

The Oxford International Diabetes Summit: Implications of the DAWN study

7–8 April 2002, Oxford, UK

The DAWN (Diabetes Attitudes, Wishes and Needs) study was instigated by Novo Nordisk in order to assess the perceptions and attitudes of people with diabetes and health care providers to the management and care of diabetes. The study was conducted between August 2000 and September 2001 in 11 countries or regions: Australia, France, Germany, India, Japan, Poland, Spain, The Netherlands, United Kingdom, Scandinavia (Denmark, Norway and Sweden) and the USA, with the focus on drivers of effective self-management amongst over 5400 people with diabetes and over 3800 diabetes health care providers (specialist doctors, GPs and nurses).

The objective of the DAWN study was to provide information of value in improving diabetes care and the well being of diabetic patients and to enhance and complement data derived from other reported psychosocial studies. To this end, the first Oxford DAWN International Summit met to consider its implications and resolve ways in which the findings of the DAWN study could be implemented. The interactive nature of the summit was enhanced by the use of computer-linked individual keypads, so that delegates could participate interactively and vote on a range of issues. Following presentations on the key issues surrounding DAWN, a series of participant workshops considered the issues that had been raised and produced their recommendations for future action.

Opening the Summit, Chairman Dr David Matthews (Chairman of the Oxford Centre for Diabetes, Endocrinology and Metabolism, Oxford, UK) commented on its multi-national and multi-disciplinary nature and how this was bringing together different stakeholder perspectives. Use of the keypads showed that Denmark, USA, Germany and the UK (in that order) were the best represented. Delegates included diabetologists, nurses, behavioural scientists, GPs, patients and health payors. These different perspectives would be important in arriving at conclusions. The DAWN study had endeavoured to discover the person behind the patient and to establish to what degree self-care management truly involved a partnership between patient and health care provider. Dr Matthews emphasised the psychosocial nature of the survey and the ways in which this aspect of care had perhaps been somewhat neglected in the past. DAWN represented an opportunity for change; this challenge should be welcomed. He hoped that the outcome of the summit would have a long lasting effect over the coming years.

The pandemic of diabetes

Dr Gojka Roglic

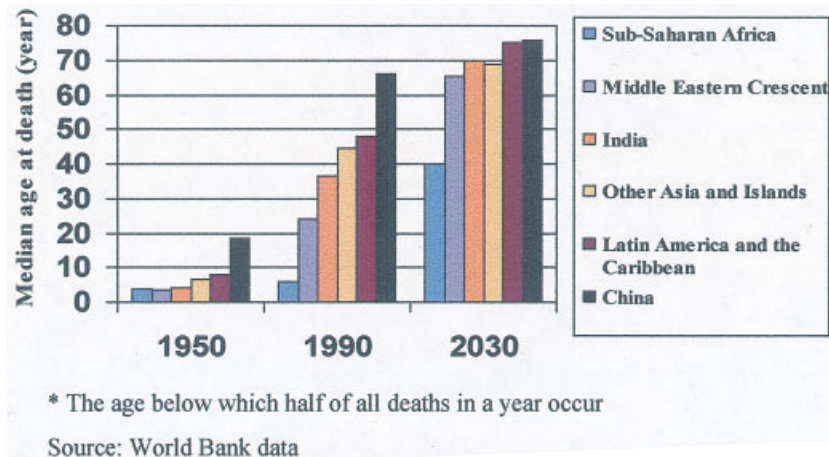
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Diabetes is now the fourth biggest cause of death worldwide with, in 1999, four million deaths attributed to it, following cardiovascular disease (17 million), infectious disease (ten million) and injuries (five million). The world population is ageing and people are living longer; both these factors

help to explain why there is growth in diabetes (Figure 1). The condition is on the increase throughout the world; however, the increases are predicted to happen at different times in different places (Figure 2). For the foreseeable future, the prevalence in the adult population will remain

highest in the established market economies and former socialist economies of Europe. However, the relative increase will be much higher in developing countries. By 2025, India, China and the USA are expected to have the greatest numbers of people with diabetes (Figure 3).

Figure 1. Median age at death by demographic region: 1950, 1990, 2030.



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Figure 2. Prevalence of diabetes in the adult population by year (1995, 2000, 2025) and region (developed and developing countries).

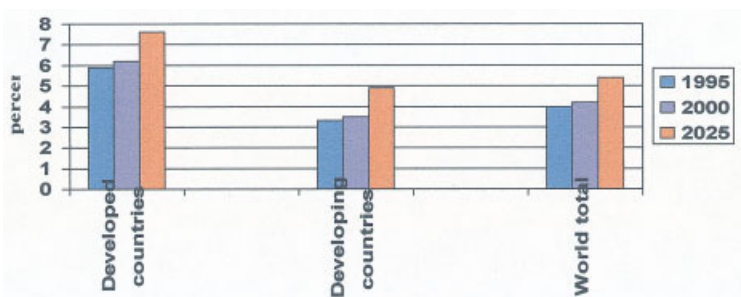


Figure 3. Top ten countries for estimated numbers of persons with diabetes (1995, 2025).

1995			2025		
Rank	Country	No. (millions)	Country	No. (millions)	
	India	19	India	57	
	China	16	China	38	
	U.S.A.	14	U.S.A.	22	
	Russian F.	9	Pakistan	15	
	Japan	6	Indonesia	12	
	Brazil	5	Russian F.	12	
	Indonesia	5	Mexico	12	
	Pakistan	4	Brazil	12	
	Mexico	4	Egypt	9	
	Ukraine	4	Japan	9	
	All other countries	59		104	
	Total	135		300	

Implementing the St Vincent declaration

Dr David Matthews

Chairman, Oxford Centre for Diabetes Endocrinology and Metabolism, Oxford, UK

The St Vincent Declaration set the goals of reducing blindness due to diabetes by one-third or more, reducing the number of people entering end-stage diabetes renal failure by at least one-third, halving the rate of limb amputations, cutting morbidity and mortality from coronary heart disease by vigorous programmes of risk factor reduction and achieving pregnancy outcomes in diabetic women equal to those of non-diabetic women.

Although none of these goals have been met, the declaration represented a breakthrough in recognising the importance of collaboration between the different stakeholders – the patients, healthcare professionals, employers, governments, industry

and bodies such as the WHO and the IDF. In particular, the central role of managing the condition primarily by people with diabetes themselves was recognised.

St Vincent started a movement and was followed by a number of further initiatives – for example, the Budapest Statement, Acropolis Affirmation, Libyan Charter, Declaration of the Americas, Lisbon Statement and Western Pacific Region Declaration – and these have changed the political process. Furthermore St Vincent has stimulated the development of outcome research and the placement of real systems to measure performance and outcomes in place of guesswork. After all, there was no way to measure progress if

there was no knowledge of the starting or the end points.

Dr Matthews queried the value of the plethora of diabetes treatment guidelines that had been produced. A delegate poll revealed that 67% had been involved in producing guidelines; however, only 48% were currently using them actively. The problem with guidelines, said Dr Matthews, was that the human component was missing. However, it is now recognised that the management of diabetes should be a collaboration between the patient and the healthcare professional, rather than a series of *dictats* laid down by the latter. It was now essential to develop new ways of working in partnership with patients.

Milestone diabetes studies

Dr Richard R Rubin

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The three main studies

Much of the dramatic change for the better in the management of diabetes over the past 20 years has been driven by new insights into genetics, biology and pharmacology, and much of this has been driven by milestone studies, in particular the DCCT, the UKPDS and, most recently, the DPP. All these show that intensified treatment improved outcomes (Figures 4–6) and is dependent on patient behaviour.

The DCCT showed that when HbA_{1c} was reduced by about one percentage

point, this translated to about a 30% reduction in microvascular complications in type 1 diabetes. The UKPDS showed that blood pressure control was equally important in reducing microvascular complications in people with type 2 diabetes. The DPP showed that intensive lifestyle changes had the greatest effect – compared with metformin or placebo – in people who were at risk of type 2 diabetes. Treatment adherence was better in the group assigned to lifestyle changes and this adherence had led to the greatest mean weight change.

Figure 4. Intensified treatment improves outcomes – DCCT.

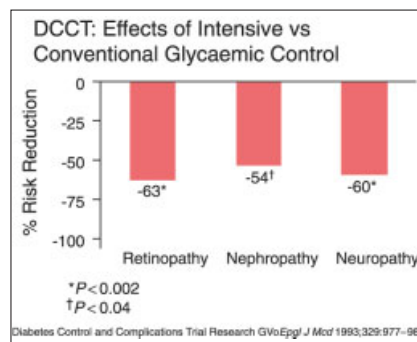


Figure 5. Intensified treatment improves outcomes – UKPDS.

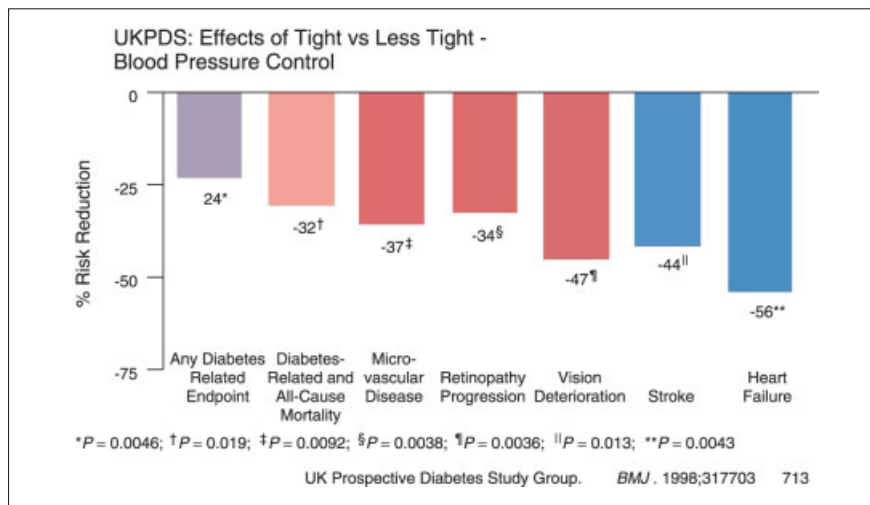


Figure 6. Intensified treatment improves outcomes – DPP.

	Placebo	Metformin	Lifestyle
Incidence of diabetes (percent per year)	11.0%	7.8%	4.8%
Reduction in incidence compared with placebo	---	31%	58%
Number needed to treat to prevent 1 case in 3 years	---	13.9	6.9

The Look Ahead Trial – which has just started in the USA – aims to investigate whether intensive weight loss intervention will confer long-term protection from heart attack and stroke on people with type 2 diabetes.

Factors influencing effective self-management

Intensified treatment is dependent on patient behaviour and effective self-man-

agement. Such self-care is complex and demanding and determined by many factors. The DAWN study has indicated the key factors influencing effective self-management (Figure 7). The two areas in which the data are strongest are psychological health of the patients and the provision of healthcare.

Psychological health

Patients who have an active coping style tend to have better self-care and metabolic control. A five-day outpatient intervention course conducted at Dr Rubin’s Centre has shown that, at both six months and one year after the programme, diabetes self-care skills, emotional coping skills and HbA_{1c} levels all improved.

It is particularly important to recognise the role of depression in diabetes; this is associated with less active self-care, higher glucose and an increased number and

severity of complications. Lustman *et al.* have shown that whilst in the general population the risk of being clinically depressed is between 5 and 7%, among people with diabetes it is between 15 and 20%. Effective interventions – both pharmacological and behavioural – are now available and are associated with more remission of depression and improved glucose control.

Healthcare provision

There are strong data showing that health outcomes are improved by providing diabetes self-management training. This means education, quality care (especially in effective communication among providers and patients) and autonomy support by the healthcare provider. Interventions that employ follow-up maintain glycaemic control longer. There is a need to facilitate self-care as technology burgeons; without this, the gap between technical potential and human reality will widen, and efforts to reduce the burden of diabetes will be frustrated.

Professor Rubin explained that his interest in diabetes had begun at an early age when his sister was diagnosed as type 1. The psychosocial issues – addressed by DAWN – were clear to him almost immediately because his family worried constantly about his sister’s condition. ‘In fact, after 43 years with diabetes she has had fewer complications than most people who have had the condition that long, but she has been burdened by the weight of her responsibility and has suffered from depression for much of her life. Depression is a chronic condition for most people who have diabetes.’

Figure 7. The ten major factors contributing to effective self-management.



DAWN – the main implications

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As data from the key findings of the DAWN study are being published separately in *Practical Diabetes International*, this article limits itself to summarising the main implications presented at the Oxford Summit.

Patient concerns

First, the survey shows that many patients are not well aware of their type of diabetes. Approximately 40% of the patients that had self-reported to be type 1 patients were, based on time of diagnosis and treatment, most likely to be, in fact, type 2 patients. The study confirms the importance of social support and emotional well-being as pivotal to the achievement of effective self-management. Those without such good networks of support feel worse in themselves and do not manage the condition as effectively. On the other hand, when family or social networks put too much pressure on them, this has a markedly negative effect on how they deal with their condition. Many patients are socially isolated, do not exercise, feel 'burnt out', find treatment complicated and are anxious and/or depressed about their condition. Patients are also anxious about their weight, are constantly afraid that their disease will worsen and worry about hypoglycaemic events. Most concerning is that type 2 patients worry about starting insulin. As the majority of respondents think that they control their condition reasonably well, it is worth asking why over 50% are in poor glycaemic control.

Ib Brorly (*Denmark*), a person with type 2 diabetes, said that changes were needed in the patterns of how to deal with diabetes. Much diabetes care at a primary level was based on experiences with type 1 patients. Type 1 patients – often diagnosed young – had adapted early to the necessary life-style changes, 'followed the rules' and were properly insulin regulated. Type 2 patients had different problems. They usually had no prior warning (before diagnosis) about their condition and, due to their greater age, had difficulties in changing their lifestyles. Furthermore, they did not always receive step-by-step motivation, and this was compounded by the fact that there was a lack of good type 2 information available to them.

Primary health care provider attitudes

Primary health care providers believe that the key reasons for poor control are patients not understanding the seriousness of their disease, not organising their lives effectively or being unwilling to accept the reality of diabetes. Providers recognise the psychological problems of their patients, but emphasise the lack of professional support in dealing with these. They think that most patients do adhere to their treatments (some providers admit to using the threat of insulin to 'encourage' adherence!). Generally, they consider that they have good relationships with their patients, but accept that these patients often have difficulties in explaining their problems and communicating.

Line Kleinebreil MD, a primary care physician in Paris, France, said that, looking at the data in DAWN, it became even clearer to her what a different and complicated disease type 2 diabetes really is. Type 2 patients suffered the same symptoms and complications as type 1 patients: often more frequently. The increase in the number of people with diabetes would mainly affect primary care. However, although knowledge was available at this level, did GPs know how to apply it? And did they have the courage to do so? Were they transferring their own anxieties to their patients? Dr Kleinebreil admitted to having been initially 'afraid' of insulin but was now proud of the number of type 2 patients she had on this therapy.

The specialist perspective

As many diabetes specialists are really specialists in type 1 diabetes – type 2 patients being mainly seen by primary care physicians – it has to be asked whether they are imparting the right knowledge for type 2 diabetes. Furthermore, unlike type 1 disease (which involves routine insulin dosing), type 2 diabetes is very much a 'communicating disease,' making demands on specialists' hard-pressed time, and, although the survey shows that whilst 80% of patients find it easy to go and see a specialist, it has to be asked whether they are always given the opportunity to do so, or whether they remain in the hands of their GPs.

From the data it seems that there is a proportion of patients who would benefit from better emotional psychological support. Unfortunately, in some of the countries, specialists have a negative attitude towards involving psychologists.

Professor Helmut Henrichs (*Professor in Diabetic Medicine, Diabetes Centre, Quackebrock, Germany*) said that the solution to the antipathy to psychologists was to rename them behavioural assessors. Furthermore, one way of overcoming any specialist lack of insight into type 2 diabetes could be to rename it as a metabolic vascular disease, embracing hyperlipidaemia and hypertension as much as hyperglycaemia. Professor Henrichs stressed the importance of motivation. He suggested that short-term management by fear – rather than being an obstacle to good control – could be a motivating force, a 'shock' treatment when seeking a certain goal within a short time. However, in the long term this strategy would inevitably fail (on the subject of using insulin as a threat to type 2 patients, he urged doctors to stop discussing perceived adverse effects, as this could present a real problem in terms of hypoglycaemia). He was not surprised at the gap between a feeling of being in control (amongst patients) and poor glycaemia results: HbA_{1c} was not the measure for good or bad control amongst type 2 patients, he said. He thought that patients did not receive enough praise from their physicians and stressed the importance of the team approach, in which patients would have many contacts and would find the ones who suited them best.

The nurse perspective

The DAWN Study shows that nurses feel their main responsibility is to give patients a feeling of security. They hope to act as intermediaries between patients and their doctors. Nurses felt that some of the frustrations on the patient's side are not expressed clearly to physicians; for example, at least 55% of them say that one of their roles is to brief doctors about possible psychological problems. A majority believe that they have more time for their patients and are better listeners. There are large differences between countries in terms of

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responsibilities, although many nurses are willing to take on more of these: either now or with additional training. There is a potential here that could benefit the diabetes care community and this is a resource that could be better exploited.

Ruth Colagiuri (*Director, Australian Centre for Diabetes*) thought that the combined data might not reflect substantial differences between specialist and non-specialist nurses and suggested that there might be more similarities between specialist doctors and specialist nurses. She was surprised that the nurses, when asked about their responsibilities, tended to discuss being go-betweens, helpers and supporters rather than their clinical roles. She queried whether the nursing workforce was being used to its best advantage, such as taking on a more clinical role in order to free up doctors to concentrate on medical matters that nurses are not able to do. One message from DAWN was that better ways could be found to use – to the patients' advantage – the sensitivity that nurses had to their condition and feelings (such as more advanced training in counselling).

Finance and infrastructure

The DAWN Study shows that a lack of

public funding for diabetes treatment is an issue amongst one-third of patients. Financial pressures contribute to poor control in almost a quarter of the patients. Some 40% of physicians say that the remuneration system might be a barrier to the effective management of diabetes. This is an interesting observation; perhaps there is something built into the system – in the way that we pay for healthcare services – that actually prevents doctors working effectively. DAWN shows that less than half the healthcare providers consider that their healthcare systems are organised effectively for dealing with chronic diseases.

There is almost a consensus amongst physicians and nurses that they need a better understanding of the psychosocial consequences of diabetes. It may be asked whose responsibility is it to provide this: medical associations, nurses' associations or healthcare services? Specialists and nurses agree that there should be more psychologists available to diabetes patients in need of psychosocial support; GPs believe this to be somewhat less important.

However, there is general agreement that the team approach is extremely

important. A high number of healthcare providers think that there should be more nurse educators or specialist diabetes nurses available.

Difficulty in communication with minority ethnic groups is perceived as a problem and there is agreement on the need for public awareness campaigns – particularly focused on type 2 diabetes, as this is where the problem lies.

Edward Hughes (*Professor of Preventive Medicine, Northwestern University, USA*) noted that many physicians believed that the system was not well organised for diabetes and chronic disease. He argued that until there were changes in the way healthcare was financed, there would be little success in the care of diabetes. He contended that while public health professionals were predominantly driven by professionalism, 'a desire to do the right thing', but argued that there was evidence that economic incentives are often important drivers of clinical behaviour. Professor Hughes said that we would not reach therapeutic, clinical or psychological goals in diabetes until there was an alignment of economic resources and incentives among payors, care givers and patients.

The workshop conclusions

There were 18 different workshops held during the summit. The main conclusions – based on an analysis of all of these – are summarised below.

On public awareness

It was agreed that there was a lack of sufficient awareness, understanding and acceptance of diabetes amongst the general population. Similar misconceptions and ignorance applied to the problems and lifestyles of people with diabetes. This lack of awareness appeared to be strongest amongst younger members of the general public.

On patient education

It was agreed that there was insufficient individual education for patients, as well as a lack of instruments or skills to evaluate and measure the therapeutic impact of such education. In particular, there was a lack of effective education on lifestyle issues related to diabetes. Moreover (a point particularly stressed by nurses), the education of patients was not perceived as a 'team' priority. In fact, the entire group of delegates saw education primarily as the

nurses' focus, and seemed to imply that while this was the current reality, it was not necessarily an adequate one. Education, as a therapeutic strategy, was seen to be all team members' responsibility – even the patient's – with the nurses playing the specialist role in this arena.

On professional behaviour

It was agreed that GPs lacked in-depth knowledge of diabetes. Specialists had insufficient time, resources and appropriate training in interpersonal communications, which sometimes resulted in patients not being treated as individuals. By and large, healthcare providers lacked the psychosocial and communication skills on matters not directly related to medical treatment. 'Management by fear of insulin' led to the 'insulin dilemma' in type 2 diabetes: this was counterproductive. The roles of different types of healthcare provider had

become, to some extent, ossified and stagnant. This was not conducive to an interdisciplinary team approach. Finally, the behaviour of healthcare providers might be influenced adversely by the lack of incentives.

The political agenda

It was agreed that lack of awareness of the impact and incidence of diabetes amongst politicians might already be causing problems that affect management and care. These included the curtailment of the professionals' time to communicate and the lack of availability of (or poor access to) such specialist staff as psychologists. In terms of funding, the lack of economic resources was a direct consequence of ignorance amongst politicians that diabetes could be prevented. Finally, there was a lack of professional medical leaders to drive the political agenda.

The workshop recommendations for action

On public awareness

- Create campaigns aimed at the media, politicians, research universities, diabetes pharmaceutical/product manufacturers, voluntary groups, school teachers/doctors and non-pharmaceutical/healthcare companies (for their worldwide presence). The purpose of the campaign is to create greater understanding and acceptance of people with diabetes, and as an additional benefit make sure that more people are open to early diagnosis or referrals.
- Such awareness campaigns should be globally based, delivering the same consistent message with the aim of building a recognised image for the disease. Regional campaigns, augmenting this, but reflecting the nuances of local circumstances and culture should be developed under this global umbrella.
- For public relations campaigns to carry credibility, *accurate* data on the numbers of people with diabetes and 'pre-diabetes' – globally and for each country/region – must be generated.
- Campaigns should be endorsed by recognised opinion leaders and bodies (such as WHO, ADA, IDF, EASD, FEND etc) and strategic events such as World Diabetes Day should be used more actively to gain public and political attention.
- Other successful healthcare, behavioural/lifestyle campaigns (smoking cessation, AIDS etc) should be studied and relationships should be developed with appropriate related medical specialist interest groups (for example, cardiovascular, obesity).

On patient education

- Healthcare provider skills in patient

education must be upgraded in line with the growing body of knowledge about its impact on disease outcomes.

- Therapeutic education – the cornerstone of effective self-management – should be a mandatory component of services for people with diabetes in the 21st century. Therapeutic education must be more accurately defined in terms of its principles, theory and application and impact.
- In order to enhance personalised approaches, which address individual patient needs, nurses (and their colleagues) have to develop and maintain competencies, and create tools for the assessment of effectiveness and performance.
- Patients' families should participate very closely in the patients' self-care management programmes and, whenever possible, participate at consultations.

On professional behaviour

- *GPs* – initiatives directed at them should be practical and aimed at the needs of the primary care level. These should include books, CD-ROMs and dedicated web-sites. More training is essential in multicultural traditions (with emphasis on culturally appropriate language), psychosocial issues and patient self-management and patient communication skills. Remuneration incentives should be introduced for GPs, based on health outcomes and knowledge.
- *Specialists* – psychosocial/communication skills should be built into their formal education. For currently practicing physicians, training should be prioritised, with videotaped consultations for measuring communication skills and building expertise.
- *Teams* – should include a psychosocial

expert, who would not only work with patients, but who would also act as a consultant, trainer and referral resource for the team.

The political agenda

- Funding of diabetes treatment must be based on equity. The creation of two classes of diabetes patient – based on ability to pay – has to be overcome.
- Resources must be made available in all economies for the treatment and early diagnosis of the disease, as it has far reaching consequences on the scale of AIDS or even worse. Individual opinion leaders and bodies must lobby patients, government, local administrations and funds, employing bodies, supportive alliances, scientists, other relevant healthcare providers, the diabetes-related industry, other chronic disease organisations and media and professional organisations. *This must be considered an urgent priority.*

The summit ended with an interactive voting session on a number of the issues aired either during the keynote presentations or during the workshops. Psychosocial issues were considered very important, with 98% of delegates agreeing that these should appear in guidelines. 62% considered that psychological factors were critical to successful outcomes. Sixty-four per cent wanted to see an expansion of the GP's role in the management of diabetes and 36% thought that specialists should be made more psychosocially oriented. The usefulness of the summit was underlined by a massive vote of 93% in favour and by 94% requesting that it become an annual event. The Second International Diabetes Summit is now scheduled tentatively for early May 2003.