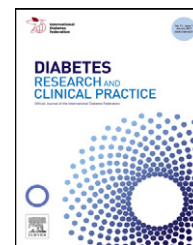


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# Diabetes Attitudes Wishes and Needs 2 (DAWN2): A multinational, multi-stakeholder study of psychosocial issues in diabetes and person-centred diabetes care

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## ABSTRACT

**Aims:** The Diabetes Attitudes Wishes and Needs 2 (DAWN2) study aims to provide a holistic assessment of diabetes care and management among people with diabetes (PWD), family members (FM), and healthcare professionals (HCPs) and explores potential drivers leading to active management.

**Methods:** DAWN2 survey over 16,000 individuals (~9000 PWD, ~2000 FM of PWD, and ~5000 HCPs) in 17 countries across 4 continents. Respondents complete a group-specific questionnaire; items are designed to allow cross-group comparisons on common topics. The questionnaires comprise elements from the original DAWN study (2001), as well as psychometrically validated instruments and novel questions developed for this study to assess self-management, attitudes/beliefs, disease impact/burden, psychosocial distress, health-related quality of life, healthcare provision/receipt, social support and priorities for improvement in the future. The questionnaires are completed predominantly online or by telephone interview, supplemented by face-to-face interviews in countries with low internet access. In each country, recruitment ensures representation of the diabetes population in terms of geographical distribution, age, gender, education and disease status.

**Discussion:** DAWN2 aims to build on the original DAWN study to identify new avenues for improving diabetes care. This paper describes the study rationale, goals and methodology.

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## 1. Introduction

In 2001, the Diabetes, Attitudes, Wishes and Needs (DAWN) study showed that self-management of diabetes was considered poor by people with diabetes (PWD) and healthcare professionals (HCPs). Diabetes-related distress was common amongst PWD and hampered efforts to self-manage their condition, but few received psychological treatment [1]. Although recognition by HCPs of emotional problems and diabetes-specific distress amongst PWD was low, HCPs desired a better understanding of such issues [2]. Collaboration among diabetes care providers was identified as an important factor for improving diabetes outcomes, but interdisciplinary team care was uncommon [2], and there was some resistance by PWD and HCPs to the timely initiation of effective therapies [3].

Following DAWN, patient representatives and an interdisciplinary group of diabetes care experts discussed how the DAWN findings could be translated into improved diabetes care [4]. The resulting ‘DAWN Call to Action’ [5] encouraged multiple stakeholders (HCPs, PWD and their family members [FMs]/carers, payers, policy makers, industry and non-government organisations) to implement person-centred diabetes care, and actively involve PWD in self-management with support from an interdisciplinary team of HCPs [2].

The DAWN findings support a paradigm shift from an acute care model to a person-centred, integrated chronic care model, such as the WHO Innovative Care for Chronic Conditions framework to diabetes [6]. This model involves care at three levels: micro, meso and macro, which refer to individual, healthcare organisation/community, and policy levels, respectively [6]. Optimal diabetes care is best achieved by collaboration between PWD, FM, community partners and healthcare teams that are informed, motivated, prepared, and able to work together. This collaboration is supported and influenced by the broader healthcare organisations and communities, and by the policy environment [6]. Scientific evidence provides the foundation for the approaches to care [6], but the PWD perspective is important in informing all levels of healthcare [7]. PWD have the right to be informed and educated, to have access to proper diabetes care and optimal medicine, and not to be discriminated against because of their condition [8].

It is a decade since the DAWN study highlighted the need for collaborative action across countries to improve self-management and psychosocial support. Despite major advances in collaborative care many PWD still do not achieve desirable treatment outcomes. The growing burden of diabetes calls for stronger and broader globally-coordinated efforts. As more countries recognise the effect of diabetes on population health, and the economic and personal burdens, we must expand our knowledge to include the diverse social institutions and cultures of these countries. As our knowledge has advanced, we have identified gaps in our knowledge of the role of support from family and community in living with and caring for PWD. Across nations, there is a pressing need for a new global translational research initiative that can form the foundation for measurement-guided multi-stakeholder collaboration for the advancement of person-centred diabetes care world-wide. Thus, it is time for a new DAWN.

The DAWN2 study initiative, undertaken by Novo Nordisk in partnership with the International Diabetes Federation (IDF), the International Alliance of Patient Organisations (IAPO), the Steno Diabetes Center, and a range of other national, regional and global partners, aims to (a) improve our understanding of the unmet needs of PWD and their care-takers, (b) facilitate dialogue and collaboration among all key stakeholders to strengthen patient involvement and improve self-management and (c) establish a cross-culturally validated multi-national survey framework for assessing and benchmarking psychosocial and educational aspects of diabetes care delivery. The overall aim is to identify avenues for improvement at all three levels of care – at the meso and macro-levels for diabetes care funding and care provision, and at the micro level for delivery of care. The study explores how PWD, FMs and HCPs perceive diabetes care and investigates the value of a person-centred model of diabetes care that emphasises the needs of the individual in the context of current chronic care, self-management education and psychosocial support. This paper describes the study methodology.

## 2. Materials and methods

### 2.1. Study objectives

Within a national and international setting, the predefined objectives of the DAWN2 study are:

Primary objective:

- To assess potential barriers to and facilitators of active and successful management of diabetes among PWD, FMs, and HCPs.

Secondary objectives:

- To establish national benchmarks for health status, quality of life (QoL), access to self-management education and to self-care in diabetes.
- To assess the access to, and use and benefit of, support from healthcare teams, family and friends, communities and society.
- To explore and pinpoint the most important facilitators and barriers to person-centred chronic care for each stakeholder group.
- To identify successes, wishes, needs, preferences and priorities for change among all key stakeholders in diabetes.

### 2.2. Study design

DAWN2 is a multinational, interdisciplinary and multi-stakeholder study designed in February 2011 to examine the experiences and unmet needs of PWD, FMs, and HCPs (UTN No: U1111-1123-7509; NCT01507116). DAWN2 has been developed and overseen by the Global DAWN2 Study Group under the auspices of the IDF, IAPO and the Steno Diabetes Center with input from experts from: American Association of Diabetes Educators, Federation of European Nurses in Diabetes, Primary Care Diabetes Europe, Behavioral Research in Diabetes Group Exchange, Psychosocial Aspects of Diabetes Study Group of the European Association for the Study of

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