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NDSS National Development Programme

Young People with Diabetes

Evaluation of the *Youth Transition Pack*

May 2015

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Executive Summary

Introduction

In 2010, the National Diabetes Services Scheme (NDSS) implemented the Youth Transition Pack (YTP) with the aim of engaging and supporting young people with diabetes, and their families, through the transition from paediatric to adult diabetes care.

The YTP comprises an annual birthday card sent to young people with diabetes (aged between 12 and 20 years), and an accompanying letter to their parents providing information on age-relevant issues in the management of diabetes; e.g. alcohol and diabetes, getting a driver's licence and registering with the relevant licensing agency.

This report describes an evaluation of the YTP initiative to assess its value to parents and young people, and to explore how it might be improved. Two separate surveys were conducted for the evaluation:

- Young people with diabetes aged 12–20 years and parents'/carers' survey
- Healthcare Professionals' (HCPs') survey.

The HCPs' survey sought to identify and understand issues arising from any misinterpretation of the letters. This was in response to feedback received from a clinician working in a paediatric diabetes setting who suggested that there had been cases of the parents' letter resulting in some young people not attending their paediatric clinics.

Methods

Young people with diabetes and parents'/carers' survey

Survey instruments were developed to gather feedback from young people and their parents about the value of the YTP initiative. The survey sample (N=5,602) was selected from the NDSS database to include 4,000 parents of young people living with diabetes (aged 12–18 years) and 1,602 young people aged 19–20 years, who had had a birthday in the previous six months. Invitations to participate were sent (by mail) directly to 19–20 year-olds and to the parents of 12–18 year-olds, who were asked to complete the survey themselves with their child's input.

Surveys were administered online and completed by 1,161 respondents:

- 439 (11%) parents and
- 622 (11%) young people.

Healthcare Professionals' (HCPs') survey

Invitations to participate in an online survey were emailed to a selection of relevant HCPs through the use of purchased lists. Information about the survey and the survey link were distributed through the newsletters of various professional diabetes networks.

The survey went 'live' on 14 May 2014 and data collection ran for a period of six weeks.

Feedback was received from 149 HCPs. Approximately half (53% of respondents) work in one medical setting, while the remainder (47%) work in more than one setting. Almost half (44%) worked in a diabetes clinic within a general public hospital. Thirty-six per cent of respondents were diabetes educators and 30% were endocrinologists.

Key findings

Recall, engagement and perceived usefulness of the card/letter among parents and young people:

- 85% of *parents* and 87% of *young people* recalled receiving at least one letter/card over the past three years; 75% of *parents* and 84% of *young people* recalled receiving a letter/card in the past 12 months.
- Almost all *parents* (98%) opened and read at least some of the letter; 76% read all or most of it.
- 89% of *parents* said the letter contained relevant information and 81% said the information was helpful.
- 61% of *parents* said the letter provided a new source of information.
- 97% of *young people* opened and read the birthday card.
- 73% of *young people* 'liked' or 'loved' the card, higher for younger respondents (i.e. 93% for 12 year-olds).
- 88% of *young people* who read their parent's letter said the information was useful.

Healthcare Professionals' awareness of the YTP

- Awareness of the YTP were much lower among *HCPs*.18% of *HCPs* were aware of the YTP, while the majority (82%) were not.
- The largest proportion of *HCPs* who knew about the YTP prior to participating in the survey became aware of the Programme through talking to colleagues or other HCPs.

- 96% of young people seen by the *HCPs* surveyed did not mention the YTP letter during their consultations.
- Two *HCPs* reported that their patients had expressed approval or satisfaction with the YTP letter and/or card.
- Six *HCPs* reported that patients (or their carers/ parents) had expressed concern or dissatisfaction with the YTP letters and/or cards. (These concerns centred on confusion (i.e. having two sources advising them what to do) and the dissatisfaction was being reminded that they have a chronic condition).

The YTP is well administered

- 89% of *young people* received the birthday card close to their birthday, with 47% receiving it in the week of their birthday. Only 2% received the card late, i.e. 3 to 4 weeks after their birthday.
- 96% of *young people* received card with the correct age, 3% did not look in the card and 1 person reported that the age in the card was wrong.

Tone and language of letter was considered appropriate

- *Parents* felt positive about the tone of the letter with 59% indicating it was ‘professional’ and 58% indicating it was ‘friendly’. Most parents (70%) indicated the letter was easy to understand, while 19% felt it was somewhat easy to understand.
- One *parent* misread the letter – she thought it was directing her daughter to stop attending the paediatric clinic. Due to the seriousness of this misinterpretation, improvement of wording and further focus testing is recommended.

Subject areas of interest to parents (for inclusion in future YTP letters)

- 63% of *parents* wanted information to assist their child to develop independence in diabetes care, and 62% wanted information on alcohol and its impact on diabetes; these subjects were of interest to parents irrespective of the age of their child.
- Burnout and how to spot it was also a common concern expressed by 58% of *parents*, but less so among *parents* of 15 and 17-year-olds.
- Mental health and psychological wellbeing was of interest to 52% of *parents*, and was of more importance to *parents* of 17 and 18-year-olds.

Action taken as a result of receiving the letter or card was positive

- 70% of *parents* had talked, or intended to talk, to their child about the content of the letter and 33% had talked, or intended to talk, to their child’s HCP about the letter.
- Over 50% of *parents* had looked, or intended to look, at diabetes websites such as NDSS or Diabetes Australia as a result of receiving the letter.

- 18% of *young people* had looked at a diabetes website as a result of receiving the birthday card, higher (29%) for 19-year-olds.
  - *Young people* using adult or transition clinics were more likely to seek further information/look on websites than respondents using paediatric diabetes services. This may suggest that older respondents, who are aiming to become more independent in their care, are actively seeking out more information. An information-rich, transition 'go to' website could work well for this group.
- Despite having the myD website printed in the birthday card, only 3% looked at it – three times more respondents looked at the NDSS or Diabetes Australia websites.

Attitudes – the YTP promotes the NDSS in a positive way

- 83% of *parents* agreed that the letter sent an underlying message that the NDSS and Diabetes Australia was there to assist and 77% agreed that the letter made them feel part of a supportive diabetes community.
- 76% of *parents* also agreed that the letter provided useful information on transition.
- 18% of *parents* agreed that there were probably better things the NDSS could do to help transition and 12% agreed that the letter was not really necessary, as it simply repeated information they already knew.
- 89% of *young people* agreed that the birthday card was a friendly reminder that NDSS and Diabetes Australia were there to support people with diabetes, and 82% agreed that the card was a nice way to keep in touch with people who have diabetes.
- 71% of *young people* agreed that they would like to continue receiving the birthday card, with only 15% agreeing with the statement, "I don't think young people like me really care about getting cards".

Discussion

It is clear from the evaluation survey findings that the YTP is valued by young people and their parents, and is effective in terms of:

- **Coverage** – 85% of *parents* and 87% of *young people* recalled receipt of the card and/or letter
- **Administration** – over 89% of cards arrived close to the young person's birthday and 97% had the child's correct age
- **Engagement** – 97% of *young people* and 98% of *parents* reported opening the envelope and reading the card or letter, and a high proportion responded positively about content (73% of *young people* liked/loved the card's appearance and 81% of parents reported that the information was useful)
- **Action** – 71% of parents had talked, or intended to talk, to their child about the NDSS letter, and over half had looked, or intended to look, at a diabetes-related website as a result of receiving the letter. Among young people, 18% had looked at a diabetes website as a result of receiving the card, increasing to 29% among 19-year-olds.

The evaluation demonstrates that the YTP is successful in reaching and engaging with parents and young people, and is thus an effective channel for communication between the NDSS and these groups.

The overall recommendation is that the YTP continue, generally in its present form.

However, the findings also highlight:

- areas that require further assessment and/or action to be undertaken in the immediate or short term, and
- areas where opportunities exist for extending/enhancing the YTP in the future so that the impact and effectiveness of the initiative is optimised.

When asked how NDSS could best support young people through their transition to adult services, approximately one-third of *HCPs* (31%) indicated that the role for NDSS was to provide quality information to young people and their families. The second most common theme to emerge from this open question was that of maintaining contact with young people to ensure they are not lost to follow-up (13% of responses); followed by the development of a publicly available database containing an up-to-date directory of diabetes services across Australia (12% of responses).

A small number of *HCPs* stated that the NDSS could directly support transition co-ordinators (n=4) or set up a telephone/online transition support service (n=2).

Recommendations

Overall, the results of both the young peoples'/parents' surveys and the HCPs' survey provide good evidence to support the continuation of the YTP. Suggestions for further improvement and review of this programme are outlined below.

Seventy seven per cent of young people who had received birthday cards for the past three years were keen to continue receiving the cards.

Receiving the letter and their child's birthday card made parents feel part of a supportive diabetes community; 56% agreed and 21% strongly agreed with this statement. This level of engagement can be built upon moving forward to promote the NDSS' field of resources and information available for young people and their families.

Actions for the immediate or short term

Further review and focus testing of the letters
Although the majority of parents indicated the letter was easy to understand, feedback from one parent revealed that she thought the letter was advising her child to stop attending the paediatric clinic. In parallel, NDSS received feedback from a clinician in NSW also indicating that a small number of parents/patients had misunderstood the NDSS letter. Given the potential damage of such a misunderstanding, it is recommended that the letters be reviewed, redrafted and further tested among a range of parents.

Review use of myD website in the cards
Despite having the myD website printed in the birthday card, only 3% of young people visited this site as a result of receiving the card; 10% looked at the DA website and 13% at the NDSS website. The promotion or prompt regarding the myD website needs to be stronger, alternatively, further investigation needs to be undertaken to determine which website the birthday card should promote as the 'go to' website for transition information. The selected website and subsequent promotion of this website should aim to maximise access and the use of NDSS transition information.

Retain the current age of 12 years for commencing the YTP
However, the best time to specifically mention transferring to adult health care should be reviewed. Survey results show that parents for this age group desire information on school and diabetes.

Allow parents/young people to opt out of the YTP initiative
While the clear majority of respondents felt very positive towards the YTP, a small number of parents and young people felt negative about it (~5% each); some parents saw the birthday card as a reminder of how their child is 'different'. These parents/young people did not find the cards helpful and would like to have them stopped. Although this reaction was not common among survey respondents, it needs to be acknowledged and there should be a mechanism that allows parents or young people to opt out of the YTP.

Increasing the impact and effectiveness of YTP

Opportunities exist for enhancing the content of the pack (based on client feedback), strengthening behaviour prompts and including more substantial information for young people.

Broadening the platform to ensure the information is accessible and retrievable online through appropriate websites could also potentially offer gains in terms of increasing access and the availability of information for both target groups.

Further recommendations to enhance the YTP include:

- use of a stronger prompt to encourage parents to initiate earlier transition-specific discussions with a HCP should be considered
- consideration should be given to providing more substantial information directly to young people, possibly through a dedicated transition website or through child-friendly versions of the parent's letter
- Providing material addressing the worries and concerns parents and young people have in relation to the transfer to adult care through additional content or via a transition website
- A review of the content of the parent letter to ensure that subject areas of interest and importance to parents (as per survey results) are covered for each age group
- Western Australia recorded lower-than-average recall/coverage (by almost 10%) for both parents and young people. Given that both target groups recorded lower-than-average recall of the card and letter for both time periods, this finding perhaps warrants further investigation to explore reasons for lower receipt/recall figures in this state.

Further information on the above is provided in the Discussion section of this report.

Introduction

In 2010, as an outcome of a NDSS Strategic Development Grant, the National Diabetes Services Scheme (NDSS) implemented an initiative to engage young people with diabetes across Australia. This initiative is known as the Youth Transition Pack (YTP) and consists of:

- a birthday card, containing a happy birthday message and the myD website address, sent directly to all young people living with diabetes aged 12–20 years
- a letter sent to their parents (until the child is 18 years) outlining age-related issues relevant to the management of diabetes. As well as providing useful information, the letter also aims to prompt parents to start thinking about, and discussing, their child's transition from paediatric to adult healthcare services.

The card and letter are sent annually around the time of the young person's birthday.

Aims

The aim of the young people and parent/carer survey was to invite feedback from parents and young people on the birthday card and letter, specifically on their recall of the card or letter, their impressions of the content, and their actions as a result of receipt of the card or letter.

The main objective of the follow-up Healthcare Professionals' (HCPs') survey was to gather feedback from diabetes HCPs about their awareness and opinion of the YTP initiative and, if they were aware of it, how useful they considered the programme to be for the young people with whom they worked.

Methods

Participants

Participants included in the evaluation survey were:

1. young people living with diabetes who are registered with the NDSS, aged 12–20 years, with their birthday falling from May to October
2. parents of young people living with diabetes who are registered with the NDSS, aged 12–18 years.

The criteria of having had a birthday in the past six months was intended to maximise recall of the letter and birthday card. Young people and their parents from all states and territories were included in the mail-out.

As outlined previously, a Healthcare Professionals' (HCPs') survey was undertaken from 14 May 2014 and data collection ran for a period of 6 weeks. A total of 149 HCPs responded, with 139 (93%) completing the survey within the first three weeks.

Diabetes HCPs who responded to the survey came from all states and territories across Australia, with the majority from Victoria (48%), NSW (23%) and Queensland (15%).

Most survey respondents (75%) were from a metropolitan location, while 27% were from regional areas and 10% were located in rural areas.

Survey respondents were most likely to be credentialled diabetes educators (36%) or endocrinologists (30%).

While 53% of respondents currently work in one medical setting, approximately half (47%) work in more than one setting (35% work in two settings; 8% work in three; and 4% work in four settings). The most common settings the respondents work in are shown in Table 2. Most respondents work in a diabetes clinic within a general public hospital (44%).

Procedure

All evaluations were conducted using an online survey method.

Postcard invitations and a covering letter were sent by post to the parent or carer of young people with diabetes aged 12–18 years. Parents were invited to participate in the survey and asked to pass the survey invitation on to their child. The postcard invitation was double-sided: one side provided information for parents while the other side provided information for their child. Young people aged 19 and 20 years were sent an invitation directly unless their parent or carer was listed as their main contact.

Postal invitations were mailed to home addresses on 29 November 2013, with a reminder letter posted approximately two weeks later on 16 December. The survey was closed in mid-January 2014.

Two survey questionnaires were developed – one for parents and one for young people (see details below).

Invitations to participate in an online survey were emailed to a selection of relevant HCPs through the use of purchased lists. Information about the survey and the survey link were distributed through the newsletters of various professional diabetes networks. The survey went 'live' on 14 May 2014 and data collection ran for a period of six weeks.

Measures

Given that parents and children received different elements of the YTP, a survey questionnaire was designed specifically for each target group.

The questionnaire for *parents* was designed to gather feedback on:

- their recall of receiving the NDSS letter (in the previous 12 months, and in the previous 3 years)
- the extent to which the letter was read
- their views on content of the letter (was it relevant, useful and helpful? did it provide new information?)
- their attitudes towards the card/letter in general; i.e. did it provide positive feelings of support or was it seen as intrusive, unnecessary or a waste of money?
- what actions, if any, they undertook as a result of reading the letter
- whether the letter prompted any discussion with their child or their diabetes HCP about transition.

For *young people*, the questionnaire gathered feedback on:

- their recall of receiving the card
- whether they opened and read the card
- what they thought about the appearance of the card
- whether the card arrived on time and had their correct age inside
- their attitudes towards receiving the card (positive or negative)
- any actions taken as a result of receiving the card.

As well as gathering feedback on the letter and birthday card, both surveys included a section of more general questions on the current management of the young person's diabetes and their preparedness for the move from paediatric to adult diabetes services.

Statistical analysis

This report provides a descriptive analysis of the results for each survey question. Results are presented as n (%). Each finding is attributed to either young people or parents or both (where both surveys asked the same question of both groups).

Where the sample size is sufficient and it is meaningful to examine the differences in responses by sub-groups (e.g. state, age group or location), any statistically significant differences are reported.

Results presented from the subsequent HCPs' survey relate only to awareness of and opinions on the YTP.

More general questions concerning the transition process of young people to adult care were also included in this survey. This information has been analysed for future resource development and these results are not presented in this report as they do not directly relate to an evaluation of the YTP.

Limitations of the survey

A key limitation is the small response rate[1] (11% among both *parents* and *young people*). This is very typical of other such projects requiring involvement of this cohort. However, it cannot be assumed that non-respondents would report similar feedback.

While it is difficult to provide an accurate response rate for the HCPs' survey (as the number of HCPs who received the survey link is not known), we believe the survey received an adequate number of responses, particularly given the difficulty of obtaining feedback from this time-poor target group. Furthermore, no incentive was used to engage this group.

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[1] *NB. Response rates have **not** been adjusted to take into account letters that were returned to sender, as these were not collected systematically.*

Results

Participant characteristics – young people and parents' survey

Postal invitations were sent to 4,000 parents of young people living with diabetes (aged 12–18 years) and 1,602 young people living with diabetes aged 19–20 years, who had had a birthday in the previous six months, i.e. May to October. Those who responded to the survey included:

- 439/4,000 (11%) *parents*
- 622/5,602 (11%) *young people*
  - 478/4,000 (12%) 12–18 year-olds
  - 144/1,602 (9%) 19–20 year-olds

Across states and age groups, the proportions of respondents reflect those in the NDSS mail-out sample (Table 1).

Table 1: Respondent characteristics by state, age and sex

	Parents		Young people		% of NDSS mail-out sample
	N=402 [a]	%	N=595 [a]	%	
State					
NSW	121	30%	178	30%	31%
Vic	84	21%	135	23%	25%
Qld	90	22%	129	22%	21%
WA	40	10%	64	11%	10%
SA	43	11%	55	9%	7%
Tas	12	3%	21	4%	3%
ACT	10	2%	9	2%	2%
NT	2	0.5%	4	1%	1%
Age of young people					
12 years	59	15%	67	11%	7%
13 years	63	16%	74	12%	8%
14 years	59	15%	61	10%	9%
15 years	56	14%	74	12%	11%
16 years	53	13%	79	13%	11%
17 years	46	11%	62	10%	12%
18 years	44	11%	48	8%	13%
19 years	11	3%	66	11%	13%
20+ year	12	3%	78	13%	15%
Sex					
Male	61	15%	276	46%	50%
Female	341	85%	318	54%	50%
Location					
Metro	214	53%	288	49%	
Regional	134	33%	198	34%	
Rural/Remote	54	14%	103	18%	

– *continued*

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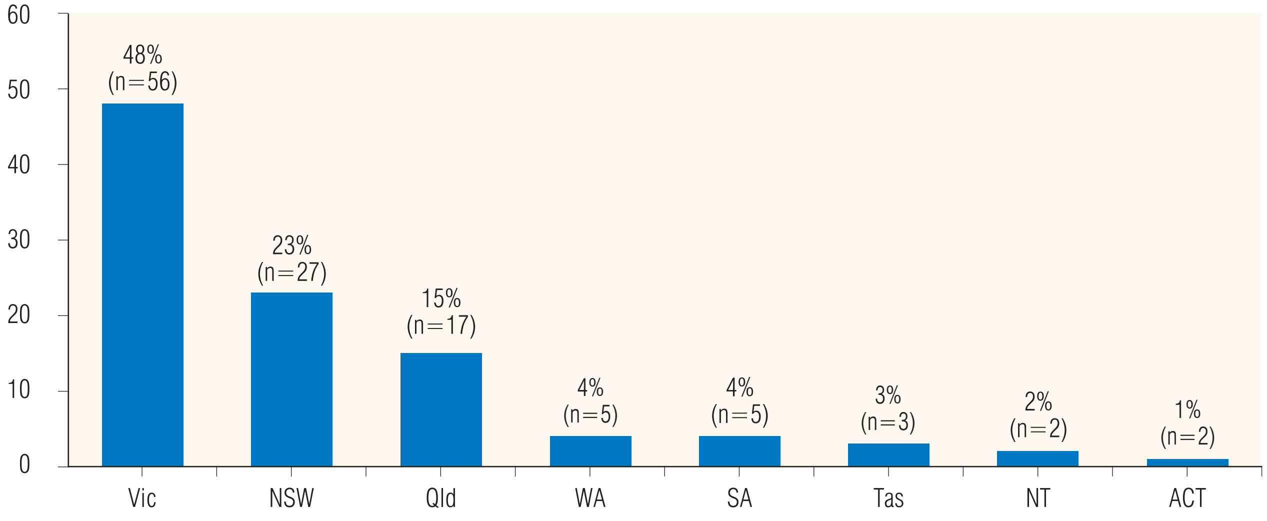
	Parents		Young people		% of NDSS mail-out sample
	N=402 [a]	%	N=595 [a]	%	
Current diabetes provider [b]					
Paediatric team	300	74%	286	48%	
Adult clinic	40	10%	98	16%	
YADS [c]/adolescent clinic	49	12%	67	11%	
A mix/other	14	3%	38	6%	
Don't know/other	–	–	108	18%	

[a] *Totals do not add to 439 parents or 622 young people as not all respondents answered every demographic question*
[b] *Based on survey responses*
[c] *Young Adult Diabetes Service*

Participant characteristics – Healthcare Professionals' (HPCs') survey

Diabetes HCPs respondents came from all states and territories across Australia, with the majority from Victoria (48%), NSW (23%) and Queensland (15%) (see Figure 1).

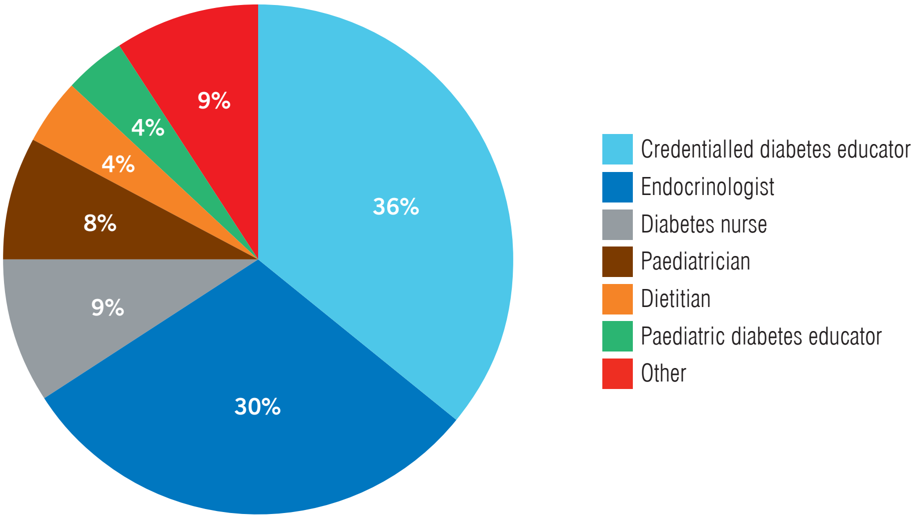
Figure 1: HCPs survey respondents by state



Most survey respondents (75%) were from a metropolitan location, while 27% were from regional areas, and 10% were located in rural areas.

As shown in Figure 2, survey respondents were most likely to be credentialled diabetes educators (36%) or endocrinologists (30%).

Figure 2: Professional roles of survey respondents



While 53% of respondents currently work in one medical setting, approximately half (47%) work in more than one setting (35% work in two settings; 8% work in three; and 4% work in four settings). The most common settings the respondents work in are shown in Table 2. Most respondents work in a diabetes clinic within a general public hospital (44%).

Table 2: Medical settings in which respondents work (all settings and main setting)

What type of medical setting do you work in?	All settings N [a]	Main setting %
Diabetes clinic in a public general hospital	67	44%
Private practice/private hospital	51	26%
An adolescent/YADS clinic in a public general hospital	38	11%
Diabetes clinic in a public paediatric hospital	15	8%
An adolescent/YADS clinic in a public paediatric hospital	10	–
Community Health Clinic	9	8%
Other [b]	3	4%

[a] *Respondents could tick more than one option*
[b] *Gestational Diabetes Mellitus (GDM) clinic in a private hospital, general practice clinic, pharmacy retail*

Recall of YTP letter and birthday card

Recall of the YTP letter and birthday card was high:

- 85% of *parents* and 87% of *young people* recalled receipt of the letter/card in the past 12 months
- 75% of *parents* and 84% of *young people* recalled receipt of the letter/card in the past 12 months
- 53% of *parents* and 50% of *young people* recalled receipt of two or three letters/cards over the previous three years[2].

When comparing results across states (on the assumption that mail delivery may vary depending on location), Western Australia (WA) had lower proportions of respondents reporting receipt of the birthday card and letter:

- 60% of *parents* (and 73% of *young people*) from WA recalled receipt of the birthday card in the previous 12 months, compared to a mean across all other states of 77% ($p<0.022$) and 85% ($p<0.015$), respectively
- 23% of *parents* from WA stated they had not received any YTP letters in the previous three years, compared with a mean of 15% across all other states; this difference was not statistically significant.

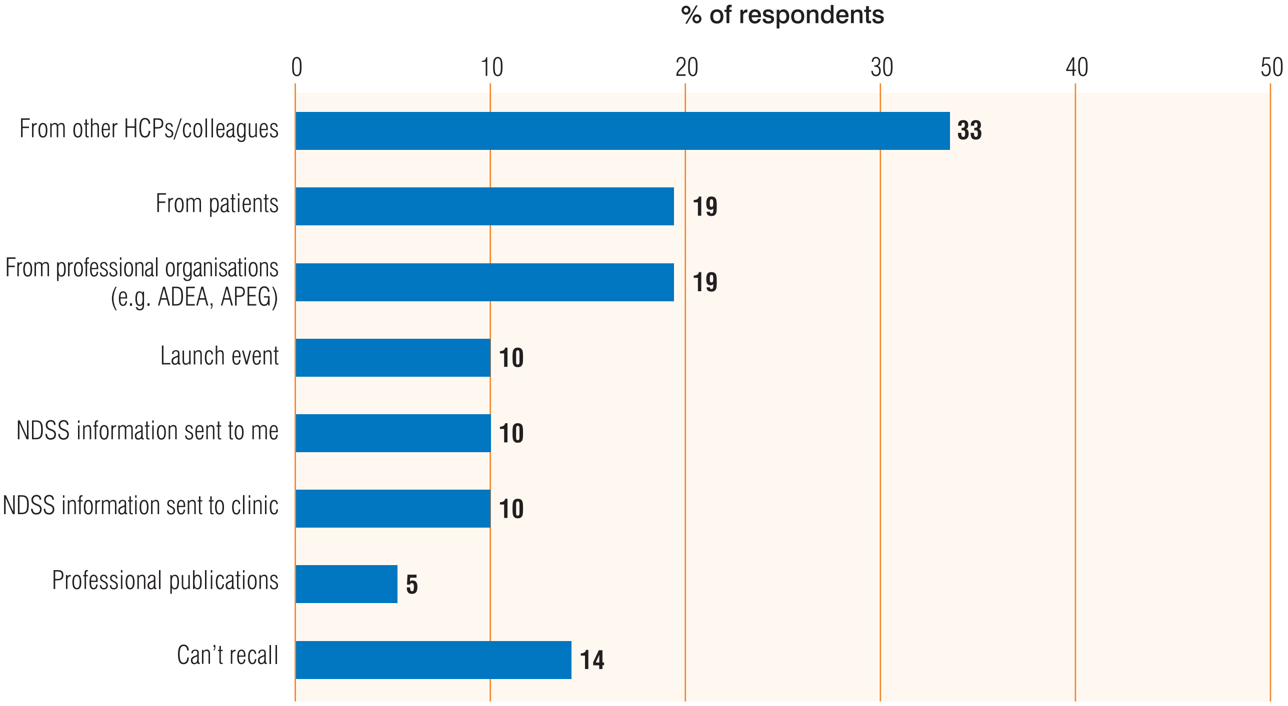
No differences in recall of receipt were found based on rurality (metropolitan, regional or remote).

The majority of HCPs (82%) were not previously aware of the YTP, while 18% (n=27) were aware of it. Of those who were aware of the initiative:

- 56% (n=15) knew about it when it started in 2010
- 22% (n=6) found out about it in 2011–12
- 11% (n=3) found out about it this year (i.e. 2014)
- 11% (n=3) could not recall when they found out about it.

The main way in which respondents found out about the YTP was from colleagues or other HCPs (see Figure 3).

Figure 3: How HCPs found out about the YTP (N=27)



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[2] *NB. Although the programme has been running for three years, there have been two periods of 2–3 months where no cards or letters were sent due to database overhaul.*

Engagement with birthday card/letter

Engagement with the YTP was high (see Figure 4):

- 76% of *parents* reported opening and reading all/most of the letter
- 97% of *young people* reported opening and reading the card.

The appearance of the card

When asked about the card's appearance:

- 7 in 10 *young people* gave a positive response, stating they 'liked' or 'loved' it (55% and 18%, respectively)
- 5% did not like the look of the card
- the remaining 22% had no opinion or could not recall it.

Higher proportions of males were 'neutral' about the look of the card compared to females (26% vs 11%).

The youngest respondents, 12-year-olds, were more likely to 'like'/'love' the card (93% vs. 77% average, $p<0.023$). Beyond this, no consistent pattern emerged across other age groups. Indeed, the group next most likely to 'like'/'love' the card was 19 year-olds (84%) (Figure 5).

Consideration needs to be given to the fact that each age group receives a different card and it is not reasonable to assume that any particular card could be designed that would appeal to *all* young people receiving it.

Figure 4: Engagement with the YTP by (a) parents and (b) young people

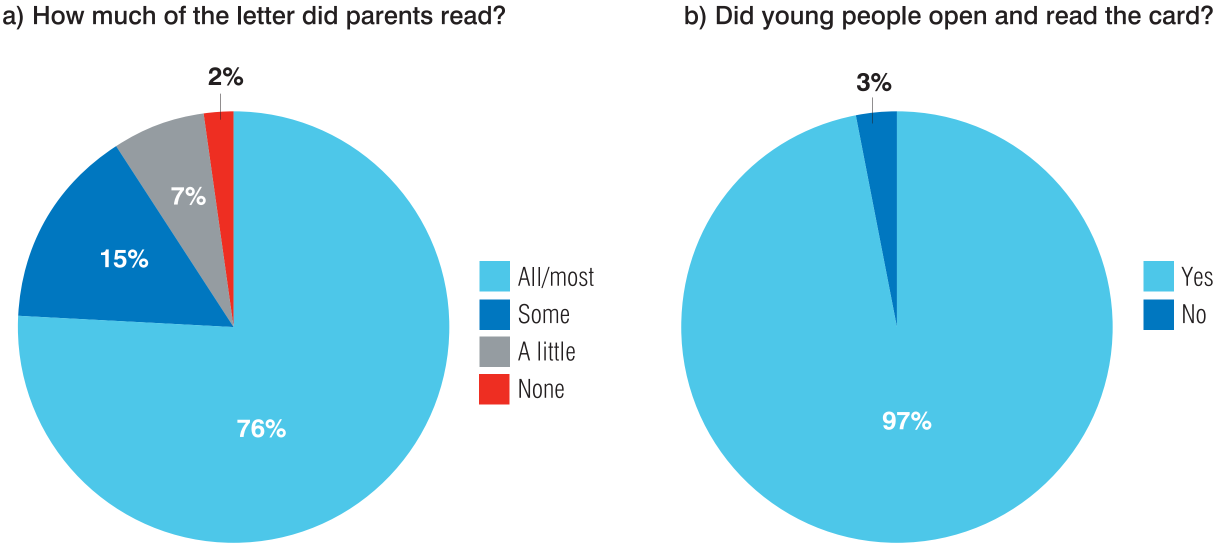
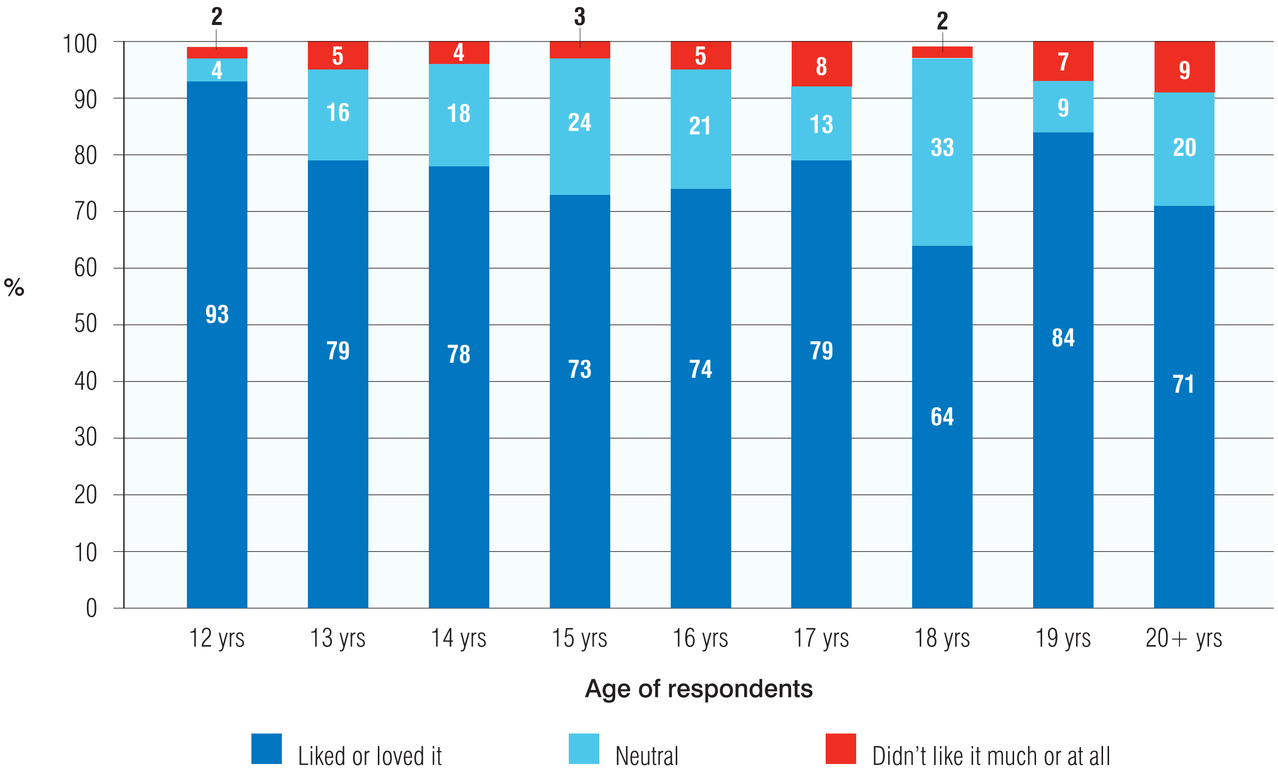


Figure 5: Perception of appearance of card by young respondents by age group



Resp: 12yrs, n=45; 13yrs, n=61; 14yrs, n=49; 15yrs, n=66; 16yrs, n=62; 17yrs, n=54; 18yrs, n=42; 19yrs, n=57; 20yrs, n=59

Timing of card and correct age

Most young people indicated that the cards arrived before (and fairly close to) their birthdays (see Table 3). One respondent indicated that the age printed on the card was wrong (see Table 3).

Table 3: Timing of card and age correct on card

When did the card arrive? (N=527)	Was the age on the card correct? (N=527)
47% in the week of their birthday	96% said the age was correct
36% before their birthday	1 respondent said it was wrong
6% 1–2 weeks after their birthday	3% could not recall or did not look at it
2% 3–4+ weeks after their birthday	
9% could not recall when it arrived	

Content of letter – feedback from parents

Did it provide new information?

Almost two-thirds of *parents* (61%) indicated that the YTP birthday letters provided a source of new information, including material of which they were not previously aware. One in five respondents (22%) reported the letter did **not** provide new information and the remaining 17% could not remember.

Was content relevant and helpful?

The majority of parents reported the content of the letter to be relevant and helpful (see Figure 6):

- 89% stated that the content of the letter was (at least somewhat) relevant
- 81% stated it was (at least somewhat) helpful.

Did young people think the parent letter was useful?

Young people aged 12–18, who were aware that the NDSS also sent a letter to their parents, were asked whether they had read or discussed the letter with their parents, and whether or not they thought the letter content was useful/helpful. Although fewer than half of young respondents, 42%, were aware of the letter, almost two-thirds of this group, 62%, had read or discussed the letter with their parents, and 88% of those found the information useful (see Figure 7).

NB. The results from the parent survey indicate that around 70% of *parents* have talked, or plan to talk, to their child about the content of the letter. While this figure is higher than the figure indicated in the young people's survey, it is possible that parents have discussed the issues with their child without making a direct reference to the YTP letter.

Figure 6: Parents' perceptions of relevance and helpfulness of YTP letter

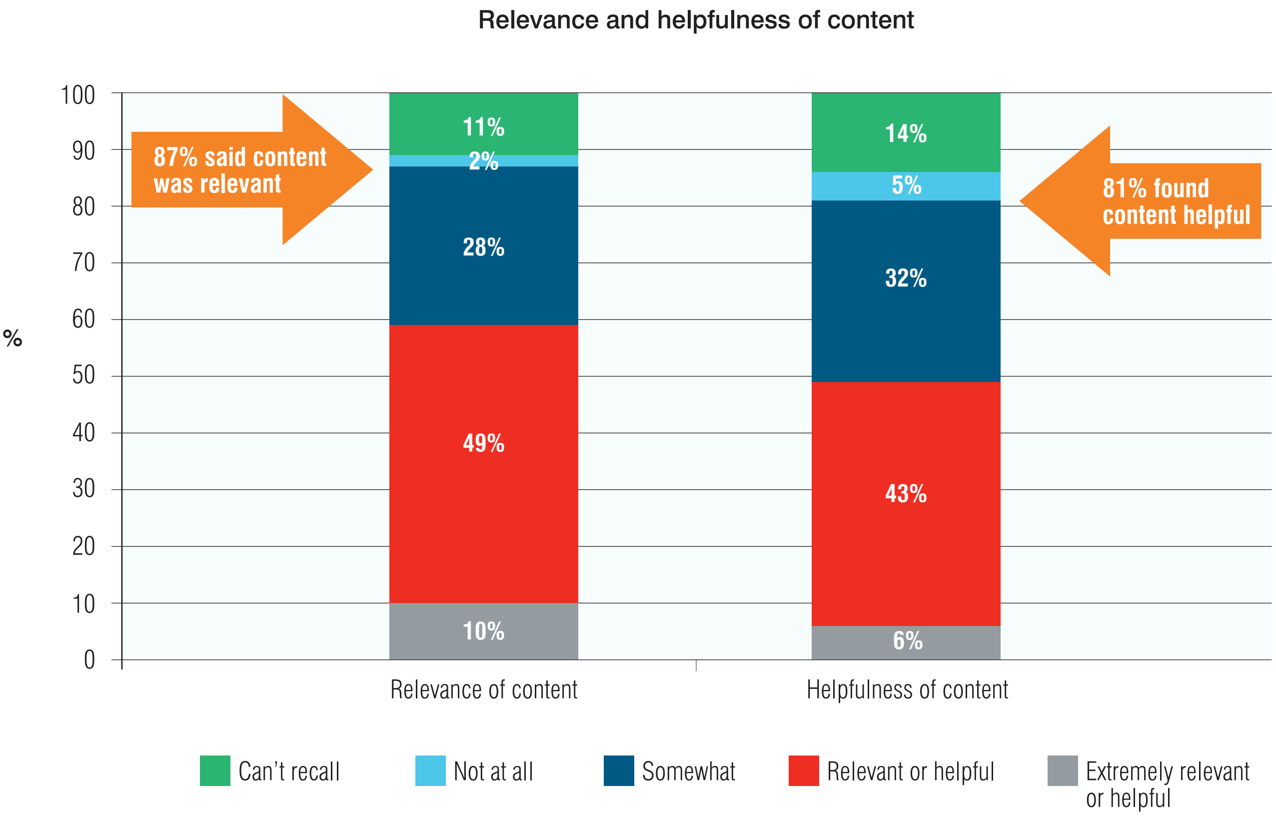
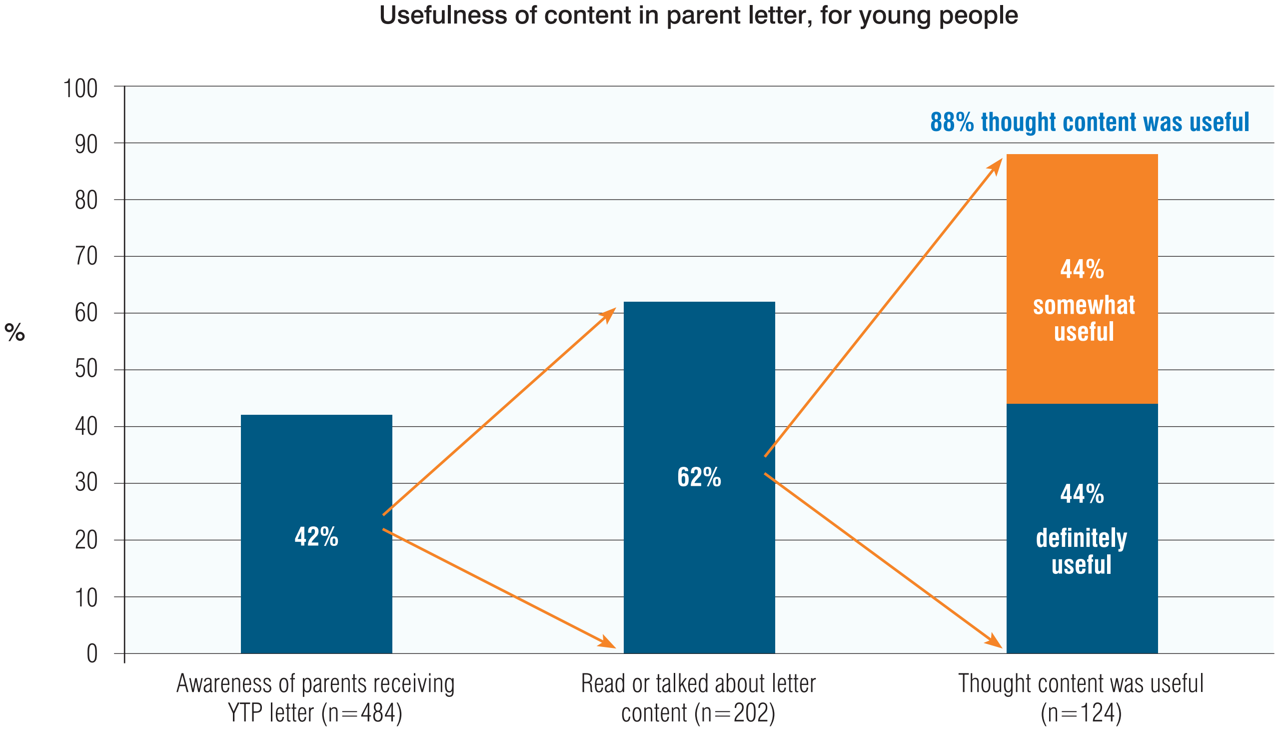


Figure 7: Young people's view on the usefulness of information provided in the parent letter



Inappropriate content in letter

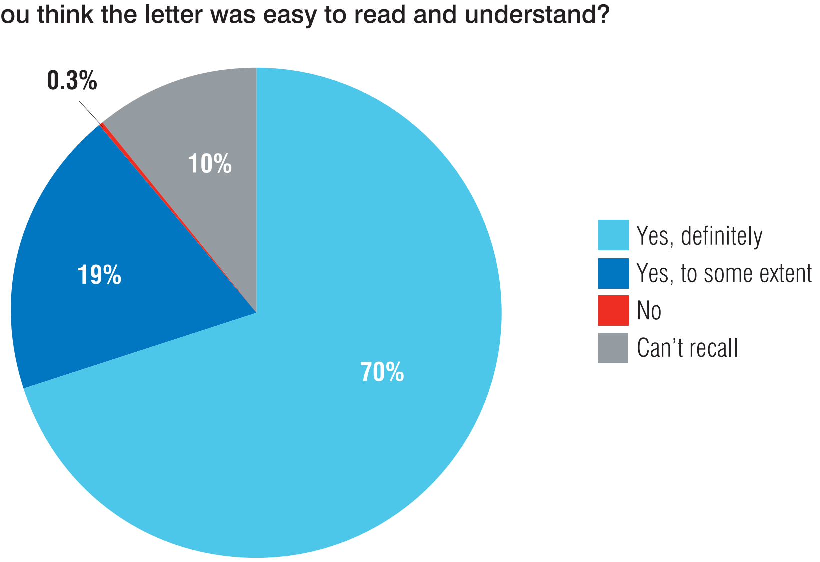
In response to an open question asking *parents* if they considered any content in the letter **not** appropriate to their child, only three parents commented that the letters were not very relevant to younger children and suggested that the letters should not start until the child is older:

> *"My son is only 12, I didn't think we needed this information yet."*
>
> *"12 is a little too young – maybe 15 is a more independent age, I kind of brushed it off and had the attitude that this doesn't apply to us as yet."*
>
> *"It was aimed at an older teenager not somebody who had just turned 13."*

Another parent raised the issue of location, with no differentiation between metropolitan and regional areas:

> *"The letter was much too generalised and I assume the same letter that is sent to region/rural parents is sent to the metropolitan parents, which is ignorant of the challenges faced by regional/rural parents as opposed to metropolitan parents."*

Figure 8: Ease of reading and understanding the letter



Ease of understanding the letter

The majority of *parents* (70%) reported the letter was easy to understand while 19% felt it was somewhat easy to understand. Only one respondent reported it was not easy to understand and 10% could not recall (see Figure 8).

In one case, however, the letter was (seriously) misinterpreted[3]. A *parent* commented the letter was interpreted to mean that they should **stop** seeing the paediatrician now (at age 13). Consequently, the letter caused distress and clearly had the potential to lead to an unintended outcome:

> *"At age 13, the letter sounded like it was saying our daughter had to move out of the Paediatric Clinic ... now! Quite distressing until we were able to confirm this was wrong, via our educator nurse."*

'Tone' of the letter

Parents were presented with a list of words (both positive and negative) describing the tone of the YTP letter and asked to mark which of these they felt applied. Respondents could select as many as they thought applicable. The majority of parents provided positive feedback on the tone of the letter:

- 59% 'professional'
- 58% 'friendly'
- 45% 'supportive'
- 41% 'positive'.

Less positive feedback included the following:

- 2% (n=7) 'authoritative'
- <1% 'cold' (n=2), 'negative' (n=1) or 'condescending' (n=2)

Thirteen per cent (n=44) could not recall the tone of the letter.

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[3] *Although only one parent raised this issue in the survey, feedback from other sources outside of this evaluation indicate one or two other instances where the letter has been misinterpreted in the same way described above. The ramification of misunderstanding the information in this way is serious and will need to be investigated further. An additional strand of research has been proposed and approved by the NDSS.*

Healthcare Professionals' (HCPs') accounts of patient feedback about the YTP

A series of questions were asked to explore whether patients were talking to their HCPs about the letters or cards they receive as part of the YTP and, if so, what attitudes were expressed about the initiative. Responses reveal that most young people/parents **did not discuss** the YTP letters or cards with the HCPs during their consultations:

- two *HCPs* reported that their patients had **expressed approval** or satisfaction with the YTP letters and/or cards
- six *HCPs* reported that patients (or their carers/parents) had **expressed concern** or dissatisfaction with the YTP letters and/or cards.

Those HCPs who reported patients expressing concern about the YTP were asked to provide further details (see Box 1).

Box 1: HCPs' accounts of concerns expressed by patients about the YTP

"We already discuss transition here – when it is appropriate – and they [young people with diabetes] felt they would have to leave our service, but they do not."

"It creates confusion as we do not transition our clients to adult services until their late 20s."

"Reminds them on their birthday that they have diabetes."

"Sent after the birthday has been celebrated!"

"The birthday card, not appreciated by young people with type 1 [diabetes]."

When asked if they, or their colleagues, had any concerns about the YTP letters and/or birthday cards, 60% indicated no concerns. Eight per cent (n=11) reported having their own reservations about the YTP, while 1% indicated that colleagues had expressed reservations. The remaining 32% indicated that they could not provide informed comment, suggesting that they had no concerns themselves but could not be sure that colleagues did not have concerns or that they did not know enough about the programme to comment. Of the 11 who had concerns, 10 provided comments (see Box 2).

Box 2: HCPs' concerns about the YTP

"Reminds them on their birthday that they have diabetes."

"It creates confusion."

"Because we already discuss transition here when it is appropriate and they felt they would have to leave our service but they do not."

"Happy Birthday – PS: don't eat the cake coz you have diabetes!"

"Having now read some samples online I did not feel the information provided was appropriate for all ages. I think some changes are needed."

"I think that the wording could be improved to be a bit more user-friendly."

"It will improve the management but will it make the patient feel that life is just about being a diabetic and they cannot live normally. Sending it at Christmas or new year may be a good option. It is 'naughty' time of the year and does not link diabetes with your birthday."

"One patient said to me it is like getting a reminder on your birthday that you have type 1 as if you didn't know or wanted to be reminded on your birthday."

"What benefit does sending a card/letter, from an organization whose mandate is that of raising community awareness, registering individuals as having type 1 diabetes, on their birthday? I am not sure how this benefits the patients I care for. Is it supposed to make them 'feel better'? Receiving a card on my birthday from an external organisation would instantly raise red flags for me; I actually would find it insincere. Money from this exercise would be better spent on raising the community's awareness of young adults with type 1 diabetes or supporting programmes that help them manage their condition during this transitory time in their lives. While a nice gesture, it wouldn't necessarily make me warm up to the NDSS – what is the intent in sending a card?"

"While I support the idea, I do think that the team should know when you send information to the families and be briefed prior to this. We think that transition is an essential part of good diabetes care but are also aware that models vary throughout Australia due to location and hospital structure. I also think that the current information available fails to strongly indicate the value and importance of MDT (Multi-disciplinary team) diabetes care which is a reality in all major centres and many smaller centres but is logistically challenging in smaller centres. I think that your message is most important in the smaller centres but that there needs to be an active dialogue between diabetes teams and DA about how we can work more closely in this area."

Information/subjects of interest to parents

From a list of potential subject areas, parents were asked to indicate which they would be interested in receiving more information about in the YTP (see Table 4).

Information of interest to parents was analysed on the basis of the age of their child, as this could be useful in terms of informing letter content and ensuring adequate coverage of the subject areas of interest to parents. The top four areas for each age group are shown in Table 5. Subject areas are colour-coded so similarities across age groups can be seen. For instance, alcohol and diabetes (i.e. the orange squares) and assisting their child to develop independence (i.e. the blue squares) were included in the top four areas of interest for **each age group**.

Burnout and how to spot it was also common across age groups (except 15 and 17), while mental health was of more importance to the parents of young people in the two older age groups, 17 and 18 years.

Table 4: Information areas of interest to parents

Subject areas	%	N=336
Information on how to support my child's independence in relation to medical care and appointments	63%	211
Awareness of issues such as alcohol and impact on managing diabetes	62%	209
Messages about watching out for diabetes burnout and how to spot it	58%	196
Messages on mental health and psychological wellbeing	52%	176
Outline of ongoing health care regimen	49%	166
Tips on how to get my teenager to start to talk to the paediatric team and to ask questions	47%	159
How to manage diabetes better at school	45%	152
The importance of letting the drivers' licensing agency know that your teenager has diabetes	43%	143
Messages to prompt me to talk to paediatric services about my child's move to adult health services	40%	136
Information on sexual health and issues specific to diabetes	39%	130
Information on sourcing public clinics and/or private endocrinologists in my local area	33%	111
Messages about getting my child's own Medicare Card	29%	99
Pregnancy planning and issues specific to diabetes	12%	39

Table 5: The top four subject areas of interest to parents, by age of child

Age of child	Top 4 subject areas of interest (in descending order from left to right)			
12 years	Managing diabetes at school	Alcohol and managing diabetes	How to assist child's independence re medical care	Burnout and how to spot it
13 years	Burnout and how to spot it	How to assist child's independence re medical care	Managing diabetes at school	How to help child to ask questions directly to doctors
14 years	How to assist child's independence re medical care	How to help child to ask questions directly to doctors	Alcohol and managing diabetes	Burnout and how to spot it
15 years	Alcohol and managing diabetes	How to help child to ask questions directly to doctors	How to assist child's independence re medical care	Information on driving and licensing
16 years	Alcohol and managing diabetes	How to assist child's independence re medical care	Burnout and how to spot it	Prompts to help child talk to paed re transferring to adult service
17 years	Outline of ongoing health regime	How to assist child's independence re medical care	Information on mental health and wellbeing	Alcohol and managing diabetes
18 years	Burnout and how to spot it	Information on mental health and wellbeing	How to assist child's independence re medical care	Alcohol and managing diabetes

Action taken as a result of receiving the YTP letter – feedback from parents

When asked about the actions taken or planned as a result of receiving the letter:

- 70% of *parents* had talked, or planned to talk, to **their child** about the content of the letter
- 33%, had talked, or planned to talk, to their child's HCP about the letter
- over 50% of *parents* had looked, or planned to look, at diabetes-related websites, such as NDSS or Diabetes Australia. **This indicates that websites are a useful place to signpost and provide further information on the transition process.** (This is further backed-up by responses given by young people.)

Action by parents did not seem to increase or decrease on the basis of their child's age. The proportion of parents who took action as a result of receiving the letter is shown in Table 6.

Table 6: Action reported by parents as a result of receiving the YTP letter

Action taken by parent as a result of receiving the letter	Actioned (I have done this)	Intention (I plan to do this)	Total action (taken or planned)	None
Talk to my child about the content of the letter	54%	17%	71%	30%
Talk to the healthcare team/doctor about the content of the letter	14%	19%	33%	66%
Look at the Diabetes Australia website	38%	19%	57%	44%
Look at the NDSS website	31%	24%	55%	45%
Look at other diabetes websites	31%	19%	50%	50%
Look at the myD website	9%	28%	37%	62%
Contact the NDSS (via phone or other means)	5%	9%	14%	86%

Action taken as a result of receiving the birthday card – young people

The birthday card carried a ‘happy birthday’ message and the web address for the myD website. The card also included the NDSS logo and the relevant state’s DA logo.

As such, the card did not contain a strong ‘call to action’. Despite this, however, feedback indicates that one in five *young people* (18%) looked at a diabetes website as a result of receiving the birthday card; this increased to 29% for 19-year-olds (see Figure 9).

Analysis was undertaken to assess whether particular sub-groups were more likely than others to take action as a result of receiving the birthday card.

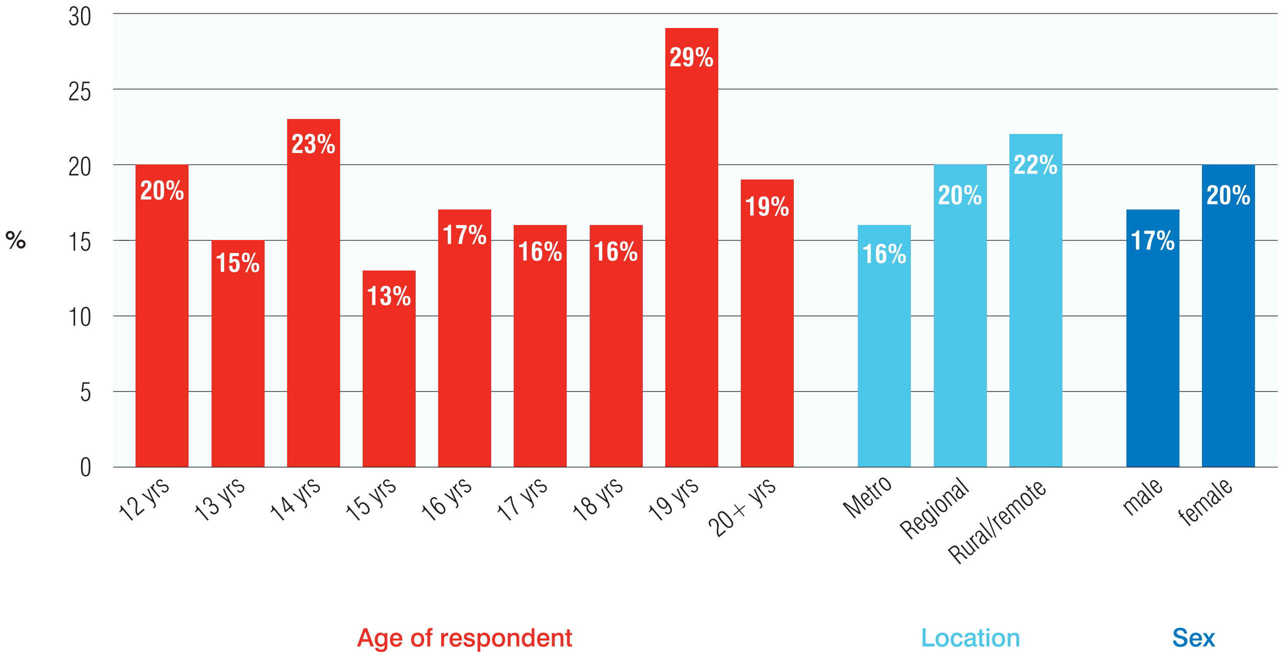
Older respondents (i.e. those closer to transition) were more likely to have sought further information, thus suggesting that transition-specific information would most likely be utilised by this age group:

- 29% of 19-year-olds had looked at diabetes websites as a result of receiving the card, compared with 18% (average of other age groups; $p<0.027$); they were most likely to have looked at NDSS or DA websites (21% or 19% respectively)
- 25% of those already using Adult Diabetes Clinics or Transition Clinics, e.g. Young Adult Diabetes Services (YADS), had taken action, compared with 16% of respondents using paediatric diabetes services ($p<0.039$).

There were no statistically significant differences by geographical location or by sex.

The specific actions taken by young respondents are shown in Table 7. Although the birthday card included the MyD website address, young people reported they most commonly accessed the NDSS website as a result of receiving the card.

Figure 9: Proportion of young people who took action as a result of receiving the card by age, location and sex



Sample sizes for the age groups in the figure above, in order or age, were: N=49, 62, 53, 70, 66, 57, 44, 59 and 64.

Table 7: Action reported by young people as a result of receiving the card

Action	% Actioned (N=525)
Looked at the NDSS website	13%
Looked at the Diabetes Australia website	10%
Looked at 'myD.net.au' website	3%
Looked at other diabetes websites	5%
Contacted the NDSS by phone or other	3%
None of the above/no action taken	82%

The majority of users of both NDSS and myD websites found the information from them useful:

- of those who used the NDSS website, 84% indicated the information was useful and 16% reported it was partially useful
- 71% reported the information from myD website was useful, 25% partially useful and 4% could not find what they were looking for.

NB. Only 69 and 39 respondents respectively were in this analysis. Although higher numbers of young people looked at the websites (74 for NDSS and 60 for myD, respectively), not all respondents were looking for specific information.

Attitudes towards the letter/transition pack – parents

In order to assess attitudes towards the YTP in general, *parents* were presented with a number of statements and asked, for each statement, to indicate whether they agreed or disagreed. Both positive and negative statements were included.

Responses from *parents* were very positive and indicated that the YTP provides useful information on transition and also provides a strong message of support for families living with diabetes:

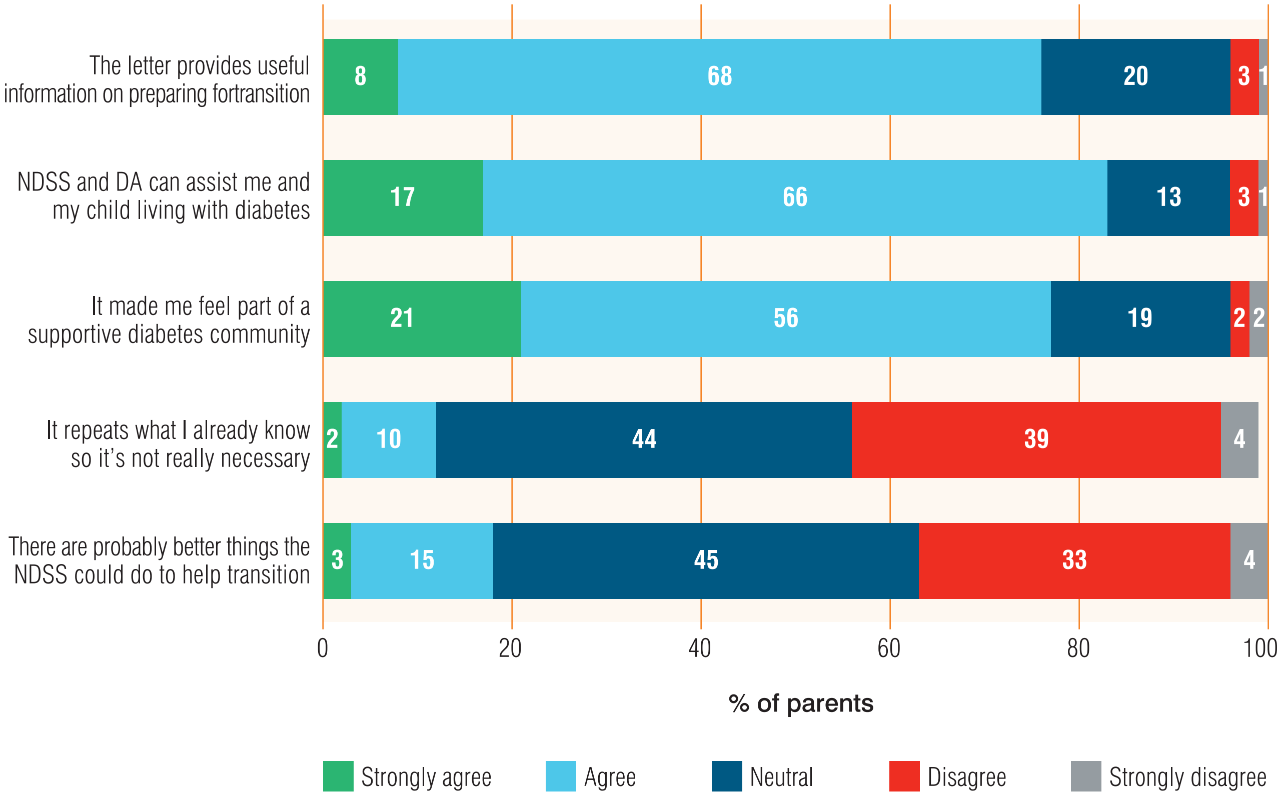
- 83% agreed that the letter sent a message that *"NDSS and Diabetes Australia are there to assist"*
- 77% agreed that the letter made them *"feel part of a supportive diabetes community"*
- 76% agreed that the letter provided *"useful information for transition"*.

Little support was shown for the negatively phrased statements:

- fewer than one in five *parents* (18%) agreed that *"there are probably better things the NDSS could do to help transition"*, while double this proportion, 37%, disagreed with this statement, and the remainder were neutral
- 12% agreed that *"the letter repeats what I already know so it's not really necessary"*, however, more than three times this proportion, 43%, disagreed with the statement, and the remainder were neutral.

The results for each statement are shown in Figure 10.

Figure 10: Proportion of parents who agreed or disagreed with statements about the letter and pack (n=335)



Further positive views about the letter and birthday card were given by parents in response to the open question which asked for any further comments (below is a sample of these comments):

> *"My son loves getting the birthday card – it makes him feel special as his younger brother does not have diabetes and does not receive one. Please keep them coming."*
>
> *"My child enjoys receiving the birthday card as it shows she is a part of a supportive community."*
>
> *"… It has been extremely important for [child] to know we are part of a wider diabetes community."*
>
> *"I think this information is very supportive, even if I knew some of the information, it is great to have confirmed."*
>
> *"I think the way the NDSS programme interacts directly with my son is a positive experience as he is preparing to become an independent adult."*

> *"I think it is important to have these 'unsolicited' reminders. You can often go day-to-day, and life is so busy, it is easy to forget the things you need to be planning for. It is also a good reminder to discuss change and options with the child."*
>
> *"Send it again to remind people to access websites (in the middle of the two birthdays)."*

A couple of parents, however, felt that the birthday card was negative – a reminder about 'being different' from others:

> *"I am not sure if the birthday is a good idea as my daughter thought it was a reminder of how long she has had diabetes and it emphasised she was different to her friends, but others may like it."*
>
> *"Please stop sending birthday cards, what a sad reminder of the day-to-day difficulties these children live with."*

Attitudes towards the letter/transition pack – young people

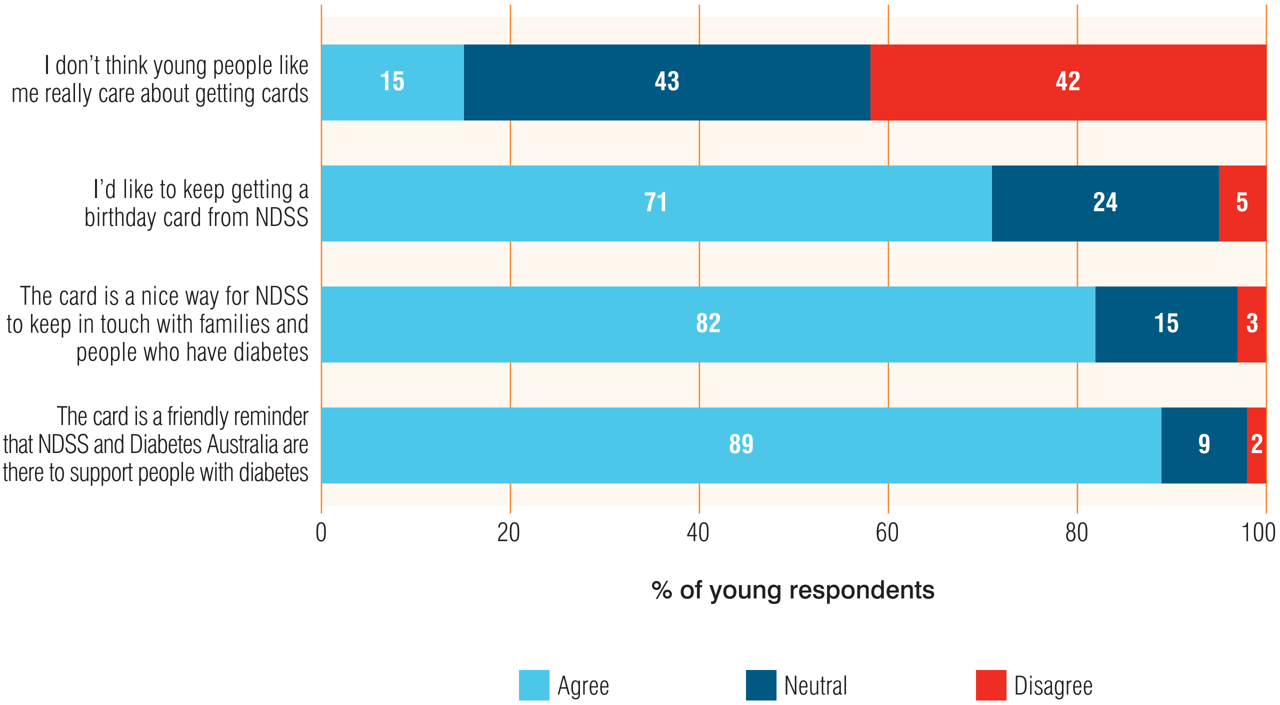
Young respondents were also given a set of statements with which to agree or disagree. Similarly to the results for parents, it was common for young people to respond positively. Results for each statement are provided below (and in Figure 11):

- 89% (n=463) agreed that the card was a *"friendly reminder"* that NDSS and Diabetes Australia are *"there to support people with diabetes"*, 9% had no opinion on this statement
- 82% (n=427) agreed that the card was a *"nice way for NDSS to keep in touch"* with families and people who have diabetes, 15% had no opinion
- 71% (n=368) *"would like to keep getting a birthday card"* from NDSS, 24% had no opinion on this statement and 5% said they would NOT like to continue receiving a card
- 15% (n=76) felt that *"young people like me really don't care about getting cards"*, while almost three times this proportion, 42%, disagreed and 43% had no opinion.

Analysis of results across age groups showed a non-significant trend for older respondents to be less positive than younger ones about the card:

- 65% of respondents aged 19–20 years agreed with the statement *"I'd like to keep getting the card"*, compared to 71% average of other age groups (non-significant)
- 24% of respondents aged 20 years agreed with the statement that *"young people like me don't really care about getting cards"*, compared to 15% average of other age groups (non-significant).

Figure 11: Proportion of young respondents who agreed or disagreed with statements about the card



Suggestions on how the programme could be improved – parents

At the end of the evaluation questions parents were asked if they had any further comments or suggestions for improving the information provided by the programme.

Approximately 10% of *parents* (n=39) provided a response to this question. Common suggestions included:

- more networking and learning opportunities for young people such as seminars, camps or webinars
- the provision of child-friendly information/direct contact with the child/an actual 'transition pack'
- more online contact.

A sample of the comments follows.

> *"I'd love to see a programme where the teens can get together in a safe environment to discuss their issues, receive training and encouragement face-to-face – in rural areas too, not just capital cities."*
>
> *"I feel my son at 13 needs to interact with other T1D teenagers to help and support each other as hitting puberty it can be very lonely for some."*
>
> *"Any other material I receive should be directed to her in tone and language in a different format than that of the parental letter. It is the children that are in transition and aiming information at them would be really beneficial in letting them own the process of becoming part of the adult programme."*
>
> *"I would also like information sheets sent to me that I can pass onto my son that is teenage friendly (speaks his language/cool/trendy etc.)"*
>
> *"I think a formal transition pack would be quite useful as the transition from paediatric to adult services occurs at the same time as driving, alcohol, change from school to university/workplace and sexual health transition."*
>
> *"Having email contacts to ask questions about my daughters care would be helpful."*

How can the NDSS best support young people to transition successfully to adult diabetes services?

In most cases, *HCPs* indicated that the role for NDSS was to provide quality information to young people and their families, including a database of services across Australia. Others indicated the NDSS could directly support transition coordinators or set-up a telephone/online transition support service.

A range of other responses were reported using an 'open text' format. Common themes are presented in Table 8.

Table 8: HCPs' views on how to best support young people in transition

How can the NDSS best support young people in transition?	N=100
Provision of information e.g. on the transition process/targeted to parent; for young people/provide a checklist of important checks and general information/information to help upskill young people/information to employers so they understand the needs of people with diabetes/NDSS to provide a booklet for use in all clinics	31
Maintain contact with young people Card programme sounds good/maintain regular contact with young people/ensure they are not lost to follow-up/send annual reminder of important check-ups to prevent complications	13
Data-base of diabetes services/diabetes specialists across Australia Provide up-to-date information on diabetes services available in each locality/phone help or online directory to help locate services	12
Actively monitor and conduct follow-up with young people Develop and monitor a national database of young people and track to ensure follow-up/specialist appointments/conduct appointment reminders/follow-up with those not attending services/track down non-attenders/send reminders about check-ups after they have left children's hospital and continue this until around 24 years of age	12
More support/assistance for YADS/support a national network of transition co-ordinators/support/fund transition co-ordinators	4
Phone help line or internet help line	2
Events/workshops to educate on transition/face-to-face information sessions locally	2
Recruitment and retention of specialists in rural areas	1
Continue to advocate for standard of care	1
Provide transport to appointments	1
Deliver community promotional mass media that raises awareness of young adults with type 1 diabetes	1

Impact of the programme over time – young people and parents

For many key questions, those *young people* who had received three cards in the past three years often gave more positive responses than those who had only received one (see Figure 12); this trend was not statistically significant. This suggests that the impact of the YTP might be enhanced when contact with young people living with diabetes is experienced as an ongoing programme rather than a 'one-off'; it highlights the importance of maintaining the YTP year-on-year in order to maximise engagement and the potential benefits of the initiative.

The pattern of responses among *parents*, on the basis on having received one, two or three letters in the previous three years is shown in Figure 13. Similar to the young people, there was a non-significant trend for *parents* who had received two or three letters (i.e. experiencing the YTP as a programme rather than a 'one-off') to give positive responses than those who had received one letter only.

Figure 12: Proportion of young respondents who took action, read parent's letter, and want to keep receiving the card, by number of cards received

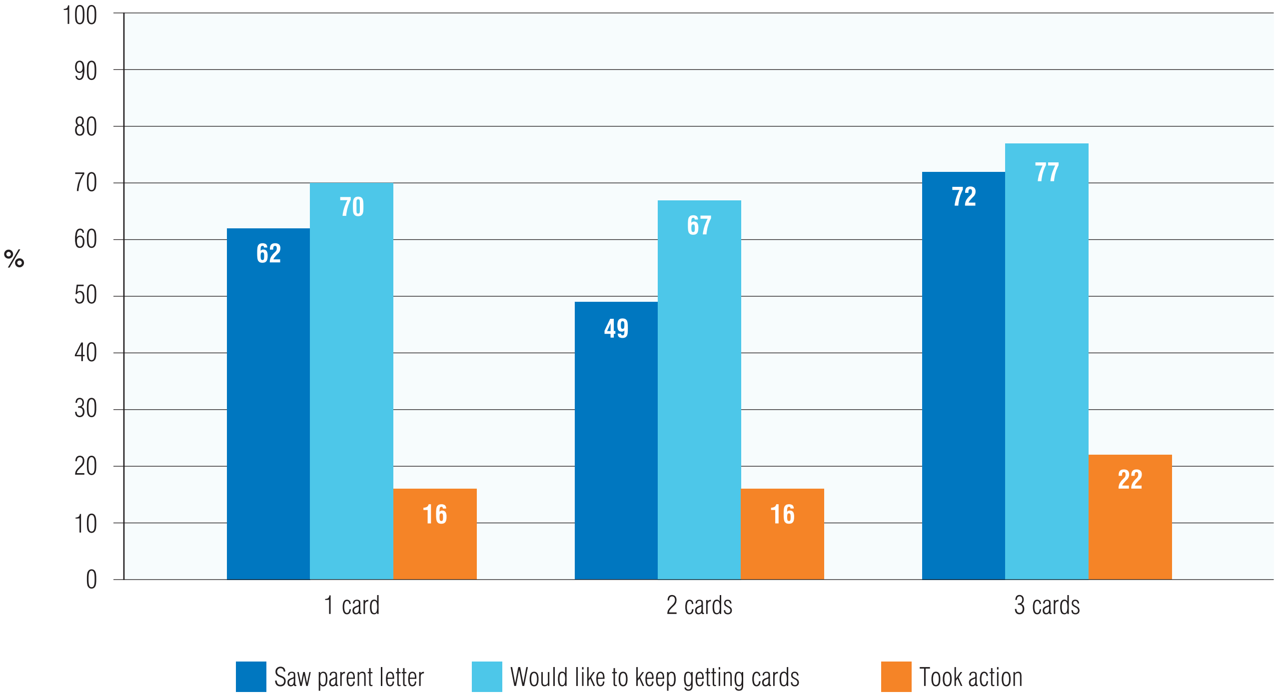
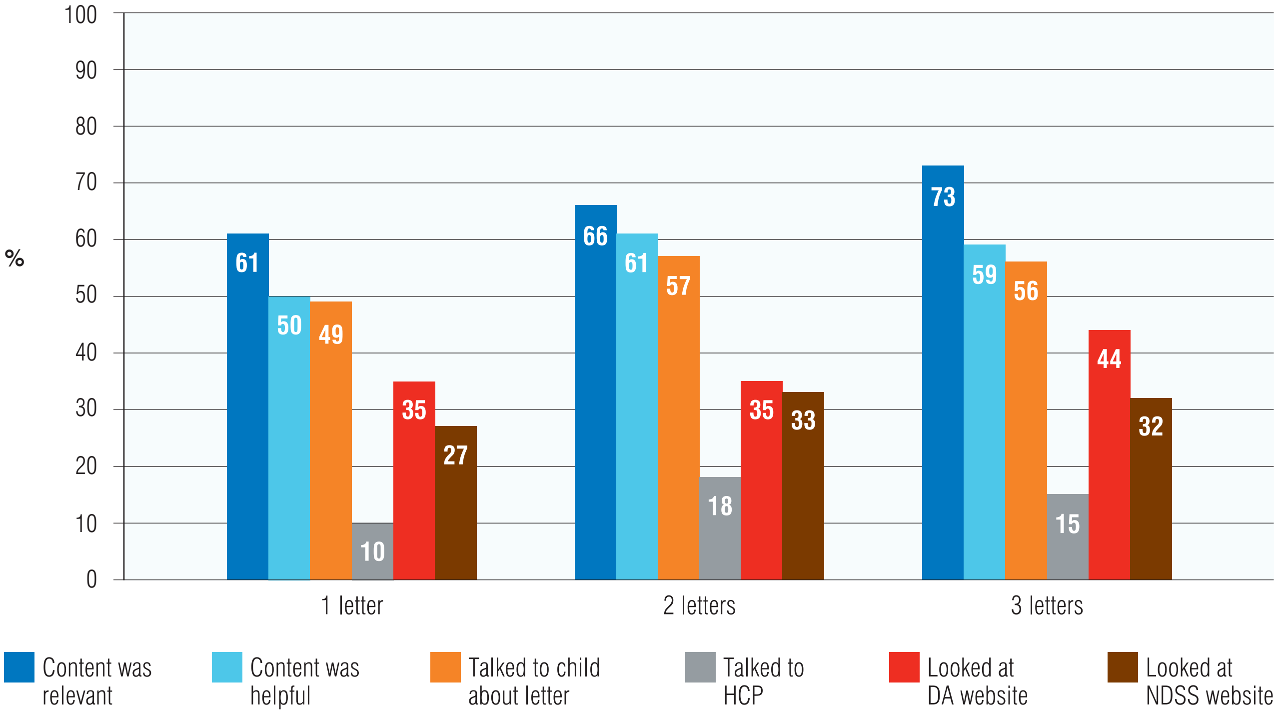


Figure 13: Proportion of parents who gave positive responses to specific questions, by number of letters received over the past three years



Questions on care and transition

As well as the YTP evaluation questions, the surveys included questions about managing diabetes and preparedness for transition to adult services.

Current diabetes services used by young respondents

Table 9 below shows the proportion of respondents (*parents* and *young people*) using each type of diabetes service. Almost one in five young respondents were not sure which services they were currently using.

Age of transferring from paediatric clinic

Of those *young people* who had already moved from their paediatric care:

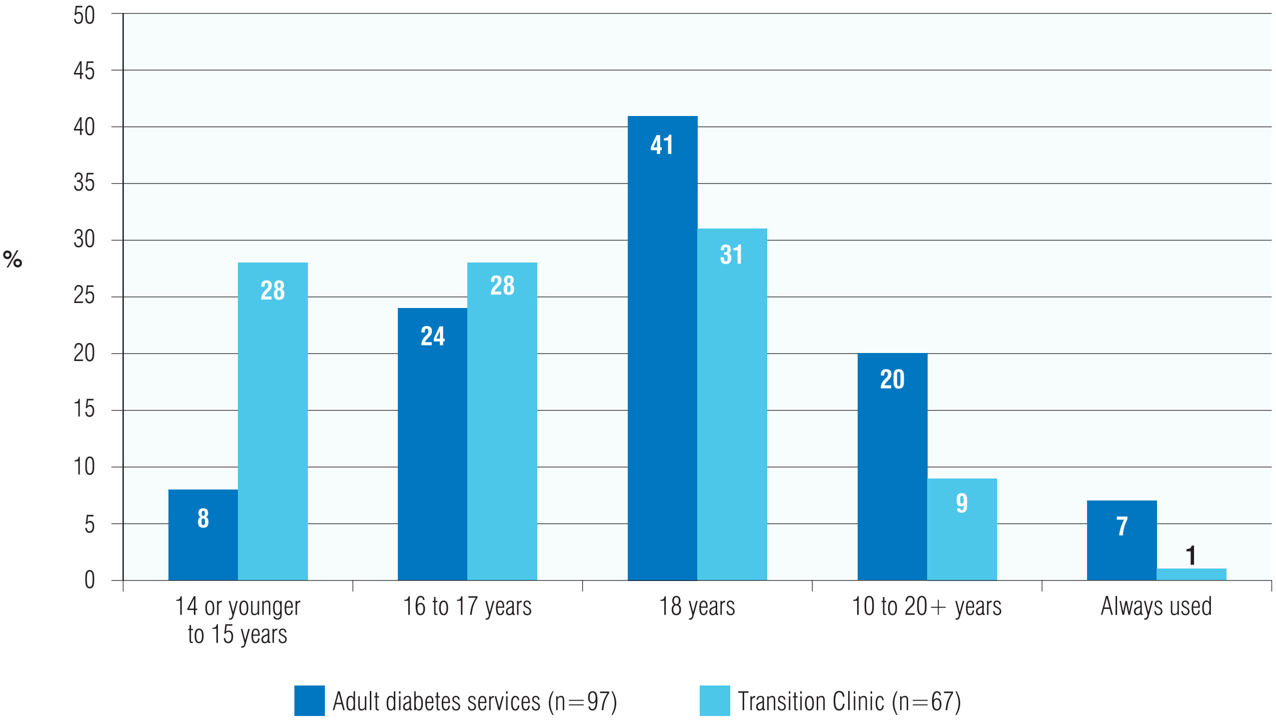
- Of those who had moved to an adult diabetes services, the most common age of transition was 18 years (41%), followed by 16 or 17 years (24%).
- Of those who had moved to a transition clinic, the most common age for transfer was between the ages of 14–17 years (56%), followed by 18 years, (31%).

Results based on the young people's survey responses are shown in Figure 14.

Table 9: Main diabetes services currently used by young respondents

Main diabetes service currently used	Parents (re child) (n=402)	Young respondents (N=597)
Paediatric services	76% (n=304)	48% (n=286)
Transition service (e.g. YADS clinic)	12% (n=50)	11% (n=67)
Adult diabetes services	10% (n=40)	16% (n=98)
A mix of both	–	3% (n=19)
Not sure	–	18% (n=108)
Other	2% (n=8)	3% (n=19)

Figure 14: Age of transfer from paediatric care, for adult and transition services



Age of transfer to adult services

The most common age at which young people with diabetes usually transfer from paediatric to adult care was 18 years (stated by 32% of HCPs), or within the age range of 16–18 years (stated by a further 20%). A range of other responses were reported using an ‘open text’ format (see Table 10).

Who initiated the move?

Parents indicated that the most common person initiating the transfer to adult or other services was:

- the paediatric diabetes team (38%), followed by
- the diabetes educator, 20%
- endocrinologist, 13%
- parent, 11%
- GP, 5%
- child, 4%
- other, 9%.

Initiating discussion about transfer to adult diabetes health services

Eighty-nine per cent of *HCPs* stated that they initiate the conversation about young people transferring to adult diabetes services, while 12% indicated the parent initiates the discussion and 8% indicated the young person initiates the discussion; these figures add to more than 100% as, in some cases, the discussion is initiated by more than one person.

The age at which HCPs start discussions about transfer to adult diabetes health services

The discussion about transferring to adult care is most likely to be initiated by HCPs when the young person is aged 15–16 years (stated by 41%) or 14–15 years (stated by 26%). A range of other responses were reported using an ‘open text’ format (see Table 11).

Table 10: Typical age at which young people transfer to adult diabetes clinic (n=117)

Age	N	%
15 years	2	2%
16 years	11	10%
16–18 years	22	20%
16–20 years	5	4%
18 years	36	32%
18–20 years	2	2%
19 years	3	3%
22–25 years	3	3%
26 years	3	3%
Other*	15	11%

**No definite age/age varies (n=8), When left school (n=5), No service to move to (n=2)*

Table 11: Age at which HCPs start to discuss transition to adult services (n=73*)

Age	N	%
10–13 years	7	10%
14 years, 15 years, 14–15 years	19	26%
15–16 years, 16 years	30	41%
17 years, 16–18 years	12	16%
24 years	1	1%
It varies/depends	4	6%

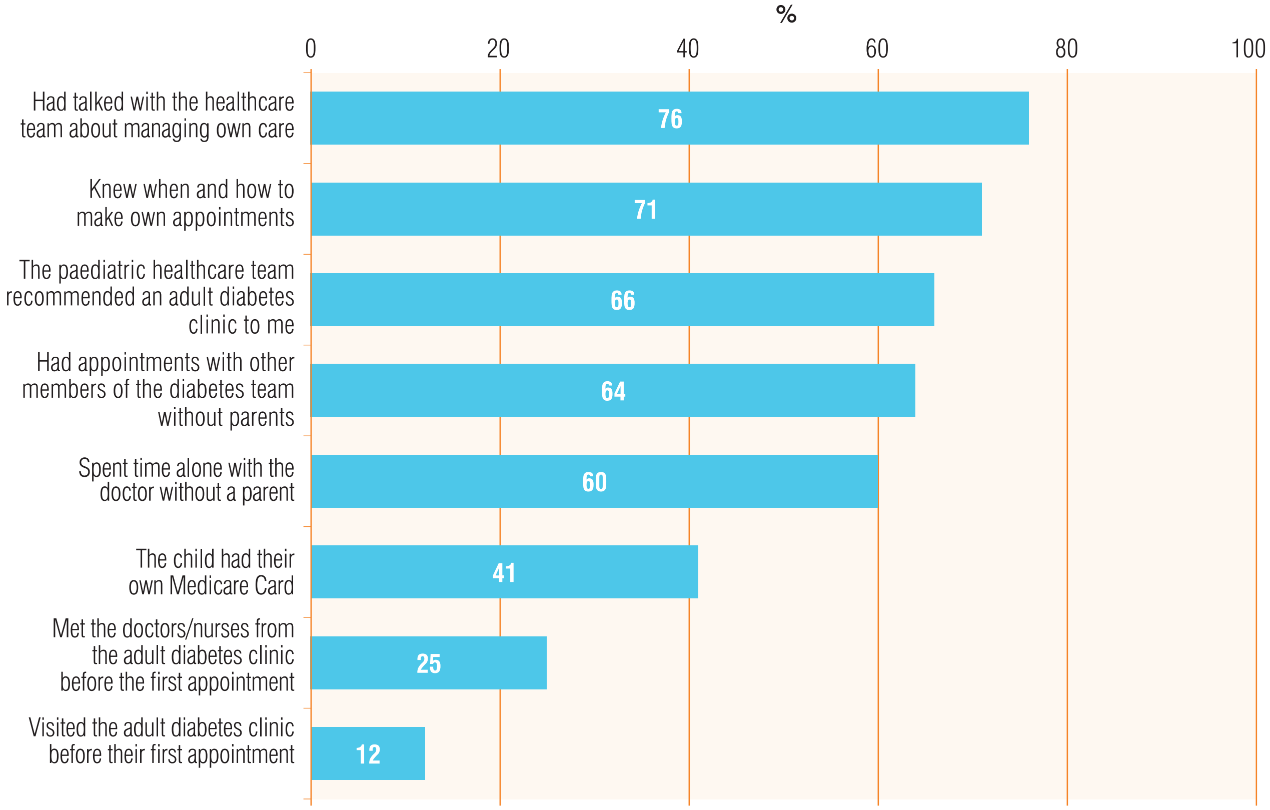
**NB. 24 HCPs responded 'not applicable' and are excluded from the analysis*

Transition – preparedness among those who had transferred from paediatric care

The survey asked those young people who had already moved from paediatric services, a series of questions to assess how 'prepared' they were before the move took place.

While the majority of young people had *"talked to the healthcare team about managing own care"* (76%) and said they *"knew how to make own appointments"* (71%), only one-quarter had *"met the doctors/nurses from the adult diabetes clinic before the first appointment"*. The extent to which they had undertaken various experiences 12 months before their move is shown in Figure 15.

Figure 15: The various experiences reported by young people in the 12 months before moving from paediatric services



The sub-sample answering these questions were those young people who had already transitioned to adult diabetes services, a transition clinic/YADS or both (N=177)

When asked how the transition experience could be improved, one of the most common themes to emerge was *"meeting the new doctor before their first appointment"* and/or *"visiting the new clinic"*. These experiences occurred for less than one-third of respondents.

Role of paediatric team in preparing the respondent for the move

When asked whether their paediatric team did enough to help them move to adult or transition services:

- 59% (n=105) of young respondents felt the paediatric team *"did enough to help me transition to adult health care"*
- 41% (n=72) felt their team *"could have done more"*, of whom:
  - 26% (n=45) said they did *"a little, but could have done more"*
  - 12% (n=27) said the paediatric team *"didn't do much"*
  - 3% (n=5) said they did *"nothing at all"*.

These results, shown in Figure 16 below, suggest that paediatric HCPs could be more proactive and helpful in assisting young people to transition from paediatric care. This finding could assist in informing content for the transition pack in terms of providing a list of actions for the types of support young people could expect from – or at least discuss with – the paediatrician in preparing for transition.

HCPs were also asked what they believed to be the most important aspect of preparing a young person for the move to adult diabetes services. Based on the comments from 121 respondents, the key themes are listed in Table 12.

Figure 16: Feedback from young people on whether their paediatric team helped enough to prepare them for the move to adult or transition services

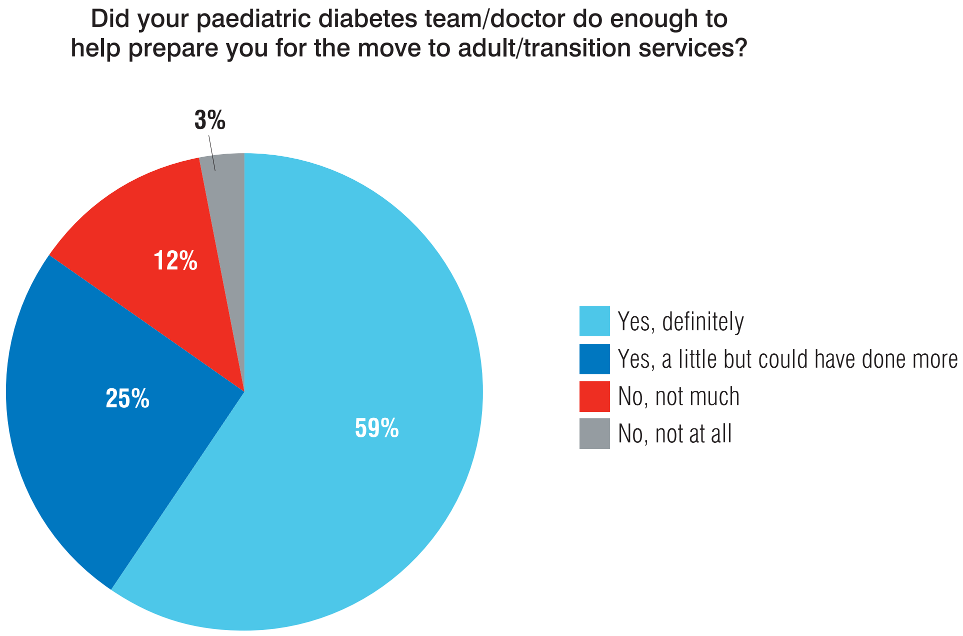


Table 12: Most important aspect of preparing a young person for transition

Most important aspect of preparing a young person for transition	N
Teaching independence/skills to ask questions/helps break away from depending on parents/empowering them	23
Talk about transition early/help them prepare for differences in adult service	22
Continuity/keeping them linked with GP/service	12
Provide adequate information/self-care education	11
Introduce them to the new clinician/orientation day in new clinic	10
Finding them the right service/endo/giving information about services	9
Teaching positive attitude/keeping them motivated/giving them confidence	6
See them alone/no parents	3

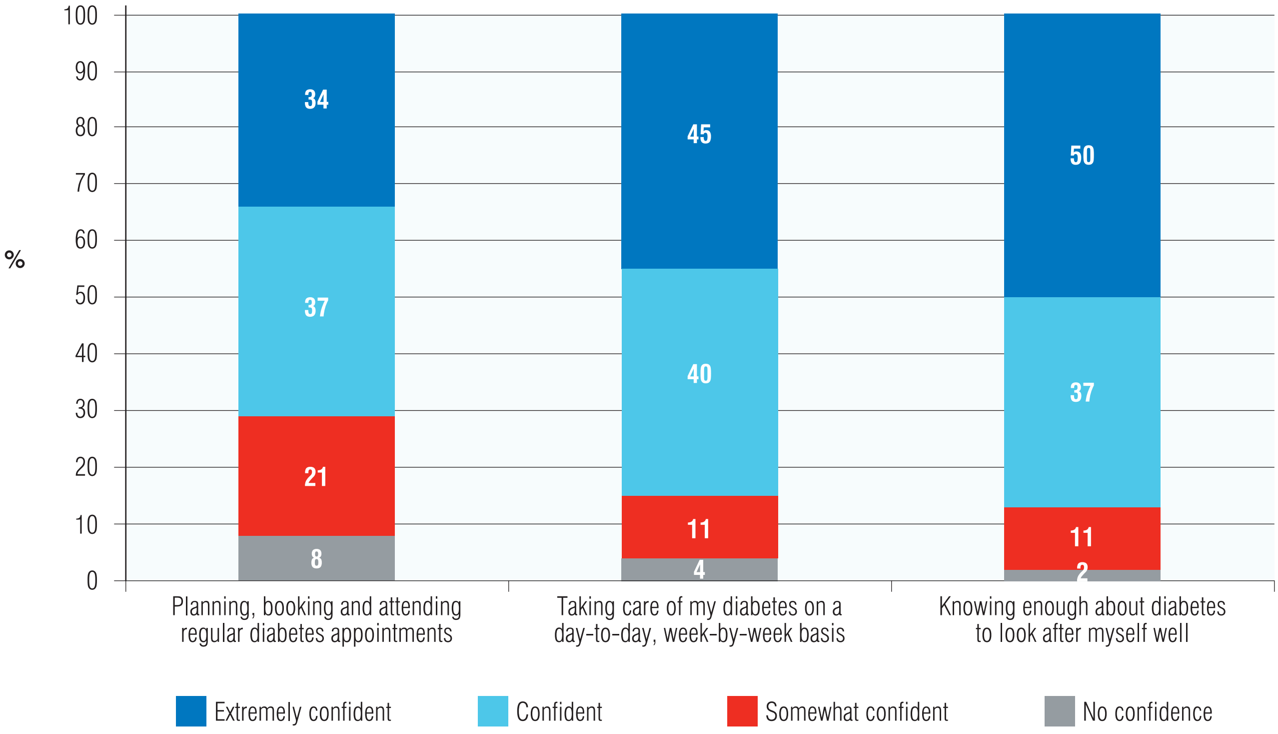
Level of confidence in looking after own diabetes – parents and young people

Young people who were already using an adult or transition diabetes service were asked about their levels of confidence in three aspects of managing their own care:

- 87% felt they knew enough about diabetes to look after themselves well
- 85% had confidence in their ability to manage their diabetes on a day-to-day, week-to-week basis
- 72% felt confident about booking and attending regular appointments.

These results are shown in Figure 17.

Figure 17: Confidence in diabetes care among young people already using adult or transition services (N=185)



While fairly similar to young people in relation to questions on self-management, *parents* were much **less confident** about their child's capacity to book and attend medical appointments (one-third of parents had **no confidence** compared to just 8% of young respondents).

A comparison of parents' and young people's responses regarding levels of confidence is shown in Table 13.

Overall experience of the transfer (for those who had moved already)

Parents and young respondents who were no longer using paediatric diabetes services were asked about their overall experience of moving to adult/transition services:

- 70% (n=56) of parents reported that the experience of their child's transition was a smooth one with no real problems or issues
- 73% (n=129) of young people described their experience as a good one.

Table 13: Comparison of parental and young people's confidence in the young person's ability to manage their diabetes and book medical appointments

Most important aspect of preparing a young person for transition		% feel confident	% somewhat confident	% not at all confident
Manage diabetes on day-to-day, week-to-week basis	**Parents (n=103)**	65%	29%	6%
	Young respondents (n=185)	85%	11%	4%
Book and attend appointments with the necessary health professionals	**Parents (n=103)**	38%	31%	32%
	Young respondents (n=185)	71%	21%	8%

NB. These questions were only asked of parents and those young people who were already using transition or adult clinics

Table 14: Experience of transferring from paediatric to adult health services

Experience of transfer from paediatric to adult or transition service	Parents (n=80)	Young respondents (n=177)
Smooth/good with no real problems	70%	73%
Experienced minor issues only	6%	11%
Experienced major issues	4%	2%
Too early to tell	20%	14%

NB. Results were similar across states and other variables.

Where problems had been experienced, respondents were asked to provide further details on their experience.

A common theme to emerge from parents was the distress associated with 'breaking away' from a good, long-term relationship with the paediatric team and attempting to form a new relationship in an environment that is more time pressured and less focused on the individual.

For young people, it was clear that the change of culture (between paediatric and adult services) was problematic, as many of them were not aware of, nor prepared for, the differences in care between an adult and paediatric clinic.

A couple of comments also revealed the dangerous repercussions of an unsuccessful move – that is, the young person simply stops attending their appointments.

Other common issues raised included the difficulty of accessing medical experts, getting timely appointments and affordability.

Those still using paediatric services

Discussion with HCPs about child moving to adult diabetes services

Almost one-third (30%) of *parents* whose children were using paediatric diabetes services (n=302), had discussed transition with a member of their child's diabetes team in the last 12 months.

As might be expected, discussion about transition was more likely to have occurred if the child was 17 or 18 years old:

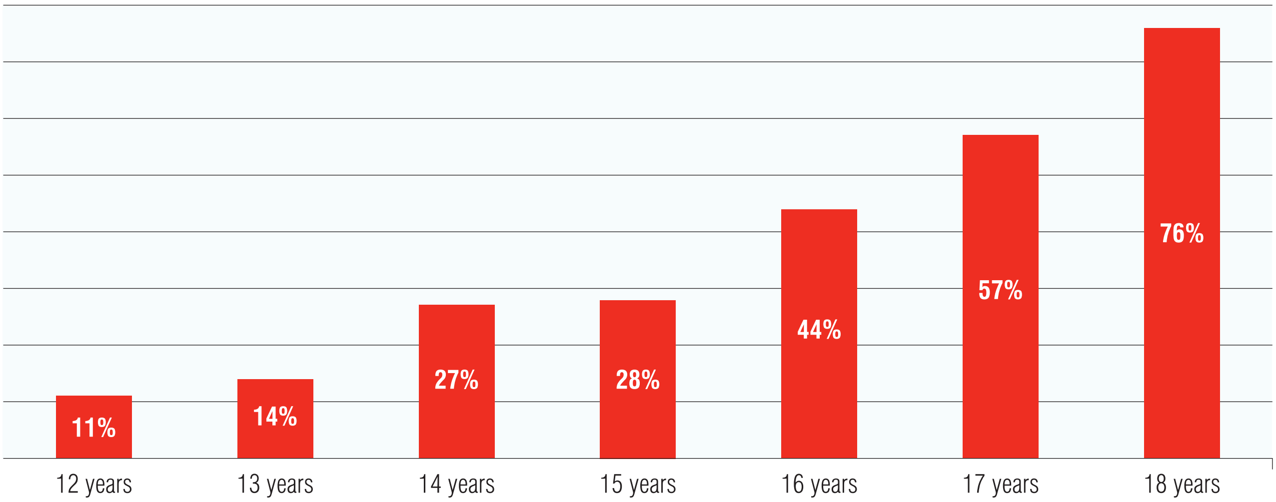
- more than half of the *parents* of 17-year-olds (57%), had discussed transition with a member of their child's diabetes team the previous 12 months, as had
- three quarters (76%) of the *parents* of 18-year-olds.

In two-thirds of all cases (66%), the transition discussion was initiated by a member of the diabetes healthcare team. It was also clear that HCPs were more likely to initiate this discussion as the child neared 18 years of age (see Table 15).

Table 15: Parent and HCP discussion about transition in the previous 12 months, by age of child

Age of child (still using paediatric service)	Parent has discussed transition in last 12 months with HPC	Parent has discussed transition in last 12 months with HPC
12 years (n=55)	11% (n=6)	All initiated by HCP
13 years (n=57)	14% (n=8)	50% initiated by HCP
14 years (n=59)	27% (n=16)	56% initiated by HCP
15 years (n=47)	28% (n=13)	46% initiated by HCP
16 years (n=39)	44% (n=17)	71% initiated by HCP
17 years (n=28)	57% (n=16)	75% initiated by HCP
18 years (n=17)	76% (n=13)	69% initiated by HCP

Figure 18: Proportion of parents who have discussed transition with a HCP in the last 12 months by age of child (N=302 parents of young people using paediatric services)



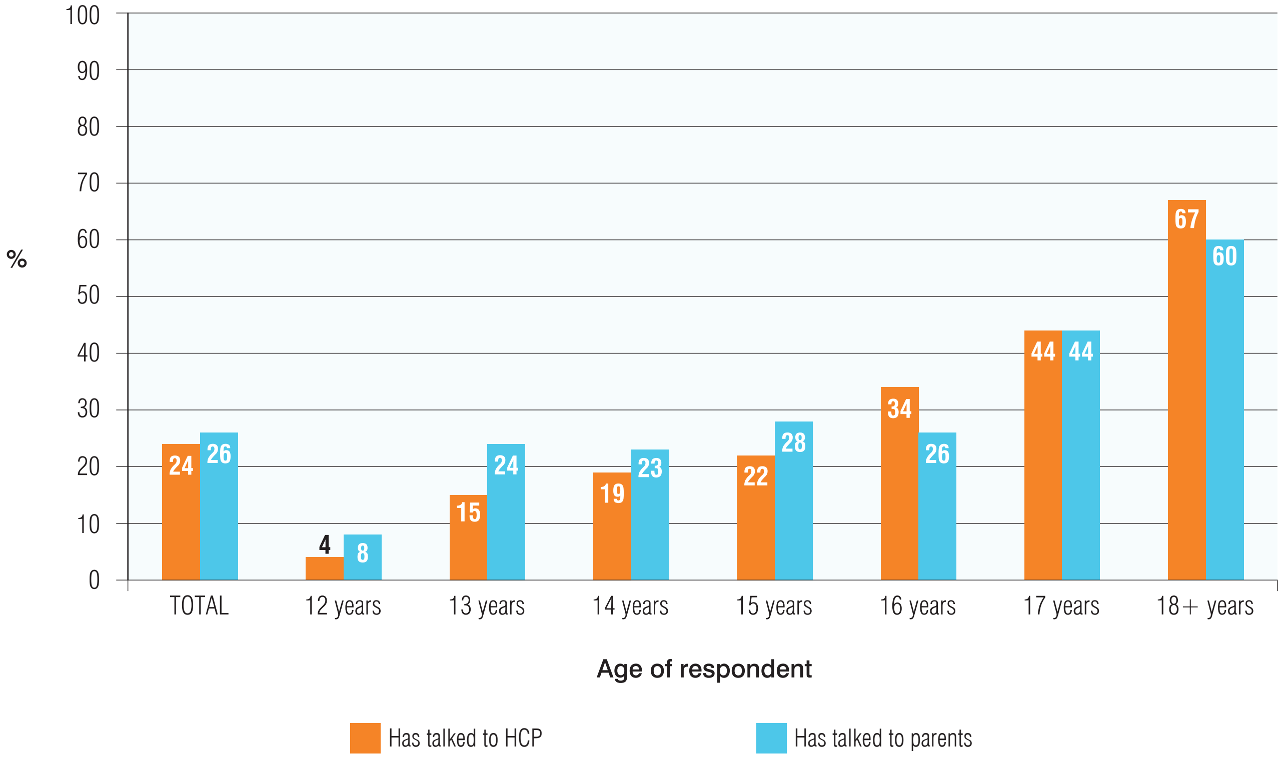
Have young respondents talked with their parents or HCP about transferring to adult diabetes services?

Of *young people* who were currently using paediatric services:

- 26% had discussed transition *with their parents*
- 24% had discussed transition *with their HCP*
- 65% had not yet discussed it *with either*.

Reflecting upon findings from the parents' survey, the older the respondent, the more likely they were to have discussed transition with either their parents or healthcare team (see Figure 19). Among respondents aged 18-years-old, more than two-thirds had spoken to a HCP about transition, while 60% had talked to their parents.

Figure 19: Proportion of young people, currently using paediatric services, who have spoken with parents or HCPs about transition to adult diabetes care by age (N=286)



Age for transferring from paediatric services

Just over half (52%) of *parents* felt that their child would be ready to transfer between the age of 18 and 20 years, followed by 22% who felt 16–17 years was the right age. Only 9% nominated an age above 20 years.

Preparing for transition

From a list of actions, *young people* were asked what might be useful in terms of helping them prepare for their move to transition or adult services:

- 64% (n=182) would like to meet the new doctor/nurse before making the move
- 51% (n=145) would like their current doctor to help choose an adult provider
- 48% (n=138) would like to learn more about self-managing their diabetes
- 19% (n=55) would like to have an appointment with the clinician on their own.

Parental worries or concerns about transition

While 57% of *parents* did not have any worries or concerns about the transition process, 43% did. The common concerns for parents included:

- worries about a lower level of care in adult services/lower level of support/less attention/less personal/getting ‘lost’ in adult system. These issues were mentioned by around one-third of parents, see following responses:

> *"Concerned that there won't be enough support."*
>
> *"Concerned the level of care will drop."*
>
> *"(I'm worried) about (not) receiving the same level of care we have had in the paediatric system."*
>
> *"I hope they receive as much care and are not forgotten."*
>
> *"(I'm worried about my child) becoming lost in the system."*
>
> *"She won't receive the same close attention that she currently receives and things will go un-noticed."*
>
> *"I think adult care will be less supportive."*
>
> *"They will not take as much time with the appointments or understand what a young adult needs."*

- worries about the child's ability to manage their diabetes independently/child's level of maturity and ability to cope with a big change at this stage of life/child's ability to book and attend appointments/that child will miss appointments.

> *"As a parent you worry constantly about their health. I worry about his maturity to handle it. Also he has a dislike for medical appointments, so I worry he may not follow up."*
>
> *"She is not adequately equipped with the maturity to work independently with adult diabetes care."*
>
> *"[I worry about] whether she will understand it all and keep up all the hard work of maintaining her hba1c levels as good as we have."*
>
> *"I am concerned that he will forget to book appointments and will not speak to anyone if there are issues with his diabetes control."*
>
> *"[I worry] about him missing the appointments which he has done on two occasions now."*

- having to build trust and rapport with a new doctor/having to build new relationships all over again/starting again from scratch

> *"The paeds team have been through everything with us, we have a bond with the team, starting fresh with a new team is a bit worrying."*
>
> *"Trust has been built with our paediatrician, it is concerning to have to build a new relationship with the same level of trust."*
>
> *"… the educators have known (my son) since he was 7 yrs old and even though on paper it is all passed on to adult clinics the personal relationships are lost (it's a) downfall until new relations are made."*
>
> *"My child … has established a strong link with her doctor, (and is) used to continued care with the same doctor. During clinic visits, her paediatric doctor may vary and I notice she has more faith in her original female doctor. I worry she may not be as open and confident with another doctor."*

- worried about lack of information – *"No information on how it works and what adult diabetes care means"*.

Worries and concerns about transition among young people

When *young people* were asked if they had any concerns or worries about transferring to adult services 38% reported 'no', 9% reported 'yes' and 53% indicated they had not yet thought about it. The high proportion who had not yet thought about it, generally decreased with age (see Figure 20). As might be expected, the figure also shows that 17-year-olds have more worries and concerns than younger respondents.

Among the sub-sample of those who had thought about moving to adult diabetes services, 20% reported having worries or concerns, increasing to 30% among 17-year-olds.

For young respondents, most concern was in relation to leaving their current doctors, whom they trusted and felt knew a lot about them and their condition.

A few mentioned cost as a concern, and also the expectation that adult services would not be as kind and friendly as their current doctor.

HCPs were asked to describe the two most common problems they felt were experienced by young people when they transitioned to adult healthcare. Based on the comments from 121 respondents, the most common themes are listed in Table 16.

Figure 20: Proportion of young people using paediatric care who have worries or concerns about transition to adult care, by age

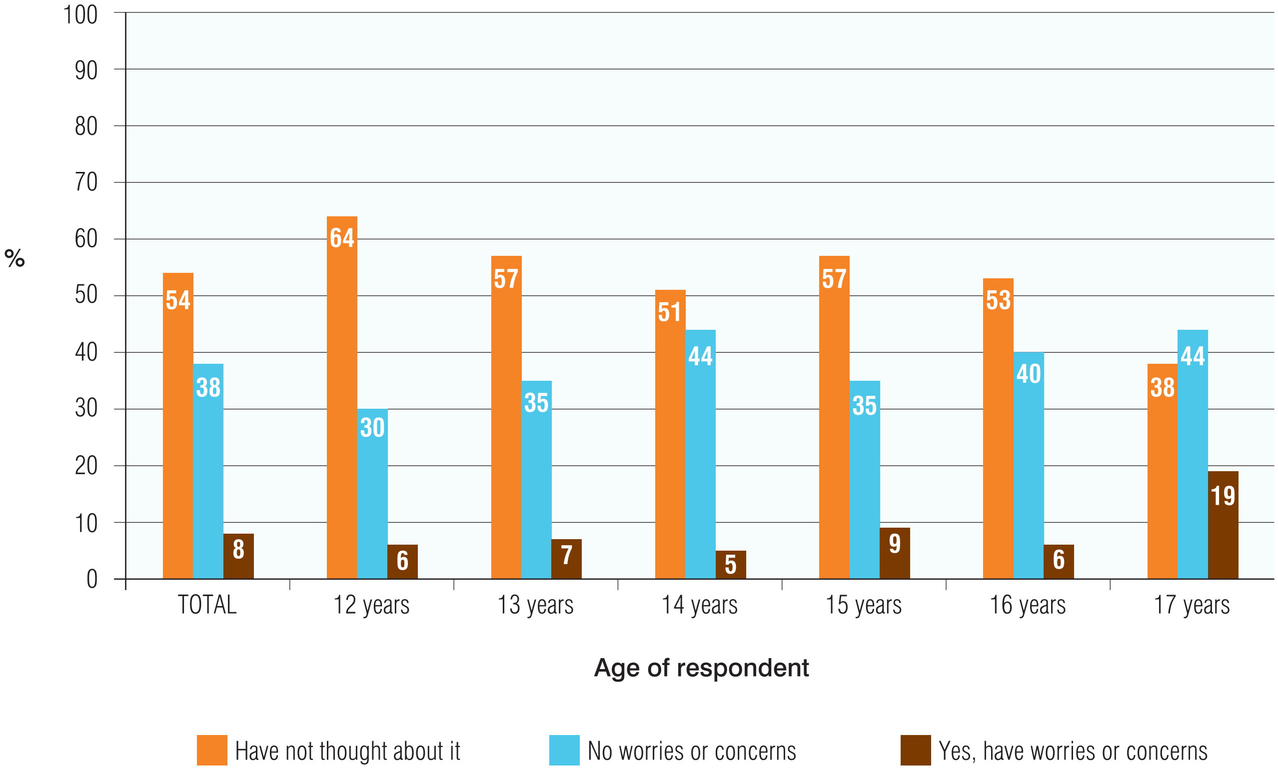


Table 16: Most common problems facing young people during transition according to HCPs

Main issue facing young people during transition	N
Leaving well known doctor/having to build new relationship	23
Attendance/keeping appointments	13
Access to services/endocrinologists	11
Adapting to different model of care/not as holistic	10
Lack of comprehensive transition/lack of information/no information on where to go	10
Transition occurs at wrong time/too much going on in their life at this time	10
Taking on responsibility of self-care/compliance	9
Fitting in appointments in busy life	4
No continuity of care/different doctor each visit	2
Lose contact with endocrinologist	2

Discussion and recommendations

Coverage and administration of the YTP

It is clear from the evaluation survey findings that the Youth Transition Pack (YTP) is valued by young people and their parents, and is effective in terms of coverage, engagement and eliciting the desired actions from the people it is aimed at.

Programme coverage is good, with high proportions of parents (75%) and young people (84%) recalling receipt of a card or letter in the last 12 months, and 85% of parents and 87% of young people recalling receipt of at least one card or letter over the past three years.

Western Australia, however, had lower-than-average recall/coverage (by almost 10%) for both parents and young people, for both time periods. This anomaly warrants further investigation and efforts to be made to achieve consistently high coverage across all states and territories.

The administration of the programme is good as evidenced by the findings that over 90% of cards arrived close to the young person's birthday and had the child's correct age (97%).

Engagement with target groups

Engagement with the YTP outputs is high for each target group.

Almost all (97%) young people opened and read the card, and reported that it reminded them that there is support for people with diabetes. Most young people felt positive about the appearance of the card (73%), and seven in 10 (71%) agreed that they would like to continue receiving it.

Almost all parents (98%) read at least some of the letter, with more than three-quarters reading all or most of it. Over 80% reported that the information provided in the letters was helpful and relevant.

These are all strong indicators that the YTP is of benefit and is valued by parents and young people, and should therefore continue.

General awareness of the YTP among Healthcare Professionals (HCPs) was low – approximately only one in five had heard of it and most had found out through colleagues rather than from information provided by the National Diabetes Services Scheme (NDSS). This is possibly due to the relative newness of the programme (2 – 3 years) but also suggests that more needs to be done by the NDSS to create awareness of such initiatives if it is considered that awareness among HPCs is important to the initiative.

The low level of awareness also suggests that young people and their parents/carers are not discussing the letters with the clinicians or taking them to their appointments. This is not necessarily a negative thing, and we know from the YTP evaluation that while parents do not generally take the letter to discuss at appointments, they may still talk to the clinician about issues raised in the letter. We also know from the YTP evaluation that discussion about transition to adult healthcare services is mostly initiated and led by the clinician rather than parents. As stated in the YTP evaluation, if the NDSS wants parents to actively raise and discuss particular issues with the clinicians, then a stronger prompt is required. This may take the form of clear instructions in the letter (e.g. things to ask your clinician about on your next visit) or a checklist etc.

Only a small number of HCPs had received direct feedback from young people or their parents about the YTP letters – of these, two were positive and six were negative. The issue of confusion was raised (i.e. with parents receiving letters about their child transferring to adult services when the clinics' practise is to transition much later), as was the point that young people may not want a birthday card reminding them of their condition.

A recommendation in the YTP report was that the birthday card programme should allow young people and their parents/carers to opt out if they wish.[4]

It is important therefore, that information provided by the NDSS is 'general' (so as not to contradict different approaches used in different clinics), and states clearly that different clinics adopt different approaches, encouraging young people and their parents to be informed about the approach used in their specific clinic. That is, the NDSS needs to convey a clear message to young people and parents to 'discuss' and become 'informed'.

Clarity of letter

The tone of the letter was considered by the majority of parents to be 'friendly' and 'professional', and the language used seemed generally appropriate, with 70% of parents reporting it was 'easy to read and understand'.

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[4] *The Youth Transition Pack Evaluation Survey Report 2014, DA for NDSS*

The clarity of the letter, however, may need some improvement, given that one parent misinterpreted the content. In parallel, the NDSS received feedback from a HPC working in paediatric diabetes care in NSW indicating that a small number of patients and parents had similarly misunderstood the NDSS letter. Given the potentially negative outcome of such a misunderstanding (i.e. to stop attending the paediatric clinic), further testing of the letters among specific parent groups needs to be undertaken, as well as further feedback obtained from diabetes health professionals. This work has subsequently been approved by the NDSS and is scheduled as an extension of this evaluation.

Other concerns about the programme centred on the content of the letters, with some HCPs indicating the information could be more user-friendly, and another stating that the information was not targeted appropriately for the different age groups. A few doctors made the point that such information should be written with input from clinicians. (This step had been taken prior to the original launch of the YTP.) As recommended in the YTP evaluation report[5], all YTP letters need to be reviewed, re-written and re-tested with parents. It would also be appropriate to include HCPs' feedback in this process to encourage their support of the programme.

Action taken by parents as a result of receiving the YTP letter

While the YTP letter was effective among the majority of parents in triggering the desired action of discussing the letter's content with their child (71% had talked/intended to talk to their child about the content of the YTP letter), it was less successful in terms of prompting parents to talk to their child's HCP about transition or specific topics covered in the letter (33% had done this or planned to, increasing to 57% for parents of 17 year-olds).

The potential advantage of having more parents/young people initiate transition discussions with their HCP might be that engagement and focused discussion on transition begins earlier thus allowing sufficient time to plan and arrange events/experiences that, based on the survey findings, are likely to facilitate a smoother transition for the young person (e.g. meeting the new doctor before the first appointment, or getting help from the paediatric team to help choose an adult provider etc.).

Survey results indicate that, at present, discussions are mostly initiated by the HCP and generally take place when the child is 17 or 18 years old – however, at 17, approximately half of the young people and 43% of their parents still hadn't discussed transition with their HPC. With transfer from paediatric services most commonly occurring at age 18, this leaves little time to plan for the arrangements that are important to young people.

Hence, if earlier parent-initiated discussion on transition with the HCP is desired by the NDSS, a stronger prompt to encourage this could be further explored. This could be achieved by providing more information to parents specifically on the transition process and the role of the HCP. For example, a transition checklist, care plan or progress sheet which involves input from all parties (i.e. parents, the child and HCPs) could potentially provide a direct and strong prompt to encourage parents/young people to engage doctors earlier in transition preparation.

Action taken by young people as a result of receiving the YTP card

Action among young people was modest, with almost one in five young people logging onto diabetes-related websites following receipt of their birthday card, increasing to 29% among 19-year-olds. Given the relatively, and intentionally, low strength of the prompt – the card contains a 'happy birthday' message and the myD website address – engaging one in five young people to take action appears relatively successful.

The finding, however, that the myD website was the website young people were least likely to view of the three listed in the survey indicates that this is **not** their preferred 'go to' site. Results show that 3% looked at the myD website compared to 10% for the DA website and 13% for the NDSS website.

As such, the placement and emphasis on the website address contained in the birthday card should be reviewed. In addition, the user analytics for each website could be reviewed to see if this finding is supported.

Could the YTP do more for young people living with diabetes?

Almost nine in 10 young people found the content of the YTP parent letter helpful. However, based on respondents' recall, only around one-third of young people saw or discussed the letter that was sent to their parents.

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[5] *Ibid*

It is important to note that one-third of parents said they had not discussed (or did not plan to discuss) the contents of the YTP letter with their child.
If more substantial information was provided directly to young people (rather than only a simple birthday message in the card), this might be utilised and welcomed.

Any addition to the simple birthday message would need to be fully debriefed with young people and their parents to ensure its suitability for the target audience. Broadening the YTP to provide child-friendly information will maximise the opportunities for young people to access information relevant to transition and empower them to become more aware of their own diabetes care needs as they move towards adulthood.

It is also important to note the idea of producing information in a 'child-friendly' format for young people was a common suggestion from parents.

Indeed, when HCPs were asked how the NDSS could best support young people through transition, the largest number of respondents stated 'through the provision of information'.

Others also mentioned by 'staying in touch with young people' and the set up and maintenance of a diabetes services directory. While the first two suggestions have already been undertaken by the NDSS (and are in the process of being enhanced and improved), the third suggestion could be considered as a future initiative.

Could websites be used more for transition information?

To ensure **all** young people have access to age-relevant information, the key messages from the parent letters could be made available for young people in a written format or via a transition portal on the NDSS/DA (or other appropriate) websites.

Visits to websites were triggered by receipt of the letter and birthday card (over half of all parents and up to one-third of young people looked at a website). Having online access to the information covered in the YTP letters was also mentioned by some parents when asked how the YTP could be improved. Websites therefore provide an excellent platform for the provision of further information on transition and other subject areas nominated by parents.

Possibly a YTP portal could be developed specifically for transition information with specific suites of information targeted to young people and parents. Each year the birthday card could provide a log on or reminder to access the information relevant to their age group. Any further tools developed to assist transition (e.g. checklists on preparedness or a care plan) could be stored on the site and promoted with the outputs of the YTP.

Target age group for the YTP

Some parents commented that the letters were **not very relevant** to **younger children** and suggested that the YTP should not start until the child is older. The NDSS is aware that this was raised in informal feedback from a HCP.

However, survey responses from young people suggest that contact for this age group is important – 12-year-olds were most likely to 'like or love' the cards, and high proportions wanted to continue receiving the cards. Furthermore, they were among the top three age groups to log onto a diabetes website as a result of receiving the card.

It is recommended therefore, that the age of 12 remain as the starting point for receipt of the YTP. Going to high school is a major change in young people's lives, so it is probably a good point for the NDSS to establish contact with young people and their families, and provide ongoing information and support throughout the teenage years.

However, for the 12 and 13 years age group, the content of the letter could potentially focus on diabetes and school – the information most commonly wanted by parents of 12-years-olds.

The topic of transition (i.e. leaving paediatric services) should possibly be introduced at a later age, for example, 14 or 15 years. This would be consistent with the American Diabetes Association guidelines, which recommend initiating conversations about the transition process one or two years prior to the planned transfer to adult care.

Preparing for transition – the YTP could do more

Just over 40% of young respondents thought that their paediatric healthcare team could have done *more* to help them prepare for the move to adult diabetes healthcare. For example, many young people would have liked the paediatric provider to help them choose an appropriate adult provider.

Although it is beyond the scope of the YTP to directly influence the behaviour of HCPs, the initiative could – through the provision of information – help build the confidence and expectations among young people (and their parents) regarding support from HCPs. For example, these findings indicate that young people would like the opportunity to meet their new doctor before transferring, and would also like the paediatrician to help them choose an adult health provider. Information provided to young people could reassure them that these are *reasonable requests* to ask of their paediatricians, and could suggest how best to approach this.

Ensuring letters provide relevant information

The survey question on subject areas of interest to parents showed that information on *alcohol and diabetes management* was wanted by parents of children of all ages (from 12 to 18 years), as was *information on assisting the child to develop independence in their diabetes care* and *hints for spotting burnout*. It is therefore recommended that the letters be reviewed on the basis of this feedback to assess whether the letters cover the subject areas that parents see as important to them and their child.

Given that information on some topics is wanted across all age groups, online access (through the appropriate websites or transition portal) to the information contained in the letters would allow parents to retrieve/access the information at any time/stage of their child's development.

The YTP letters could also be an effective vehicle for addressing/minimising the worry parents and young people feel in relation to transition. Survey results reveal that around 40% of parents and, depending on age, up to 30% of young people who are still in paediatric care, have worries and concerns about transferring to adult services.[6] A main theme to emerge in relation to parents' worries and concerns was the *lack of knowledge about the process of transition/transfer*. For young people, worries emerged as a result of *not knowing how adult diabetes services would differ* from their current service and *not knowing what would be expected of them*.

Reasons given for recording a negative transition experience often centred on the 'culture shock' young people felt when they moved from paediatric to adult diabetes care. Information provided through the YTP letters and card could help to fill these knowledge gaps, and in doing so, assist in addressing and minimising concerns.

From the point of view of HCPs, the most common problems experienced by young people when transferring to adult healthcare services included the difficulties associated with leaving a long-trusted doctor and having to form a new relationship with a different doctor (usually, one who has less time).

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[6] *When asked if they had worries or concerns about transferring to adult diabetes services, most young people (around 50%) said they hadn't yet thought about it. However, when looking at those who had thought about it, 20% said they did have worries or concerns (increasing to 30% of 17-year-olds).*

Another common problem was the stress and uncertainty around adapting to a new service model. HCPs felt that this stress was often enhanced due to young people's lack of prior knowledge about what to expect from adult services and how they differ from those of the paediatric system. The issues raised in this survey by HCPs were also commonly raised by parents and young people in the YTP evaluation. Both evaluations therefore clearly point to knowledge gaps among young people that the NDSS is well placed to assist in filling.

A further 'problem' mentioned by HCPs, as well as parents and young people, was the notion that transition occurs at the 'wrong time' for young people – at a time when there is too much going on in their lives and too many other changes taking place (such as final year of high school, leaving home, starting a job). It was suggested that having to cope with a move to new healthcare services may be asking a lot of these young people, and that the effort and attention required to do this successfully, at this point in time, may not be a priority of the young person. Furthermore, if the initial experiences of the adult service are then negative, this will compound the effort and attention required of the young person and, potentially, contribute to 'drop-out'.

While these points were recognised by HCPs, the survey results nevertheless indicate that 17–18 is the most common age for transferring young people to adult services. Potentially, this is an area the NDSS could research further or consider advocacy (in collaboration with health providers) to change the systemic issues contributing to this typical transition age.

'Teaching independence', 'providing self-care education' and 'helping to empower patients to ask questions of their clinicians' were seen by HCPs to be important aspects in preparing young people for the move to adult services.

Again, this provision of knowledge and patient empowerment can, to some extent, be provided by the NDSS through the provision of well-written and well-presented information resources.

Should the YTP be extended to older adolescents?

Although it was beyond the scope of the evaluation, consideration needs to be given to extending the programme to provide **ongoing contact with young people older than 20 years**. In cases where young people have ceased attending appointments or are thinking about doing this due to problems in the transition period (e.g. not liking the new clinician), NDSS information could remind them of the importance of maintaining optimal diabetes management and encourage them to try another doctor if they feel things are not working with their current doctor. Given the drop-out rate can be as high as 25% following transition to adult diabetes services, support and encouragement in the form of an annual NDSS letter (possibly up to age 24–25 years) seems appropriate.

Conclusion

This evaluation suggests that the YTP is well administered, is valued by both parents and young people, and should therefore continue largely in its current form.

However, there are opportunities for **enhancing the content** of the pack (based on survey feedback), **strengthening behaviour prompts** and including **more substantial information** for young people.

Broadening the platform to ensure the information is accessible and retrievable **online through appropriate websites** could also potentially offer gains in terms of increasing access and the availability of information for both target groups.

In light of the feedback that showed the letter could be seriously misinterpreted (although in a small number of cases), it is also recommended that **the letters be reviewed and re-tested** with parents from a range of socio-demographic backgrounds.

Specific recommendations include:

- the letters should be **reviewed and further tested** among parents to minimise the potential for misunderstanding
- content should **also be reviewed** to ensure the **subject areas of interest and importance to parents are covered** for each age group
- the **worries and concerns parents** and **young people** have in relation to the transfer to adult care should be addressed in the letters or provided on a website which the letters refer and link to
- the age for commencing the YTP should remain at 12 years, however, the best time to specifically mention transferring to adult health care should be reviewed. (Survey results show that information on school and diabetes is wanted by parents for this age group)
- consideration should be given to providing **more substantial information directly to young people**, possibly through a dedicated transition website or through child-friendly versions of the parent's letter
- consider using a **stronger prompt to encourage parents to initiate discussions with the HCP** on transition earlier (if this is seen as an important goal of the YTP)
- the use (placement/emphasis) of the **myD website** on the birthday card should be **reviewed**
- the YTP should allow parents and/or young people to **opt out** if they prefer **not** to receive the letter and/or card
- lower coverage in WA should be investigated.

As recommended in the YTP evaluation, all YTP communications/letters need to be reviewed, re-written and re-tested with parents – and, potentially, with HCPs. In the role as information provider, NDSS needs to a) continue to seek input from relevant HCPs when developing content and materials, and b) aim to inform HCPs of the materials/programmes they are implementing. HCPs are eager to be involved in NDSS initiatives, and have provided feedback on how best to communicate with them to obtain their input. Respondents to the survey suggested that a database of HCPs be established by NDSS and regularly updated/maintained for this purpose. The NDSS Online Service Directory already exists and it may be appropriate to increase awareness of this service through further promotion.

The NDSS may wish to consider conducting further research into or advocate for a change to the typical age at which transition to adult services occurs.

Acknowledgements

The Youth Transition Pack was launched in 2010 as an outcome of a NDSS Strategic Development Grant. The National Diabetes Services Scheme is an initiative of the Australian Government administered by Diabetes Australia. This initiative was implemented to engage young people with diabetes across Australia. In 2014 surveys were conducted with young people with diabetes, their parents and Healthcare Professionals working in this area in order to evaluate the success and awareness levels of the programme. This work was undertaken as part of the NDSS Young People with Diabetes National Development Programme. The NDSS is an initiative of the Australian Government administered by Diabetes Australia.

The surveys and final report were complied as part of the NDSS Young People with Diabetes National Development Programme in collaboration with researchers at The Australian Centre for Behavioural Research in Diabetes (ACBRD), a partnership for better health between Diabetes Victoria and Deakin University.

For further information about:

- the NDSS, visit: www.ndss.com.au
- the ACBRD, visit: www.acbrd.org.au

Research team

All surveys were led by:

- Renza Scibilia, NDSS National Development Programme Leader for Young People with Diabetes
- Professor Jane Speight, Foundation Director of the ACBRD

The research team included Dianna McDonald (Research Fellow).

Reference group

The design of these surveys was informed by the NDSS National Development Programme Young People with Diabetes Expert Reference Group (ERG). This reference group comprises a range of multi-disciplinary, national experts and consumer representatives who were invited to share their expertise in paediatric/behavioural diabetes research.

The reference group were consulted on the content of the surveys, and will continue to be involved in considering the response to the evaluation and collaborating with the research team in the preparation of peer-reviewed publications arising from this evaluation report.

Survey respondents

Last, but certainly not least, we would like to thank our survey respondents:

- young people (aged 12 – 20 years) with type 1 or type 2 diabetes
- parents of young people (aged 12 – 18 years) with diabetes
- Healthcare Professionals

The findings from these surveys will be used by Diabetes Australia to identify priorities and opportunities to expand and/or improve the support services provided to young people with diabetes and their families through the National Diabetes Services Scheme.

Appendix 1 – How could the move to adult diabetes health services be made easier?

Comments from young people who had transferred from paediatric services

"A bit more preparation would have been nicer. And possibly meeting the doctors more than once before I started to see them at my appointments (every 3 months)."

"A little bit more support in the transition."

"As a rural living individual, it would be better for myself and other rural diabetics if adult healthcare teams were willing to travel, like the paediatric teams did, to the town I live at. I ended up having to drive 2.5 hours to the nearest appropriate adult clinic and was unfamiliar with the hospital's layout."

"Being more similar to the children's one."

"Being part of a group with other type 1 diabetic teenagers, so we could be with someone when we move."

"Better specialists."

"By having a few appointments with both the paediatrician and the adult doctor to make the transition easier."

"Changes practice to practice, however all public sector paediatrics staff were excellent."

"Doctors with better understanding."

"Don't make it a six month wait just to get in to be able to see them, I have had major issues in the last two months, I lost 20kgs in two weeks (I didn't see it as a bad thing but my local GP insisted it wasn't good) I haven't been able to keep any food down & have had multiple visits to the hospital because of lows yet I can't get in to see anyone until February of next year?"

"Endocrinologists to spend more than just a five minute visit with you and to take more interest in young adults so that the transition isn't as dramatically different to paediatric care."

"Firstly I would have liked to have an introductory appointment with my adult care doctor and possibly had this with a member from my paediatric team so there would be more of a handover and someone there to make sure that the transition happened smoothly. I think that the support from the paediatric team is very important during transition, and possibly having the option of further support from NDSS or Diabetes SA would help during transition."

"Have one in the town I live and not 600 km away."

"Have people anonymously make comments on the services that the adult clinics provide and then have the comments passed onto people who are looking into going to an adult clinic. This will hopefully give the people who are looking into different doctors and specialists an idea of what they will be facing."

"Having an all-in-one clinic like paediatric but for adults."

"Visits prior to start date. Outline with differences in the service. Step-by-step instructions on how to book and what is needed when you attend. Asking patient what doctor or service they would like, rather than just what happens to be convenient."

"I had a lung transplant and got moved over to the adult hospital while there so I had no choice."

"I would have liked an introduction to a few adult services to choose an appropriate one for me and my needs."

"I would have liked to meet the adult diabetes care team before my first appointment."

"I would think constant support and a little more freedom to make the choices concerned with one's health."

"If had a little more information about the doctor I was going to be seeing."

"If the YADS could ask what type of care would be needed from each individual rather than just assuming that every three months is enough for every person."

"If they didn't wait so long after saying they would do it two months before."

"In all honesty I just assumed I would be seeing the same doctor, because they knew me, I had been seeing them since I was 18 months old and as of 19 I was moved on, now I understand that I probably should have seen that coming or known earlier, but it just never occurred to me so I was surprised."

"Information given on the types of people that you are likely to come into contact with as well as personality profiles on the team so you can chose who best suits you."

"Introduction to doctors and medical team before first appointment."

"Issues were more related to the lung transplant and forced transfer to adult services which couldn't deal with kids' diabetes."

"It actually happens, and I get to talk to a doctor."

"It could be useful to receive a 'fresh' set of information about diabetes and its relationship to this transition stage of life, i.e. I was given a book on managing diabetes for kids and teens when I was first diagnosed, but perhaps resources tailored to this age group (18 to early 20s) would be helpful."

"It could have been delayed further until I was older, unfortunately this was not able to be achieved as living in Darwin made the availability to see the paediatrician not an option. However the move to see an endocrinologist was fine and there are no real problems, it has been no different to what the few appointments I had with the paediatrician were."

"It is a lot easier if the patient takes responsibility for looking after themselves, as they are able to understand what is required to maintain their blood sugars/insulin injections at a healthy level. What has made things easier for me is taking responsibility (booking my own appointments, talking to my doctor one-on-one) to gain an understanding of what I need to do to keep myself healthy. Having my licence has made it much easier for me to get things done myself; attending my adult diabetes health clinic in Werribee is a massive breather as I live nearby."

"It was pretty good but just gradually introduce full independence so it doesn't become too overwhelming. Also gradually introduce making appointments and giving them the responsibility to follow up on results, plans etc., so they have responsibility and know that they have to put effort in and not everything is done for them."

"It was very easy, the diabetes clinic set up information sessions that were very helpful."

"It would be great if my notes from other health services (non-diabetes services from the same children's hospital) got sent to the adult clinic when I transferred."

"Just by being friendly and helpful."

"Make online booking."

"Maybe a little more exposure to the different environment and support teams/doctors/educators."

"Maybe meeting the team and being let know what they expect when you have an appointment. I wasn't aware that adults didn't use the finger prick HBA machine anymore and needed to get a blood test!"

"Maybe support groups, or you could transition with other similar age group diabetics to the clinic. At the YADS clinic, appointments were scheduled during similar times of the age group you were in, but that isn't so much the case with the adult clinic. There is less support there, and less of a chance to meet similar people in the same situation as other young adult diabetics, hence why I think many feel lost, confused or embarrassed going to uni and going out etc., and having to manage their condition. I know from talking to past friends at the YADs clinic that they have often neglected their health for the sake of feeling 'normal' in front of their non-diabetic peers, for lack of understanding on their friends' part and lack of support or encouragement from similar diabetic peers. I think it would be great if maybe a few optional gatherings or informative evenings or events where similar age diabetics could also meet may also help the move to the adult diabetes health service a little easier."

"Meeting the transition doctors before the first clinic."

"Mention was made about having a follow up appointment with my paediatrics doctor but that did not occur. It would have been good to have an appointment with my old doctor to confirm that my new doctor was suitable and that there were no concerns."

"More advice on the move by brochures etc. from the health people."

"More financial help."

"More information."

– continued

– continued

“More information could have been provided and being notified at an earlier stage would have been helpful.”

“More information provided – with this they should be keep short, but informative.”

“More information regarding the changes in the support given.”

“More information should have been given.”

“More structure to rural areas.”

“More support and guidance. Due to unforeseeable commitments I was unable to make my first appointment and was never followed up on after that – I was unsure what I was meant to do with making an appointment as I was no longer linked to the paediatric clinic and had no connection with the YADS clinic.”

“More time to organise appointments for doctors.”

“My doctor who treated me whilst I was a child didn’t refer me to any adult diabetes service. My GP ended up referring me.”

“My first few appointments were with a registrar, and my doctor only came in for a minute at the end of every session. The registrar was not competent in providing scripts and while I appreciate my doctor has many patients and is busy, essentially only seeing the registrar, particularly on my first visit I think has impacted on the relationship I have with my doctor (two years in and neither of us really knows the other).”

“My transition was a little different because this year I moved five hours away from home for uni. However, my move was made really easy with my doctor and diabetes educator talking me through the whole transition from living at home to being pretty much independent. They made it very clear that my health and wellbeing were now in my hands. Although every break when I come home I have another appointment to catch up.”

“Need access to doctors straight away, especially when you move away from home for the first time and your diabetes is out of whack. Need to meet diabetes educators who are readily accessible. Difficult time because you also don’t have a GP.”

“Need to come to Kambalda nurse post instead of going to Kalgoorlie Hospital every three months.”

“No comment – My transition was fine :).”

“No easier, was very organised and smooth.”

“Not much transition was needed as I was diagnosed at 17.”

“Not sure, I think it’s done well to make the move easy as it is.”

“Not sure. The current transition method has been brilliant, in my opinion.”

“Not that much at all, but I would recommend that parents who are helping their child’s way through it, try to involve their kids in the process of managing diabetes and visiting doctors, instead of handling it all by themselves.”

“Overall, my transition to adult diabetes health services was very easy. This is because it was in the exact same centre, with the same doctors. So, I believe that nothing could have been changed to make it easier, as it already was!”

“Perhaps if past medical records were sent to the doctor in advance. This probably happens but for me it didn’t and given I have a large set of notes it was very annoying explaining everything. First thing my endo said was that paediatric and adult care are managed very differently and I wish my paediatric educator had told me a little about that beforehand.”

“Personally I haven’t found it difficult but it will become more difficult if my diabetic educator nurse is no longer available as she has made the transition effortless.”

“Possibly making it consistent from all doctors, so at one point all health services move from children’s to adult. As opposed to different doctors changing at differing times.”

“Possibly more meeting with the adult team of doctors to get used to them.”

“More education.”

“Recognise that I’m still a teenager and not an adult.”

“Seeing the same people e.g. diabetes educators instead of brand new people and starting over again.”

“Should have asked more questions. Could have been given more direct contact numbers when I got confused.”

“Talk about it more while still in the paediatrics clinic and/or talk about it earlier, rather than once or twice and a sudden change.”

"Teaching me to count carbs."

"That the adult diabetic clinic returned phone calls and got back to me when I had a problem."

"The adult diabetes health services are great! I think they are easy enough already."

"The Brisbane Mater has provided lots of helpful info and the ongoing care."

"The changeover was absolutely fine, I didn't need any other information."

"The people who are the face of the department could be more relateable e.g. actual diabetics as they have firsthand experience."

"The process is a little confusing. Although my team was very helpful, an online or written guide to transitioning would have been useful. The guide could detail who to contact, where to go, who does what etc."

"They already offer a great service."

"In my experience the transition from the child/adolescent service to young adult was very easy and did not seem to be very different."

"In my experience, the system was very efficient and I knew the options that were available to me. No improvements I can see."

"It was perfect, all information I needed was provided."

"It was perfect for me."

"It didn't really need to be easier."

"I was diagnosed just before my 18th birthday."

"I was happy with the outcome."

"I was only diagnosed on my 18th birthday (this year) so this isn't applicable."

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