

# 2nd International DAWN Summit: a call-to-action to improve psychosocial care for people with diabetes

At this two-day meeting held in London on 5–7 November 2003, over 150 diabetes experts and opinion leaders from 32 countries discussed ways in which to translate the findings of the DAWN Study into improved diabetes care. They agreed on a call-to-action to address the people behind the disease and improve psychosocial aspects of diabetes management. The Summit was organised by Novo Nordisk, attended by a number

of diabetes organisations, including IDF,\* and jointly chaired by Professor David Matthews (*Oxford, UK*), Professor Philip Home (*Newcastle upon Tyne, UK*) and Professor Richard Rubin (*Baltimore, USA*). James Wroe reports.

\*Diabetes organisations represented at the Summit included ADA, EASD, EDID, FEND, IDF, ISPAD, OCDEM, PCDE, PROUD, PSAD, STENO.

## Background to the DAWN Summit

The Diabetes Attitudes, Wishes and Needs (DAWN) Study, initiated by Novo Nordisk under the scientific supervision of an expert international advisory panel (Table 1), was the largest psychological survey of its kind among diabetes stakeholders (Table 2). The preliminary results<sup>1</sup> included the findings: social support and emotional well-being are pivotal to the achievement of effective self-management of diabetes; current standards for diabetes care do not include evidence-based approaches to dealing with psychosocial issues; and improved outcomes in diabetes may be achieved by combining specific psychosocial support with appropriate medical care.

## Introduction to the Summit

**David Matthews, Professor of Diabetic Medicine, University of Oxford; Chairman, Oxford Centre for Diabetes, Endocrinology and Metabolism; Joint Chairman, 2nd International DAWN Summit**

Professor Matthews said that the DAWN Study had demonstrated that it was necessary to address the people behind the disease in order to improve outcomes. DAWN had shown up important differences in perception between patients (= health care consumers [HCCs]) and health care professionals (HCPs) and barriers to effective therapy. It had highlighted an aware-

**Table 1.** DAWN International Expert Advisory Board

<b>Ib Brorly</b> Person with diabetes, Denmark
<b>Ruth Colagiuri</b> VP, Australian Diabetes Educators Association; Director, Australian Centre for Diabetes Strategies
<b>PHLM Geelhoed-Duijvestijn</b> Haaglandlen Hospital, The Netherlands
<b>Hitoshi Ishi</b> Tenri Yorozu Soudanjyo Hospital, Japan
<b>Line Kleinebreil</b> DiabCare France, Hôpital Jean Verdier, France
<b>Rudiger Landgraf</b> Medizinische Klinik, Universität München, Germany
<b>Torsten Lauritzen</b> Department of General Practice, University of Aarhus, Denmark
<b>David Matthews</b> OCDEM, UK
<b>Richard Rubin</b> John Hopkins University School of Medicine, USA
<b>Frank Snoek</b> VU University Medical Centre, The Netherlands
<b>Giacomo Vespasiani</b> Centro di Diabetologia e Malattie del Ricambio, Italy

ness among many HCPs that they were unable to provide the psychological support their patients needed (Figure 1). A first multidisciplinary Summit to discuss the implications

**Table 2.** Participants in the DAWN Study

<b>People with diabetes</b> 5426 adults (a third with type 1 diabetes, a quarter with insulin-treated type 2 and the balance with non-insulin-treated type 2 diabetes)
<b>Health professionals</b> 2194 primary care physicians 556 diabetologists/endocrinologists 1122 specialist and general nurses
<b>Countries</b> Australia, Denmark, France, Germany, India, Japan, Norway, Poland, Spain, Sweden, The Netherlands, United Kingdom, USA

of DAWN had been held in Oxford in April 2002.<sup>2</sup> It had identified the following five key challenges: to enhance communications between HCCs and HCPs; to promote communication and coordination between HCPs; to promote active self-management; to reduce barriers to effective therapy; and to enable better psychological care for HCCs.

## Welcome from IDF and Novo Nordisk

Professor Pierre Lefèbvre, President of the International Diabetes Federation, welcomed delegates on behalf of the IDF and expressed its strong support for DAWN. It was very much in tune with the 'triple A'



global diabetes campaign of IDF, namely Awareness, Advocacy and Action. The basis for the IDF strategy, as for the DAWN programme, was promoting patient empowerment and patient-centred care.

Lise Kingo, Executive Vice President of Novo Nordisk, added a welcome on behalf of the company and spoke about the importance of dialogue and partnership to reduce the global burden of diabetes. The DAWN programme was considered a very important investment for Novo Nordisk. It could assist HCPs in addressing more effectively the barriers to self-management of diabetes, thus making current treatments more successful and improving patients' quality of life. Ms Kingo announced the Novo Nordisk DAWN Award (see page 208a of this issue).

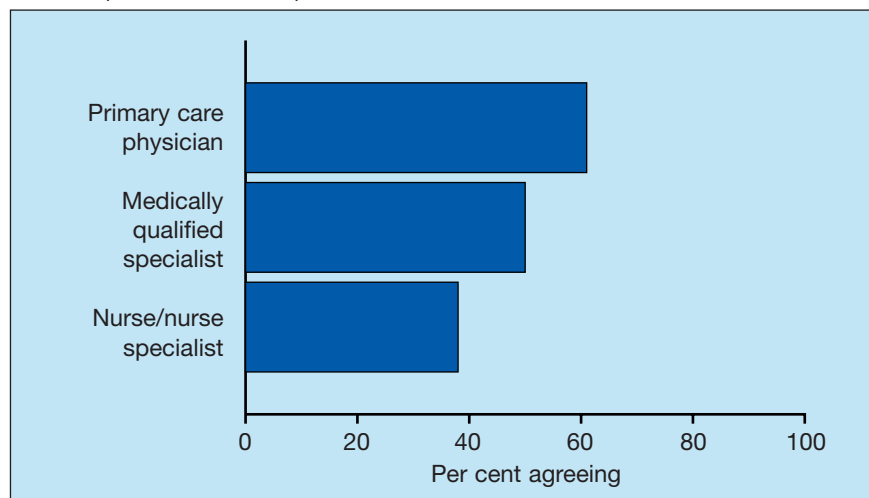
### Optimising self-management – a new paradigm for chronic disease management

**Raphael Bengoa, Director, Department of Management of Non-communicable Diseases, World Health Organisation, Geneva, Switzerland**

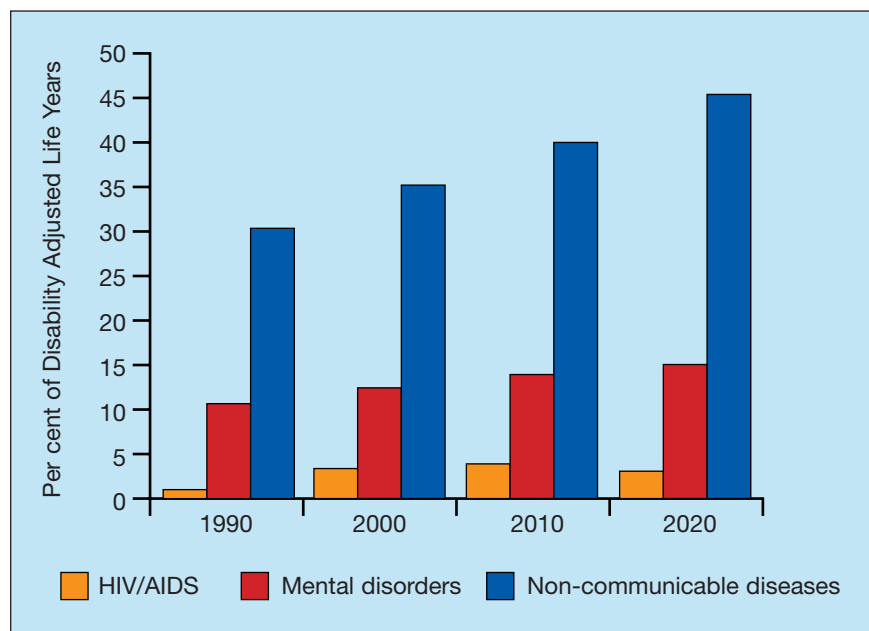
Dr Bengoa reminded delegates of the rising global burden of chronic disease (Figure 2). The current approach to chronic disease management (CDM) is that the patient appears, is treated, discharged and then disappears. It was not surprising that, according to WHO, less than 50% of people with diabetes managed their treatment appropriately. A new paradigm was needed, emphasising the patient's primary role in management and redefining HCPs as consultants and supporters.<sup>3</sup> Self-management involved more than education, namely problem-solving, decision-making, resource-utilisation, forming a patient/health care provider relationship and taking action to cope with emotions and adjust to personal and societal roles. Much depended on how diabetes met these challenges, as it was widely regarded as a model for CDM.

Dr Bengoa also said that chronic diseases rarely appear alone; most people have two or more co-morbidities and should therefore be man-

**Figure 1.** Percentage of health professionals in the DAWN survey who said they were able to provide all the psychological support their patients needed (D Matthews, UK)



**Figure 2.** The rising global burden of disease due to major chronic conditions (R Bengoa, Switzerland). Reproduced from: Murray CJL, Lopez AD. *The global burden of disease*. Boston, MA: Harvard School of Public Health, 1996



aged in an integrated way and not one-by-one. One-by-one management does not achieve synergies in patient empowerment.

### Global vision to local action for patient empowerment

**Bob Anderson, Professor and Senior Research Scientist, Department of Medical Education, University of Michigan, USA**

In a short but thoughtful address, Professor Anderson emphasised that personal vision was fundamen-

tal, for people with diabetes as well as HCPs. Under his guidance, all participants at the Summit joined in an interactive exercise, grouped in pairs, to explore personal visions to improve diabetes care.

### Translating DAWN into practice: experiences in three countries

#### Germany

**Susan Woods-Buggeln, Medical Psychologist, Hamburg, Germany**

Unrealistic assumptions about



**Table 3.** Practical schema for psychotherapeutic management during regular medical visits (A Kokoszka, Poland)

- Welcoming and gaining contact
- Discussing the implementation of the last homework
- Settling the goal of the present visit
- Medical examination
- A brief medical psychotherapeutic diagnosis – evaluation of the patient's psychological situation and attitudes
- Socratic dialogue leading to a realistic evaluation of the main problem's source and its possible solutions
- Settling the realistic homework for the period prior to the next visit
- Recapitulation of the visit by the patient

health behaviour change led to feelings of helplessness and anger, said Dr Woods-Buggeln, and this led in turn to withdrawal of support/contact by HCPs and confirmation of negative expectations by patients. In Germany, one answer was NovoAcademy interactive workshops for diabetes health care teams. They discussed difficult cases, practised role-play and helped HCPs empathise with the patient's perspective, question dysfunctional assumptions, generate realistic alternatives, improve communication strategies and reduce emotional barriers. The long-term effectiveness of the workshops was being evaluated.

**Poland**

**Andrzej Kokoszka, Professor of Psychiatry, Medical University of Warsaw, Poland**

The DAWN Study suggested that 72% of patients in Poland were very worried about their disease getting worse and 73% about having to start on insulin. Polish doctors used threats to persuade patients to follow their recommendations and exhibited a general lack of psychological knowledge. Professor Kokoszka reported that, in response to these needs, a National Programme for People with Diabetes had been initiated,

in collaboration with the Polish Diabetic Society, the National Diabetic Consultant, the Polish Diabetes Association and Novo Nordisk, to improve patients' quality of life, help them learn more about diabetes, break down psychological barriers and increase public awareness about psychosocial aspects. Conferences, workshops and educational programmes were 'training the trainers' in psychological aspects. A practical schema for psychotherapeutic management had been devised (Table 3).

**India**

**Ambady Ramachandran, Director, Diabetes Research Centre and WHO Collaborating Centre for Research, Education & Training in Diabetes, Chennai, India**

**Sanjeev Kelkar, Medical Director, Novo Nordisk Education Foundation, Bangalore, India**

**Abhay Mutha, Consultant Diabetologist, Diabetes Care and Research Centre, Pune, India**

Professor Ramachandran's centre was involved in a pilot diabetes project to train 3000 doctors and 1080 nurses from six states, over a three-year period in India. The planned outcome would be improved diabetes care for nearly five million

patients and, hopefully, a model for other parts of India. Sanjeev Kelkar said the DAWN findings had led to eight workshops attended by 600 leading diabetologists who had agreed on a call-to-action (Table 4). DAWN had stimulated interest in patient empowerment, a team approach to diabetes care and better communications. He concluded with the challenge: 'We did it without resources – why not you?' Abhay Mutha reported on a nationwide study, ICEON, involving 13 070 patients with type 2 diabetes across India, which showed that good glycaemic control achieved with early insulin initiation significantly increased patients' sense of well-being, levels of satisfaction with treatment and participation in self-care.

**International developments towards team-based, patient-focused care**

**Linda Siminerio, Executive Director, Diabetes Institute, University of Pittsburgh, USA; Vice-President, International Diabetes Federation**

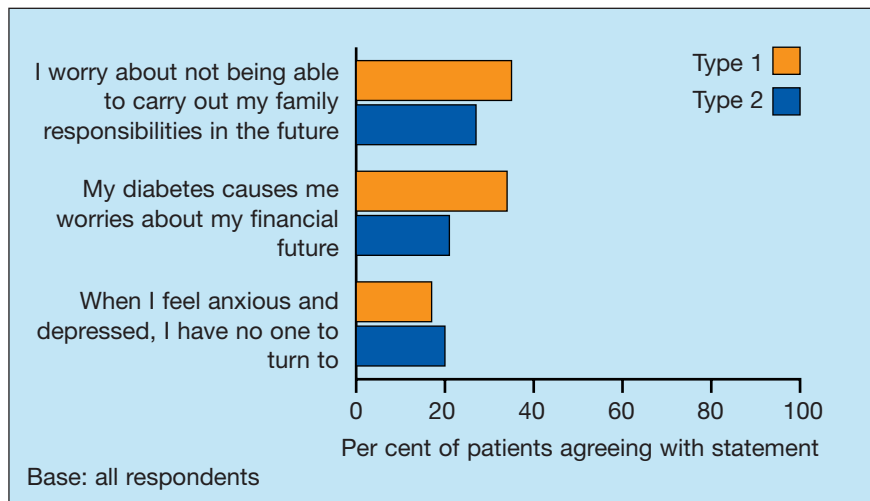
Linda Siminerio spoke about the need, identified in DAWN, for team care and more communication between HCPs. Many HCPs still adopted an inappropriate acute care approach and focused on providing information rather than encouraging behaviour change. Result: staff burn-out. A shifting of roles was essential but the diabetes educator was under-recognised, under-resourced and feared by some doctors. Implementing good team care meant ensuring leadership, blending and complementing strengths and skills, gaining support from providers and promoting communication, tracking, reporting and follow up.

**Table 4.** Recommendations of eight workshop groups of leading diabetologists in India (S Kelkar, India)

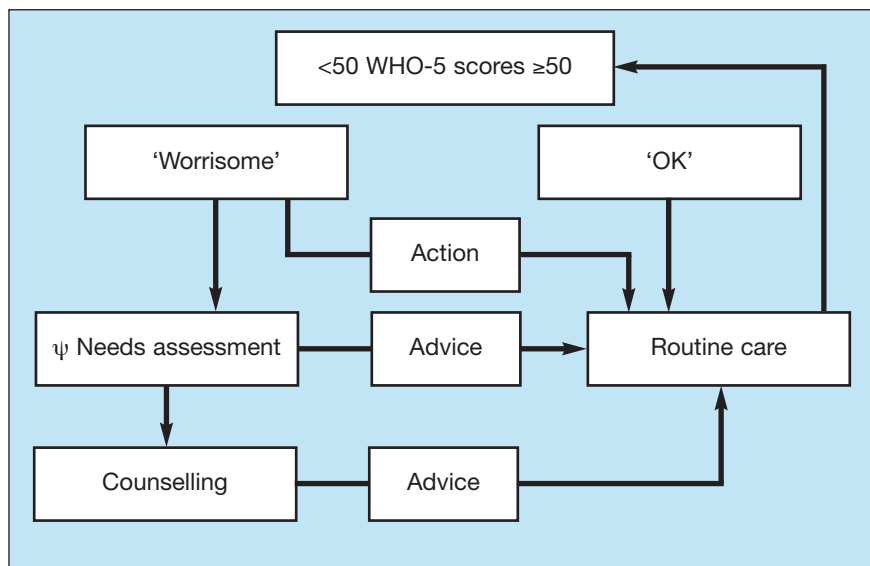
Groups' recommendations	1	2	3	4	5	6	7	8	Total
Team approach	✓	✓	✓	✓	✓	✓	✓	✓	8
Patient education	✓	✓	✓	✓	✓	✓	✓	✓	8
Mass awareness	✓	✓			✓	✓	✓		5
Develop care guidelines		✓			✓		✓	✓	4
Address costs and insurance	✓	✓				✓	✓		4
Patient and family involvement			✓	✓	✓				3



**Figure 3.** How do patients feel about their diabetes? DAWN Study results (F Snoek, The Netherlands)



**Figure 4.** Algorithm for WHO-5 monitoring (F Snoek, The Netherlands)



**How to assess and address psychological needs**

**Frank Snoek, Professor of Medical Psychology, VU University Medical Centre, Amsterdam, The Netherlands**  
 Psychological well-being and diabetes control were interdependent, said Professor Snoek. In the DAWN Study findings, diabetes was associated with negative feelings (Figure 3). Common problems involved coping, maladjustment, depression, anxiety, eating, sexual dysfunction and interpersonal relations. Computerised assessment tools had been developed for monitoring well-being, for example WHO-5 (Figure 4). To address patients' psychosocial needs properly required a patient-friendly clinical

environment, good communications, coping-oriented self-management programmes, recognition of monitoring of well-being as an integral part of care and the inclusion of a mental health care specialist in the diabetes team.

**The emotional barriers to effective therapy**

**Health professionals**  
**Torsten Lauritzen, Professor, Department of General Practice, University of Aarhus, Denmark**  
 Professor Lauritzen reported that in a Danish study more than 50% of patients with type 2 diabetes had poor blood glucose control but only 17% were on insulin.<sup>4</sup> In another

recent study<sup>5</sup> the proportion of patients achieving an HbA<sub>1c</sub> <7% at six years from baseline was much higher in those receiving intensive glucose control with insulin alone or with OHAs combined with insulin than in those receiving conventional glucose control with OHAs alone. Once they were on insulin, patients felt better and their attitude towards it improved rapidly.<sup>6</sup> The barriers often came from doctors who felt that insulin treatment was difficult and dangerous and to be regarded as a personal failure by the patient (Table 5).<sup>7</sup> This was reflected in the DAWN findings (Figure 5).

**People with diabetes**

**Sue Cradock, Consultant Nurse in Diabetes Care, Portsmouth, UK**

Actual fear of self-injecting was very rare,<sup>8</sup> said Ms Cradock. Only a small percentage of all patients had difficulty managing injections once they had started. But a concern about starting was understandable (Table 6). Insulin was more demanding, and could cost more and require more attention to avoid hypoglycaemia. Fears that prevented patients from accepting insulin treatment were usually based on irrational beliefs or lack of knowledge. Patients might mistakenly believe injections were into a vein, which was painful and difficult. They might not believe insulin was necessary and might fear insulin would result in a loss of independence and even employment and lead to the onset of new complications. They might associate insulin therapy with a past failure to care properly for themselves. Much of the initial resistance to insulin could be attributed to lack of adequate information. Starting people on it was not difficult but needed to be demystified. A helpful step was to involve people already using insulin. Once on it, patients' attitudes changed.

**The DAWN experiment**

**Martha Funnell, Director for Administration, Michigan Diabetes Research and Training Center, Michigan, USA; Past-President of the American Diabetes Association**  
 Martha Funnell discussed effective communication as a two-way process

**Table 5.** Negative attitudes among HCPs toward insulin<sup>7</sup> (T Lauritzen, Denmark)

'People with diabetes don't want to use insulin'
'Injections are painful'
'Insulin will not improve diabetes control'
'Insulin is difficult to dose down'
'Patient will require more time from me'
'Will have to refer to the specialist'
'Intensified glycaemic control is not cost-effective'

that included speaking to patients in a way that ensured the message was clear and perceived as relevant and helpful and, most importantly, also listening to patients in a way that

ensured they felt understood, respected and cared for. Ms Funnell engaged participants at the meeting in a second interactive exercise entitled 'the DAWN experiment' designed to develop active and supportive listening skills. She then encouraged participants to experiment with this approach after they returned home, just as patients are encouraged to experiment with behavioural changes and then evaluate the results. The benefit of an experimental approach is that there is the opportunity to learn and improve whether or not the experiment works.

**Driving advocacy for diabetes care: a political perspective**

**Adrian Sanders, Liberal Democrat MP for Torbay, UK; Chair, House of Commons All Party Group on Diabetes**  
The principle factors in influencing the health care policy of the UK Government (Figure 6) and the

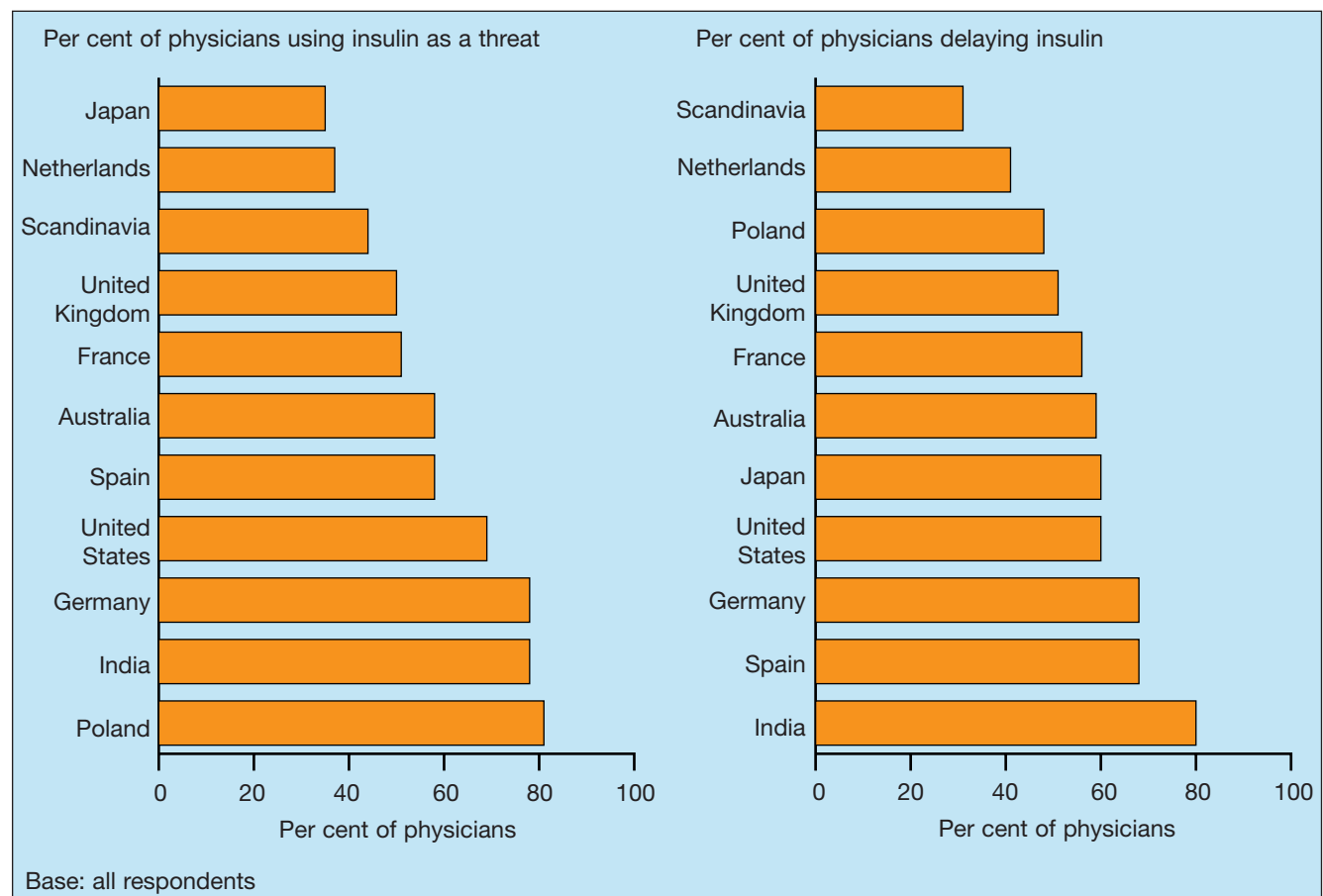
European Union (Figure 7) were persistence and professionalism. As examples, Mr Sanders cited the UK campaigns to get pen needles onto the NHS drug tariff and to modify driving licence restrictions. Their success owed much to multi-layered campaigning strategies and independent evidence about the reduction of suffering and the financial bottom line. International comparisons and the involvement of role models such as Sir Steve Redgrave were also helpful.

**Health care environment changes needed to bring DAWN into practice**

**Russell Glasgow, Senior Scientist, Kaiser Permanente Clinical Research Unit, Denver, Colorado, USA**

Components of a planned CDM model, according to Dr Glasgow, were clinical information systems, decision support, organisation of care, practice design, self-management support, and community

**Figure 5.** Physician barriers to insulin treatment (T Lauritzen, Denmark)





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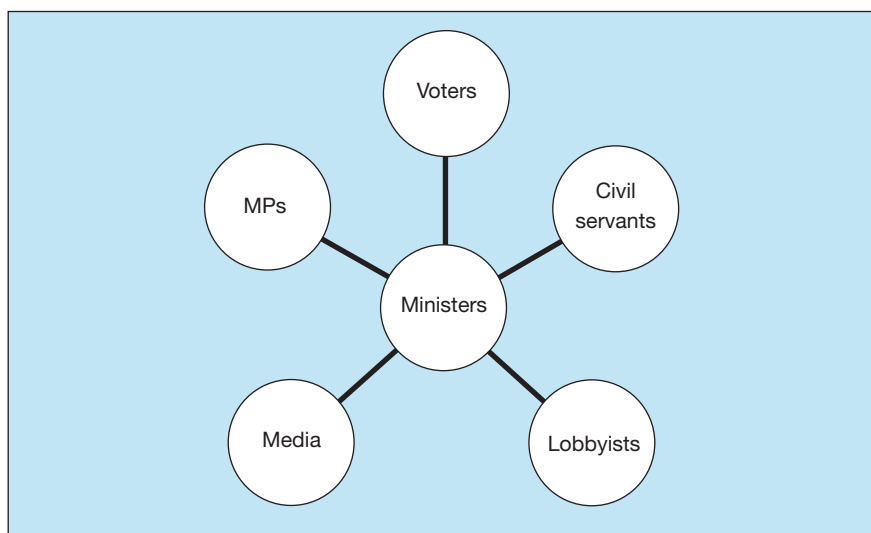
**Table 6.** Mistaken beliefs about insulin among patients prior to starting insulin therapy (S Cradock, UK)

'Insulin therapy means that the illness has got worse. Then you become a slave to the little black box – you've got to carry it in your pocket all the time'

'Insulin is the final step that forces you to face the whole disease much more intensely. Taking pills makes diabetes seem not too serious'

'You're no longer as independent as before. When you go out, you'll be constantly worrying about having forgotten something'

**Figure 6.** Influences on UK Government health care policy (A Sanders, UK)



resources.<sup>9</sup> The model was proactive, population-based and patient-centred but miraculous improvements in quality of life should not be expected, because of dilution effects (Table 7). An ideal DAWN system would incorporate integrated information and feedback that included: health behaviours; a collaborative, patient-centred approach; accessible evidence-based problem-solving training; and a supportive environment. Next best (in the real world) would be: shared validated assessments; clinicians who solicited patient views and set collaborative goals; more patient education; evidence-based health system and community prevention programmes; and demonstration projects to enhance food choices and physical activity.

'To every complex question there is a simple answer ... and it is wrong.' HL Mencken, quoted by Russell Glasgow

**Bringing the patient perspective into diabetes care guidelines**

**Frank Snoek, Professor of Medical Psychology, VU University Medical Centre, Amsterdam, The Netherlands**  
**Elize van Ballegooye, Assistant to the DAWN Programme, Amsterdam, The Netherlands**

Professor Snoek presented an impressive review of 42 recent national diabetes guidelines, of which only five (Australia, Germany, The Netherlands, Romania and the UK) included a substantial section on psychosocial issues. Depression, anxiety, eating disorders, resistance to insulin treatment, maladaptive coping strategies and cognitive and behavioural disorders were mentioned in these guidelines. As part of the DAWN programme, consideration of the following issues was proposed: translation of intentions into clinical practice; using existing guidelines as a model for other

countries; cultural translation from Western to non-Western countries; concerted advocacy to address the problems of reimbursement for psychosocial services; and more research to provide evidence to justify effective psychosocial care.

**Building psychological issues into national diabetes programmes**

**Ruth Colagiuri, Director, Australian Centre for Diabetes Strategies; Senior Lecturer, Faculty of Medicine, University of New South Wales, Sydney, Australia**

Following on from Professor Snoek, Ruth Colagiuri emphasised again that a large percentage of people with diabetes were worried, stressed, anxious or afraid (Figure 8), but not much was being done about it. Could DAWN be used to improve national diabetes programmes in this regard? Why not include psychological status in national best practice cycles of care? This would entail the implementation of consistent standards, the delineation of service roles, the training of staff and the provision of information. A useful tool was a consumer card (Figure 9).

The integration of psychological care in diabetes was missing, necessary and feasible and could be facilitated by DAWN.

**Workshop conclusions**

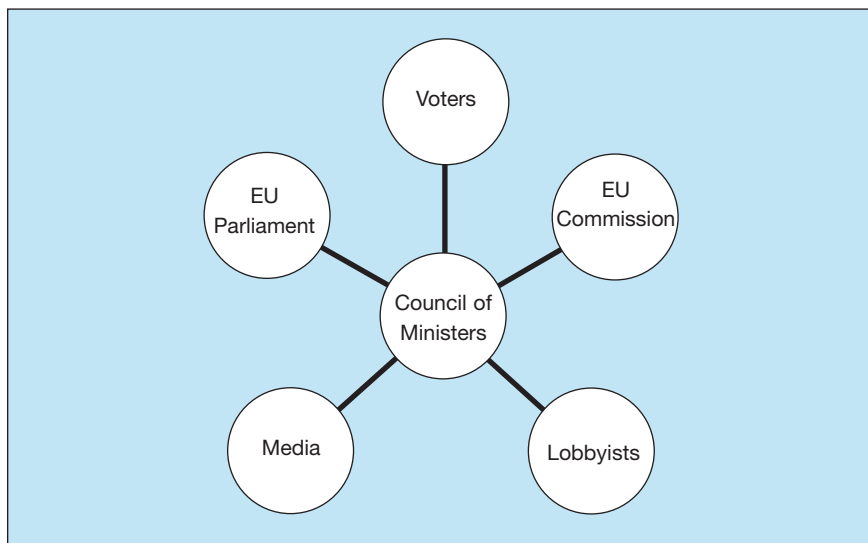
**First workshops: global mission statements**

**Chair: Richard Rubin, Associate Professor in Medicine and Pediatrics, John Hopkins University School of Medicine; Consultant, Diabetes Center and Pediatric Diabetes Clinic, John Hopkins Hospital, Baltimore, USA**

**Second workshops: specifying concrete actions**

**Chair: Philip Home, Professor of Diabetes Medicine, University of Newcastle upon Tyne, UK; Consultant Physician, Newcastle Diabetes Centre, Newcastle upon Tyne, UK**

On day 1, workshop teams were asked to draft mission statements for use as a starting point for a DAWN global call-to-action. On day 2, the

**Figure 7.** Influences on European Union health care policy (A Sanders, UK)

**Table 7.** Ultimate impact of the magic DAWN QoL Scale (R Glasgow, USA)

Dissemination step	Concept	% impact
50% of clinics use	Adoption	50%
50% of clinicians administer	Adoption	25%
50% of patients participate	Reach	12.5%
50% use scale correctly	Implementation	6.2%
50% of those benefit	Effectiveness	3.2%
50% continue to benefit after six months	Maintenance	1.6%

task for the same teams was to specify concrete actions to help accomplish these. Each workshop team comprised a multinational mix of HCCs, HCPs and health care decision makers/administrators. They shared ideas that it would be feasible for participants to implement locally. This required them to extend their personal perspectives on how to improve diabetes care.

All of the workshop teams endorsed the need for a major DAWN philosophy shift, which would focus on inclusion, dialogue and communication with HCCs at its core and encourage greater collaboration between professional organisations, patient associations, industry and government bodies. Many specific proposals for manageable pilot programmes, which could be used to start a snowball effect, were developed by the workshops. There was

agreement that these should be supported by DAWN ambassadors around the world. The emphasis would be on realism and effective utilisation of existing resources, using simple and easy to access tools. To secure more resources additional evidence for benchmarking outcomes was required.

Professor Rubin and Professor Home summarised the messages from the workshops as follows.

*Communication between HCC and HCP.* Adopt a diabetes care model that promotes dialogue between HCPs and HCCs to reach shared goals leading to informed choices about self-management that improve health and quality of life. Create tools to facilitate HCC/HCP efforts to improve communication.

*Communication between HCPs.* Develop and maximise team member roles through implementation

of core competencies to ensure flexible, seamless and consistent care for the HCC. Identify team coordinator. Use guidelines. Train team members. Push for the IDF and WHO to incorporate the team concept into their plans. The process should start with physicians but be driven by HCCs to push for the inclusion of a patient perspective in every diabetes care decision.

*Self-management.* Promote active self-management as an essential requirement to obtain optimal control of diabetes and quality of life. Recognise the need for user-friendly information, education and training for HCCs, support organisations and HCPs. Create initiatives to raise awareness and develop appropriate policies.

*Barriers among HCPs.* Progressively improve and optimise diabetes care through actions that reduce globally HCPs' cognitive, emotional and educational barriers to using effective therapies. Take action to raise awareness to this end.

*Barriers among HCCs.* Identify and overcome significant barriers to insulin and other effective diabetes therapies among HCCs. Advocate for psychosocial/educational research, for adoption, implementation and dissemination of national and international guidelines, and for reimbursement for a universal and comprehensive care system.

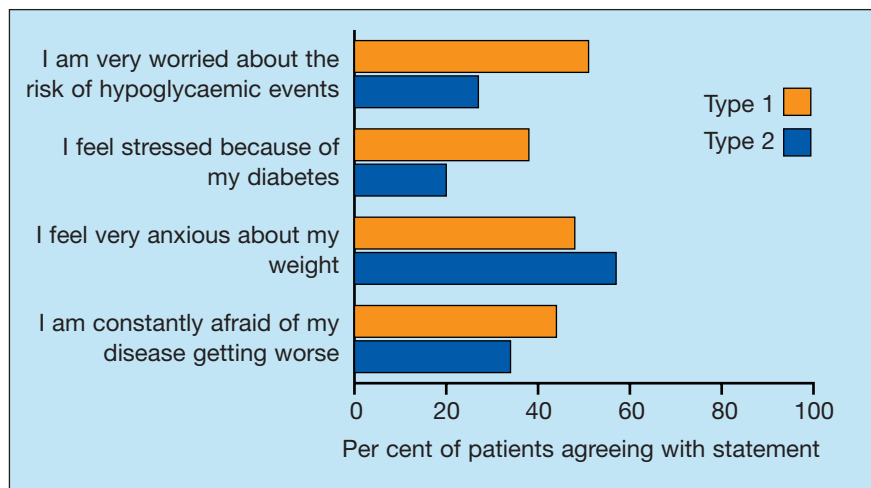
*Psychological needs (1).* HCPs and HCCs to give equal value to psychological, social and physical factors in diabetes management. Increase awareness, identification and appropriate management of psychological issues. Put pressure on the IDF to hold a Mental Health in Diabetes Week. Suggest a worldwide collaboration to administer WHO-5 to all individuals passing through the diabetes service, in the week of Diabetes Day 2004, and to use it as a standard questionnaire in diabetes consultations.

*Psychological needs (2).* Enable better psychological care for people with diabetes and address the need for psychological treatment. Create partnerships with patient/professional organisations and industry to increase as required the staff and financial resources.



Highlights from the 2nd International DAWN Summit

**Figure 8.** Percentage of people with diabetes who experience worry, stress, anxiety and fear about their condition (R Colagiuri, Australia)



**Figure 9.** A consumer card (R Colagiuri, Australia)

<p><b>See</b> a diabetes educator and dietitian to learn how to look after your diabetes</p> <p><b>Eat</b> sensibly. Eat mostly carbohydrates like fruit, vegetables, legumes, bread and less fatty food</p> <p><b>Do</b> some regular physical activity</p> <p><b>If</b> you smoke, stop smoking</p> <p><b>At</b> every visit, remind your health professionals that you have diabetes</p>	<p><b>What you need to do:</b></p> <hr/> <p><b>What your doctor needs to do:</b></p>	<p><b>HbA<sub>1c</sub></b> a blood test to assess your overall blood sugar control</p> <p><b>Cholesterol</b> a blood test to check your blood fats</p> <p><b>Microalbuminuria</b> a urine test for early signs of diabetic kidney problems</p> <p><b>Blood pressure</b> a check for signs of general health problems</p> <p><b>Foot examination</b> a check for signs of ulcers, infections or abnormalities</p> <p><b>Eye examination</b> a check of the back of your eyes</p>
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**Worldwide call-to-action**

At the end of the Summit, delegates accepted overwhelmingly David Matthews' challenge to commit themselves personally to the following steps within the next six months:

- To create partnerships with patient/professional organisations

and industry to increase staff and financial resources for the psychosocial aspects of diabetes care

- To recognise the need for user-friendly information and training to be developed and made available to patients (through local and district self-help diabetes groups), to diabetes support organisations and to health care professionals.

In a final vote, a large majority of delegates declared themselves confident that they could change things for the better.

*Note: further information about the DAWN (Diabetes Attitudes, Wishes and Needs) programme and the full text of the DAWN global call-to-action can be found on the website, [www.dawnstudy.com](http://www.dawnstudy.com).*

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**Erratum**

*Practical Diabetes International* 21(4) May 2004 p. 170a. News round-up item entitled 'Testing times for blood glucose monitoring'.

The correct email address for the Diabetes Monitoring Forum who produced a series of new blood glucose monitoring leaflets is [info@dmforum.org.uk](mailto:info@dmforum.org.uk)