Diabetes Atlas

The status of national diabetes programmes: A global survey of IDF member associations

Ruth Colagiuri*, Robyn Short, Alexandra Buckley

The Diabetes Unit—Menzies Centre for Health Policy, Victor Coppleson Building DO2, University of Sydney, NSW 2006, Australia

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Abstract

The 42nd World Health Assembly (1989) issued a global call to action on the prevention and control of diabetes. Four regional diabetes declarations followed – Europe, the Americas, the Western Pacific, and Africa – which paved the way for national diabetes programmes (NDPs) in many countries.

As a result of the UN Resolution on Diabetes (2006), the International Diabetes Federation (IDF) resolved to reinvigorate NDPs and established a Task Force for this purpose. Despite the growth of NDPs over the past 20 years, no formal global evaluation of their status appears to have been undertaken. Consequently, in 2008, the Task Force conducted a baseline survey of IDF member associations (n = 202) worldwide seeking information on the existence, scope and status of NDPs. The survey achieved a 47% response rate with 61% of respondents indicating their country had an NDP. Of these, 83% had a prevention component, and 96% had type 2 diabetes as the most commonly occurring focus.

Overall, the survey indicated a strong core of cohesive national action on diabetes worldwide but highlighted the need for a concerted effort to develop and implement comprehensive national prevention and care plans aimed at reducing the personal, familial and societal burden of diabetes.

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1. Introduction

Twenty years ago, at its May 1989 meeting in Geneva, Switzerland the 42nd World Health Assembly passed a global call to action on the prevention and control of diabetes in the form of Resolution WHA42.36 [1]. Resolution WHA42.36 recognised the huge and growing personal and societal cost of diabetes complications and set out a framework which urged a cohesive worldwide effort to combat diabetes and:

1. Invited Member States to:
   (i) assess the national importance of diabetes;
   (ii) implement population-based measures, appropriate to the local situation, to prevent and control diabetes;
   (iii) share with other Member States opportunities for training and further education in the clinical and public health aspects of diabetes;
   (iv) establish a model for the integrated approach to the prevention and control of diabetes at community level;
2. Requested the Director-General to strengthen WHO activities to prevent and control diabetes, in order to:
   (i) provide support for the activities of Member States with respect to the prevention and community control of diabetes and its complications;
   (ii) foster relations with the International Diabetes Federation and other similar bodies with a view to expanding the scope of joint activities for the prevention and control of diabetes;
   (iii) mobilise the collective resources of the WHO collaborating centres on diabetes.

Since then, four of the seven IDF Regions (Europe, North America, the Western Pacific and Africa) have initiated diabetes declarations.

Europe was the first to respond to WHO Resolution WHA42.36 and in October 1989, in the town of St. Vincent, Italy, the St. Vincent Declaration (SVD) was born [2]. The St. Vincent Declaration brought together diabetes representatives from the World Health Organisation (WHO) and International Diabetes Federation (IDF) with delegates from patient organisations and ministries of health to design and plan a pan-European action programme to combat diabetes. The St. Vincent Declaration brought immeasurable benefits globally by providing leadership, inspiration, motivation, and a role model on advocacy and action for diabetes which had a worldwide influence. It was followed in 1994 by the Declaration of the Americas [3], in 2000 by the Western Pacific Diabetes Declaration and Plan of Action [4,5], and in 2006 by the Declaration and Diabetes Strategy for Sub-Saharan Africa [6].

These regional diabetes declarations and action plans fostered the growth of national diabetes programmes (NDPs) which initially focused on diabetes care and health systems.

Over many years, and with the benefit of an ever-increasing evidence base about diabetes, these strategies and plans evolved in breadth, depth and sophistication to include prevention as well as care; cardiovascular diseases and hypertension as well as diabetes; and a range of government sectors and non-government organisations as well as ministries of health.

On December 20, 2006, another landmark diabetes resolution was passed supporting the development of NDPs. UN Resolution 61/225 [7] contained three core messages, the third of which called for:

“...Member States to develop national policies for the prevention, treatment and care of diabetes in line with the sustainable development of their health care systems, taking into account the internationally agreed development goals including the Millennium Development Goals”.

In 2007, to operationalise this clause of the Resolution, the IDF established a Task Force on National Diabetes Policy and Action (NDPA) to promote and support the development and implementation of NDPs globally. Whilst diabetes care audits which include monitoring and assessing progress with NDPs have been conducted under the SVD and the EU as well as in some IDF Regions, the number of countries with NDPs and the nature and extent of in-country activity around NDPs had not previously been assessed on a global scale except as a component of chronic diseases more broadly. Consequently, the first aim of the IDF Task Force on National Diabetes Policy and Action was to identify the current status of NDPs by developing a baseline profile of NDPs globally against which future progress could be measured.

2. Methods

A cross sectional survey of IDF member associations was conducted between May and August 2008. The survey tool [8] was a semi-structured questionnaire composed of 16 open-ended and closed questions designed to seek information on:

(a) the existence and endorsement of an NDP;
(b) nature, scope and funding;
(c) implementation, target population and topics addressed by the NDP;
(d) goals and objectives;
(e) evaluation/outcomes of the NDP.

A specific open-ended question addressing future plans for developing and implementing an NDP was included for countries without an NDP.

The questionnaire was first piloted by one developed and one developing country before being translated from English.
into Spanish and French and subsequently circulated electronically to all 202 IDF member associations covering 190 countries. Particular attention was given to matching the dominant language of the Region with the appropriate questionnaire. Member associations were given approximately one month to complete and return the survey via fax or email. At least two follow-up communications were conducted by email (one by the authors and one by the IDF Brussels Office) to optimise the response rate.

The dichotomous (yes/no) data and other quantitative information were analysed for frequencies using Excel. Qualitative information was analysed for synergies and recurrences in the themes occurring in the responses.

3. Results

3.1. Response rate

Of the 190 countries surveyed a total of 89 countries replied, giving an overall response rate of 47%. Fig. 1 shows the percent of respondents by Region which varied from 33% in North America to 67% in Europe.

3.2. Confirmation of the existence and endorsement of an NDP

Fifty-four (61%) of the 89 countries that responded reported having an NDP. A regional breakdown of current NDPs is presented in Fig. 2. As illustrated, South East Asia had the lowest percentage of respondents and Europe the highest. Of the 54 countries with an NDP, 50 (93%) reported that there was official documentation of the NDP, but only 48 (89%) had government endorsement. The NDP was recognised as formally documented and publicly available in 36 of these countries (67%).

Of the 35 countries (39%) that reported not having an NDP, 26 (74%) confirmed plans to implement and develop components of an NDP. These plans included:

- formal diabetes training workshops for all health workers;
- development of a national diabetes registry;
- funding for diabetes research;
- improve access to care, self-care education, therapeutics and devices for people with diabetes and their carriers;
- development of national diabetes standards/clinical guidelines;
- implement an active screening plan for diabetes, prediabetes and co-morbidities.

Seven of the 26 countries (27%) did not provide an outline of their development plans.

3.3. NDP scope and funding

In stating who was actively involved in the development of the NDP, 51 of 54 (94%) countries reported government officials as primary contributors followed by health care workers (93%) and national diabetes association/action groups (91%). For 65% of countries with an NDP, the NDP functions as an integrated component of a national non-communicable disease strategy. Only 24 of the 54 countries (44%) reported their NDP acting as a stand-alone strategy. Dedicated funding for the NDP was reported in 34 (63%) of the 54 countries that responded.

3.4. NDP implementation, target population and topics addressed

Seventy-six percent of countries reported their NDP had been implemented. As shown in Fig. 3 this varied considerably by region, with South and Central America reporting the highest levels of implementation, and all regions except Africa and South East Asia reporting over 70% implementation. In these countries, the key figures responsible for implementing the NDP were health care workers (85%), government officials (78%) and non-government/private organisations (65%). Thirty-five (65%) of countries reported that people with diabetes were involved in implementation. One country that
reported ‘yes’ to implementation did not report the process by which this occurred.

In 52 (96%) of the 54 countries the primary target of the NDP was people with type 2 diabetes. People with type 1 diabetes and people at risk of developing diabetes were targeted in 89% and 85% of NDPs respectively and gestational diabetes was a target in 83%, with 72% of the NDPs targeting the whole population.

As shown in Table 1, the most commonly reported focus of NDPs was on routine clinical care and secondary prevention of complications (both 91%) with psychological and behavioural issues being the least commonly reported focus (59%). Results clustered in the 80–90% range for all other topics.

Health worker training programs, clinical guideline development and implementation, strengthening health services/resources, and use of information systems were the leading activities reported (87%, 83%, 85%, and 80% respectively). Fifty-two percent of countries reported that a national diabetes registry was part of their NDP. With regard to a patient-centred approach, 80% of countries reported that patients with diabetes were consulted about their needs, and 76% focused on ensuring equal access to healthcare. Sixty-five percent of countries agreed that their NDP takes into account individual differences, preferences and cultural diversity. Fifty-seven percent of countries reported that people with diabetes were in fact represented on the committee responsible for implementing the NDP in their country.

3.5. Monitoring and surveillance

National monitoring and surveillance of the diabetes burden occurred in 45 (83%) of the NDPs. Table 2 presents which aspects of the disease burden are monitored and shows the overall cost of essential medications and diabetes prevalence are the most frequently monitored aspects, closely followed by clinical services, with cost to individuals and families being the least monitored aspect.

3.6. NDP goals and objectives

The following themes consistently appeared in the respondents’ specification of their country’s NDP goals:

- raising public awareness – national promotion, information and education;
- prevention: primary (reduce diabetes incidence), secondary (early diagnosis and behaviour change), tertiary (reduce complications, mortality, minimise impact);
- improve quality of diabetes treatment and care: accessible, community-based, multi-disciplinary teams, patient-centred approach;
- ongoing professional development/training for diabetes care personnel (health workers);
- development of national clinical guidelines for diabetes;

![Fig. 3 – NDPs implemented, by IDF Region, Question 8 of the survey asked if and when the NDP had been implemented. Regional responses varied from nil in South East Asia to 100% in South and Central America.](image)

Table 1 – Topics addressed by National Diabetes Programmes. The survey specifically questioned respondents about the topics covered, providing a list of possibilities and asking respondents to check yes or no.

<table>
<thead>
<tr>
<th>NDP topic field</th>
<th>Total countries with an NDPa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community awareness</td>
<td>46 (85%)</td>
</tr>
<tr>
<td>Primary prevention</td>
<td>45 (83%)</td>
</tr>
<tr>
<td>Screening/early diagnosis</td>
<td>46 (85%)</td>
</tr>
<tr>
<td>Routine clinical care and services</td>
<td>49 (91%)</td>
</tr>
<tr>
<td>Essential medications and supplies</td>
<td>45 (83%)</td>
</tr>
<tr>
<td>Secondary prevention of complications</td>
<td>49 (91%)</td>
</tr>
<tr>
<td>Vascular disease complications</td>
<td>48 (89%)</td>
</tr>
<tr>
<td>Psychological and behavioural issues</td>
<td>32 (59%)</td>
</tr>
</tbody>
</table>

Table 2 – Aspects of the diabetes burden monitored by National Diabetes Programmes. In addition to a general question asking if the NDP involved monitoring and surveillance of the diabetes burden, the survey included a list of possible subject areas and asked respondents to check yes or no.

<table>
<thead>
<tr>
<th>Aspects monitored</th>
<th>Total countries with an NDPa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence and incidence</td>
<td>40 (74%)</td>
</tr>
<tr>
<td>Details of old cases/total cases on treatment</td>
<td>27 (50%)</td>
</tr>
<tr>
<td>Routine clinical care and services</td>
<td>39 (72%)</td>
</tr>
<tr>
<td>Essential medications and supplies</td>
<td>40 (74%)</td>
</tr>
<tr>
<td>Cost to the health system/government</td>
<td>27 (50%)</td>
</tr>
<tr>
<td>Cost to the individual/family</td>
<td>18 (33%)</td>
</tr>
<tr>
<td>Community awareness</td>
<td>32 (59%)</td>
</tr>
</tbody>
</table>

a Number of responses followed by percentage in brackets.
- support for research into diabetes;
- establish a diabetes register (type 1 diabetes).

3.7. NDP evaluation and outcomes

Thirty percent of all countries with an NDP reported that their NDP had been evaluated and all but two countries reported the process by which this occurred. For those that did report their means of evaluation, the main evaluation processes were:

- prevalence of diabetes;
- biochemical indicators and physical assessment: HbA1c levels, BMI;
- diabetes patient education: knowledge of disease, success of self-management;
- techniques and behaviour modification;
- complications: referrals and treatment;
- collaboration between health care services and diabetes associations;
- working national diabetes registry.

For those 38 countries whose NDP was not currently being formally evaluated, seven countries reported having no formal process planned whilst several were undertaking discussion to determine means of evaluation.

4. Discussion

The NDP survey received a credible response rate of 47% with over half of all countries reporting that they have active NDPs. The majority of countries identifying as not having an NDP reported that action is being taken at a national government level to rectify this but most of these were unable to provide any definite timeframes for the development and implementation of an NDP. Nonetheless, the recurrence of common themes in responses about planning for the development and implementation of future NDPs in countries without NDPs showed encouraging synergies with the stated goals and objectives of countries with active NDPs.

Although WHO has previously conducted surveys aimed at assessing the need for technical and strategic assistance with NCD strategies [9,10], this survey appears to be the first to focus explicitly on national diabetes programmes and provides a foundation on which future large scale evaluations can build. However, it is important to note that the survey provides information from an IDF member association perspective only and, as such, is neither exhaustive nor comprehensive. For example it does not include information from government sources, WHO STEPS surveys or regional surveys and audits which may have been conducted by government and non-government organisations and which may centre on or be relevant to NDPs.

Whilst the survey yielded useful insights into where national diabetes programmes exist and where they are absent, it was not capable of providing sufficient detail to assess the effectiveness of existing programmes. Further, the survey questionnaires were distributed in English, French and Spanish and it was not possible within the resources for the project to translate the questionnaires into individual national languages. Consequently, language may have posed a barrier to the understanding of some questions and the accuracy of responses and, in some cases, may have deterred national diabetes associations from responding at all.

A little over half (59%) of countries identifying as having an NDP responded to the specific question which asked about the inclusion of psychological and behavioural issues in NDPs. It is difficult to interpret this finding. On the one hand it is pleasing that so many respondents report that this is being addressed in NDPs. On the other, it demonstrates that much work needs to be done globally to raise awareness of the importance of this issue. The level of consumer/patient involvement in NDP implementations evokes a similar response. Perhaps these issues, among others, could be addressed by the development of standards for the inclusion of certain core elements in the design and implementation of NDPs.

The survey demonstrated that there is a strong core of cohesive national activity on diabetes around the world. However it also illustrates the need for a concerted effort to encourage and support those countries without NDPs and those whose NDPs are inactive, to develop and implement comprehensive prevention and care plans aimed at reducing the personal, family and societal burden of diabetes. Specifically, there is a need to mobilise government support and dedicated funding. Future diabetes programmes will also need to engage the private corporate sector and work closely with ministries of health to engage other government sectors.

5. Conclusion

Observing the evolution of regional diabetes declarations over time, it is clear that their scope has broadened considerably and the gap between concentration on the care of the diagnosed and preventing the development of diabetes is gradually closing. Nonetheless, if the tide of diabetes is to be turned, more effort needs to be directed to primary prevention and this focus needs to include an environmental, whole-population approach in addition to the identification and reduction of risk factors in susceptible people. Inevitably the success or otherwise of broad public health policy and advocacy interventions such as NDPs ultimately centre on the question of whether or not they are sustainable. It is now clear that the movement that started 20 years ago with WHO Resolution WHA42.36, and is currently being reinvigorated by UN Resolution 61/225, is durable and has the capacity to mount a robust, sustained and successful battle against diabetes.

Insights into the current status of the NDPs both globally and regionally are critical to designing and shaping directions and needs-based strategies for combating diabetes. The results of this survey help to establish a global and regional baseline profile of NDPs on which future evaluations of NDPs can be based, whilst highlighting areas of deficiency for attention.

Conflict of interest

There are no conflicts of interest.
Acknowledgements

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REFERENCES