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Australasian young adults' transition from paediatric to adult diabetes services: a complex picture of choice and access

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Background

- Type 1 diabetes affects 0.7% of populations in Australasia
- 140,000 Australia & 15,000 New Zealand
- 10-15% of all cases of diabetes
- Approximately half of all people with Type 1 diabetes diagnosed in childhood, and therefore 'transition'

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'Transition' in diabetes care

Society for Adolescent Medicine:

- "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented healthcare systems" (Blum et al, 1993)

Diabetes Australia National Review of Transitional Care:

- "a period for many people who were diagnosed with Type 1 diabetes as children or teenagers in which they move from paediatric care to adult-focussed management and care of their diabetes - often at the same time as many other life changes are occurring as they reach adulthood" (Diabetes Australia, 2007)

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The problem

Transition is recognised as a major problem in Type 1 diabetes care:

- 18-19 year-olds have the worst glycaemic control of any age group (JDRF Needs Analysis, 1997)
- Many people with diabetes experience a marked deterioration in metabolic control in teenage years (Fleming et al, 2001)
- Failure of transition planning contributed to more than doubling of young adult admissions to Royal Children's Hospital, Melbourne 1992 to 2001. (Lam et al, 2005)
- Dropping out of the system: "Problem of non-attendance has been an issue for more than twenty years." (Rapley, et al, 2007)

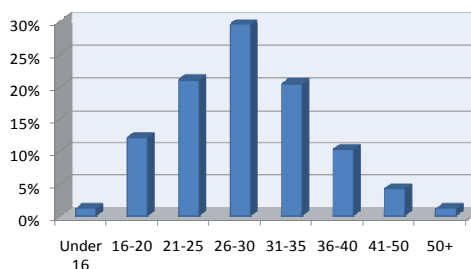
Method

- Web-based survey June 2007
- 20 questions
- Health service data appended to survey of information needs
- Validated by focus group
- 168 responses (24% male, median age group 26-30 yrs)
- Living in Australia or New Zealand during transition period (16-20 years of age)



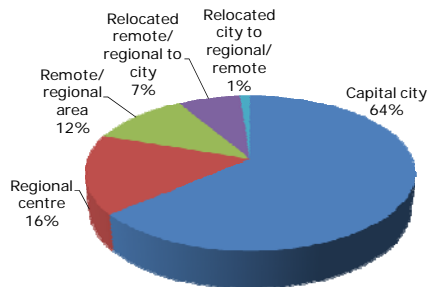
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Age of respondents



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Residence during transition



Analysis of 3 key questions:

1. Type of paediatric care
2. Method of transition (if any)
3. First contact with adult services

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Service use through transition

- **Optimal transition:** Supported and timely transfer from paediatric diabetes services to a dedicated young adult clinic in the adult system (Kipps et al, 2002; Fleming et al, 2002)



4% (n=166)



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Service use during childhood

- **19% not yet diagnosed**
- 400 Australians 15-24 years of age diagnosed per year (Australian Institute of Health and Welfare, 2006)

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Where diabetes in childhood



Children's hospital diabetes clinic – 51%



Private endocrinologist – 50%



Adult hospital – 18%



GP only – 3%

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Supported transition ?

Which of the following BEST explains how your medical team arranged for you to 'transition' from children's services to adult services for support with your diabetes?

My children's hospital made appointment for me at an adult hospital or endo	11%	Level of support
I was given the details of an adult hospital	15%	
All the dealings were done through my parents and I wasn't directly involved	15%	↓
I looked into options myself	7%	
I moved away from home and found my own in the adult system where I moved to	4%	N/A
I stayed away from hospitals and doctors after I was too old for children's care	15%	
I never really transitioned as I was attending an adult hospital when I was a child	14%	}
Newly-diagnosed during transition period	19%	

First contact with adult system



A 'young adult clinic' or 'transition clinic' in a public hospital – 16%



Private endocrinologist – 49%



A diabetes clinic not especially for young adults – 28%



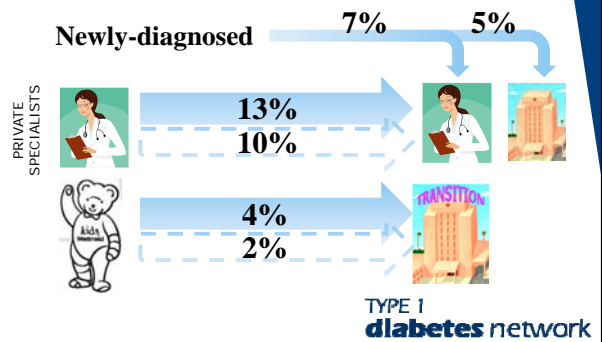
Diabetes specialist nurse – 11%



GP – 8%

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Models of transition



General Practice



Only GP as child + GP first contact with adult system → 2%

Royal Australian College of GPs & Diabetes Australia
Guidelines for Diabetes Management in General Practice :
All Type 1 diabetes should be referred to a 'specialist physician'

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Dropping out of the system

"I stayed away from hospitals and doctors for a while after I was too old for children's care" → 15%

- Irregular 'clinic attendance' important predictor for the development of diabetic kidney disease (Krolewski et al, 1985)

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Limitations

- This study was limited by dependence on self-reported data
- Recall bias
- Sample size (n= 166)
- Bias towards patients with internet access
- Gender bias: 24% male respondents

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Key findings

- Optimal transition**, as it is defined in the literature, is very rare.
- New diagnoses** occur frequently in the 'transition' period and need to be considered in service development.
- Use of **private specialist physicians** is a common medical management model during the transition period.

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Discussion

- The literature draws target populations from **clinics in public hospitals**.
- This study suggests significant numbers of adolescents and young adults **outside** of these services.
- **Role of consumer organisations** in health services research:
 - Include people outside of the health services
 - Independent? Disengaged? Marginalised?

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Conclusions

- **Wide range of medical management models** are being used during 'transition': public clinics, private specialists, none of the above.
- **Further comparative research** studies required into the nature and outcomes of different models.
- **Information and support outside of the traditional health services**, such as websites and peer networks, may be important for supporting the entire population of adolescents with diabetes through the period known as 'transition'.

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