



MOVING TOWARDS ACTION THROUGH CONSENSUS: A Type 1 Diabetes Issues Statement?

The Challenge

- **Evidence-based clinical targets, essential monitoring and management of risk factors are achieved by less than 20% of Australians with Type 1 diabetes** (Bryant, Greenfield et al. 2006; Gilbert, Thornley et al. 2006).
- Health outcomes for people with Type 1 diabetes remain poor:
 - Death rate of girls with diabetes aged 10-17 is 5 times greater than non-diabetic peers;
 - Eating disorders are eight times as common amongst pre-teens;
 - Rates of psychological ill health in diabetic youth are 'disturbingly high';
 - Depression is twice as common in Type 1 diabetes;
 - Over 40% of people with Type 1 diabetes develop severe kidney disease by the age of 50; and
 - 80% develop retinopathy (vision-threatening eye disease) after 15 years of Type 1 diabetes.
- The Diabetes Control and Complications Trial (1993) showed conclusively that tight self-management of blood glucose levels significantly improved health outcomes for those with Type 1 diabetes.
- Diabetes is a self-managed condition. It is the patient who monitors their blood glucose levels, adjusts and administers insulin and manages a life time of multidisciplinary care.
- Government policy, research and service delivery have focused on Type 2 diabetes (which differs significantly) whilst Type 1 diabetes, representing 10-15% of all diabetes in Australia yet 42% of the cost has fallen significantly behind in priority and action.
- The challenge is finding a cost-effective means of supporting people with Type 1 diabetes to achieve optimal control of blood glucose levels and other risk factors and improve key outcomes.

Recommendation

There is an urgent need for all stakeholders in Type 1 diabetes to collaborate in sharing information and developing evidence-based strategies to deliver quality care at all stages of life and course of disease. It is vital that people living with diabetes participate in the dialogue if health outcomes are to be improved.

The Type 1 Diabetes Network, a consumer-led health promotion charity, is proposing to host a consultation and collaboration process including teleconferences and online collaboration of key stakeholders to develop a consensus statement that is launched at the forthcoming diabetes health professionals' conferences to be held in Melbourne in August 2008.

The objective would be:

- To inform future service development and policy initiatives by publishing a statement of issues affecting Australians with Type 1 diabetes that has been developed in consultation with all stakeholders including consumers, health service providers, government and researchers.

Other outcomes may include:

- Raising awareness of the issues faced by people with Type 1 diabetes and the health professionals who work to support them; and
- Ongoing networking and information sharing amongst key opinion leaders and greater collaboration between users and providers of healthcare.

Background

The Type 1 Diabetes Network is a ten year-old health promotion charity. The Network is run by volunteers who have diabetes and contribute a broad range of professional skills and experiences from health and other relevant sectors.

Through our work, we have supported people with Type 1 diabetes, and the health professionals who work in this field, with educational resources, online communities, networking and educational events, psychosocial and health services research, and by representing the interests of our members to government, health professional forums and the media.

We have grown increasingly concerned at the stagnant nature of policy and service development for Type 1 diabetes, and in the year of our 10th anniversary are proposing to host a series of activities that will strengthen and activate the Type 1 diabetes community as a whole.

A review of Type 1 Diabetes In Australia is included as Appendix 2.

The role of an Issues Statement

There is an urgent need for issues, opportunities and examples of success to be brought together and shared with all affected by the condition, both personally and professionally.

The forthcoming diabetes health professionals' conferences being held in Melbourne in August 2008, present a focus for the culmination of activity which would achieve this goal.

The objectives would be:

- To publish a statement of issues affecting Australians with type 1 diabetes
- To involve all relevant stakeholders including consumers, health professionals, policy makers and researchers in the development of this statement
- To disseminate the statement widely to all health services, policy makers, consumer organisations and others
- To inform the development of future service development and policy initiatives.

Other outcomes may include:

- Media reporting of the forum and the issues raised
- Raising public awareness of issues facing people with Type 1 diabetes and the health system which supports us
- Ongoing networking and information sharing amongst key opinion leaders which can focus and unite the diabetes community

Proposed Consultation and Collaboration Process

The Issues Statement would be developed through a process of consultation and collaboration, an outline of which is provided below:

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| Formation of a core group of opinion leaders in Type 1 diabetes (proposed invitation list, Appendix 1) | Feb 2008 |
| Opinion Leaders Teleconference – introductions, and agree framework for development of the statement | Mar 08 |
| Publish background papers online (with comment function) | Mar 08 |
| Online Forum for issues discussion amongst Opinion Leaders | Mar – Sep 08 |
| Consumer survey | April 08 |
| Consumer survey results published | May 08 |
| Draft Issues Statement published, for comment | July 2008 |
| Opinion Leaders Teleconference | July/Aug 08 |
| Final Issues Statement agreed (embargoed) | Aug 2008 |
| <i>Launch at Australian Diabetes Educators Association & Australian Diabetes Society Conferences, Melbourne</i> | <i>27-29 Aug 08</i> |
| Publish Issues Statement – print and online | Sep 08 |
| Distribute Issues Statement (to all NADC centres, ADEA members, CEOs DA all states, Ministers for Health, Shadow ministers, state ministers & shadow ministers) | Sep 08 |

Opinion leaders group – invitation list

Representatives of the following organisations will be invited to participate:

- Diabetes Australia *
- Juvenile Diabetes Research Foundation *
- Australian Diabetes Educators Association **
- Australian Centre for Diabetes Strategies *
- National Health & Medical Research Council
- Australian Diabetes Society
- Endocrine Society Of Australia
- Australasian Diabetes in Pregnancy Society *
- GP Registrars Association
- HypoActive consumer group for exercise and diabetes *
- Health Services Research Association
- Medicines Australia *
- The Type 1 Diabetes Network **

Representation will also be sought from:

- Tertiary hospital diabetes service *
- Children’s hospital diabetes service *
- Community health diabetes service *
- Private practicing endocrinologist *
- Health psychologist *
- Health promotion *
- Medical research *
- Medical education *
- University research *

* Organisations (or professions/industries) highlighted with an asterisk have previously collaborated with the Type 1 Diabetes Network on substantial projects and relationships are well-established so as to anticipate a positive response to the invitation.

** Organisations marked with a double asterisk have already agreed to participate.

Invitations to Launch of the Issues Statement

In addition to the organisations who will be invited to nominate a representative to participate in the lead-up and the forum, the following will be issued with personal invitations to attend the launch:

- Federal Minister of Health
- Department of Health and Ageing
- Victorian Government Minister for Health
- Department of Human Services Victoria
- Parliamentary Diabetes Support Group