#) represents the strongest statement of intent by governments to date to accelerate progress on diabetes and the related NCDs – cancer, cardiovascular disease and chronic respiratory disease. The Political Declaration contains 22 commitments covering the spectrum of the diabetes response. Full implementation and enforcement of the UN Political Declaration at the country level will improve treatment and care for the 371 million people living with diabetes, and in prevention for the millions more at risk.

In follow up to the Political Declaration, governments [agreed](#) the first ever global monitoring framework, including a set of targets and indicators, for NCDs in November 2012. This included an overarching goal to reduce preventable NCD mortality by 25% by 2025, and ambitious global targets to “halt the rise” in diabetes and obesity and achieve 80% access to affordable medicines and technologies for NCDs. All governments will have to regularly report progress on these targets at World Health Organisation (WHO) and UN level, and a comprehensive UN review of progress on NCDs since the UN Summit will be convened in 2014.

Other health and development precedents have shown how scorecards are effective tools in the successful implementation of a conventions or declaration. The HIV/AIDS community, after the UN General Assembly Special Session adopted the Declaration of Commitment on HIV/AIDS in 2001, established the crucial role of civil society in assessing national progress and driving action. ‘Citizens monitoring’ initiatives such as scorecards have also been powerful means of increasing the engagement and ownership of people in national responses to health and development issues. Scorecards are effective tools in advocacy, policy development and resource mobilization and can enable civil society to identify champion and failing countries, building incentive for progress.

The Project

The International Diabetes Federation, supported by Bupa, will develop a scorecard to measure progress on the UN Political Declaration, global NCD targets, and other important global diabetes priorities. The principle beneficiaries of the Diabetes Scorecard will be IDF’s 220 Member Associations (MAs) at the national level, with indirect beneficiaries including those living with, or at risk of, diabetes and NCDs. At the international level, IDF will establish: a global monitoring cycle to review MA results and report progress; and a select a number of ‘champion countries’ in which to focus implementation and drive government action. The aims of the Project are:

- Catalyse action on diabetes at national level and improve prevention and treatment for people with diabetes;
- Track progress and gather evidence in diabetes policy and practice at national, regional and global levels;
- Mobilise the diabetes community to engage with and make governments accountable at national level;
- Complement and inform official UN and WHO review processes at global and national level for diabetes and NCDs.

An IDF Project Team, led by Advocacy, will coordinate the project from IDF’s Executive Office. An Informal Advisory Group (IAG) will be established to provide expert input during the development of the Scorecard.

Milestones in 2013

March	Informal Advisory Group (IAG) for Project established for on-going consultation.
May	The Scorecard is officially announced by IDF President and Bupa Chair at a side event at the World Health Assembly; a two page summary of the Scorecard project is circulated with key governments and prospective ‘champion countries.’
December	Scorecard Summary Report launched at capacity workshop for IDF MAs at the World Diabetes Congress in Melbourne. The workshop will introduce MAs to the Scorecard and how it can be used for effective national advocacy.