

A Statement of Issues affecting Australians with Type 1 Diabetes



TYPE 1
diabetes
network

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The Type 1 Diabetes Opinion Leaders Group was formed in 2008 to develop a Statement of Issues affecting Australians with Type 1 Diabetes, and stimulate discussion about solutions to the issues.

Health professional bodies, non-government organisations, industry groups and consumer groups were represented alongside people with Type 1 Diabetes and parents of children with Type 1 Diabetes. Representatives of other key groups were also included: private endocrinology, psychology and counselling, adolescent diabetes services, tertiary hospitals, regional services, health promotion, general practice, pregnant women and rural families.

Public submissions were sought with 78 received from both health professionals and people affected by Type 1 Diabetes. An open nomination process was used to identify the consumer representatives with more than 50 applications received.

Over five months, the Group worked through a four-stage process to identify and explore issues affecting Australians with Type 1 Diabetes:

1. Broad scoping of the issues
2. Exploring the issues in themes
3. Identifying key issues within themes
4. Reviewing a draft statement

Numerous solutions to the issues identified were also proposed and collected through the process.

The Group used online communication to develop the statement, with a web-based discussion forum the central platform, complemented by a series of teleconferences.

The Type 1 Diabetes Network, a volunteer-run health promotion charity initiated and facilitated the process.

All members and facilitators volunteered their time. No sponsorship or grants were involved in the project. All costs were covered by the Type 1 Diabetes Network, predominantly via donations from its members, people with Type 1 Diabetes.

Ten issues require urgent attention:

1. **Access to specialist medical advice** is very limited, especially in rural and regional areas
2. **Complexity** of Type 1 Diabetes is neither well understood nor managed
3. **Coping with long-term complications** of Type 1 Diabetes is left to the individual with very limited support
4. **Hospital admissions**, planned and emergency, for people with Type 1 Diabetes are managed poorly when a diabetes team is not involved
5. **System for the essential long-term monitoring** of Type 1 Diabetes is inefficient and highly ineffective
6. **Adolescence and young adulthood** is a critical stage with the worst outcomes
7. **Access to the best treatments and medical technologies** is dependent on the ability to pay, not medical need
8. **Training teachers and schools** about the basic needs of children with Type 1 Diabetes occurs haphazardly
9. **Peer learning** opportunities for people with Type 1 Diabetes are essential but very limited and difficult to access
10. **Leadership and advocacy** for Type 1 Diabetes needs to be strengthened urgently

The issues and proposed solutions are explored further inside.

1. Access to specialist medical advice is very limited, especially in rural and regional areas

SOLUTION: A Centre for Excellence in Type 1 Diabetes needs to be established in Australia, with early tasks to develop:

- evidence-based guidelines for managing Type 1 Diabetes in adults, which currently do not exist;
- internet-based communications to extend access to specialists for people with Type 1 Diabetes and build local expertise in rural/regional areas;
- systematic review of current evidence and available consumer information;
- research and extend the evidence base where critical gaps exist (e.g. multiple autoimmune conditions, eating disorders, prevention, rare complications, exercise, diet) and disseminate to both health professionals and consumers.

2. Complexity of Type 1 Diabetes is neither well understood nor managed

SOLUTION: Telephone-based 24-hour **secondary consultation service** for GPs and hospital doctors to access team with expertise in Type 1 Diabetes.

SOLUTION: Screening and review of **mental health** should be routine and normalised, with a mental health professional attached to or affiliated with every diabetes service.

SOLUTION: Public messages about 'diabetes' must identify the type, and **communications experts** should investigate how best to communicate with the public about the complexities of Type 1 Diabetes.

SOLUTION: Education and support programs specifically for Type 1 Diabetes that are evidence-based and structured should be developed targeting key stages across the lifespan. (e.g. newly diagnosed adults, planning pregnancy, young adult re-education).

3. Coping with the long-term complications of Type 1 Diabetes is left to the individual with very limited support

SOLUTION: Everyone diagnosed with a long-term complication should be offered referral to a mental health professional or counsellor.

4. Hospital admissions, planned and emergency, for people with Type 1 Diabetes are managed poorly when a diabetes team is not involved

SOLUTION: Everyone requires a **pre-determined Diabetes Plan** that can be immediately enacted upon admission to hospital or in other emergencies.

SOLUTION: All planned admissions should include **pre-admission planning** for diabetes management in hospital with a diabetes team, supported by a comprehensive **patient information resource**.

5. System for the essential long-term monitoring of Type 1 Diabetes is inefficient and highly ineffective

SOLUTION: Urgently instigate an automated system for routine **complication screening** recall and review to increase rates from 20% currently.

SOLUTION: Medicare Benefits Schedule (MBS) must be reviewed to better support management of complex chronic diseases which cannot be prevented, such as Type 1 Diabetes, including:

- broadening the scope of professions that initiate care plans to include endocrinologists;
- ensuring indefinite referral legislation is reviewed by both patient groups and providers of services and improved so that it can be consistently issued and accepted.

SOLUTION: Centralised **electronic records** of all interventions, diagnoses and treatments, with patient primarily responsible for accessing and updating it and all professionals contributing.

SOLUTION: Type 1 Diabetes Help Desk – 24-hour phone and email access to specialist advice.

SOLUTION: **Pregnancy planning** for women and girls with Type 1 Diabetes must be routinely discussed and supported to minimise poor outcomes for mother and baby.



6. Adolescence and young adulthood is a critical stage with the worst outcomes

SOLUTION: All young people with Type 1 Diabetes need an individual, flexible plan for accessing essential medical support during adolescence, young adulthood, and beyond.

SOLUTION: Remove financial disincentives to self-care for young adults.

7. Access to the best treatments and medical technologies is dependent on the ability to pay, not medical need

SOLUTION: Treatment options must be based on clinical need rather than consumer capacity to pay for unsubsidised options.

SOLUTION: Legislation and government subsidy schemes effecting treatment options must be reviewed regularly in consultation with people living with Type 1 Diabetes.

8. Training teachers and schools about the basic needs of children with Type 1 Diabetes occurs haphazardly

SOLUTION: Develop a national system for annual education of teachers and other school and childcare staff in all jurisdictions about common medical conditions, including Type 1 Diabetes.

SOLUTION: 'Health issues' module added to training for teachers and childcare workers.

9. Peer learning opportunities for people with Type 1 Diabetes are essential but very limited and difficult to access

SOLUTION: Standard care to include facilitated introduction to others in similar situation, and those avenues developed or supported.

10. Leadership and advocacy for Type 1 Diabetes needs to be strengthened urgently

SOLUTION: Replication of the 'Cancer Voices' program for Type 1 Diabetes, to support increased involvement in policy and service development.

SOLUTION: Strong consumer involvement in a future Centre for Excellence in Type 1 Diabetes.

101 Solutions, Big and Small

The Type 1 Diabetes Opinion Leaders Group also identified 101 solutions to improve Type 1 Diabetes.

'101 Solutions for Type 1 Diabetes' can be found at www.d1.org.au/issues

Can you find one to implement today?



Are you delivering Excellent & Innovative initiatives for People with Type 1 Diabetes?

Is your organisation addressing the issues affecting Australians with Type 1 Diabetes?

Share your work by submitting it to The Type 1 Diabetes Network. Visit www.d1.org.au/issues



The following organisations and individuals contributed to the development of the Statement of Issues affecting Australians with Type 1 Diabetes:

Australian Diabetes Educators Association

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The statements in this document have not been formally endorsed by the individuals and organisations listed though we thank them for their invaluable contributions.

Rationale for a Statement of Issues

- Evidence-based clinical targets, essential monitoring and management of risk factors are achieved by less than 20% of Australians with Type 1 Diabetes.
- Health outcomes in Type 1 Diabetes remain poor:
 - Death rate of girls with diabetes aged 10-17 is 5 times greater than non-diabetic peers;
 - Over 40% of people with Type 1 Diabetes develop severe kidney disease by age of 50;
 - 80% develop retinopathy (vision-threatening eye disease) after 15 years of Type 1 Diabetes;
 - Eating disorders are eight times as common amongst pre-teens;
 - Rates of psychological ill health in diabetic youth are 'disturbingly high'; and
 - Depression is twice as common.
- The Diabetes Control and Complications Trial (1993) showed conclusively that tight self-management of blood glucose levels significantly improved health outcomes for people 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 lifetime of multidisciplinary care.
- **Government policy,** research and service delivery have focused on Type 2 Diabetes (which differs significantly). Type 1 Diabetes represents 10–15% of all diabetes in Australia yet 42% of the cost, and it 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 to improve key outcomes.**



For a review of current evidence, see 'Type 1 Diabetes in Australia, 2008' and other background to the Statement at www.d1.org.au/issues

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