Supporting patients with type 1 diabetes using continuous subcutaneous insulin infusion therapy: difficulties, disconnections and disarray

RUNNING TITLE

Supporting patients with type 1 diabetes

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CONFLICTS OF INTEREST

None.

ABSTRACT

Rationale, aims and objectives

Use of continuous subcutaneous insulin infusion therapy in type 1 diabetes management is high. However, the incorporation of this technology into self-care is not without challenges, and the support of an appropriately skilled healthcare team is recommended. This study aimed to examine the support context for patients using continuous subcutaneous insulin infusion therapy from the healthcare professional perspective, as well as contextual influences for healthcare professionals and their patients.

Methods

This ethnographic qualitative study was undertaken in New South Wales, Australia. Recruitment occurred using a snowball sampling technique, beginning with members of an established diabetes service group. Data were collected through the use of semi-structured interviews undertaken by telephone and analysed using thematic analysis.

Results

Data were obtained from 26 interviews with staff from diverse professional backgrounds. An overarching theme of difficulties, disconnections and disarray emerged, with findings indicating that participants perceived difficulties in relation to shortages of healthcare professional continuous subcutaneous insulin infusion-related expertise, and disconnected and disarrayed service structures and process, with barriers to access to these devices. Individual healthcare professionals were left to manage somehow or opted not to engage with related care.

Conclusions

Findings provide insights from healthcare professionals' perspectives into the complexity of providing support for patients using continuous subcutaneous insulin infusion therapy across diverse contexts, and provide a platform for further research and service development. The

need for consistent and coordinated care, and the infrastructure to facilitate this, flags an opportunity to drive integration of care and team-working across as well as within settings and disciplines.

INTRODUCTION

Good glycaemic control is recognised as essential for the prevention or deferral of complications in type 1 diabetes (T1D) [1]. Continuous subcutaneous insulin infusion (CSII; insulin pump) therapy, as a method of insulin delivery, has been shown to facilitate such control for some and has been linked to improved quality of life [2-4]. Consequently, in many countries CSII uptake has been high. In the United States, for example, up to one in two people with T1D are using this technology [5, 6]. Uptake is lower in other countries, at around one in ten in Germany, Sweden and Australia, but increasing rapidly [7, 8]. In Australia, most recent data indicate that CSII usage as a method of insulin delivery consistently increased by an average of 107 to 140 new users each month from 2004-2010 [7], with the majority (70%) of users situated in major cities [7, 9]. In Australia it is younger people with type 1 diabetes who predominantly choose CSII technology, with approximately one in every two CSII users under the age of 25 years [7].

In the groups in which CSII is likely to be beneficial, usage is affected by many factors. For instance, uptake can be influenced by the capacity of the individual to pay for the device and the provision of expert staff. Therefore, funding policies and related processes are important, and vary across countries. A CSII device may be provided for patients with type 1 diabetes, irrespective of financial circumstance in Ontario, Canada, for example [10, 11], whilst in Australia the government provides limited means tested funding for low income families with children with type 1 diabetes [12]. CSII devices in Australia may also be obtained through personal finance, clinical trial enrolment, charitable donations or private health insurance, which often entails a lengthy application process and hospital admission at the time of CSII commencement. The majority (88%) of CSII users in Australia receive financial assistance to acquire their device, with almost all (97%) using private health insurance [7]. The

consequence of this method of purchase is that usage is more commonplace in higher socio-economic areas (14% versus 6%) [43]. Regardless of age, the consumables needed for patients with type 1 diabetes to use CSII technology are subsidised by the Australian Government, subject to eligibility criteria, as part of the National Diabetes Services Scheme [13].

CSII use almost always necessitates support from an appropriately skilled multi-disciplinary healthcare professional (HCP) team [7, 14-17], to determine insulin dosage algorithms, provide education and strategies to manage risks and achieve the anticipated benefits of CSII therapy [18, 19]. However, many Australian healthcare services are facing difficulty in meeting the increasing service support demand for CSII use [20]. Despite these well-known service and staffing concerns, there is little information about how patients using CSII therapy are supported from the perspective of responsible HCPs. This information is needed for comprehensive service planning and quality assessment processes, particularly for those living outside metropolitan areas and young people. This study aimed to examine from the HCP perspective the support context for patients using CSII therapy, as well as contextual influences for HCPs and their patients.

METHODS

This qualitative study was undertaken using an ethnographic research design in partnership with Hunter New England Local Health District (HNELHD), a regional public health services provider in New South Wales (NSW), Australia. HNELHD provides services for approximately 850,000 residents across 130,000 square kilometres of NSW [21], including metropolitan, regional and rural areas. Participants were eligible for the study if they were HCPs with current or recent responsibility for providing care for people with T1D using CSII

therapy. Ethical approval was obtained from HNELHD and University of Newcastle Human Research Ethics Committees.

Recruitment occurred using a snowball sampling technique, as there was no list of eligible diabetes HCPs in HNELHD. Sampling began with members of an established HNELHD-wide diabetes service group. All contacts were asked to voluntarily identify HCPs they were aware of with current or previous experience with CSII therapy, regardless of whether they themselves decided to participate or not. The process was repeated until there was broad representation across HCP groups and geographical locations, and it was felt data saturation had been achieved. At first contact potential participants were supplied with a letter of introduction, study information and a consent form.

Data were collected using individual semi-structured interviews undertaken by an experienced female clinical researcher (a Registered Nurse and Credentialed Diabetes Educator) by telephone during 2011-2012. Telephone interviews were chosen to facilitate participation by rural and regional HCPs and provide privacy for sharing potentially sensitive information or opinions. The interview schedule (Appendix 1) was developed during discussion by research team members, reviewed by clinicians from another health district, piloted and provided to consenting participants ahead of the telephone interviews. Participants were also asked to briefly describe their geographical location, professional background and, depending upon their employment, either their personal or service caseload of CSII users. Each interview commenced with an introduction and explanation of confidentiality principles. All interviews were audio recorded and brief field notes collected.

Audio data and interview field notes were transcribed and imported into NVivo 10 software. All data were de-identified. Data analysis was guided by Gibb's [22] framework and organised thematically. The framework included transcription and familiarisation, code building, theme development, data consolidation and interpretation. Transcripts were read by three authors (SJ, RG and LP) with coding initiated by one author (SJ). This was followed by emergent coding and organisation of themes, developed during discussion with all authors to reach consensus. Multiple investigators for the analysis allowed development of complementary and divergent understandings, and provided a context in which beliefs, values, perspectives and assumptions could be revealed and contested. Transcripts were not returned to participants though local presentation of findings provided opportunities to comment.

RESULTS

Twenty-seven semi-structured telephone interviews were conducted with a variety of HCPs working at diverse sites across metropolitan (n=15), regional and rural areas (n=12); one non-metropolitan interview was inaudible. Interviews analysed lasted mean (SD) 30 (14.4) minutes and participants identified themselves as diabetes nurse educators (n=12, one also a health service manager), dietitians (n=3), endocrinologists (n=5, 3 paediatric and 2 adult), paediatricians (n=3), and general practitioners (n=3). The paediatric CSII caseloads of HCPs ranged from one to one-hundred and fifty; those of adult HCPs ranged from two to sixty-five patients.

An overarching theme of difficulties, disconnections and disarray emerged from the data. Difficulties occurred partly as a result of the availability and range of appropriate CSII

expertise, which was perceived to exert a pervasive effect. This was in addition to barriers to access to CSII devices, consequent to government and private health insurance policy conditions. A lack of shared access to documentation and communication between adult and paediatric services, between separate components of the health service and with HCPs across organisations, resulted in disconnections which hindered a consistent, coordinated and informed approach to care. Finally, disarray followed the absence of consensus or definition for some key organisational processes and the subsequent delivery of care that was sometimes not standardised or consistent. There was also no consensus or policy for the specific training processes required by HCPs to provide CSII-related care.

Shortages of HCP expertise

Participants (particularly those working in non-metropolitan locations) expressed frustration with the lack of specific HCP expertise available for their patients, which they considered essential to support CSII use:

> *"Because we have no endocrinologist up here…. in effect there is really no service for young adults here on insulin pump therapy."* (HCP 26: non-metropolitan)

However, there was no consensus or policy for the specific training processes required by HCPs to provide CSII-related care. Competence was often obtained serendipitously and in many cases was funded by the individuals themselves or provided by diverse CSII manufacturers. This unsystematic approach to education may have contributed to the inconsistent support for CSII use. The availability and range of appropriate CSII expertise was perceived to exert a pervasive effect, including determination of whether CSII use was initiated or even raised as an option with a patient. Even more problematic, some health

providers were reported as declining to engage in discussion or management of diabetes with current CSII users. As one paediatric endocrinologist stated:

> *"The system doesn't allow for initiating or monitoring children or adolescents, or young adults on pumps here anyway."* (HCP 12: non-metropolitan)

This apparent failure of the system to acknowledge and engage with this care need occurred across the continuum of care, including while the patient was admitted to hospital, unwell and in need of support. This was most commonly reported in non-metropolitan areas.

The consequences of the lack of CSII expertise were far-reaching: those experts that were available had limited time, so extra efforts had to be made by non-expert staff to maximise the experts' time to address patients' issues. This could occur in metropolitan areas as well, as explained by a diabetes nurse educator:

> *"It's a real effort trying to contact support doctors because we don't have any on site. The only time we have people on site is for the…. clinic so if I've got any issues that are burning I'll confront them…. at the clinic."* (HCP 04: metropolitan)

The lack of expertise in hospital settings also meant that expert staff (predominantly the diabetes nurse educators) reported commonly going above and beyond their work requirements by providing personal telephone numbers to patients and their immediate families. However, the processes applied in identifying who required this extra support and for whom the HCPs were willing to disrupt their home life were unclear, but it was obvious that some degree of personal risk was perceived by participants:

"It sort of sounds bad but it depends on the client…. I always give my home number and my mobile number if they need it, but I might be a bit careful with some people about giving that out if I think that it's going to backfire on me." (HCP 16: non-metropolitan)

Despite this, few of the more expert participants expressed concern about their colleagues' difficulties. Only one interviewee (a diabetes nurse educator) raised other HCPs' needs or expressed a sense of responsibility to support those in non-metropolitan settings:

"I think we should have maybe a few meetings where the issues with insulin pump therapy…. what the guys out in the country need." (HCP 20: metropolitan)

Service structure and process shortfalls

The lack of shared access to documentation and communication between adult and paediatric services, between separate components of the health service and with HCPs across organisations hindered a coordinated approach to care. Where patients had been lost to follow-up, participants (predominantly physicians) reported being unaware whether patients had connected with a diabetes service in another location. The assessments and plans activated by one professional could be largely unknown to another, resulting in patients repeating their history and providers duplicating efforts. One general practitioner emphasised his frustration at not having reciprocal access to the records of the local hospital, children's hospital or community health:

"*They* [healthcare records] *all seem to be in three separate places, so they* [HCPs] *all have to take another full history and go through it all."* (HCP 27: non-metropolitan)

Lack of access to records meant that specialists could be asked to make recommendations based on very little information. For example, this endocrinologist expressed discomfort at signing approvals to commence CSII therapy:

> *"A lot of patients come into clinic as a one off…. use me as a one off specialist to sign them off for the pump, which I'm not really happy about. They* [the patients] *have never seen me before…. I don't know what level of knowledge and skills they have."* (HCP 21: metropolitan)

Another deficit was the absence of consensus or definition for some key organisational processes. Subsequently, care provided was not standardised with potential for advice to CSII users to vary for initiation, maintenance and support of this technology when considering aspects such as patient selection, expertise provided and follow-up, depending on the location and individual HCPs they attended. 'Hit and miss' processes potentially resulted in inconsistent patient follow-up:

> "*At the moment there's no recognised program in place. It's all hit and miss .... There's a real risk, in the current setup, that we put people on pumps, we see them perhaps a couple of times afterwards and then they sort of disappear into the wilderness."* (HCP 29: metropolitan)

CSII device access

The ability of patients to commence CSII therapy or update their CSII device was ultimately influenced by access to funding. Individuals who did not have private health insurance or

personal resources often could not afford initial set-up costs. Some CSII users had the device provided in childhood through a government subsidy but had difficulties as they transitioned from childhood because the subsidy ceased and, starting their working lives, their financial circumstances prohibited purchase. This sometimes meant low income young adults continuing to use their CSII device beyond the life and optimal function of the equipment. Participants had no option but to continue providing support in this situation, even if it was not what they saw as the patient's best interest:

> *"The pump itself is faulty because it's very old and at the moment she* [the patient] *doesn't have the resources to acquire another pump."* (HCP 26: non-metropolitan).

Private health insurance providers' requirements for funding CSII devices influenced service delivery. All private health insurance funds required a physician specialising in diabetes to sign an approval to commence CSII therapy; many also required a hospital admission at the time of commencement. Many participants (particularly rural staff) viewed this requirement as useful both socially and economically because of the distances some patients would have to travel, in the event of technical, operational or related medical problems. Others (particularly metropolitan staff), however, saw this in a more negative light, considering the disruption to patients' lives and costs to the public healthcare system irrespective of clinical need. Some participants navigated around this requirement by creating virtual wards so patients were not physically admitted, thereby reducing the impact of an admission on their patients and the wider public health system.

Collectively, from HCPs' perspectives, issues illustrated difficulties, disconnections and disarray in the support for patients using CSII, and how this context functions for HCPs and

their patients. Inequities and uncoordinated healthcare were described. This reflected lack of specific expertise in some locations but also lack of teamwork and common agreed care policies and processes, all undermined by lack of common data systems, communication infrastructure and connectivity. This left unsupported individuals unwilling to contribute to CSII care, and forced others to decide for themselves which patients received what forms of support.

HCPs perceived benefits and shortfalls accruing to government and private health insurance policy conditions. Government policy recognised the importance of supporting equity of access for disadvantaged children. However, eligibility for the CSII device subsidy ceased at age 18 years, whereas the economic disadvantage could persist beyond this. Private health insurers requiring a hospital admission for CSII commencement irrespective of clinical need potentially benefited some patients but unnecessarily burdened others and the public healthcare system, causing further difficulties and disarray.

DISCUSSION

This study provides insights into HCPs' perspectives of the complexity of providing support for patients using CSII therapy across diverse contexts, and lays out a platform for further research and service innovation. Previous local and international research focusing on service support for T1D, and chronic disease in general, have also demonstrated deficiencies in planning and provision of specialist HCP expertise and management [23-26]. This group of HCPs indicated that these were live issues not just for patients but for their healthcare providers.

CSII users need ongoing support and monitoring, and their healthcare teams need to be able to deliver this, to provide the best chance to delay or deter the development of vascular complications that are seen in people with T1D at young ages [27, 28], and their associated costs [29]. Economic analysis under research conditions has demonstrated the benefit of CSII versus multiple daily injections [30]. What is needed now is to put into daily clinical practice those elements that are required to translate the benefits seen in research into 'business as usual' clinical practice. The findings of this study flag important deficits that may need attention, in order for this to occur.

Ways to promote and support engagement, both for patients and HCPs, should be considered [20]. Eligibility criteria for a CSII device subsidy from the Australian Government includes the stated presence of a system to ensure follow-up and ongoing support [12]. However, there are no in-built facilitators, inducements or monitoring to ensure that this is honored. Further, outside of National Diabetes Services Scheme registration requirements there are no in-built facilitators or inducements to promote regular engagement of CSII users with diabetes health-care teams; in this study the risk of patients being lost to CSII-related follow-up was highlighted. This flags, at minimum, the need for integration of healthcare records on a mandatory rather than voluntary basis, with pan-Australian access accorded to healthcare providers across primary to tertiary services. Financial incentives to maintain contact with health services such as those in Ontario, Canada, could also be considered [31].

Many staff (predominantly in metropolitan areas) expressed the need for improved and perhaps dedicated services for CSII users. This strategy could support development of a structured team approach, potentially enabling more consistent patient follow-up and perhaps better patient outcomes from CSII usage. A place to start might be in the dissemination and

adoption of Australian evidence-based CSII therapy clinical guidelines [15]. Policies and procedures to translate guidelines into practice should be formulated. These should consider the appropriate selection of patients for CSII use and self-management, as well as the expertise required by HCPs to care for CSII users and support other staff [14-16]; to enable professional development of competent HCPs to support CSII related care. Australian state-based guidelines for in-hospital CSII care are available [32].

To augment the dedicated services suggested above, phone, online and electronic support can be considered, particularly for young people [24] and staff in rural areas. Technologies such as video-conferencing may also benefit and facilitate the provision of peer support amongst diabetes HCPs, and HCP support for patients where this is otherwise locally lacking [33]. Whether CSII is the best option for a patient needs to be carefully considered, including at the time of transition, also taking account of ongoing access to appropriate supportive care.

Findings also suggest that policy innovation may also be required to enable equitable CSII access. Australian government funding for access to a CSII device, supportive of children, could potentially be extended to cover the early adult years of eligible young people with T1D [20]. Aspects such as device and consumable provision, upgrades and the technology support required to achieve the anticipated benefits for the entire period of CSII therapy use should be further investigated. Given the complex nature of patterns of socio-economic advantage and disadvantage amongst the community, it is possible that increased financial support alone might exacerbate rather than ameliorate inequalities between those who can afford to use CSII and those who cannot.

The representative nature of the sample from which findings derived is impossible to gauge. Nonetheless the sample comprised a large proportion of healthcare providers covering a very large geographical area. The use of snowball sampling may have generated sampling bias due to initial participants nominating HCPs they knew, who may have shared opinions as well as experiences, and whose recruitment was by self-selection. These HCPs were employed by a single public healthcare provider, albeit participants worked as members of multiple different local teams. Findings reflect their experiences and perceptions at one point in time.

In summary, findings clearly indicate the need for policy and practice innovation to better enable staff to support patients with T1D using CSII therapy, and to support staff providing this care, especially in non-metropolitan areas. The need for consistent and coordinated care, and the infrastructure to facilitate this, drives an opportunity to reconfigure relationships between acute centres (often the repositories of specialist expertise) and community/primary care, where such expertise is required for preventive care but often lacking. It presents an opportunity to drive integration of care, and team-working, across as well as within disciplines and settings.

Comprehensive service planning and monitoring involving diabetes HCPs nationwide may be required; in many geographical areas appropriate resource allocation and use of other technologies to promote engagement with and between diabetes services may be warranted to demonstrate the comparative cost effectiveness of service redesign. Diabetes technology is advancing rapidly, requiring a skilled and responsive workforce and flexible health services capable of adapting rapidly to change. The need for service innovation and redesign is pressing.

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AUTHOR'S CONTRIBUTIONS

Study proposal developed by LP, JL, JD and KS. Analyses conducted by SJ and LP. Paper drafted by SJ, LP, RG and JL; revised and agreed by all authors. All authors read and approved the final manuscript.

REFERENCES

1. The Diabetes Control and Complications Trial Research Group, *The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus.* N Engl J Med, 1993. **329**: p. 977-986.
2. McMahon, S., F. Airey, D. Marangou, et al., *Insulin pump therapy in children and adolescents: improvements in key parameters of diabetes management including quality of life.* Diabet Med, 2005. **22**: p. 92-96.
3. Misso, M., K. Egberts, and M. Page, *Continuous subcutaneous insulin infusion (CSII) versus multiple insulin injections for type 1 diabetes mellitus. CD005103.* Cochrane Database Syst Rev, 2010.
4. Yeh, H., T. Brown, N. Maruthur, et al., *Comparitive effectiveness and safety of methods of insulin delivery and glucose monitoring for diabetes mellitus: a systematic review and meta-analyses.* Ann Intern Med, 2012. **157**(5): p. 336-347.
5. Alsaleh, F., F. Smith, S. Keady, et al., *Insulin pumps: From inception to the present and toward the future.* J Clin Pharm Ther, 2010. **35**: p. 127-138.
6. Beck, R., W. Tamborlane, R. Bergenstal, et al., *The T1D exchange clinic registry.* J Clin Endocrinol Metab, 2012. **97**(12): p. 4383-4389.
7. Australian Institute of Health and Welfare, *Insulin pump use in Australia.* Diabetes series no.18; Cat. no. CVD 58. Australian Government: Canberra, 2012.
8. Selam, J., *CSII in Europe: where are we, where are we going? An analysis of articles published in Infosystems International.* Diabetes Res Clin Pract, 2006. **74**((Suppl. 2)): p. s123-s126.
9. Department of Health, *Work of the Australian Government on diabetes, Available at: www.health.gov.au, accessed 4th February 2014.*
10. Ontario Ministry of Health and Long-Term Care, *Assistive Devices Program. Insulin Pump Therapy, Available at: www.health.gov.on.ca/en/public/programs/adp/insulin_pamp.aspx, accessed 12th April 2016.*
11. Pharmaceutical Management Agency, *Funding of New Zaland Medical and Scientific Insulin pump and consumables approved, Available at: www.pharmac.govt.nz/2012/08/08/2012-08-08%20Notification%20of%20Insulin%20pumps.pdf, accessed 12th April 2016.*
12. Juvenile Diabetes Research Foundation, *Insulin Pump Grants, Available at: http://jdrf.org.au/type-1-diabetes/insulin-pmp-program-information, accessed 12th April 2016.*
13. Diabetes Australia, *National Diabetes Services Scheme - Product and Supply, Available at: https://www.ndss.com.au/product-and-supply, accessed 1st August 2016.*
14. Grunberger, G., J. Abelseth, T. Bailey, et al., *Consensus statement by the American Association of Clinical Endocrinologists /American College of Endocrinology insulin pump therapy task force.* Endocr Pract, 2014. **20**(5): p. 463-489.
15. The Australian National Adult Insulin Pump Therapy Working Group, *Provision of Quality Care for Adults with Type 1 Diabetes Requiring Insulin Pump Therapy (IPT).* Infosyst Asia, 2013. **8**(1): p. 1-12.
16. The Australian National Adult Insulin Pump Therapy Working Group, *Healthcare Professional Requirements for the Care of Adult Diabetes Patients Managed with Insulin Pumps in Australia.* Intern Med J, 2015. **45**(1): p. 86-93.
17. James, S., L. Perry, R. Gallagher, et al., *Diabetes Educators' intended and reported use of common diabetes-related technologies: discrepancies and dissonance.* J Diabetes Sci Technol, 2016: p. 1-10; DOI: 10.1177/1932296816646798.
18. Lynch, P., A. Riedel, N. Samant, et al., *Resource utilization with insulin pump therapy for type 2 diabetes mellitus.* Am J Manag Care, 2010. **16**: p. 892-896.
19. Wheeler, B., K. Heels, K. Donaghue, et al., *Insulin Pump - Associated Adverse Events in Children and Adolescents - A Prospective Study.* Diabetes Technol Ther, 2014. **16**(9): p. 1-5.
20. Diabetes Australia, *Insulin Pump Therapy in Australia. The Case for Action.* Diabetes Australia; Canberra: Australian Government, 2014.
21. Hunter New England Health, *Our District, Available at: www.hnehealth.nsw.gov.au/Pages/Our-District.aspx, accessed 10th March 2016.*
22. Gibbs, G., *Analysing Qualitative Data, London: Sage Publications.* 2012.
23. Perry, L., K. Steinbeck, J. Dunbabin, et al., *Lost in transition? Access to and uptake of adult health services and outcomes for young people with type 1 diabetes in regional New South Wales.* Med J Aust, 2010. **193**(8): p. 444-449.

24. Perry, L., J. Lowe, K. Steinbeck, et al., *Services doing the best they can: service experiences of young adults with type 1 diabetes mellitus in rural Australia.* Journal of Clinical Nursing, 2012. **21**(13-14): p. 1955-1963.
25. Von Sengbusch, S., E. Müller-Godeffroy, S. Häger, et al., *Mobile diabetes education and care: intervention for children and young people with Type 1 diabetes in rural areas of northern Germany.* Diabetic Medicine, 2005. **23**: p. 122-127.
26. Brundisini, F., M. Giacomini, D. DeJean, et al., *Chronic disease patients' experiences with accessing health care in rural and remote areas: a systematic review and qualitative meta-synthesis.* Ontario Health Technology Assessment Series, 2013. **13**(15): p. 1-33.
27. James, S., R. Gallagher, J. Dunbabin, et al., *Prevalence of vascular complications and factors predictive of their development in young adults with type 1 diabetes: systematic literature review.* BMC Res Notes, 2014. **7**(593): p. 1-11.
28. James, S., L. Perry, R. Gallagher, et al., *Service Usage and Vascular Complications in Young Adults with Type 1 Diabetes.* BMC Endocr Disorders, 2014. **14**(39): p. 1-9.
29. Colagiuri, S., A. Brnabic, M. Gomez, et al., *DiabCo$t Australia Type 1: assessing the burden of type 1 diabetes in Australia.* Diabetes Australia: Canberra, 2009.
30. Roze, S., J. Smith-Palmer, W. Valentine, et al., *Cost-effectiveness of continuous subcutaneous insulin infusion versus multiple daily injections of insulin in Type 1 diabetes: a systematic review.* Diab Med, 2015. **34**(11): p. 1415-1434.
31. Cheung, R. and Mui, *Reimbursement Programs and Health Technology Assessment for Diabetes Devices and Supplies: A Canadian Perspective.* J Diabetes Sci Technol, 2015. **9**(3): p. 706-710.
32. Queensland Health, *Inpatient Guidelines: Insulin Infusion Pump Management.* Queensland Health: Brisbane, 2012.
33. Dunbabin, J., L. Perry, K. Steinbeck, et al., *Can Telehealth Engage Young People with Type 1 Diabetes? Experiences from the YOuR-Diabetes Project.* Aust Diabetes Educ, 2015. **18**(3): p. 32-34.

Appendix 1 – Semi-structured interview schedule

Thinking about the young people with type 1 diabetes on your caseload who use an insulin pump, now or in the recent past:

1. Have any of your patients ever used an insulin pump? How many would you have, and can you tell me a little about them, including where they were started on their pump or who initiated their insulin pump treatment?
2. What is your role in their ongoing care? For example, are you actively involved in supporting and monitoring their pump use? If so, please describe.
3. Within your area, how many healthcare professionals are actively involved with initiating, monitoring and supporting young people with insulin pumps? What are their roles?
4. Are there sufficient services and knowledgeable health care professionals available to treat young adults with pumps in your area?

   If not, which areas are well serviced and which could be strengthened?
5. Have there been any recent changes to improve services in your area? If so, please describe them.

   What sort of differences are they making? (to service provision and to the cost of service provision)
6. What are the enablers and barriers to interactions with other service providers (GPs, physicians, hospital staff, private providers like dietitians, podiatrists, optometrists, ophthalmologists, and pathology) in better managing young people using insulin pumps?

   Can you suggest anything that might improve this?

7. What are your thoughts about the adequacy of current service models and processes for initiation, maintenance and support of young people on insulin pumps to meet future demand in your diabetes service?
8. Is there anything else you would like to add?