BMJ Open

# Diabetes outpatient care for adolescents: associations between adolescent experiences, parent experiences and HbA1c



| | |
|---|---|
| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2019-032201 |
| Article Type: | Research |
| Date Submitted by the Author: | 11-Jun-2019 |
| Complete List of Authors: | Iversen, Hilde; Norwegian Institute of Public Health ,<br>Bjertnaes, Oyvind; Norwegian Institute of Public Health<br>Skrivarhaug , Torild; Oslo University Hospital, Division of Paediatric and Adolescent Medicine, The Norwegian Childhood Diabetes Registry; University of Oslo, Institute of Clinical Medicine |
| Keywords: | patient experiences, parent experiences, diabetes, questionnaire, HbA1c |
| | |

# Diabetes outpatient care for adolescents: associations between adolescent experiences, parent experiences and HbA1c

**Authors:**

Hilde Hestad Iversen[1] (hilde.hestad.iversen@fhi.no, +47 46400425) (Corresponding author)

Oyvind Bjertnaes[1] (oyvindandresen.bjertnaes@fhi.no)

Torild Skrivarhaug[2,3] (torild.skrivarhaug@medisin.uio.no)

**Affiliations:**

[1]Norwegian Institute of Public Health, PO Box 4404 Nydalen, N-0403 Oslo

[2]Division of Paediatric and Adolescent Medicine, The Norwegian Childhood Diabetes Registry, Oslo University Hospital, PO Box 4956 Nydalen, N-0424 Oslo

[3] Institute of Clinical Medicine, University of Oslo, PO Box 1078 Blindern, N-0316 Oslo

**Keywords:** patient experiences, parent experiences, diabetes, questionnaire, adolescent HbA1c

**Word count:** 2,507

# Abstract

## Objective

The aim of the current study was to determine the association between the experiences of adolescents and their parents with paediatric diabetes care at hospital outpatient departments and the association between these experiences and the HbA1c levels of adolescents.

## Design

Cross-sectional survey.

## Setting

Paediatric diabetes care at hospital outpatient departments in Norway.

## Participants

Parents of all outpatients registered in the Norwegian Childhood Diabetes Registry and patients in the same registry aged 12–17 years.

## Intervention

1,399 parents participated in a national pilot survey, and 335 patients aged 12–17 years from the 4 largest paediatric outpatient departments in Norway responded in another pilot study. 181 paired parental and patient questionnaires were analysed.

## Main outcome measures

The correlations between single items, indicator scores and overall scores were explored, as was that between indicator scores and HbA1c levels.

## Results

There was a moderate but significant correlation between the responses of the patients and parents, and a weak but significant negative correlation between the indicator scores of parents

and the HbA1c levels of the adolescents. There was no significant correlation between HbA1c level and patient indicator scores.

**Conclusions**

These results highlight the need to obtain information from both parents and adolescents, and indicate that the views of adolescents are not always mirrored by their parents. Most of the parent experience indicators were significantly related to the HbA1c levels of adolescents, implying that interventions to improve parent experiences also might improve clinical outcomes.

# Article Summary

## Strengths and Limitations

- The study used validated instruments whose survey content and response scales were adapted for the specific patient/parent and age groups included.
- Both parents and adolescents experiences and adherence were explored, and the results can provide guidance concerning the most appropriate care to provide at outpatient clinics.
- The surveys were performed by an independent third party that was not involved in providing health care.
- While the parent survey was nationwide, the adolescent survey was restricted to four clinics and the results should be replicated in larger surveys.
- Another limitation is that our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

# Introduction

Norway has one of the highest incidences of childhood-onset type 1 diabetes in the world, and 0.6% (*n*=28,000) of the total population has type 1 diabetes [1]. Type 1 diabetes usually develops in childhood or early adolescence, and parents therefore play an important role in the day-to-day management of the disease. This responsibility places considerable demands on parents, and family involvement is a crucial component of optimal diabetes management [2].

Adolescents experience challenges to adherence that are intrinsic to their developmental stage and demands for peer normality [3]. Diabetes may become a daily struggle against undesirable blood glucose levels and risk complications, hormonal changes can lead to insulin resistance, and there are several other factors underlying poor glycaemic control in this phase of life [4].

Norwegian children attend follow-up appointments with a paediatrician and a diabetes nurse at their local paediatric outpatient department in hospitals approximately four times yearly. Dieticians and psychologists can also be consulted if requested. Given the importance of the parental role in the health-care decisions and daily follow-up of adolescents, the interactions between the adolescent and parent plus those with the health-care provider are an important component of the outpatient visit.

There is a growing recognition of the importance of assessing the experiences of patients with health care when attempting to provide patient-centred health services. Reviews have found that better patient experiences and satisfaction are associated with higher levels of adherence to recommended prevention and treatment interventions as well as better clinical outcomes [5–7]. An adult population-based survey of patients with type 2 diabetes found that strategies that increased patient satisfaction also contributed to improving the clinical outcomes [8]. Another

study found that the parent ratings of the quality of outpatient diabetes care were negatively correlated with the mean HbA1c levels of their children. In the same study adolescents aged >13 years who reported a higher quality of care had lower HbA1c levels [9]. However, other studies have not found significant correlations between the satisfaction of young peoples with diabetes care and their HbA1c levels [10–12].

Parents or caregivers are usually asked to respond on behalf of children younger than a certain age. The views of children and adolescents have largely been ignored in large-scale patient-experience surveys, despite evidence that children may be willing to respond from the age of 8 years and that their health-care priorities diverge from those of their parents from the age of 12 years [13–15]. A cross-sectional analysis of national survey data in England showed that including inpatients aged 8–15 years in a patient-experience survey was both feasible and enhanced the information obtained from the responses of parents alone [13].

The results from previous studies show that there are discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20]. A review found that young people aged 16–24 years consistently report worse health-care experiences compared to older adults [18]. Another study found a strong correlation between the quality of diabetes care as perceived by parents and adolescents, but differences in the importance that the two populations placed on different aspects of care [9]. The level of agreement is generally better between parents and their chronically sick children than between parents and their healthy children [21].

Information about potential differences in perceptions could be useful for providers when delivering outpatient care, and when trying to balance the needs and expectations of adolescents and their parents. Also, such findings can provide guidance when measuring and monitoring patient and parent experiences with outpatient care for the purpose of quality improvement. The

aim of the present study was to determine the association between the experiences of adolescents and parents with paediatric diabetes care at hospital outpatient departments, and the association between these experiences and the HbA1c level of the adolescents. To our knowledge, only two previous studies have simultaneously assessed the associations between parent experiences, adolescent experiences and clinical outcomes for this patient group [9, 12], and none of them were performed in Norway. Based on those previous studies, we hypothesized that there would be a correlation between the perceptions of parents and the adolescents about the quality of outpatient care, but no correlation with the HbA1c level.

# Methods

## Data

Responses from adolescents were collected in a pilot study that included all patients at the four largest outpatient departments in Norway who were aged 12–17 years, had type 1 diabetes and were registered in the Norwegian Childhood Diabetes Registry (NCDR) ($n$=685). The sample was contacted by post in April 2017. The request included a letter with information about the survey, a printed version of the questionnaire, a prepaid return envelope and also an option to answer electronically. Non-responders were sent up to two postal reminders. The national parent experience survey has been described elsewhere [22, 23] and here we include 181 parents that were matched with the adolescent survey.

All paediatric departments report the results of annual standardized examinations to the NCDR. Background data were transferred from the NCDR to the Norwegian Institute of Public Health

(NIPH) after data collection was completed, but for a few patients data on HbA1c and the number of consultations were not complete at the time of transfer.

## Measures

Two new measures were developed and tested in accordance with the standard methodology of the national user-experience survey programme in Norway [22, 23]: the Parent Experiences of Diabetes Care Questionnaire (PEQ-DC) and the Adolescent Patient Experiences of Diabetes Care Questionnaire (APEQ-DC) [22]. The questionnaires were designed to be applied in surveys of parents of children and adolescents with type 1 diabetes of all ages and of adolescents with type 1 diabetes aged 12–17 years visiting paediatric outpatient departments in Norway, and are included in Additional file 1 and 2.

We asked about experiences at the paediatric outpatient clinic that the child visited for follow-up appointments. Five-point scales with response options that ranged from “not at all” (1) to “a very large extent” (5) were used for most items relating to the experience of care. Smiley faces were used to illustrate the response options in the APEQ-DC. Many items also included a “not applicable / don’t know” option. An open-ended question on the last page asked for further comments.

The PEQ-DC and APEQ-DC had similar (but not identical) contents. The results obtained in the development process showed that certain themes or questions were not relevant for both groups. The process highlighted the importance of ensuring that the patient questionnaire was as short as possible while also comprising age-appropriate items. The psychometric testing of the PEQ-DC identified six indicators: consultation, organization, equipment, nurse contact, doctor contact and

outcome. Five indicators were identified for the APEQ-DC: consultation, information on food/exercise, nurse contact, doctor contact and outcome.

The HbA1c level is a measure of long-term blood glucose levels and reflects the average level over the preceding 4–12 weeks, weighted towards the most-recent 4 weeks. Data were obtained from the NCDR and reported as percentages and in millimoles per mole (mmol/mol).

### Statistical analysis

Overall scores for each respondent were calculated by summing the scores for all of the indicators and dividing by their total number. The relationship between the patient and parent experiences at the outpatient clinic was tested by calculating Pearson correlation coefficients for indicator scores and the overall scores. Direct comparisons were possible between the self-reported experiences of the parents and patients for eight questions.

The indicator scores and overall scores were also correlated with the HbA1c level analysed as a continuous variable. Correlations were assessed using Pearson's *r* values.

All statistical analyses were conducted using SPSS version 23.0.

### Approval

The study was approved by the Data Protection Authority at Oslo University Hospital. Registration in the NCDR is based on a signed informed consent from the child (older than 12 years) and/or the child's parents. The consent form informs the patient and/or the parents that

consent may result in requests to answer questionnaires on patient experiences. Returning the questionnaire constituted consent in the survey.

### Patient and public involvement

The survey was about patients and parents experiences with experiences with health care. Patients and parents were included in the development process of the instrument, to secure that the questionnaire included the most important topics for patients and parents.

## Results

1,399 (55.4%) parents responded to the questionnaire, while questionnaire responses were received from 335 (53.6%) adolescent patients. The characteristics of the 181 included adolescents and their parents are presented in Table 1. Fifty-four percent of the adolescents were boys, and their mean age was 14.7 years (Table 1). The mean age when diagnosed with type 1 diabetes was 9.4 years, and the mean HbA1c level at the last registration in the NCDR was 8.2% (66.1 mmol/mol). The mean age of the parents was 46.0 years and 78.8% were female (Table 1), while 70.4% had a university or college education.

Table 2 lists the indicator scores and item scores for both adolescents and parents. The adolescent indicators had scores ranging from 57.2 (for information on food/exercise) to 87.3 (for doctor contact), and the overall score was 78.5. The parent indicator scores ranged between 60.6 (for equipment) and 79.9 (for nurse contact), and the overall score was 72.9.

Table 3 presents the coefficients for the correlations between the indicator scores of the adolescents and parents. All of the correlations were statistically significant except the parent score for doctor contact and the adolescent score for nurse contact. The correlation coefficients ranged from $r$=0.16 to $r$=0.44. The strongest correlations were between the adolescent score for the consultation indicator and the parent score for the organization indicator ($r$=0.44, $P$<0.001), the overall score indicator ($r$=0.44, $P$<0.001), and the outcome indicator ($r$=0.40, $P$<0.001). The coefficient for the correlation between the parent and adolescent overall scores was $r$=0.40 ($P$<0.001).

Table 4 indicates that all correlations between individual questions with identical wordings in the two surveys were significant. The strongest correlation was for the questions pertaining to meeting the same doctor ($r$=0.46, $P$<0.001) and training in how to use equipment ($r$=0.38, $P$<0.001).

No significant correlations were found between the adolescent indicators and their HbA1c level (Table 5). Five of the seven parent indicators were significantly correlated with the HbA1c level. The strongest correlation was found between nurse contact and HbA1c level ($r$=0.22, $P$<0.01).

## Discussion

This study found high average ratings from both adolescents and parents, but with the evaluations from parents being somewhat more critical. The parent experiences did not accurately represent the views of the patient, as demonstrated by weak-to-moderate correlations. Most parent experience indicators were correlated with the HbA1c level, but this was not the case for the adolescent experiences.

Most previous studies have found discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20], which is in line with our findings. However, one of the very few studies related to diabetes outpatient care found a very strong correlation between patient and parent assessments [9]. There are several possible reasons for explaining the lack of convergence, but we believe the questionnaires used and the measurement approach might be the main reasons. That previous study initially used a general patient-experience questionnaire for adult patients, then adjusted it to an adolescent diabetes version and a parent version [9] but without performing further testing and validation [24]. Although this was not stated explicitly, it appears that the two surveys of how patients and parents perceived the care received were carried out simultaneously. If so, the surveys were not independent, and the parents and adolescents might have completed the questionnaires jointly [24]. This raises questions about the validity of both questionnaires, the measurements made and the estimated correlations.

Unlike the results obtained in previous surveys [13, 16, 19], the current study found that the average indicator scores for adolescents were higher than the average indicator scores for their parents. These previous studies had varying contexts and methodologies, but none of them based their comparisons on questionnaires that were developed and validated specifically for each group. Furthermore, our finding is in accordance with the general patient-satisfaction literature indicating that proxies are more critical than patients [25–30]. The indicator score for adolescents in our study was lowest for information on food/exercise, suggesting that more time should be spent on providing adolescents with such information. These findings are in accordance with previous research highlighting communication and information as an area for improvement [9, 13, 19, 20]. Adolescents gave the highest ratings for the doctor contact indicator, while the parents scored equipment the lowest and nurse contact the highest.

No significant associations between the adolescent indicators and HbA1c level were found, in line with previous studies [10–12]. However, five of the seven parent indicators were correlated significantly with the adolescent HbA1c levels. Previous studies and reviews have found associations between patient experiences or satisfaction and adherence to recommended prevention and treatment processes and clinical outcomes [5–9]. In this setting it therefore seems that parents have a closer connection to clinical quality than do the adolescents themselves. The implication is that interventions to improve parent experiences also might improve clinical outcomes.

The assumption that adults can answer for children has traditionally gone unchallenged. The views of children and adolescents have largely been ignored in large-scale surveys, and parents or carers are often asked to respond on their behalf. There is a need to develop methods that allow young people to provide feedback on the quality of health care that they themselves consider relevant. The two instruments applied in this study were developed in a rigorous manner. Considering the important role played by parents in diabetes treatment regimes, studies exploring the relationship between experiences and adherence must take into account the perspectives and needs of both parent and adolescent. Understanding differences and similarities between these two groups can provide guidance concerning the most appropriate care to provide at outpatient clinics.

This study was subject to some limitations. While the parent survey was nationwide, the adolescent survey was restricted to four clinics. This raises questions about the generalizability of the findings, and the results should be replicated in larger surveys. Also, our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

## Conclusions

All but one of the correlations between the indicator scores of the parents and adolescents were statistically significant, but the agreements between the reported experiences were all only weak or moderate. The results highlight the need to collect information from both parents and adolescents, and confirm that the views of adolescents are not always mirrored by their parents. Most parent experience indicators were significantly related to the adolescent HbA1c level, implying that interventions to improve parent experiences also might improve clinical outcomes. Understanding the correspondence between the viewpoints of parents and adolescents is potentially useful for informing interventions aimed at improving the health care provided at paediatric outpatient departments [22].



## Funding

This work was supported by the Knowledge Centre at the NIPH, the NCDR and "Lillian and Werner Næss legat". The NCDR is funded by the South-Eastern Norway Regional Health Authority.

## Competing interests

On behalf of both authors, the corresponding author states that there is no competing interests.

## Author contributions

T.S. initiated the study. H.H.I. planned the study in consultation with O.A.B. and T.S. H.H.I. performed the statistical analyses with O.A.B. and T.S., and drafted the manuscript. O.A.B. and T.S. participated in the planning process, critically revised the manuscript draft and approved the final version of the manuscript. H.H.I. was the project manager for the two surveys. All authors read and approved the final manuscript.



## Acknowledgements

We thank Inger Opedal Paulsrud, Olaf Holmboe, Johanne Kjøllesdal and Nam Pham from the Knowledge Centre at the NIPH for their help in developing and conducting the surveys, including performing administrative and technical tasks for the data collection. We further thank Ann Kristin Drivvoll from the NCDR for extracting data from the registry.

## Availability of data and material

The data sets generated and/or analysed during this study are not publicly available due to the need to protect personal data.

# References


1. Strøm H, Selmer R, Birkeland KI, Schirmer H, Berg TJ, Jenum AK, et al. No increase in new users of blood glucose-lowering drugs in Norway 2006–2011: a nationwide prescription database study. BMC Public Health. 2014;14 (1):520.
2. Laffel LM, Vangsness L, Connell A, Goebel-Fabbri A, Butler D, Anderson BJ. Impact of ambulatory, family-focused teamwork intervention on glycemic control in youth with type 1 diabetes. J Pediatr. 2003;142(4):409–16.
3. Borus JS, Laffel L. Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. Curr Opin Pediatr. 2010;22(4):405–11.
4. Datye KA, Moore DJ, Russell WE, Jaser SS. A review of adolescent adherence in type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. Curr Diab Rep. 2015;15(8):51.
5. Anhang Price R, Elliott MN, Zaslavsky AM, Hays RD, Lehrman WG, Rybowski L, et al. Examining the role of patient experience surveys in measuring health care quality. Med Care Res Rev. 2014;71(5):522–54.
6. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3(1):e001570.
7. Ofman JJ, Badamgarav E, Henning JM, Knight K, Gano AD Jr, Levan RK, et al. Does disease management improve clinical and economic outcomes in patients with chronic diseases? A systematic review. Am J Med. 2004;117(3):182–92.
8. Alazri MH, Neal RD. The association between satisfaction with services provided in primary care and outcomes in type 2 diabetes mellitus. Diabet Med. 2003;20(6):486–90.

9. Hanberger L, Ludvigsson J, Nordfeldt S. Quality of care from the patient's perspective in pediatric diabetes care. Diabetes Res Clin Pract. 2006;72(2):197–205.
10. de Wit M, Delemarre-van De Waal HA, Bokma JA, Haasnoot K, Houdijk MC, Gemke RJ, et al. Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improve psychosocial well-being: a randomized controlled trial. Diabetes Care. 2008;31(8):1521–6.
11. Gray S, Cheetham T, McConachie H, Mann KD, Parr JR, Pearce MS, et al. A longitudinal, observational study examining the relationships of patient satisfaction with services and mental well-being to their clinical course in young people with type 1 diabetes mellitus during transition from child to adult health services. Diabet Med. 2018;35(9):1216–22.
12. Koves IH, Boucher A, Ismail D, Donath S, Cameron FJ. Satisfaction of care in a tertiary level diabetes clinic: correlations with diabetes knowledge, clinical outcome and health-related quality of life. J Paediatr Child Health. 2008;44(7-8):432–7.
13. Hargreaves DS, Sizmur S, Pitchforth J, Tallett A, Toomey SL, Hopwood B, et al. Children and young people's versus parents' responses in an English national inpatient survey. Arch Dis Child. 2018;103(5):486–91.
14. Ambresin A-E, Bennett K, Patton GC, Sanci LA, Sawyer SM. Assessment of youth-friendly health care: a systematic review of indicators drawn from young people's perspectives. J Adolesc Health. 2013;52(6):670–81.
15. Santelli JS, Rosenfeld WD, DuRant RH, Dubler N, Morreale M, English A, et al. Guidelines for adolescent health research: a position paper of the Society for Adolescent Medicine. J Adolesc Health. 1995;17(5):270–6.

16. Chesney M, Lindeke L, Johnson L, Jukkala A, Lynch S, Disch J, et al. Comparison of child and parent satisfaction ratings of ambulatory pediatric subspecialty care. J Pediatr Health Care. 2005;19(4):221–9.

17. Sawyer SM, Ambresin A-E, Bennett KE, Patton GC. A measurement framework for quality health care for adolescents in hospital. J Adolesc Health. 2014;55(4):484–90.

18. Hargreaves DS, Viner RM. Children's and young people's experience of the National Health Service in England: a review of national surveys 2001-2011. Arch Dis Child. 2012;97(7):661–6.

19. Byczkowski TL, Kollar LM, Britto MT. Family experiences with outpatient care: do adolescents and parents have the same perceptions? J Adolesc Health. 2010;47(1):92–8.

20. Hopwood B, Tallett A. Little voice: giving young patients a say. Nurs Times. 2011;107(49-50):18–20.

21. Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a systematic review. Qual Life Res. 2001;10(4):347–57.

22. Iversen HH, Helland Y, Bjertnaes O, Skrivarhaug T. Parent experiences of diabetes care questionnaire (PEQ-DC): reliability and validity following a national survey in Norway. BMC Health Serv Res. 2018;18 (1):774.

23. Bjertnaes O, Iversen HH, Skrivarhaug T. A randomized comparison of three data collection models for the measurement of parent experiences with diabetes outpatient care. BMC Med Res Methodol. 2018;18 (1):95.

24. Hanberger L. Quality of Care in Children and Adolescents with Type 1 Diabetes: Patients' and Healthcare Professionals' Perspectives. Linköping: Linköping University Electronic Press; 2010.

25. Bjertnaes O. Patient-reported experiences with hospitals: comparison of proxy and patient scores using propensity-score matching. Int J Qual Health Care. 2013;26(1):34–40.

26. Elliott MN, Beckett MK, Chong K, Hambarsoomians K, Hays RD. How do proxy responses and proxy-assisted responses differ from what Medicare beneficiaries might have reported about their health care? Health Serv Res. 2008;43(3):833–48.

27. Epstein AM, Hall JA, Tognetti J, Son LH, Conant L Jr. Using proxies to evaluate quality of life. Can they provide valid information about patients' health status and satisfaction with medical care? Med Care. 1989;27(3 Suppl):S91–8.

28. O'Malley AJ, Zaslavsky AM, Elliott MN, Zaborski L, Cleary PD. Case-mix adjustment of the CAHPS Hospital Survey. Health Serv Res. 2005;40(6 Pt 2):2162–81.

29. Strasser S, Schweikhart S, Welch GE 2nd, Burge JC. Satisfaction with medical care. It's easier to please patients than their family members and friends. J Health Care Mark. 1995;15(3):34–44.

30. Walker AH, Restuccia JD. Obtaining information on patient satisfaction with hospital care: mail versus telephone. Health Serv Res. 1984;19(3):291–306.

**Table 1:** Background characteristics of the adolescents (*n*=181) and the parents (*n*=181).

| *Characteristic* | *%/mean* |
|---|---|
| **Adolescents** | |
| Sex, % | |
| Male (*n*=98) | 54.1 |
| Female (*n*=83) | 45.9 |
| Mean age, years (*n*=181) | 14.7 |
| Mean age when diagnosed with diabetes, years (*n*=181) | 9.4 |
| Mean diabetes duration, years (*n*=181) | 5.4 |
| Mean HbA1c level, % (*n*=165) | 8.2 |
| Number of consultations during previous year (mean: 6.2), % | |
| 1–3 (n=40) | 24.4 |
| 4–6 (n=48) | 29.3 |
| 7–9 (n=57) | 34.8 |
| 10–21 (n=19) | 11.6 |
| General condition today, % | |
| Very poor (n=1) | 0.6 |
| Fairly poor (n=3) | 1.7 |
| Neither poor nor good (n=31) | 17.2 |
| Fairly good (n=89) | 49.4 |
| Very good (n=56) | 31.1 |
| Norwegian % | |
| Yes (*n*=169) | 93.4 |
| No (*n*=12) | 6.6 |
| **Parents** | |
| Sex, % | |
| Male (*n*=38) | 21.2 |
| Female (*n*=141) | 78.8 |
| Mean age, years (*n*=179) | 46.0 |
| Education, % | |
| Primary school (*n*=3) | 1.7 |
| Secondary school (*n*=50) | 27.9 |
| University or college (0–4 years) (*n*=54) | 30.2 |
| University or college (>4 years) (*n*=72) | 40.2 |
| Living with the child's other parent, % | |
| Yes (*n*=140) | 78.7 |
| No (*n*=38) | 21.3 |
| Number of consultations during previous year, (mean:4.3), % | |
| None (*n*=3) | 1.7 |
| 1 (*n*=7) | 4.0 |
| 2 (*n*=21) | 11.9 |
| 3 (*n*=58) | 32.8 |
| 4 or more (*n*=88) | 49.7 |

Data are % or mean.

**Table 2:** Indicator scores of adolescents and parents.

| | *Mean* | *SD* |
|---|---|---|
| **Adolescents** | | |
| Consultation (7 items) | 79.5 | 14.4 |
| Information on food/exercise (2 items) | 57.2 | 25.7 |
| Nurse contact (3 items) | 85.2 | 14.7 |
| Doctor contact (3 items) | 87.3 | 13.7 |
| Outcome (1 item) | 83.2 | 19.4 |
| Overall score | 78.5 | 14.1 |
| Well received | 4.3 | 0.7 |
| Waiting time | 3.8 | 0.7 |
| Same nurses | 4.0 | 0.9 |
| Nurses knowledgeable | 4.5 | 0.7 |
| Same doctor | 4.0 | 1.1 |
| Doctor knowledgeable | 4.4 | 0.8 |
| Training in how to use equipment | 3.8 | 1.0 |
| Follow-up helped the patient | 3.9 | 0.9 |
| **Parents** | | |
| Consultation (6 items) | 73.7 | 17.5 |
| Organization (5 items) | 67.9 | 14.2 |
| Equipment (3 items) | 60.6 | 23.6 |
| Nurse contact (4 items) | 79.9 | 14.8 |
| Doctor contact (4 items) | 79.1 | 20.0 |
| Outcome (5 items) | 76.6 | 18.3 |
| Overall score | 72.9 | 14.2 |
| Well received | 4.4 | 0.7 |
| Waiting time | 3.7 | 0.8 |
| Same nurses | 4.2 | 0.7 |
| Nurses knowledgeable | 4.6 | 0.6 |
| Same doctor | 4.2 | 0.9 |
| Doctor knowledgeable | 4.7 | 0.6 |
| Training in how to use equipment | 4.3 | 0.8 |
| Follow-up helped the patient | 4.3 | 0.8 |

All indicators were scored from 0 to 100, where 100 was the best possible experience. Individual items were scored from 1 to 5, where 5 is the best possible experience.

**Table 3:** Correlations between adolescent and parent experience indicators.

| | Indicators: adolescents | | | | | |
|---|---|---|---|---|---|---|
| **Indicators: parents** | Consultation | Information on food/exercise | Nurse contact | Doctor contact | Outcome | Overall score |
| Consultation | 0.36*** | 0.29*** | 0.23** | 0.29*** | 0.26*** | 0.36*** |
| Organization | 0.44*** | 0.25** | 0.27*** | 0.27*** | 0.31*** | 0.37*** |
| Equipment | 0.37*** | 0.23** | 0.17* | 0.16* | 0.18* | 0.28*** |
| Nurse contact | 0.35*** | 0.27*** | 0.29*** | 0.25** | 0.21** | 0.34*** |
| Doctor contact | 0.20** | 0.21** | 0.02 | 0.19* | 0.20* | 0.21** |
| Outcome | 0.40*** | 0.27*** | 0.24** | 0.30*** | 0.32*** | 0.38*** |
| Overall score | 0.44*** | 0.31*** | 0.25** | 0.30*** | 0.30*** | 0.40*** |

Data are *r* values.
***$p$<0.001, **$p$<0.01, *$p$<0.05.

**Table 4:** Correlations between adolescent and parent experiences for single items.

| Item | *p* |
|---|---|
| Well received | 0.31*** |
| Waiting time | 0.24** |
| Same nurses | 0.22** |
| Nurses knowledgeable | 0.33*** |
| Same doctor | 0.46*** |
| Doctor knowledgeable | 0.23** |
| Training in how to use equipment | 0.38*** |
| Follow-up helped the child | 0.28*** |

Data are *r* values.
***$p<0.001$, **$p<0.01$.

**Table 5:** Correlations of adolescent and parent experiences with HbA1c level.

| Indicator/item | HbA1c |
|---|---|
| **Adolescents** | |
| Consultation | 0.05 |
| Information on food/exercise | 0.00 |
| Nurse contact | 0.00 |
| Doctor contact | –0.04 |
| Outcome | –0.01 |
| Overall score | 0.00 |
| **Parents** | |
| Consultation | –0.12 |
| Organization | –0.18* |
| Equipment | –0.08 |
| Nurse contact | –0.22** |
| Doctor contact | –0.16* |
| Outcome | –0.16* |
| Overall score | –0.19* |

Data are *r* values.
**$p<0.01$, *$p<0.05$.

Norwegian Institute of Public Health

# Your experiences with the paediatric outpatient clinic

The questions below concern your experiences with the paediatric outpatient clinic your child attends for diabetes.

## Arrival and waiting

**1. Are you and your child well received at the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**2. Do you feel there's a lot of waiting at the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**3. Do you find the waiting room satisfactory?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

## Organisation

**4. Do you feel that the outpatient clinic is well organised?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**5. Do you feel that the doctors and nurses cooperate well?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**6. Do you feel that the person you have the appointment with is well prepared?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## The nurses

**7. Do you and your child see the same nurses every time you attend the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**8. Do you and your child get enough time with the nurses?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**9. Do the nurses appear to know a lot about diabetes and diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**10. Do you feel that the nurses show care and concern for your child?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## The doctor

The questions below are about the doctor. If you see more than one doctor, please give us your overall assessment of all the doctors you see.

**11. Do you and your child see the same doctor every time you attend the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**12. Do you and your child get enough time with the doctor?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**13. Does the doctor appear to know a lot about diabetes and diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**14. Do you feel that the doctor shows care and concern for your child?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## More about what is discussed at appointments

**15. In your opinion, do the topics discussed at the appointments meet your child's needs?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**16. Is it clear to you and your child what should be followed up before the next appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**17. Do you and your child have a say in what should be followed up before the next appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Being a parent/guardian at the clinic

**18. Are your views as a parent/guardian taken seriously?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**19. Do you get enough time for conversations without your child being present?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**20. Are you given satisfactory information and guidance on how to follow up on your child's diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**21. Do you get the support you need to let your child take more responsibility for his or her diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Information and training

**22. Do you receive satisfactory information about the results of tests and examinations?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**23. Do you receive satisfactory information about the development in your child's health and the risk of complications?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**24. Do you receive satisfactory information from the outpatient clinic about available devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**25. Do you and your child receive good training in managing the devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Availability

**26. In your opinion, does your child have access to the best possible devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**27. Does your child have satisfactory access to a nutritionist?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**28. Does your child have satisfactory access to a psychologist?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**29. Is it easy to get in touch with the outpatient clinic outside of appointments?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**30. How do you feel about the number of appointments at the outpatient clinic?**

- ☐ Too few
- ☐ A sufficient number
- ☐ Too many
- ☐ *Not applicable / Don't know*

## Usefulness

**31. Do you feel that your child benefits from attending the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**32. Do you, as a parent/guardian, benefit from attending the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Other questions

**33. Does the follow-up at the outpatient clinic make you and your child more capable to live a good life with diabetes?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**34. All in all, how dissatisfied or satisfied are you with how the outpatient clinic has followed up on your child and the diabetes treatment?**

- ☐ Very dissatisfied
- ☐ Rather dissatisfied
- ☐ Both dissatisfied and satisfied
- ☐ Rather satisfied
- ☐ Very satisfied

**35. All in all, how dissatisfied or satisfied are you with how the outpatient clinic has met you as a parent/guardian?**

- ☐ Very dissatisfied
- ☐ Rather dissatisfied
- ☐ Both dissatisfied and satisfied
- ☐ Rather satisfied
- ☐ Very satisfied

## Background questions

**36. In the last year, how many times have you been present for all or part of your child's appointment?**

- ☐ Never
- ☐ 1 time
- ☐ 2 times
- ☐ 3 times
- ☐ 4 or more times

**37. Are you male or female?**

- ☐ Male
- ☐ Female

**38. What age are you?**

☐ Number of years

**39. What is your highest level of educational attainment?**

- ☐ Primary school
- ☐ Secondary school
- ☐ Higher education/university (up to 4 years)
- ☐ Higher education/university (4+ years)

**40. Do you live with the child's other parent/ guardian?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable*

Any additional comments about experiences with the outpatient clinic or comments on the questionnaire:

Thank you for taking the time to answer.

Norwegian Institute of Public Health

Norwegian Institute of Public Health

# Your experiences with the children's outpatient clinic

The questions below concern your experiences with the outpatient clinic you attend for diabetes. Please tick only one answer for each question.

## When you arrive at the outpatient clinic

**1. Are you well received at the outpatient clinic?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent

**2. Do you feel there's a lot of waiting at the outpatient clinic?**

- 😀 ☐ Not at all
- 🙂 ☐ To a small extent
- 😐 ☐ To some extent
- ☹ ☐ To a large extent
- ☹ ☐ To a very large extent

## The nurses

**3. Do you see the same nurses every time you attend the outpatient clinic?**

- ☹ ☐ Never
- ☹ ☐ Rarely
- 😐 ☐ Sometimes
- 🙂 ☐ Often
- 😀 ☐ *Always*
- ☐ *Not applicable / Don't know*

**4. Do the nurses speak to you in a way that you understand?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent

**5. Do the nurses appear to know a lot about diabetes and diabetes treatment?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent

**6. Do you feel safe bringing up things with the nurses that are difficult to discuss?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## The doctor

The questions below are about your doctor. If you see more than one doctor, please consider all the doctors you see when you are answering the questions.

**7. Do you see the same doctor every time you attend the outpatient clinic?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ *Always*
- ☐ *Not applicable / Don't know*

**8. Do the doctor speak to you in a way that you understand?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**9. Do the doctor appear to know a lot about diabetes and diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**10. Do you feel safe bringing up things with the doctor that are difficult to discuss?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## More about your diabetes check-ups

**11. Are you given good advice to help you choose the right insulin dose?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**12. Do you have a say in what should be followed up before the next appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**13. Do the staff who work at the outpatient clinic appear to understand what it's like to be young and have diabetes?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**14. Do you get enough time with the doctor or nurse during you appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**15. How do you feel about the number of appointments you have at the outpatient clinic each year?**

- ☐ Too few
- ☐ A sufficient amount
- ☐ Too many
- ☐ *Not applicable / Don't know*

## Food and exercise

**16. Are you given good information and guidance about food?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**17. Are you given good information and guidance about exercise?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Devices/equipment

**18. Are you involved in deciding which devices/equipment you should use?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**19. Do you receive good training in managing the devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Appointment with others

**20. Can you get an appointment with a nutritionist if you need one?** *(A nutritionist gives advice about food and diet)*

- ☐ Yes
- ☐ No
- ☐ *Not applicable/Don't know*

**21. Can you get an appointment with a psychologist if you need one?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable/Don't know*

## Bringing parents/guardians with you

**22. How often do your parents/guardians attend the outpatient clinic with you?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

**23. If your parents/guardians attend the appointment with you, who does the doctor or nurse mostly speak to?**

- ☐ Mostly to me
- ☐ Mostly to my parents/guardians
- ☐ About the same to each of us
- ☐ Parents/guardians do not come with me

**24. If needed, can you get an appointment with your doctor or nurse without your parents/ guardians being present?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable/Don't know*

## Other questions

**25. All in all, has attending the outpatient clinic helped you with your diabetes?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**26. Who completed this questionnaire?**

- ☐ Me on my own
- ☐ Me and my parents/guardians together
- ☐ My parents/guardians on their own

**27. All in all, how are you feeling today?**

- ☐ Very bad
- ☐ Fairly bad
- ☐ Both and
- ☐ Rather good
- ☐ Very good

**28. Do you alternate between living with each of your parents/guardians?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable*

## Any additional comments about the outpatient clinic or how you found completing the questionnaire:

Thank you for taking the time to answer.

# Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectionalreporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

| | | Reporting Item | Page Number |
|---|---|---|---|
| **Title and abstract** | | | |
| Title | #1a | Indicate the study's design with a commonly used term in the title or the abstract | 2 |
| Abstract | #1b | Provide in the abstract an informative and balanced summary of what was done and what was found | 2,3 |
| **Introduction** | | | |
| Background / rationale | #2 | Explain the scientific background and rationale for the investigation being reported | 4-6 |
| Objectives | #3 | State specific objectives, including any prespecified hypotheses | 2,7 |
| **Methods** | | | |
| Study design | #4 | Present key elements of study design early in the paper | 2, 7 |
| Setting | #5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 7-9 |
| Eligibility criteria | #6a | Give the eligibility criteria, and the sources and methods of selection of participants. | 2,8 |

| | | | |
|---|---|---|---|
| | #7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 8,9 |
| Data sources / measurement | #8 | For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable. | 8,9 |
| Bias | #9 | Describe any efforts to address potential sources of bias | 4,13 |
| Study size | #10 | Explain how the study size was arrived at | 7,8 |
| Quantitative variables | #11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why | 8-10 |
| Statistical methods | #12a | Describe all statistical methods, including those used to control for confounding | 8-10 |
| Statistical methods | #12b | Describe any methods used to examine subgroups and interactions | 8-10 |
| Statistical methods | #12c | Explain how missing data were addressed | n/a |
| Statistical methods | #12d | If applicable, describe analytical methods taking account of sampling strategy | n/a |
| Statistical methods | #12e | Describe any sensitivity analyses | n/a |
| **Results** | | | |
| Participants | #13a | Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable. | n/a |
| Participants | #13b | Give reasons for non-participation at each stage | n/a |
| Participants | #13c | Consider use of a flow diagram | n/a |
| Descriptive data | #14a | Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable. | 10,20 |
| Descriptive data | #14b | Indicate number of participants with missing data for each variable of interest | n/a |
| Outcome data | #15 | Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable. | n/a |
| Main results | #16a | Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | n/a |

| | | | |
|---|---|---|---|
| Main results | #16b | Report category boundaries when continuous variables were categorized | n/a |
| Main results | #16c | If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | n/a |
| Other analyses | #17 | Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses | n/a |
| **Discussion** | | | |
| Key results | #18 | Summarise key results with reference to study objectives | 11, 13-14 |
| Limitations | #19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias. | 13 |
| Interpretation | #20 | Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence. | 12,13 |
| Generalisability | #21 | Discuss the generalisability (external validity) of the study results | 13 |
| **Other Information** | | | |
| Funding | #22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 14 |

BMJ Open

# Associations between adolescent experiences, parent experiences and HbA1c: results following two surveys based on The Norwegian Childhood Diabetes Registry (NCDR)

| | |
|---|---|
| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2019-032201.R1 |
| Article Type: | Original research |
| Date Submitted by the Author: | 18-Sep-2019 |
| Complete List of Authors: | Iversen, Hilde; Norwegian Institute of Public Health ,<br>Bjertnaes, Oyvind; Norwegian Institute of Public Health<br>Skrivarhaug , Torild; Oslo University Hospital, Division of Paediatric and Adolescent Medicine, The Norwegian Childhood Diabetes Registry; University of Oslo, Institute of Clinical Medicine |
| Primary Subject Heading: | Health services research |
| Secondary Subject Heading: | Paediatrics, Diabetes and endocrinology, Patient-centred medicine |
| Keywords: | patient experiences, parent experiences, diabetes, questionnaire, HbA1c |
| | |

# Associations between adolescent experiences, parent experiences and HbA1c: results following two surveys based on The Norwegian Childhood Diabetes Registry (NCDR)

**Authors:**

Hilde Hestad Iversen[1] (hilde.hestad.iversen@fhi.no) +47 46400425) (Corresponding author)

Oyvind Bjertnaes[1] (oyvindandresen.bjertnaes@fhi.no)

Torild Skrivarhaug[2,3] (torild.skrivarhaug@medisin.uio.no)

**Affiliations:**

[1]Norwegian Institute of Public Health, PO Box 4404 Nydalen, N-0403 Oslo

[2]Division of Paediatric and Adolescent Medicine, The Norwegian Childhood Diabetes Registry, Oslo University Hospital, PO Box 4956 Nydalen, N-0424 Oslo

[3] Institute of Clinical Medicine, University of Oslo, PO Box 1078 Blindern, N-0316 Oslo

**Keywords:** patient experiences, parent experiences, diabetes, questionnaire, adolescent HbA1c

**Word count:** 2,974

# Abstract

## Objective

The aim of the current study was to determine the association between the experiences of adolescents and their parents with paediatric diabetes care at hospital outpatient departments and the association between these experiences and the HbA1c levels of adolescents.

## Design

Cross-sectional survey.

## Setting

Paediatric diabetes care at hospital outpatient departments in Norway.

## Participants

Parents of all outpatients registered in the Norwegian Childhood Diabetes Registry and patients in the same registry aged 12–17 years.

## Intervention

1,399 parents participated in a national pilot survey, and 335 patients aged 12–17 years from the four largest paediatric outpatient departments in Norway responded in another pilot study. 181 paired parental and patient questionnaires were analysed.

## Main outcome measures

The correlations between single items, indicator scores and overall scores were explored, as was that between indicator scores and HbA1c levels.

## Results

There was a moderate but significant correlation between the responses of the patients and parents. For 40 of the 42 associations the correlations were significant, ranging from 0.16 to 0.42.

A weak but significant negative correlation was found between the indicator scores of parents and the HbA1c levels of the adolescents. The strongest correlations were between HbA1c level and nurse contact and organization, both with a correlation coefficient of 0.21 ($P<0.01$).There was no significant correlation between HbA1c level and patient indicator scores.

**Conclusions**

These results highlight the need to obtain information from both parents and adolescents, and indicate that the views of adolescents are not always mirrored by their parents. Three of the seven parent experience indicators were significantly related to the HbA1c levels of adolescents, but replication in future research with larger sample sizes is warranted.

# Article Summary

## Strengths and Limitations

- The study used validated instruments whose survey content and response scales were adapted for the specific patient/parent and age groups included.
- Both parents and adolescents experiences were explored, and the results can provide guidance concerning the most appropriate care to provide at outpatient clinics.
- The surveys were performed by an independent third party that was not involved in providing health care.
- While the parent survey was nationwide, the adolescent survey was restricted to four clinics and the results should be replicated in larger surveys.
- Another limitation is that our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

# Introduction

Norway has one of the highest incidences of childhood-onset type 1 diabetes in the world, and 0.6% (*n*=28,000) of the total population has type 1 diabetes [1]. Type 1 diabetes usually develops in childhood or early adolescence, and parents therefore play an important role in the day-to-day management of the disease. This responsibility places considerable demands on parents, and family involvement is a crucial component of optimal diabetes management [2].

Adolescents experience challenges to adherence that are intrinsic to their developmental stage and demands for peer normality [3]. Diabetes may become a daily struggle against undesirable blood glucose levels and risk complications, hormonal changes can lead to insulin resistance, and there are several other factors underlying poor glycaemic control in this phase of life [4].

Norwegian children attend follow-up appointments with a paediatrician and a diabetes nurse at their local paediatric outpatient department in hospitals approximately four times yearly. Dieticians and psychologists can also be consulted if requested. Given the importance of the parental role in the health-care decisions and daily follow-up of adolescents, the interactions between the adolescent and parent plus those with the health-care provider are an important component of the outpatient visit.

There is a growing recognition of the importance of assessing the experiences of patients with health care when attempting to provide patient-centred health services. Reviews have found that better patient experiences and satisfaction are associated with higher levels of adherence to recommended prevention and treatment interventions as well as better clinical outcomes [5–7]. An adult population-based survey of patients with type 2 diabetes found that strategies that increased patient satisfaction also contributed to improving the clinical outcomes [8]. Another

study found that the parent ratings of the quality of outpatient diabetes care were negatively correlated with the mean HbA1c levels of their children. In the same study adolescents aged >13 years who reported a higher quality of care had lower HbA1c levels [9]. However, other studies have not found significant correlations between the satisfaction of young peoples with diabetes care and their HbA1c levels [10–12].

Parents or caregivers are usually asked to respond on behalf of children younger than a certain age. The views of children and adolescents have largely been ignored in large-scale patient-experience surveys, despite evidence that children may be willing to respond from the age of 8 years and that their health-care priorities diverge from those of their parents from the age of 12 years [13–15]. A cross-sectional analysis of national survey data in England showed that including inpatients aged 8–15 years in a patient-experience survey was both feasible and enhanced the information obtained from the responses of parents alone [13].

The results from previous studies show that there are discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20]. A review found that young people aged 16–24 years consistently report worse health-care experiences compared to older adults [18]. Another study found a strong correlation between the quality of diabetes care as perceived by parents and adolescents, but differences in the importance that the two populations placed on different aspects of care [9]. The level of agreement is generally better between parents and their chronically sick children than between parents and their healthy children [21].

Information about potential differences in perceptions could be useful for providers when delivering outpatient care, and when trying to balance the needs and expectations of adolescents and their parents. Also, such findings can provide guidance when measuring and monitoring patient and parent experiences with outpatient care for the purpose of quality improvement. The

aim of the present study was to determine the association between the experiences of adolescents and parents with paediatric diabetes care at hospital outpatient departments, and the association between these experiences and the HbA1c level of the adolescents. To our knowledge, only two previous studies have simultaneously assessed the associations between parent experiences, adolescent experiences and clinical outcomes for this patient group [9, 12], and none of them were performed in Norway. Based on those previous studies, we hypothesized that there would be a correlation between the perceptions of parents and the adolescents about the quality of outpatient care, but no correlation with the HbA1c level.

# Methods

## Data

Responses from adolescents were collected in a pilot study that included all patients at the four largest outpatient departments in Norway who were aged 12–17 years, had type 1 diabetes and were registered in the Norwegian Childhood Diabetes Registry (NCDR) (*n*=685). The purpose of the pilot study was to determine the data quality, validity and internal consistency reliability of the newly developed instrument. A report published in 2018 documents the development of the instrument and the data collection method [22]. The sample was contacted by post in April 2017. The request included a letter with information about the survey, a printed version of the questionnaire, a prepaid return envelope and also an option to answer electronically. Non-responders were sent up to two postal reminders. The national parent experience survey has been described elsewhere [23, 24] and here we include 181 parents that were matched with the

adolescent survey. Unique patient identification numbers were used to match parent responses with that of their children.

All paediatric departments report the results of annual standardized examinations to the NCDR. Background data were transferred from the NCDR to the Norwegian Institute of Public Health (NIPH) after data collection was completed, but for a few patients data on HbA1c and the number of consultations were not complete at the time of transfer.

### Measures

Two new measures were developed and tested in accordance with the standard methodology of the national user-experience survey programme in Norway [23, 24]: the Parent Experiences of Diabetes Care Questionnaire (PEQ-DC) and the Adolescent Patient Experiences of Diabetes Care Questionnaire (APEQ-DC) [23]. The questionnaires were designed to be applied in surveys of parents of children and adolescents with type 1 diabetes of all ages and of adolescents with type 1 diabetes aged 12–17 years visiting paediatric outpatient departments in Norway, and are included in Additional file 1 and 2.

We asked about experiences at the paediatric outpatient clinic that the child visited for follow-up appointments. Five-point scales with response options that ranged from “not at all” (1) to “a very large extent” (5) were used for most items relating to the experience of care. Smiley faces were used to illustrate the response options in the APEQ-DC. Many items also included a “not applicable / don’t know” option. An open-ended question on the last page asked for further comments.

The PEQ-DC and APEQ-DC had similar (but not identical) contents. The results obtained in the development process showed that certain themes or questions were not relevant for both groups. The process highlighted the importance of ensuring that the patient questionnaire was as short as possible while also comprising age-appropriate items. The psychometric testing of the PEQ-DC identified six indicators: consultation, organization, equipment, nurse contact, doctor contact and outcome. Five indicators were identified for the APEQ-DC: consultation, information on food/exercise, nurse contact, doctor contact and outcome.

The HbA1c level is a measure of long-term blood glucose levels and reflects the average level over the preceding 4–12 weeks, weighted towards the most-recent 4 weeks. Data were obtained from the NCDR and reported as percentages and in millimoles per mole (mmol/mol).

### Statistical analysis

Overall scores for each respondent were calculated by summing the scores for all of the indicators and dividing by their total number.

The Mann-Whitney *U* test was used to test the differences in scores between patients that reached the recommended < 7.5% treatment goal, and patients that did not reach the recommended treatment goal. Corresponding analyses were conducted for the parents, based on the HbA1c value of their children. The Mann-Whitney *U* test was also used to compare the self-reported experiences of the parents and patients for eight single items.

The relationship between the patient and parent experiences at the outpatient clinic was tested by calculating Spearman's rank correlation coefficients for indicator scores, the overall scores and

single items. Multivariate linear regression analyses were used to further assess the associations between the patient and parent experiences, controlling for age, gender and HbA1c level.

The indicator scores and overall scores were also correlated with the HbA1c level analysed as a continuous variable. Correlations were assessed using Spearman's rank correlation. Multivariate linear regression analyses were used to assess the associations, controlling for age and gender.

All statistical analyses were conducted using SPSS version 23.0.

### Approval

Both surveys were approved by the Data Protection Authority at Oslo University Hospital. Registration in the NCDR is based on a signed informed consent from the child (older than 12 years) and/or the child's parents. The consent form informs the patient and/or the parents that consent may result in requests to answer questionnaires on patient and parent experiences of diabetes care. Returning the questionnaire constituted consent in the survey.

### Patient and public involvement

The survey was about patients and parents experiences with experiences with health care. Patients and parents were included in the development process of the instrument, to secure that the questionnaire included the most important topics for patients and parents.

## Results

1,399 (55.4%) parents responded to the questionnaire, while questionnaire responses were received from 335 (53.6%) adolescent patients. We were able to match 181 parents with the adolescent survey, and the overall coverage rate in this study was 26.4%. The characteristics of the 181 included adolescents and their parents are presented in Table 1. Fifty-four percent of the adolescents were boys, and their mean age was 14.7 years (Table 1). The mean age when diagnosed with type 1 diabetes was 9.4 years, and the mean HbA1c level at the last registration in the NCDR was 8.2% (66.1 mmol/mol). The mean age of the parents was 46.0 years and 78.8% were female (Table 1), while 70.4% had a university or college education.

Table 2 lists the indicator scores and item scores for both adolescents and parents. The adolescent indicators had scores ranging from 57.2 (for information on food/exercise) to 87.3 (for doctor contact), and the overall score was 78.5. The parent indicator scores ranged between 60.6 (for equipment) and 79.9 (for nurse contact), and the overall score was 72.9. Analyses showed that for four of the single items the adolescent scores were significantly higher than the parent scores (results not shown). Table 2 also shows the indicator scores and item scores for patients who achieved the recommended < 7.5% treatment goal and patients who did not achieve the < 7.5% treatment goal. Corresponding results are shown for parents, based on the HbA1c values of their children. No significant differences in scores were found for patients who achieved the < 7.5% treatment goal and patients who did not achieve the treatment goal. Parents of children who reached the treatment goal had significantly higher scores on one of the single items (nurses knowledgeable).

Table 3 presents the coefficients for the correlations between the indicator scores of the adolescents and parents. All of the correlations were statistically significant except the adolescent score for nurse contact and the parent score for doctor contact, and the adolescent score for doctor

contact and the parent score for equipment. The significant correlation coefficients ranged from 0.16 to 0.42. The strongest correlations were between the adolescent score for the consultation indicator and the parent score for the outcome indicator (rho=0.42, P<0.001) and the overall score indicator (rho=0.41, P<0.001) respectively. The correlation coefficient between the adolescent score for the overall score indicator and the parent score for the outcome indicator was also 0.41 (P<0.001). The coefficient for the correlation between the parent and adolescent overall scores was 0.41 (P<0.001).

Table 4 indicates that all correlations between individual questions with identical wordings in the two surveys were significant. The strongest correlation was for the questions pertaining to meeting the same doctor (rho=0.50, *P*<0.001) and if the patient and parent were well received (rho=0.32, *P*<0.001).

No significant correlations were found between the adolescent indicators and their HbA1c level (Table 5). Three of the seven parent indicators were significantly correlated with the HbA1c level. The strongest correlation was found between HbA1c level and nurse contact and organization, both with a correlation coefficient of 0.21 (P<0.01).

We also tested if the difference in overall mean scores for the parent and the adolescent had an influence on the HbA1c level, but the results did not support this association (results not shown here).

## Discussion

This study found high average ratings from both adolescents and parents, but with the evaluations from parents being somewhat more critical. The parent experiences did not accurately represent

the views of the patient, as demonstrated by weak-to-moderate correlations. Three of seven parent experience indicators were correlated with the HbA1c level, but this was not the case for the adolescent experiences.

Most previous studies have found discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20], which is in line with our findings. However, one of the very few studies related to diabetes outpatient care found a very strong correlation between patient and parent assessments [9]. There are several possible reasons for explaining the lack of convergence, but we believe the questionnaires used and the measurement approach might be the main reasons. That previous study initially used a general patient-experience questionnaire for adult patients, then adjusted it to an adolescent diabetes version and a parent version [9] but without performing further testing and validation [25]. Although this was not stated explicitly, it appears that the two surveys of how patients and parents perceived the care received were carried out simultaneously. If so, the surveys were not independent, and the parents and adolescents might have completed the questionnaires jointly [25]. This raises questions about the validity of both questionnaires, the measurements made and the estimated correlations.

Unlike the results obtained in previous surveys [13, 16, 19], the current study found that the average indicator scores for adolescents were higher than the average indicator scores for their parents. These previous studies had varying contexts and methodologies, but none of them based their comparisons on questionnaires that were developed and validated specifically for each group. Furthermore, our finding is in accordance with the general patient-satisfaction literature indicating that proxies are more critical than patients [26–31]. The indicator score for adolescents in our study was lowest for information on food/exercise, suggesting that more time should be spent on providing adolescents with such information. These findings are in accordance with

previous research highlighting communication and information as an area for improvement [9, 13, 19, 20]. Adolescents gave the highest ratings for the doctor contact indicator, while the parents scored equipment the lowest and nurse contact the highest.

No significant associations between the adolescent indicators and HbA1c level were found, in line with previous studies [10–12]. However, three of the seven parent indicators were correlated significantly with the adolescent HbA1c levels. The results from the current study also showed that parents of children who reached the recommended < 7.5% treatment goal reported better experiences related to the nurses' knowledge. Previous studies and reviews have found associations between patient experiences or satisfaction and adherence to recommended prevention and treatment processes and clinical outcomes [5–9]. In this setting it therefore seems that parents have a closer connection to clinical quality than do the adolescents themselves. The implication is that interventions to improve parent experiences also might improve clinical outcomes but more research conducted with larger sample sizes is needed to conclude upon this observed association.

The assumption that adults can answer for children has traditionally gone unchallenged. The views of children and adolescents have largely been ignored in large-scale surveys, and parents or carers are often asked to respond on their behalf. There is a need to develop methods that allow young people to provide feedback on the quality of health care that they themselves consider relevant. The two instruments applied in this study were developed in a rigorous manner. Considering the important role played by parents in diabetes treatment regimes, studies exploring the relationship between experiences and adherence must take into account the perspectives and needs of both parent and adolescent. Understanding differences and similarities between these

two groups can provide guidance concerning the most appropriate care to provide at outpatient clinics.

This study was subject to some limitations. Data on non-respondents were not available, and we were not able to compare the characteristics of the current sample with the characteristics of those who did not respond to the survey. However, results from the national parent survey was published in a recent article and showed similar background characteristics for the current sample and the total national sample of 1399 respondents. While the parent survey was nationwide, the adolescent survey was restricted to four clinics. Only 181 paired parental and patient responses were analyses, an overall coverage rate of 26.4%. This raises questions about the generalizability of the findings, and the results should be replicated in larger surveys. Also, our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

## Conclusions

All but one of the correlations between the indicator scores of the parents and adolescents were statistically significant, but the agreements between the reported experiences were all only weak or moderate. The results highlight the need to collect information from both parents and adolescents, and confirm that the views of adolescents are not always mirrored by their parents. Three of seven parent experience indicators were significantly related to the adolescent HbA1c level. However, more research is needed to further explore the associations between parent experiences and the HbA1c level. Understanding the correspondence between the viewpoints of

parents and adolescents is potentially useful for informing interventions aimed at improving the health care provided at paediatric outpatient departments [23].

## Funding

This work was supported by the Knowledge Centre at the NIPH, the NCDR and "Lillian and Werner Næss legat". The NCDR is funded by the South-Eastern Norway Regional Health Authority.

## Competing interests

On behalf of both authors, the corresponding author states that there is no competing interests.

## Author contributions

T.S. initiated the study. H.H.I. planned the study in consultation with O.B. and T.S. H.H.I. performed the statistical analyses with O.B. and T.S., and drafted the manuscript. O.B. and T.S. participated in the planning process, critically revised the manuscript draft and approved the final version of the manuscript. H.H.I. was the project manager for the two surveys. All authors read and approved the final manuscript.

## Acknowledgements

We thank Inger Opedal Paulsrud, Olaf Holmboe, Johanne Kjøllesdal and Nam Pham from the Knowledge Centre at the NIPH for their help in developing and conducting the surveys,

including performing administrative and technical tasks for the data collection. We further thank Ann Kristin Drivvoll from the NCDR for extracting data from the registry.

## Availability of data and material

The data sets generated and/or analysed during this study are not publicly available due to the need to protect personal data.

# References


1. Strøm H, Selmer R, Birkeland KI, Schirmer H, Berg TJ, Jenum AK, et al. No increase in new users of blood glucose-lowering drugs in Norway 2006–2011: a nationwide prescription database study. BMC Public Health. 2014;14 (1):520.
2. Laffel LM, Vangsness L, Connell A, Goebel-Fabbri A, Butler D, Anderson BJ. Impact of ambulatory, family-focused teamwork intervention on glycemic control in youth with type 1 diabetes. J Pediatr. 2003;142(4):409–16.
3. Borus JS, Laffel L. Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. Curr Opin Pediatr. 2010;22(4):405–11.
4. Datye KA, Moore DJ, Russell WE, Jaser SS. A review of adolescent adherence in type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. Curr Diab Rep. 2015;15(8):51.
5. Anhang Price R, Elliott MN, Zaslavsky AM, Hays RD, Lehrman WG, Rybowski L, et al. Examining the role of patient experience surveys in measuring health care quality. Med Care Res Rev. 2014;71(5):522–54.
6. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3(1):e001570.
7. Ofman JJ, Badamgarav E, Henning JM, Knight K, Gano AD Jr, Levan RK, et al. Does disease management improve clinical and economic outcomes in patients with chronic diseases? A systematic review. Am J Med. 2004;117(3):182–92.
8. Alazri MH, Neal RD. The association between satisfaction with services provided in primary care and outcomes in type 2 diabetes mellitus. Diabet Med. 2003;20(6):486–90.

9. Hanberger L, Ludvigsson J, Nordfeldt S. Quality of care from the patient's perspective in pediatric diabetes care. Diabetes Res Clin Pract. 2006;72(2):197–205.
10. de Wit M, Delemarre-van De Waal HA, Bokma JA, Haasnoot K, Houdijk MC, Gemke RJ, et al. Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improve psychosocial well-being: a randomized controlled trial. Diabetes Care. 2008;31(8):1521–6.
11. Gray S, Cheetham T, McConachie H, Mann KD, Parr JR, Pearce MS, et al. A longitudinal, observational study examining the relationships of patient satisfaction with services and mental well-being to their clinical course in young people with type 1 diabetes mellitus during transition from child to adult health services. Diabet Med. 2018;35(9):1216–22.
12. Koves IH, Boucher A, Ismail D, Donath S, Cameron FJ. Satisfaction of care in a tertiary level diabetes clinic: correlations with diabetes knowledge, clinical outcome and health-related quality of life. J Paediatr Child Health. 2008;44(7-8):432–7.
13. Hargreaves DS, Sizmur S, Pitchforth J, Tallett A, Toomey SL, Hopwood B, et al. Children and young people's versus parents' responses in an English national inpatient survey. Arch Dis Child. 2018;103(5):486–91.
14. Ambresin A-E, Bennett K, Patton GC, Sanci LA, Sawyer SM. Assessment of youth-friendly health care: a systematic review of indicators drawn from young people's perspectives. J Adolesc Health. 2013;52(6):670–81.
15. Santelli JS, Rosenfeld WD, DuRant RH, Dubler N, Morreale M, English A, et al. Guidelines for adolescent health research: a position paper of the Society for Adolescent Medicine. J Adolesc Health. 1995;17(5):270–6.

16. Chesney M, Lindeke L, Johnson L, Jukkala A, Lynch S, Disch J, et al. Comparison of child and parent satisfaction ratings of ambulatory pediatric subspecialty care. J Pediatr Health Care. 2005;19(4):221–9.

17. Sawyer SM, Ambresin A-E, Bennett KE, Patton GC. A measurement framework for quality health care for adolescents in hospital. J Adolesc Health. 2014;55(4):484–90.

18. Hargreaves DS, Viner RM. Children's and young people's experience of the National Health Service in England: a review of national surveys 2001-2011. Arch Dis Child. 2012;97(7):661–6.

19. Byczkowski TL, Kollar LM, Britto MT. Family experiences with outpatient care: do adolescents and parents have the same perceptions? J Adolesc Health. 2010;47(1):92–8.

20. Hopwood B, Tallett A. Little voice: giving young patients a say. Nurs Times. 2011;107(49-50):18–20.

21. Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a systematic review. Qual Life Res. 2001;10(4):347–57.

22. Iversen HH, Helland Y, Skrivarhaug T. Development of a method for measuring parent and patient experiences of outpatient care for children with type 1 diabetes. Oslo: The Norwegian Institute of Public Health, PasOpp-report 37; 2018. ISSN: 1890-1565.

23. Iversen HH, Helland Y, Bjertnaes O, Skrivarhaug T. Parent experiences of diabetes care questionnaire (PEQ-DC): reliability and validity following a national survey in Norway. BMC Health Serv Res. 2018;18 (1):774.

24. Bjertnaes O, Iversen HH, Skrivarhaug T. A randomized comparison of three data collection models for the measurement of parent experiences with diabetes outpatient care. BMC Med Res Methodol. 2018;18 (1):95.

25. Hanberger L. Quality of Care in Children and Adolescents with Type 1 Diabetes: Patients' and Healthcare Professionals' Perspectives. Linköping: Linköping University Electronic Press; 2010.

26. Bjertnaes O. Patient-reported experiences with hospitals: comparison of proxy and patient scores using propensity-score matching. Int J Qual Health Care. 2013;26(1):34–40.

27. Elliott MN, Beckett MK, Chong K, Hambarsoomians K, Hays RD. How do proxy responses and proxy-assisted responses differ from what Medicare beneficiaries might have reported about their health care? Health Serv Res. 2008;43(3):833–48.

28. Epstein AM, Hall JA, Tognetti J, Son LH, Conant L Jr. Using proxies to evaluate quality of life. Can they provide valid information about patients' health status and satisfaction with medical care? Med Care. 1989;27(3 Suppl):S91–8.

29. O'Malley AJ, Zaslavsky AM, Elliott MN, Zaborski L, Cleary PD. Case-mix adjustment of the CAHPS Hospital Survey. Health Serv Res. 2005;40(6 Pt 2):2162–81.

30. Strasser S, Schweikhart S, Welch GE 2nd, Burge JC. Satisfaction with medical care. It's easier to please patients than their family members and friends. J Health Care Mark. 1995;15(3):34–44.

31. Walker AH, Restuccia JD. Obtaining information on patient satisfaction with hospital care: mail versus telephone. Health Serv Res. 1984;19(3):291–306.

**Table 1:** Background characteristics of the adolescents (*n*=181) and the parents (*n*=181).

| *Characteristic* | *%/mean* |
|---|---|
| **Adolescents** | |
| Sex, % | |
| Male (*n*=98) | 54.1 |
| Female (*n*=83) | 45.9 |
| Mean age, years (*n*=181) | 14.7 |
| Mean age when diagnosed with diabetes, years (*n*=181) | 9.4 |
| Mean diabetes duration, years (*n*=181) | 5.4 |
| Mean HbA1c level, % (*n*=165) | 8.2 |
| Number of consultations during previous year (mean: 6.2), % | |
| 1–3 (n=40) | 24.4 |
| 4–6 (n=48) | 29.3 |
| 7–9 (n=57) | 34.8 |
| 10–21 (n=19) | 11.6 |
| General condition today, % | |
| Very poor (n=1) | 0.6 |
| Fairly poor (n=3) | 1.7 |
| Neither poor nor good (n=31) | 17.2 |
| Fairly good (n=89) | 49.4 |
| Very good (n=56) | 31.1 |
| Norwegian % | |
| Yes (*n*=169) | 93.4 |
| No (*n*=12) | 6.6 |
| **Parents** | |
| Sex, % | |
| Male (*n*=38) | 21.2 |
| Female (*n*=141) | 78.8 |
| Mean age, years (*n*=179) | 46.0 |
| Education, % | |
| Primary school (*n*=3) | 1.7 |
| Secondary school (*n*=50) | 27.9 |
| University or college (0–4 years) (*n*=54) | 30.2 |
| University or college (>4 years) (*n*=72) | 40.2 |
| Living with the child's other parent, % | |
| Yes (*n*=140) | 78.7 |
| No (*n*=38) | 21.3 |
| Number of consultations during previous year, (mean:4.3), % | |
| None (*n*=3) | 1.7 |
| 1 (*n*=7) | 4.0 |
| 2 (*n*=21) | 11.9 |
| 3 (*n*=58) | 32.8 |
| 4 or more (*n*=88) | 49.7 |

Data are % or mean.

**Table 2:** Indicator scores and single item scores of adolescents and parents in the total sample and for adolescents and parents where the patients have achieved/not achieved the treatment goal.

| | *All respondents (n=181)* | | *Patients with HbA1c < 7.5% (n=48)* | | *Patients with HbA1c > 7.5% (n=117)* | | |
|---|---|---|---|---|---|---|---|
| | *Mean* | *SD* | *Mean* | *SD* | *Mean* | *SD* | *p* |
| **Adolescents** | | | | | | | |
| Consultation (7 items) | 79.5 | 14.4 | 78.5 | 16.4 | 79.5 | 14.1 | 0.94 |
| Information on food/exercise (2 items) | 57.2 | 25.7 | 58.0 | 26.1 | 56.0 | 25.0 | 0.47 |
| Nurse contact (3 items) | 85.2 | 14.7 | 84.7 | 14.8 | 85.0 | 15.1 | 0.85 |
| Doctor contact (3 items) | 87.3 | 13.7 | 88.6 | 13.2 | 86.6 | 14.3 | 0.45 |
| Outcome (1 item) | 83.2 | 19.4 | 81.8 | 21.1 | 83.2 | 18.9 | 0.84 |
| Overall score | 78.5 | 14.1 | 78.4 | 15.3 | 78.1 | 13.8 | 0.46 |
| Well received | 4.4 | 0.7 | 4.4 | 0.7 | 4.3 | 0.7 | 0.86 |
| Waiting time | 3.7 | 0.8 | 3.8 | 0.6 | 3.7 | 0.9 | 0.72 |
| Same nurses | 4.2 | 0.7 | 4.4 | 0.7 | 4.2 | 0.7 | 0.08 |
| Nurses knowledgeable | 4.6 | 0.6 | 4.5 | 0.7 | 4.6 | 0.6 | 0.67 |
| Same doctor | 4.2 | 0.9 | 4.1 | 1.1 | 4.2 | 0.9 | 0.68 |
| Doctor knowledgeable | 4.7 | 0.6 | 4.7 | 0.6 | 4.6 | 0.6 | 0.32 |
| Training in how to use equipment | 4.3 | 0.8 | 4.2 | 0.8 | 4.3 | 0.9 | 0.52 |
| Follow-up helped the patient | 4.3 | 0.8 | 4.3 | 0.8 | 4.3 | 0.8 | 0.84 |
| **Parents** | | | | | | | |
| Consultation (6 items) | 73.7 | 17.5 | 75.1 | 17.1 | 71.5 | 17.7 | 0.35 |
| Organization (5 items) | 67.9 | 14.2 | 70.5 | 12.5 | 65.9 | 15.1 | 0.07 |
| Equipment (3 items) | 60.6 | 23.6 | 65.0 | 23.3 | 57.1 | 23.2 | 0.07 |
| Nurse contact (4 items) | 79.9 | 14.8 | 82.8 | 13.2 | 78.0 | 15.1 | 0.05 |
| Doctor contact (4 items) | 79.1 | 20.0 | 81.1 | 17.7 | 77.0 | 21.2 | 0.34 |
| Outcome (5 items) | 76.6 | 18.3 | 78.0 | 15.4 | 74.4 | 19.5 | 0.39 |
| Overall score | 72.9 | 14.2 | 75.2 | 13.2 | 70.7 | 14.4 | 0.07 |
| Well received | 4.3 | 0.7 | 4.4 | 0.5 | 4.2 | 0.7 | 0.05 |
| Waiting time | 3.8 | 0.7 | 3.8 | 0.6 | 3.7 | 0.8 | 0.89 |
| Same nurses | 4.0 | 0.9 | 4.1 | 1.0 | 3.9 | 0.9 | 0.09 |
| Nurses knowledgeable | 4.5 | 0.7 | 4.7 | 0.6 | 4.4 | 0.7 | 0.02 |
| Same doctor | 4.0 | 1.1 | 4.0 | 1.1 | 3.9 | 1.1 | 0.56 |
| Doctor knowledgeable | 4.4 | 0.8 | 4.5 | 0.8 | 4.3 | 0.8 | 0.14 |
| Training in how to use equipment | 3.8 | 1.0 | 3.9 | 0.9 | 3.6 | 1.0 | 0.13 |
| Follow-up helped the patient | 3.9 | 0.9 | 3.8 | 0.9 | 3.9 | 1.0 | 0.64 |

All indicators were scored from 0 to 100, where 100 was the best possible experience. Individual items were scored from 1 to 5, where 5 is the best possible experience. Differences in scores were tested by Mann-Whitney *U* test.

**Table 3:** Associations between adolescent and parent experience indicators measured by correlations[a] and regressions[b].

| **Indicators: parents** | **Indicators: adolescents** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Consultation | | Information on food/exercise | | Nurse contact | | Doctor contact | | Outcome | | Overall score | |
| | Correlation | Beta | Correlation | Beta | Correlation | Beta | Correlation | Beta | Correlation | Beta | Correlation | Beta |
| Consultation | 0.34*** | 0.34*** | 0.30*** | 0.26** | 0.20** | 0.20* | 0.26** | 0.26** | 0.27*** | 0.24** | 0.34*** | 0.33*** |
| Organization | 0.39*** | 0.44*** | 0.24** | 0.25** | 0.24** | 0.25** | 0.22** | 0.24** | 0.28*** | 0.30*** | 0.33*** | 0.37*** |
| Equipment | 0.33*** | 0.40*** | 0.23** | 0.24** | 0.16* | 0.17* | 0.13 | 0.15 | 0.17* | 0.20* | 0.26** | 0.29*** |
| Nurse contact | 0.34*** | 0.36*** | 0.24** | 0.27*** | 0.24** | 0.27*** | 0.22* | 0.23** | 0.20** | 0.20* | 0.31*** | 0.34*** |
| Doctor contact | 0.22** | 0.21** | 0.27*** | 0.23** | 0.00 | 0.02 | 0.23** | 0.18* | 0.23** | 0.19* | 0.23** | 0.22** |
| Outcome | 0.42*** | 0.40*** | 0.30*** | 0.26** | 0.24** | 0.20* | 0.32*** | 0.27*** | 0.33*** | 0.31*** | 0.41*** | 0.36*** |
| Overall score | 0.41*** | 0.46*** | 0.32*** | 0.32*** | 0.22** | 0.23** | 0.28*** | 0.28*** | 0.29*** | 0.30*** | 0.38*** | 0.41*** |

[a]Spearman's rank correlation coefficients;[b]Standardized regression coefficients adjusted for patient age, gender and HbA1c level.
***$p$<0.001, **$p$<0.01, *$p$<0.05.

**Table 4:** Associations between adolescent and parent experiences for single items measured by correlations[a] and regressions[b].

| Item | Correlation | Beta |
|---|---|---|
| Well received | 0.32*** | 0.28*** |
| Waiting time | 0.22** | 0.21** |
| Same nurses | 0.25** | 0.22** |
| Nurses knowledgeable | 0.26*** | 0.29*** |
| Same doctor | 0.50*** | 0.46*** |
| Doctor knowledgeable | 0.29*** | 0.22** |
| Training in how to use equipment | 0.24** | 0.41*** |
| Follow-up helped the child | 0.30*** | 0.27** |

Data are [a]Spearman's rank correlation coefficients and [b]standardized regression coefficients adjusted for patient age, gender and HbA1c level.
***$p$<0.001, **$p$<0.01.

**Table 5:** Associations between adolescent and parent experiences and HbA1c level measured by correlations[a] and regressions[b].

| Indicator/item | HbA1c | |
|---|---|---|
| | Correlation | Beta |
| **Adolescents** | | |
| Consultation | 0.01 | 0.07 |
| Information on food/exercise | -0.01 | 0.02 |
| Nurse contact | -0.02 | 0.03 |
| Doctor contact | –0.05 | –0.03 |
| Outcome | –0.03 | 0.00 |
| Overall score | -0.05 | 0.02 |
| **Parents** | | |
| Consultation | –0.12 | –0.11 |
| Organization | –0.21** | –0.14 |
| Equipment | –0.15 | –0.07 |
| Nurse contact | –0.21** | –0.19* |
| Doctor contact | –0.13 | –0.18* |
| Outcome | –0.15 | –0.15 |
| Overall score | –0.20** | –0.17* |

Data are [a]Spearman's rank correlation coefficients and [b]standardized regression coefficients adjusted for patient age and gender.
**$p$<0.01, *$p$<0.05.

Norwegian Institute of Public Health

# Your experiences with the paediatric outpatient clinic

The questions below concern your experiences with the paediatric outpatient clinic your child attends for diabetes.

## Arrival and waiting

**1. Are you and your child well received at the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**2. Do you feel there's a lot of waiting at the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**3. Do you find the waiting room satisfactory?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

## Organisation

**4. Do you feel that the outpatient clinic is well organised?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**5. Do you feel that the doctors and nurses cooperate well?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**6. Do you feel that the person you have the appointment with is well prepared?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## The nurses

**7. Do you and your child see the same nurses every time you attend the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**8. Do you and your child get enough time with the nurses?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**9. Do the nurses appear to know a lot about diabetes and diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**10. Do you feel that the nurses show care and concern for your child?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## The doctor

The questions below are about the doctor. If you see more than one doctor, please give us your overall assessment of all the doctors you see.

**11. Do you and your child see the same doctor every time you attend the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**12. Do you and your child get enough time with the doctor?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**13. Does the doctor appear to know a lot about diabetes and diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**14. Do you feel that the doctor shows care and concern for your child?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## More about what is discussed at appointments

**15. In your opinion, do the topics discussed at the appointments meet your child's needs?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**16. Is it clear to you and your child what should be followed up before the next appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**17. Do you and your child have a say in what should be followed up before the next appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Being a parent/guardian at the clinic

**18. Are your views as a parent/guardian taken seriously?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**19. Do you get enough time for conversations without your child being present?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**20. Are you given satisfactory information and guidance on how to follow up on your child's diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**21. Do you get the support you need to let your child take more responsibility for his or her diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Information and training

**22. Do you receive satisfactory information about the results of tests and examinations?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**23. Do you receive satisfactory information about the development in your child's health and the risk of complications?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**24. Do you receive satisfactory information from the outpatient clinic about available devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**25. Do you and your child receive good training in managing the devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Availability

**26. In your opinion, does your child have access to the best possible devices/equipment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**27. Does your child have satisfactory access to a nutritionist?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**28. Does your child have satisfactory access to a psychologist?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**29. Is it easy to get in touch with the outpatient clinic outside of appointments?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**30. How do you feel about the number of appointments at the outpatient clinic?**

- ☐ Too few
- ☐ A sufficient number
- ☐ Too many
- ☐ *Not applicable / Don't know*

## Usefulness

**31. Do you feel that your child benefits from attending the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**32. Do you, as a parent/guardian, benefit from attending the outpatient clinic?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Other questions

**33. Does the follow-up at the outpatient clinic make you and your child more capable to live a good life with diabetes?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**34. All in all, how dissatisfied or satisfied are you with how the outpatient clinic has followed up on your child and the diabetes treatment?**

- ☐ Very dissatisfied
- ☐ Rather dissatisfied
- ☐ Both dissatisfied and satisfied
- ☐ Rather satisfied
- ☐ Very satisfied

**35. All in all, how dissatisfied or satisfied are you with how the outpatient clinic has met you as a parent/guardian?**

- ☐ Very dissatisfied
- ☐ Rather dissatisfied
- ☐ Both dissatisfied and satisfied
- ☐ Rather satisfied
- ☐ Very satisfied

## Background questions

**36. In the last year, how many times have you been present for all or part of your child's appointment?**

- ☐ Never
- ☐ 1 time
- ☐ 2 times
- ☐ 3 times
- ☐ 4 or more times

**37. Are you male or female?**

- ☐ Male
- ☐ Female

**38. What age are you?**

☐ Number of years

**39. What is your highest level of educational attainment?**

- ☐ Primary school
- ☐ Secondary school
- ☐ Higher education/university (up to 4 years)
- ☐ Higher education/university (4+ years)

**40. Do you live with the child's other parent/ guardian?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable*

Any additional comments about experiences with the outpatient clinic or comments on the questionnaire:



Thank you for taking the time to answer.

Norwegian Institute of Public Health

Norwegian Institute of Public Health

# Your experiences with the children's outpatient clinic

The questions below concern your experiences with the outpatient clinic you attend for diabetes. Please tick only one answer for each question.

## When you arrive at the outpatient clinic

**1. Are you well received at the outpatient clinic?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent

**2. Do you feel there's a lot of waiting at the outpatient clinic?**

- 😀 ☐ Not at all
- 🙂 ☐ To a small extent
- 😐 ☐ To some extent
- ☹ ☐ To a large extent
- ☹ ☐ To a very large extent

## The nurses

**3. Do you see the same nurses every time you attend the outpatient clinic?**

- ☹ ☐ Never
- ☹ ☐ Rarely
- 😐 ☐ Sometimes
- 🙂 ☐ Often
- 😀 ☐ *Always*
- ☐ *Not applicable / Don't know*

**4. Do the nurses speak to you in a way that you understand?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent

**5. Do the nurses appear to know a lot about diabetes and diabetes treatment?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent

**6. Do you feel safe bringing up things with the nurses that are difficult to discuss?**

- ☹ ☐ Not at all
- ☹ ☐ To a small extent
- 😐 ☐ To some extent
- 🙂 ☐ To a large extent
- 😀 ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## The doctor

The questions below are about your doctor. If you see more than one doctor, please consider all the doctors you see when you are answering the questions.

**7. Do you see the same doctor every time you attend the outpatient clinic?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ *Always*
- ☐ *Not applicable / Don't know*

**8. Do the doctor speak to you in a way that you understand?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**9. Do the doctor appear to know a lot about diabetes and diabetes treatment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**10. Do you feel safe bringing up things with the doctor that are difficult to discuss?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## More about your diabetes check-ups

**11. Are you given good advice to help you choose the right insulin dose?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**12. Do you have a say in what should be followed up before the next appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**13. Do the staff who work at the outpatient clinic appear to understand what it's like to be young and have diabetes?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**14. Do you get enough time with the doctor or nurse during you appointment?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**15. How do you feel about the number of appointments you have at the outpatient clinic each year?**

- ☐ Too few
- ☐ A sufficient amount
- ☐ Too many
- ☐ *Not applicable / Don't know*

## Food and exercise

**16. Are you given good information and guidance about food?**

-  ☐ Not at all
-  ☐ To a small extent
-  ☐ To some extent
-  ☐ To a large extent
-  ☐ To a very large extent

**17. Are you given good information and guidance about exercise?**

-  ☐ Not at all
-  ☐ To a small extent
-  ☐ To some extent
-  ☐ To a large extent
-  ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Devices/equipment

**18. Are you involved in deciding which devices/equipment you should use?**

-  ☐ Not at all
-  ☐ To a small extent
-  ☐ To some extent
-  ☐ To a large extent
-  ☐ To a very large extent
- ☐ *Not applicable / Don't know*

**19. Do you receive good training in managing the devices/equipment?**

-  ☐ Not at all
-  ☐ To a small extent
-  ☐ To some extent
-  ☐ To a large extent
-  ☐ To a very large extent
- ☐ *Not applicable / Don't know*

## Appointment with others

**20. Can you get an appointment with a nutritionist if you need one?** *(A nutritionist gives advice about food and diet)*

- ☐ Yes
- ☐ No
- ☐ *Not applicable/Don't know*

**21. Can you get an appointment with a psychologist if you need one?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable/Don't know*

## Bringing parents/guardians with you

**22. How often do your parents/guardians attend the outpatient clinic with you?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

**23. If your parents/guardians attend the appointment with you, who does the doctor or nurse mostly speak to?**

- ☐ Mostly to me
- ☐ Mostly to my parents/guardians
- ☐ About the same to each of us
- ☐ Parents/guardians do not come with me

**24. If needed, can you get an appointment with your doctor or nurse without your parents/ guardians being present?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable/Don't know*

## Other questions

**25. All in all, has attending the outpatient clinic helped you with your diabetes?**

- ☐ Not at all
- ☐ To a small extent
- ☐ To some extent
- ☐ To a large extent
- ☐ To a very large extent

**26. Who completed this questionnaire?**

- ☐ Me on my own
- ☐ Me and my parents/guardians together
- ☐ My parents/guardians on their own

**27. All in all, how are you feeling today?**

- ☐ Very bad
- ☐ Fairly bad
- ☐ Both and
- ☐ Rather good
- ☐ Very good

**28. Do you alternate between living with each of your parents/guardians?**

- ☐ Yes
- ☐ No
- ☐ *Not applicable*

## Any additional comments about the outpatient clinic or how you found completing the questionnaire:

Thank you for taking the time to answer.

# Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectionalreporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

| | | Reporting Item | Page Number |
|---|---|---|---|
| **Title and abstract** | | | |
| Title | #1a | Indicate the study's design with a commonly used term in the title or the abstract | 2 |
| Abstract | #1b | Provide in the abstract an informative and balanced summary of what was done and what was found | 2,3 |
| **Introduction** | | | |
| Background / rationale | #2 | Explain the scientific background and rationale for the investigation being reported | 4-6 |
| Objectives | #3 | State specific objectives, including any prespecified hypotheses | 2,7 |
| **Methods** | | | |
| Study design | #4 | Present key elements of study design early in the paper | 2, 7 |
| Setting | #5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 7-9 |
| Eligibility criteria | #6a | Give the eligibility criteria, and the sources and methods of selection of participants. | 2,8 |

| | | | |
|---|---|---|---|
| | #7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 8,9 |
| Data sources / measurement | #8 | For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable. | 8,9 |
| Bias | #9 | Describe any efforts to address potential sources of bias | 4,13 |
| Study size | #10 | Explain how the study size was arrived at | 7,8 |
| Quantitative variables | #11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why | 8-10 |
| Statistical methods | #12a | Describe all statistical methods, including those used to control for confounding | 8-10 |
| Statistical methods | #12b | Describe any methods used to examine subgroups and interactions | 8-10 |
| Statistical methods | #12c | Explain how missing data were addressed | n/a |
| Statistical methods | #12d | If applicable, describe analytical methods taking account of sampling strategy | n/a |
| Statistical methods | #12e | Describe any sensitivity analyses | n/a |
| **Results** | | | |
| Participants | #13a | Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable. | n/a |
| Participants | #13b | Give reasons for non-participation at each stage | n/a |
| Participants | #13c | Consider use of a flow diagram | n/a |
| Descriptive data | #14a | Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable. | 10,20 |
| Descriptive data | #14b | Indicate number of participants with missing data for each variable of interest | n/a |
| Outcome data | #15 | Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable. | n/a |
| Main results | #16a | Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | n/a |

| | | | |
|---|---|---|---|
| Main results | #16b | Report category boundaries when continuous variables were categorized | n/a |
| Main results | #16c | If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | n/a |
| Other analyses | #17 | Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses | n/a |
| **Discussion** | | | |
| Key results | #18 | Summarise key results with reference to study objectives | 11, 13-14 |
| Limitations | #19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias. | 13 |
| Interpretation | #20 | Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence. | 12,13 |
| Generalisability | #21 | Discuss the generalisability (external validity) of the study results | 13 |
| **Other Information** | | | |
| Funding | #22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 14 |