

Do Diabetes Educators provide Person-centred Care?

An Australian pilot study.

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What is already known?

- Desired levels of person-centred care are not being met across healthcare professions.
- There are eight important dimensions of person-centred care.
- Person-centred care is particularly beneficial to outcomes for people with diabetes mellitus since they typically self-manage their treatment.

What this study has found

- Diabetes Educators deliver comparatively high levels of person-centred care.
- Consumer understanding of policy and system improvement areas requires enhancement.
- Survey options require revision.

What are the clinical implications of the study?

- Detailed survey and/or administration methodology adjustments are recommended to improve survey accessibility and interpretability of results.

Abstract

Aim:

To determine the extent to which Person-centred Care is experienced by consumers of Diabetes Educator community services in Victoria, Australia.

Method:

A cross-sectional survey design was implemented electronically within three clinics. The study participants were 34 adults with Type 1 or 2 diabetes mellitus and English literacy skills, able to self-manage their diabetes and attended individual appointments with a Diabetes Educator. The survey included 11 questions related to a person's most recent experience visiting a Diabetes Educator. Likert scale responses produced descriptive statistics of median and percent frequency of responses by question, total and dimension for each clinic and combined. Thematic analysis principles were broadly applied to the written responses to identify overarching themes.

Results:

Consumers experienced the highest level of person-centred care 78% of the time, with 93% of experiences positive. Participants desire increased communication with professionals outside clinic boundaries and provision of support group information. The findings indicate a clear need to enhance people's understanding of policy and system improvement areas (principles 9 and 10) before a Diabetes Educators performance can be appropriately assessed. Similarly, the survey's accessibility needs to be improved as it limited the interpretability of results.

Conclusions:

The participating diabetes educator clinics demonstrated a comparatively high rate of person-centred care provision. However, only three dimensions demonstrated clarity and confidence in the findings. The survey's accessibility should be addressed and the research methodology adjusted in line with the detailed recommendations made here, prior to further research being undertaken.

Key Words:

Patient-Centered Care; Patient experience; Diabetes Mellitus; Surveys and questionnaires; Self-Management; Australia; Health Literacy

Introduction:

There is no standard definition of Person-Centred Care (PCC) (1). However, it can be described as health care that is respectful of, and responsive to, an individual's preferences, needs and values (2). Delivery of PCC is thought to improve health and service delivery outcomes which lead to organisation and system wide benefits (3). As a result, person-centred care is being prioritised worldwide (4). Yet, literature across healthcare professions consistently indicates that desired levels of PCC are not being met (5, 6). Given improvement models typically address isolated dimensions of PCC, evaluation of where improvement is required must first occur.

Evaluating the provision of PCC is complex. In 1993 Gerties (7) published a landmark study identifying eight dimensions thought necessary to achieve PCC (Figure 1). These eight dimensions can form a framework for evaluation. To date, evaluation of PCC experiences during provision of allied health services has focused on isolated dimensions of PCC and exploring qualitative data (8) from a variety of opinions and perspectives (9, 10). Literature indicates evaluation which includes the integration of quantitative and qualitative data (2) from the consumer perspective (11) across the eight dimensions whilst maintaining anonymity (12) is required.

Figure 1: Eight dimensions of Person-Centred Care (Gerties, 1993)

1. Respect for patient's values, preferences and expressed needs
2. Coordination and integration of care
3. Information, communication and education
4. Physical comfort
5. Emotional support and alleviation of fear and anxiety
6. Involvement of family and friends
7. Continuity and transition
8. Access to care

The Australian Diabetes Educators Association (ADEA) developed a PCC toolkit which aims to assist Diabetes Educators (DE's) to evaluate the delivery of PCC (13). PCC is considered particularly beneficial when consumers self-manage treatment (14) and people with diabetes provide approximately 95% of their own care (15). Yet, the extent to which people believe they receive PCC from their DE, within which of the eight necessary dimensions, nor

use of the ADEA tool, have been reported within the literature to date. Consequently, this pilot study was guided by the question, 'To what extent do consumers of DE community services experience PCC within each of the eight dimensions?'

Research Design and Methods

A cross-sectional survey design was implemented. Ethics approval was received from Charles Sturt University Faculty of Science Human Research Ethics Committee (H400201736) which acts in accordance with the Australian National Statement on the Ethical Conduct in Human Research. This pilot study was conducted in line with coursework requirements for a Master of Health Service Management degree. Clinic governance procedures were confirmed, and piloting of procedures occurred prior to commencement.

Survey

The Consumer Survey section of the ADEA PCC Toolkit was utilised (13). The survey asks people to rate their experience of visiting the DE via a five-point Likert-scale which ranges from 'never meets' to 'consistently meets every time I visit them'. People can explain this rating if they wish, facilitating qualitative data via an open-ended question. The ten questions, referred to by developers as Principles, were mapped against the eight PCC dimensions. Mapping indicated seven of the eight dimensions were addressed by at least one Principle (see Table 4). The dimension '*Physical Comfort*' was not addressed and Principle 10 was deemed not to map. The question "is there anything we have not talked about that you would like to add?" was included by the researchers. Completion instructions were adjusted to include, "If you don't know or don't understand the question please choose a number and write that in the comments box below," following pilot phase feedback. Demographic data relating to age, diabetes type and diagnosis, clinic and payment type was also collected.

Procedure:

Three clinics across 4 sites in rural and metropolitan regions of Victoria, Australia facilitated participant recruitment. Clinics were required to have two or more DE's, administration staff and be providing individual community services. Convenience sampling was utilised with clinics screening current bookings to identify eligible participants. Eligibility criteria were, 18+ years old with the ability to read and write English, diagnosed with Type 1 or 2 diabetes

more than three months ago, self-manage treatment and attend individual, rather than group, appointments. Eligible people who visited their DE over a 9-week period were invited to participate by administration staff. Each participant completed a detail release form (DRF) consenting to receive the survey from researchers, with subsequent completion of the survey considered participation consent. Participants were requested to complete the survey anonymously online within six weeks for recall accuracy. Demographic and survey rating questions were compulsory with explanatory questions optional. Two completion reminders were sent via email at fortnightly intervals.

Data Analysis

Clinic 2 did not recruit any participants, so was excluded. Participation rates (Table 1) and participant demographic data (Table 2) were analysed by clinic and combined. Where possible, results were compared with clinic population data (Table 1). Quantitative and qualitative survey data were treated as separate data sets. Likert scale responses produced descriptive statistics of median and percent frequency of responses by question/principle, total (Table 3) and PCC dimension (Table 4); for each clinic and combined.

Thematic analysis principles were broadly applied to the qualitative data (16). Descriptive coding occurred initially to group the information within principles. Answers to 'do you have anything to add', were mapped to Principles where coding matched. Focused coding then identified overarching themes within principles (Table 4). Repeated themes were considered, however, no causal connections or further coding occurred given answers were intended to explain quantitative findings. To ensure trustworthiness a second researcher reviewed data coding.

Results

Participation Rates

11% of the clinics' populations were eligible to participate during the study period. A 20% response rate and 54% completion rate occurred meaning 2.3% (34 people) of the clinic's populations participated (Table 1).

Table 1: Available clinic population data and survey participation rates

Variable	Clinic 1	Clinic 3	Total
Staffing	1.3 FTE (3 DE's)	1.6 FTE (2DE's)	
Location	Metropolitan – 2 sites	Rural – 1 site	
No. active clients	650	815	1465
Survey Participants	3.5%	1.4%	2.3%
Type 1 Diabetes	40%	7.3%	24%
Type 2 Diabetes	47%	93%	70%
Payment assistance			
Medicare	62%	35%	48%
Private	39%	55%	47%
Other		10% rural specific fund	5%
Eligible to participate	103	65	168
Consenting participants	43 (42%)	20 (31%)	63 (38%)
Complete eligible responses	23	11	34
Ineligible responses¹	2	4	6
Response Rates²	22%	17%	20%
Completion Rate³	53%	55%	54%

1. Ineligible responses = 5 responses incomplete; 1 (Clinic 3) was completed 58 days post appointment

2. Response Rate = number of people who provided a complete and eligible response from those who were *eligible* to participate.

3. Completion Rate = number of people who provided a complete and eligible response from those who *consented* to participate.

Survey Participants

Demographic data confirmed participants' eligibility (Table 2). Results show the mean age of survey participants was 50 years, with a range of 21-76 years. People with type 1 diabetes and those funded by Medicare were over-represented as compared to clinic population data, largely because of the increased participation rates of Clinic 1 where these factors were more prevalent among the population.

Time taken to complete the survey was recorded as typically being 16 minutes. Participation rates were deemed too low to conduct subgroup analysis to determine whether demographic variables influenced the level of PCC experienced.

Table 2: Characteristics of survey participants

Demographic Variable	Clinic 1	Clinic 3	Combined
Age			
Range	21 – 75	24 - 76	21- 76
Average (mean)	50	56	51
Type 1 Diabetes	78%	9.1%	56%
Type 2 Diabetes	22%	91%	44%
Diabetes diagnosis	5 months to 48 years ago	6 months to 31 years ago	5 months to 48 years
Self-management	100%	100%	100%
Survey response time⁴			
Average (days)	11	18	13
Range (days)	1-29	0 (same day) - 42	0-42
Payment assistance			
Yes	70% (16)	45% (5)	62% (21)
No	30% (7)	55% (6)	38% (13)
Payment assistance			
Medicare	88% (14)	83% (5)	86% (19 of 22)
Private	6% (1) Family	-	5% (1)
Other	6% (1) Department of Veterans Affairs	17% (1) Pensioner rate	9% (2)
Education level			
Highschool	22% (5)	27% (3)	24% (8)
TAFE	26% (6)	18% (2)	24% (8)
Undergraduate	26% (6)	27% (3)	26% (9)
Postgraduate	17% (4)	18% (2)	18% (6)
Other	9% (2)	9% (1)	9% (3)

4.Survey response time = number of days between survey receipt and participants statement of last DE appointment

Survey Results

Participants report experiencing the highest level of PCC expected every time they visit the DE in 78% of situations (Table 3). Expressing rating and comment results by PCC dimension (Table 4) indicates *Information, Communication and Education* was the dimension within which most people experienced optimal PCC. Written information and phone follow up were the reasons for such positive results. *Access to Care* and *Coordination and Integration*

of Care produced optimal responses in 82% and 76% of cases respectively. Comments generated themes suggesting improvement may occur with provision of additional information related to support groups (*access to care*) and increasing communication with professionals outside the clinic boundaries (Clinic 1 only).

Table 3: Mode and % Frequency of response by Principle/question

Principle	Mode	% frequency of response				
		5	4	3	2	1
1	5	94	5.9	0	0	0
2	5	59	41	0	0	0
3	5	74	15	8.8	0	2.9
4	5	82	15	2.9	0	0
5	5	91	8.8	0	0	0
6	5	91	5.9	2.9	0	0
7	5	76	21	2.9	0	0
8	5	82	12	2.9	0	2.9
9	5	68	18	15	0	0
10	5	59	8.9	26	2.9	2.9
Total		78	15	6.2	0.3	0.9

Within the remaining dimensions and Principle 10 the themes generated indicate there was a combination of misunderstanding of terms used, the inability to know the answer and good examples of PCC provision (Table 4). This issue is explored further in the Discussion.

Emotional support and alleviation of fear and anxiety was the lowest rated dimension (68% rating 5). The lowest rated Principles were 2 and 10 (59% rating 5). The dimension *Respect for patient's values, preferences and expressed needs* combines principles 1 and 2. Principle 1 refers to a person's goals and overall wellbeing and 2 addresses respect for a person's culture and health beliefs. Combining these results indicates 24% of people believe there is room for improvement, yet Table 4 shows this needs to occur in relation to Principle 2 as opposed to 1, which received the highest individual rating (94%).

Continuity and Transition was the only dimension without any good examples to indicate question understanding. Participants felt the question was repetitive with others in the survey, not applicable to them because they manage their diabetes alone and continued to focus on the way they needed to adjust to fit into their environment and how the DE could

help them, as opposed to how they could communicate with others or adjust their environment. The theme of ‘importance of family support’ was generated within the *Involvement of Family and Friends dimension* (Table 4), despite many participants again noting this aspect was not applicable to them as they self-manage their condition.

The repeated theme of general respect (between survey Principles 2 and 3) and misunderstanding of additional terms (outcomes, individual adjustment, others in the community and self-management) (Table 4), limited the interpretability of results in numerous dimensions.

Table 4: Mode, % Frequency of response and qualitative data themes generated, by Dimension

Dimension	Mode	% Frequency					Themes
		5	4	3	2	1	
Respect for patient’s values, preferences and expressed needs	5	76	24	0	0	0	Principle 1: Good examples Principle 2: Misunderstanding (health beliefs); General respect focused; No cultural beliefs
Coordination and integration of care	5	76	21	2.9	0	0	Principle 7: Good examples; Within and outside clinic communication; Medical and DE communication; DE and other health professional communication
Information, communication and education	5	91	7.4	1.5	0	0	Principle 5: Good examples; Written information, Phone follow up Principle 6: Good examples; Misunderstanding (outcomes); Concern re technology information
Emotional support and alleviation of fear and anxiety	5	68	18	15	0	0	Principle 9: Good examples; Don’t know; Misunderstanding (others in community)
Involvement of family and friends	5	74	15	8.8	0	2.9	Principle 3: Good examples; Respect only focus; N/A as self-manage; Importance of family support
Continuity and transition	5	82	12	2.9	0	2.9	Principle 8: Misunderstanding (individual adjustment); DE supportive; Repeat; Not asked; N/A as self-manage
Access to care	5	82	15	2.9	0	0	Principle 4: Good examples; support groups; email updates
	5	59	8.8	26	2.9	2.9	Principle 10: Can’t know; Don’t understand; Misunderstanding (policy and service development; quality assurance)

Discussion

This small-scale project indicates relatively high levels of PCC provision. Consumers of DE community services experienced the highest level of PCC 78% of the time, reporting a positive experience (rating 5 or 4) 93% of the time. Use of this tool has not previously been reported in the literature. However, when evaluating Cancer service's responsiveness, Tremblay, Roberge (17) reported a similar generally positive experience with little variation. Others across the chronic care spectrum report PCC 'some of the time' using the Patient Assessment of Chronic Illness Care (PACIC) survey (3, 18).

Only 3 dimensions produced results which demonstrated clarity and confidence in the findings. *Information, communication and education; Access to care and Co-ordination and integration of care.* Results within these dimensions further demonstrate these clinics are providing PCC comparatively well (3, 19). Increased provision and knowledge of support groups was suggested by participants as something which would enable improved PCC provision. However, literature shows little support for the long term benefits of support groups among people with diabetes (20). This difference between consumer wants and evidence may indicate a need for the DE to discuss topics in an evidence-based manner, rather than omit topics of interest, if optimal PCC provision is to occur.

The remaining dimensions contained words and concepts which appear to have been misunderstood by survey participants; which raises concern regarding the survey's accessibility. One participant provided this reflection;

"I found it hard to answer some of these questions, they were very wordy" (Survey Results, Clinic 1).

The survey's Flesch-Kincaid Grade level is 10.1. Health literacy requirements recommend level 6-8 (21), indicating the survey's accessibility requires addressing. However, the survey was deemed the most appropriate option available for the target audience for the following reasons:

- identified as the only Australian generated, diabetes specific PCC survey which integrates qualitative and quantitative data collection from the consumer perspective
- it can be applied via methodology which maintains anonymity
- the missing dimension of pain management is not typically relevant to DE practice and
- content validity was addressed by the developers through use of literature reviews and a modified Delphi approach with consumer involvement.

Future studies should consider providing a definition of terms to complement the survey, in the absence of the developers revising the survey to a more accessible reading level or a more appropriate survey tool becoming available within the literature.

Misunderstanding of terms also limited the interpretability of results. Principle 2 themes indicate the term health beliefs was potentially misunderstood. For example, it is not clear how this comment relates to the principle of respecting a person's culture and health beliefs,

“I work in a stressful environment, this is factored into my care plan” (Survey results, Clinic 1).

Overall, it was difficult to ascertain the desired improvements relating to Principle 2 via participants' comments. The 'overlap' between comments relating to Principle 1 and Principle 2 suggest that the distinction between them might not have been fully appreciated by participants. Burton, Entwistle (22) found that the concepts encompassed within the relevant dimension *Respect for patient's values, preferences and expressed needs* are the most valued attributes of PCC. Therefore, it appears important to further explore the differences between principles 1 and 2 and participant's interpretation of and comments relating to these, to aid an understanding of how PCC can be improved. Whilst defining terms may help, in-depth interviews to explore the concepts raised may also assist (12). The ADEA toolkit incorporates a consumer interview aspect which could be utilised for this process.

The theme of importance of family support was raised but does not appear to have been intentionally addressed by the researchers within Principle 3. The need to, and importance of, involving family members has been demonstrated (23) and recognised by health professionals (19). These results combined with the many participants who indicated in Principles 3 and 8 that family/carer involvement aspects were not applicable as they self-manage their condition, indicate the need to explore this theme further. This could be done through the use of Press-Ganey questions as per the study by Heinemann, Lavela (3).

Principles nine and ten differed in that people clearly indicated they did not or could not know the answer, rather than misunderstanding the question. The pilot raised concern this may occur, which prompted adjustment to the survey instructions. However, forcing people to choose a response when they did not know the answer appears to have lowered the quality of the rating data. 26% of respondents chose 3; perhaps indicating people considered this a neutral response when they didn't know the answer. Not forcing a response results in increased item non-response rates (24). Therefore, a more optimal solution for future studies may be offering a 'don't know or 'prefer not to answer' option in the future (24) to improve the clinical utility of the tool (16).

Survey developers indicate Principles 9 and 10 relate to Policy and System Improvement rather than Health Care. Principle 9 specifically addresses partnering with consumers and their representatives to educate colleagues and the wider community, so they are better informed to make life easier for people living with diabetes, and principle 10 targets co-design of policy and services. One participant provided a clear example of what PCC in principle 10 feels like:

“I am a member of a consumer group for the hospital and all policies are debated through us. He always is willing to listen to our concerns” (Survey results, Clinic 3).

Whilst consumers are unlikely to be well placed to answer questions regarding how well their DE performs in these areas if they don't wish to be involved or utilise these aspects, consumers need to be afforded the opportunity of involvement and use. Given many participants indicated they either misunderstood or recognised they could not know the

answer to these two questions, in the least, improvement relating to informing clients of the opportunity to contribute to, understand and benefit from these aspects is required.

Study Limitations

Being a pilot project conducted within a master's program, various aspects impacted the generalisability of the results. The low response rate (20%) and percentage of clinic populations involved (2.3%) is a limitation of this study. Response rates below 80% risk nonresponse bias (25), therefore the rates need to increase to attain generalisable results.

There are many ways the methodology could be adjusted when aiming to improve the response rate. The researcher being separate from clinics limited immediate survey provision which may have negatively impacted the response rate. However, anonymity has been shown to be vital in eliciting honest responses (26) and the power differential between the DE and participants must be carefully considered when adjusting the survey procedures in future studies. More immediate response options which respect these factors include provision of the survey on a tablet device and/or paper-based completion facilitated by administration staff. Such options would likely increase the diversity of participants and benefit rural locations where home internet is less prevalent (27). Survey fatigue due to competing surveys was noted as possibly impacting on response rates by Clinics 2 and 3. Ensuring the survey occurs in isolation may therefore be important. Pre-paid incentives have been shown to increase response rates and still allow anonymity to be maintained (28).

Survey participation eligibility requirements were set at a maximum of 42 days for recall accuracy. Decreasing this timeframe should increase accuracy (29) and decrease the need for reminders; subsequently easing survey administration burden. An extended data collection period would likely increase participant numbers.

The increased expense and time associated with possible solutions for improving the response rate must be considered. Utilising paper-based options increases data entry time requirements but is a simple task. Analysis of qualitative data is time consuming and complex, yet these results demonstrate their necessity for understanding findings and identifying improvements targeted to a clinic's unique population. The importance of

administration staff facilitating survey provision in a consistent and positive manner should also be noted and was not controlled for nor evaluated in this study methodology.

The effect of demographic variables on PCC evaluation is conflicted within the literature (4, 17, 30) and the Criterion validity of the tool has not been reported (16). Future studies need to evaluate population and participant demographic data across many variables before confidently generalising results. The survey does not address the physical environment which literature indicates should be addressed by individual clinics (30).

Recommendations and Conclusions

This pilot project indicates a comparatively high rate of PCC provision within the two participating clinics, however, room for improvement remains. The findings indicate a clear need to improve communication relating to policy and system improvement areas (principles 9 and 10) to deepen people's understanding of the area before a DE's performance in these areas can be appropriately considered. It is also recommended Clinic 1 consider developing communication methods with those outside their clinic. However, the low response rate and accessibility of the tool limited the survey's ability to elicit more detailed results and the generalisability of the study. Given the need to evaluate PCC to ensure optimal health and service delivery outcomes and identification of the ADEA PCC survey tool as the best available option for doing so among this population, these results indicate further work is required to adequately inform future practice. Future research is recommended to:

- use the ADEA survey with a definition of terms or revise the tool to improve user accessibility
- offer a 'don't know' or 'prefer not to answer' option within the Likert responses
- more deeply address the theme of 'the importance of family support'
- complement the survey with interview use where deeper understanding of results is required

- adjust the methodology to employ strategies which will likely increase the response rate whilst maintaining anonymity and separation of the treating DE from survey completion
- evaluate the impact of demographic variables.

A larger study including a variety of clinics could allow the Diabetes Educators profession to have a broad understanding of the level of PCC provision occurring in the Australian context and whether there are common dimensions requiring improvement. However, individual clinic results need to be considered within broader studies, since local improvement needs are likely to differ and evaluation of the physical environment should occur locally.

Conflict of Interest Disclosure:

Neither author has a conflict of interest to declare.

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REFERENCES

1. Kogan AC, Wilber K, Mosqueda L. Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review. *Journal of the American Geriatrics Society*. 2016;64(1):e1-e7.
2. Australian Commission on Quality and Safety in healthcare. Patient-centered care: Improving quality and safety through partnerships with patients and consumers. Sydney: Australian Commission on Quality and Safety in healthcare; 2011.
3. Heinemann AW, Lavela SL, Etingen B, Miskovic A, Locatelli SM, Neumann HD, et al. Perceptions of Person-Centered Care Following Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*. 2016;97(8):1338-44.
4. Murphy K, Chuma T, Mathews C, Steyn K, Levitt N. A qualitative study of the experiences of care and motivation for effective self-management among diabetic and hypertensive patients attending public sector primary health care services in South Africa. *BMC health services research*. 2015;15(1):303.
5. Foley H, Steel A. Patient perceptions of clinical care in complementary medicine: A systematic review of the consultation experience. *Patient Education and Counseling*. 2017;100(2):212-23.
6. Rathert C, Wyrwich MD, Boren SA. Patient-Centered Care and Outcomes: A Systematic Review of the Literature. *Medical Care Research and Review*. 2013;70(4):351-79.
7. Gerties M, Edgman-Levitan, Daley J, Delbanco TL. Through the patient's eyes: Understanding and promoting patient-centred care. Michigan: Jossey-Bass; 1993.
8. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *J Adv Nurs*. 2013;69(1):4-15.
9. Brown M, Levack W, McPherson KM, Dean SG, Reed K, Weatherall M, et al. Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke. *Disability and rehabilitation*. 2014;36(12):1020.
10. Maclellan DL, Berenbaum S. Dietitians' opinions and experiences of client-centred nutrition counselling. *Canadian journal of dietetic practice and research : a publication of Dietitians of Canada = Revue canadienne de la pratique et de la recherche en dietetique : une publication des Dietetistes du Canada*. 2006;67(3):119-24.
11. Michie S, Miles J, Weinman J. Patient-centredness in chronic illness: what is it and does it matter? *Patient Education and Counseling*. 2003;51(3):197-206.
12. Tsianakas V, Maben J, Wiseman T, Robert G, Richardson A, Madden P, et al. Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both? *BMC Health Services Research*. 2012;12(1):271.
13. <https://www.adea.com.au/Home> Person-centred care toolkit Measurement instrument 2015 [cited 2016 21/10/2016]. Available from: https://www.adea.com.au/projects/person-centred-care/wp-content/uploads/2016/06/ADEA_PCC-Toolkit_COMPLETE-FINAL.pdf
14. Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient Education and Counseling*. 2002;48(1):51-61.
15. Krichbaum K, Aarestad V, Bueth M. Exploring the Connection Between Self-Efficacy and Effective Diabetes Self-f Management. *The Diabetes Educator*. 2003;29(4):653-62.
16. Liamputtong P. Research methods in health: Foundations for evidence-based practice 3rd ed. Victoria, Australia: Oxford University Press; 2017.
17. Tremblay D, Roberge D, Berbiche D. Determinants of patient-reported experience of cancer services responsiveness. *BMC Health Services Research*. 2015;15.

18. Noël P, Parchman M, Palmer R, Romero R, Leykum L, Lanham H, et al. Alignment of patient and primary care practice member perspectives of chronic illness care: a cross-sectional analysis. *BMC Family Practice*. 2014;15(57):57.
19. Holt RIG, Nicolucci A, Kovacs Burns K, Escalante M, Forbes A, Hermanns N, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): Cross-national comparisons on barriers and resources for optimal care—healthcare professional perspective. *Diabetic Medicine*. 2013;30(7):789-98.
20. Ing CT, Zhang G, Dillard A, Yoshimura SR, Hughes C, Palakiko D-M, et al. Social Support Groups in the Maintenance of Glycemic Control after Community-Based Intervention. *Journal of Diabetes Research*. 2016;2016.
21. <https://healthliteracy.nswlhd.health.nsw.gov.au/>. A checklist for health literate organisations (Brochure): New South Wales (NSW) Government; 2018 [cited 2018 16/08/2018]. Available from: <https://www.nswlhd.health.nsw.gov.au/>
22. Burton CD, Entwistle VA, Elliott AM, Krucien N, Porteous T, Ryan M. The value of different aspects of person-centred care: a series of discrete choice experiments in people with long-term conditions. *BMJ Open*. 2017;7(4).
23. Nefs G, Pouwer F, Holt RIG, Skovlund S, Hermanns N, Nicolucci A, et al. Correlates and outcomes of worries about hypoglycemia in family members of adults with diabetes: The second Diabetes Attitudes, Wishes and Needs (DAWN2) study. *Journal of Psychosomatic Research*. 2016;89:69-77.
24. Décieux Jean P, Mergener A, Neufang Kristina M, Sischka P. Implementation of the forced answering option within online surveys: Do higher item response rates come at the expense of participation and answer quality? *Psihologija*. 2015;48(4):311-26.
25. The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation. In: Frey BB, editor. Thousand Oaks,, California: SAGE Publications, Inc; 2018.
26. Bernard AW, Lindsell CJ, Handel DA, Collett L, Gallo P, Kaiser KD, et al. Postal survey methodology to assess patient satisfaction in a suburban emergency medical services system: an observational study. *BMC Emergency Medicine*. 2007;7(1):5-.
27. <https://www.abs.gov.au/>. Region summary; rest of Vic; Family and community. : Australian Bureau of Statistics; 2016 [cited 2018 20/09/2018]. Available from: http://stat.abs.gov.au/itt/r.jsp?RegionSummary®ion=2RVIC&geoconcept=ASGS_2016&dataset=ABS_REGIONAL_ASGS2016&datasetLGA=ABS_REGIONAL_LGA2017&datasetASGS=ABS_REGIONAL_ASGS2016®ionLGA=LGA_2017®ionASGS=ASGS_2016.
28. Asire A. A Meta-Analysis of the Effects of Incentives on Response Rate in Online Survey Studies. In: Olmos A, Green K, editors.: ProQuest Dissertations Publishing; 2017.
29. Cosenza FJFC. The SAGE Handbook of Applied Social Research Methods. 2009 2018/10/28. Thousand Oaks, California: SAGE Publications, Inc. 2. [375-412]. Available from: <http://methods.sagepub.com/book/the-sage-handbook-of-applied-social-research-methods-2e>.
30. Tzelepis F, Sanson-Fisher RW, Hall AE, Carey ML, Paul CL, Clinton-Mcharg T. The quality of patient-centred care: haematological cancer survivors' perceptions. *Psycho-Oncology*. 2015;24(7):796-803.



