Augmenting Communication With Before Visit Questionnaires

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Thesis

Submitted to the Faculty of the Graduate School of Vanderbilt University in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Biomedical Informatics

September 30, 2017

Nashville, Tennessee

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ACKNOWLEDGEMENTS

I would like to thank my entire dissertation committee for guiding me through this journey. Trent Rosenbloom has been a thoughtful mentor not only for this project but through my developing career as a biomedical informatician. Laurie Novak is an insightful researcher that brings great depth and dimension to all conversations. Cindy Chen is an outstanding statistician that can translate complicated concepts into comprehensible ideas. Others who have directly assisted in this dissertation work include Daniel Fabbri, Joseph Coco, and Chen Ye who developed a robust note coding platform that allowed us to obtain data for the principal components of our analysis. Preston Stein has been a wonderful friend and mentor who dedicated much of his time helping me advance the project. Matt Win and Frank Jordan dedicated many hours to our coding and data analysis efforts. I also acknowledge and appreciate the time and input of the providers who served as my research participants and the parents of our patients with pediatric diabetes who were willing to share their concerns about their children with us using the system we developed. I would like to thank Kevin Johnson, Gretchen Jackson, Cindy Gadd, and Rischelle Jenkins for giving me the opportunity to participate in this educational program and encouraging me along the way to completion. I would like to thank my peers for their support and encouragement on our educational journey together. I would like to thank my husband for all his support during the many hours I spent working on this study. This project would not have been possible without funding from the Vanderbilt Institute for Clinical and Translational Research VR14620.1 and NIH NLM grant T15LM007450-13 funding.

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I. Background & Specific Aims

Medical, social, and financial barriers faced by patients with diabetes can result in poor adherence to their prescribed plan of care. Poor adherence can lead to subsequent complications such as renal disease, cardiovascular disease, neurological disease and ultimately, premature mortality. Providers can help their patients develop self-efficacy by addressing barriers to adherence. Due to time constraints during a clinical encounter, providers are not always able to explore a patient's barriers to adherence. Decreasing the time a provider spends collecting and documenting a patient's interval history can increase the time available for them to interact with their patient. This study evaluates a workflow intervention that can facilitate patient communication about barriers and simultaneously create provider documentation.

The use of a Before Visit Questionnaire (BVQ) to collect a patient's barrier information can facilitate communication by 1) highlighting the patient's barriers to adherence and 2) using the patient's responses to facilitate the provider's documentation. This allows information to be collected which can then be used to create a summary of the interval history. That summary can be shared with the patient's providers and reviewed before the clinical encounter to give insight into the patient's challenges. Providing a generated interval history for use in a provider's clinical encounter note can also decrease the time it will take for the provider to complete that aspect of documentation. This will allow the provider more time to focus on addressing the patient's barriers to adherence. We hypothesize that patient completed BVQs can improve communication about barriers to adherence and decrease the work of documentation.

Aim 1: Develop and assess a tool that can be used to collect a patient's history and create a provider summary note from that content. The methods for this portion include the use of the web-based platform REDCap to develop a questionnaire tool to collect information about the patient's interval history, adherence problems, and barriers. The questionnaire tool leverages a piping functionality in REDcap to send answers entered by the participants into a templated form that creates a summary for their provider about the patient's interval history and barriers.

Aim 2: Evaluate how the use of the created summaries influence patient-provider communication about barriers to adherence. We used a quasi-experimental method to compare notes generated by a provider before and after receiving a created summary. We will assess how access to these created summaries impact barrier and adherence communication. We hypothesize that a provider is more likely to communicate, and subsequently document, a patient's barriers, and adherence challenges if they receive a generated summary.

Aim 3: Evaluate the experiences of the providers using the generated summaries to determine specifications for a future tool. We will perform qualitative interviews to assess provider sentiments about how the generated summaries impact their workflow. These specifications will serve as guidelines and design principles for future tools. We will compare the word count for provider notes that

include the generated summary as part of their documentation to those that do not, to evaluate the impact of the created summaries on provider work. We hypothesize the providers will have overall positive sentiments about the created summaries, and that use of the created summaries in their clinic note will decrease the amount of additional documentation.

This study will challenge existing paradigms of clinical documentation practice and demonstrate that engaging patients in their health by allowing them to contribute to their medical notes can improve their care. This research will be important for motivating future initiatives for the incorporation of patient generated content in clinical documentation.

II. Literature Review

Pediatric Type 1 Diabetes (T1D) is a chronic disease that requires regular self-care tasks to manage, including blood glucose monitoring, carbohydrate counting, and insulin administration several times a day [1]. Given the frequency and nature of these tasks, barriers to self-care such as numeracy difficulties, and financial concerns are common [2-4]. Addressing a family's barriers to diabetes self-management can help them develop self-efficacy [2]. Common barriers in pediatric diabetes management include limited resources, and parent-child conflicts [2-4]. When patients and families can communicate their barriers to adherence to their provider, the provider is in a better position to help the patient problem solve around these obstacles [5].

The Shannon and Weaver model of communication describes an information transmission model consisting of a) a sender, who is an information source that produces a message b) a transmitter, that encodes the message then sends it through a channel where it is gathered by c) a receiver who decodes and reconstructs the message. The receiver may then give feedback to the sender to confirm receipt of the information [6]. Elements of noise in the channel can interfere with the message, which may lead to a discrepancy between the signal sent and the signal received [6, 7]. We can also view the Shannon and Weaver model from a clinical communication perspective where a) the patient is the information source, b) the patient's voice is the transmitter used to express their concerns, c) the provider is the receiver who interprets the patient's needs, then provides care recommendations. Multiple factors during a clinical encounter function as "noise" and make it difficult to identify a patient's barriers to adherence. Some of these factors include a family's inability to recognize their barriers, difficulties a family may have expressing concerns, and constraints on clinical time that prevent the provider from exploring the concerns a family raises [5]. These factors can result in missed opportunities for clinicians to help the family problem solve around these barriers [5].

A Before Visit Questionnaire (BVQ) may serve as a key instrument to help a family identify their barriers to adherence and overcome the "noise" in clinical communication. A BVQ is a tool that collects information about a patient's barriers and communicates those concerns to a provider in the form of a summary note. This summary note can then be incorporated into the provider's clinic note, which can result in less documentation work for the provider during the clinical encounter. This workflow allows the provider to focus more efforts on addressing the patient's highlighted barriers to adherence. The BVQ is inspired by some of the earliest computer-based documentation systems designed to collect information from patients. Systems to collect information from patients using computers as part of the workflow have been under development since the 1960s [8, 9]. In 1966 Slack et al. developed a system using a keyboard with a cathode ray tube output to collect allergy information from patients. The collected information was printed out as an allergy summary report for the provider [9]. In 1987 Quaak et al. examined a workflow using a computer system to collect a patient's general history then generate a review note for the provider [10]. A more modern tool known as Instant Medical History is an example of a BVQ that is currently used in some EHR systems to collect interval history about a patient leading up to their medical appointment [11]. Studies have shown that using electronic input can be a feasible and accurate way to collect patient information [12], and can be acceptable to patients as well [13, 14]. While tools like Instant Medical History have been shown to help facilitate the clinical encounter in acute care settings, there have not been studies evaluating the use of a BVQ in chronic

disease management such as type 1 diabetes. Specifically, how can the use of a BVQ in a chronic condition like type 1 diabetes help to facilitate barrier identification and communication?

Collecting computerized histories from patients offers the benefit of gathering data in a structured and reusable format [15]. Having a patient's interval data in a reusable format means the provider will not have to collect and input that information into their documentation again after the patient has already shared it. The structured information provided by the patient can now be incorporated into the providers note to satisfy that element of the provider's documentation [15]. In chronic disease management, like diabetes, routine information is gathered to provide an interval history [16]. Based on this collected information, there can be a defined set of content that can be used to form a template and generate the narrative of a patient's interval history [16]. Having access to the generated interval history affords providers the opportunity to review that history prior to the clinic visit, and use the clinic visit time to focus on relevant areas of interest. Tools that communicate results of a BVQ can help providers better focus on key elements already gathered prior to the clinic visit, rather than using the clinic visit as the session for the initial discovery.

BVQs provide a unique opportunity to enable the collection of relevant information from patients including specific elements about barriers to adherence. A BVQ can thus serve as a tool to help patients become more engaged in their health and support communication with their providers. It is important to examine how these BVQs can be incorporated into a clinical workflow as providers' work towards improving patient engagement and shared decision making [17, 18]. The feasibility of this method of evaluation has not been fully explored in diabetes care. Using a BVQ to generate a summary for use in a provider's clinical encounter note may change the time it will take for the provider to complete the interval history aspect of documentation and allow the provider more time to focus on addressing the patient's highlighted barriers to adherence. Demonstrating that this strategy can facilitate patient and provider communication can result in improved clinical practice.

This project will challenge existing paradigms of clinical documentation practice and demonstrate that engaging patients in their health by allowing them to contribute to their medical documentation can improve their care delivery. This research is important for motivating future initiatives for the incorporation of patient generated content in clinical documentation. We will refine existing approaches and methodologies of collecting patient information from computerized interviews and develop a model for collecting such information from patients with chronic diseases like diabetes, with a focus on barriers to adherence. We are not aware of any previous studies evaluating the benefits of collecting this content from patients with chronic diseases or using such an approach as a means to help identify barriers to adherence.

III. Methods

Methods Overview

In Aim 1 of the study, we evaluated a questionnaire tool to identify diabetes adherence challenges and barriers and use that collected information to generate a summary note for the provider. In Aim 2 of the study, we sought to demonstrate that the use of the questionnaire will lead to increased communication about barriers to diabetes care adherence. In Aim 3 of the study, we sought to demonstrate that generated notes could decrease documentation work for the provider.

Questionnaire

Questionnaire Creation

We developed a Before Visit Questionnaire (BVQ) to collect information about patient interval histories and barriers. The questionnaire was created using REDCap, Vanderbilt's secure online data collection tool for the electronic management of clinical and research data. The questionnaire consists of questions about the participant and their child's demographics, child's medication regimen, elements of the child's interval history since their last appointment, adherence challenges, and barriers to diabetes care. Parents were asked to identify their primary medical and psychosocial adherence challenges and barriers to their child's diabetes management from a presented list of options. Parents also had an opportunity to enter free text responses for their barriers and adherence challenges. Free text responses were reviewed by two coders to determine whether the themes in the responses were represented in the barrier options presented in the BVQ. After completing the questionnaire, parents were asked to rate the usability of the questionnaire.

A technique known as piping was used to pass the information entered about the patient to a summary note template for a provider. The summary note was finalized in REDCap upon completion of the questionnaire. The generated summary note was entered into the patient's electronic health record (EHR) by the research team. These summaries were available to the provider to review in the EHR prior to the clinical encounter. Providers had the option of copying and pasting the content from the summary notes into their note for that clinical encounter.

A post visit survey was created in REDCap to examined how the parents viewed the BVQ and its overall impact on their diabetes clinical encounter. After completing the BVQ and completing their subsequent diabetes clinical encounter with their child, each parent was invited to complete the post visit survey. In the post visit survey participants were asked whether the BVQ helped them feel prepared for their clinic visit and whether the BVQ improved their clinic visit. The response options were grouped into four categories: strongly disagree, disagree, agree, strongly agree. Participants were asked whether they would have discussed their primary medical and primary psychosocial barrier without the aid of the BVQ with selection options including yes, no, and unsure.

Subjects and Setting

Participants were recruited from the Vanderbilt Eskind Pediatric Diabetes Clinic, an academic medical center in Nashville, Tennessee. Letters were sent to the parents of patients inviting their participation through a hypertext link. Inclusion criteria were: 1) having a child under 13 years of age that had been diagnosed with type 1 diabetes, 2) plans to visit the Eskind Diabetes Clinic with their child within the next 6 months of invitation receipt, 3) ability to read and understand the survey content and informed consent and 4) having access to a computer with Internet access. Each parent who completed a BVQ received a \$15 gift certificate. Each parent who completed a post visit survey received a \$5 gift certificate.

Provider Documentation

Subjects and Setting

Physician and Nurse practitioner providers from the Vanderbilt Pediatric Endocrine Division were recruited for the study. Providers were notified about the study during a presentation at the Weekly Pediatric Endocrine Lecture Series. During this presentation, providers were informed about the study aims and their potential role in the study. Providers who expressed interest in the study were consented for participation through the IRB process. Selection criteria for providers included pediatric endocrinology attending physicians and nurse practitioners that see pediatric diabetes patients at least once a week in clinic. Trainees such as fellows and residents were excluded.

Intervention and Control Notes

We reviewed clinical encounter notes written by the 16 provider participants for each of the 73 patient participants in the study.

Intervention notes were defined as clinic visit notes written by the provider for the research patients after the patient's parent had completed a BVQ to share their concerns. There were 73 intervention notes assessed in the study.

Control notes were defined as clinic visit notes written by the provider for the research patient prior to the patient's parent enrolling in the study and completing the BVQ.

When available, control notes for the two most recent encounters leading up to the intervention were assessed. If a patient only had one prior encounter note written before the intervention, because they were new to the clinic, that one note was used as the control note. There were 131 control notes assessed in the study.

Provider Note Analysis

Provider notes were coded using Vanderbilt PYBOSSA- Vanderbilt Python Berkeley Open System for Skill Aggregation (Fabbri et al.), a framework designed to navigate workflows of clinical chart reviews including 1) the architecture for storing and displaying sensitive data and 2) the development of tools to support crowd workers in quickly analyzing information from complex data sets. The system stores and displays de-identified notes to workers and allows workers to snip sections of the results and codify them. Using this framework, six coders individually coded all 204 clinic notes to identify barriers and adherence challenges. Adherence challenges were coded when the providers documented elements of poor patient compliance in their notes. Barriers were coded when

providers identified reasons patients were having difficulty adhering to their care regimen. We compared how frequently these codes were applied in the intervention vs. the control notes. The coding scheme for adherence and barriers to adherence was determined from a literature review of commonly documented constructs for diabetes barriers and adherence challenges in pediatrics. Coding results were reviewed by the PI and research team members, and final codes were assigned based on majority codes selection.

Logistic regression models with the Huber-White method to adjust the cluster effect within provider were implemented for adherence, barrier, adherence plan, and barrier plan. An ordinal logistic regression model with the Huber-White method was used for the total score, which is the summation of adherence, barrier, adherence plan, and barrier plan.

Provider Interviews

All 16 of the provider participants completed individual one-on-one interviews to provide feedback about their experience using the generated summaries to prepare for their clinical encounters. Audio recordings of the interviews with the providers were transcribed verbatim and verified. Files containing the transcribed interview notes were imported into Dedoose (Version 7.6.6), a qualitative data analysis software.

Provider statements were mapped to the theoretical model of the provider's views of how well the note served the function as a clinical decision support tool. These tenants include 1) Right information, 2) To the right person, 3) In the right intervention format, 4) Through the right channel, 5) At the right time in the workflow. Data were analyzed with Dedoose software using a grounded theory approach, including line-by-line coding and then axial coding to understand how key concepts related to one another. Focused coding then further mapped concepts regarding provider sentiments about the usefulness of the generated summaries as a decision support instrument. Design recommendations for future versions of the generated summaries were also coded. A team of three researchers trained in qualitative data analysis worked together to identify themes across the notes and code and analyze the data. These themes were used to create a codebook that included one or more codes to capture each theme that was then used to code the interview transcripts. The principal investigator and second research team member individually performed coding of all the 16 interview transcripts. Final coding between assignments was compared to identify conflicting codes, and the team had discussions to reconcile and assign a final code to any conflicting codes. A third team member served as a tie breaker to resolve code conflicts when there was no initial agreement.

All work was approved through the Vanderbilt Behavioral and Social Sciences Institutional Review Board.

Note word count

Word counts were performed using Microsoft Word 2016 Word Count tool. Intervention notes where providers copied components of the generated summary into their note were compared to intervention notes where the provider did not copy any elements of the generated summary into their note. Word counts were performed to determine how many additional words were typed by the providers in the notes where the generated summary had been copied compared to the notes that did not copy any parts of the generated summary. Wilcoxon test was used to test the difference in additional word usage between the intervention notes where providers had copied the generated summary into their final notes, and the intervention notes that did not incorporate the generated summary notes into their final note.

IV. Results

Parent Completed Before Visit Questionnaire

Participation

321 parents of children from the Eskind Clinic met the eligibility criteria for the study. 97 parents (30%) attempted to log into the system to participate in the study. 73 parents (22%) successfully completed the questionnaire and subsequent clinical encounter.

Sample Characteristics

Participants

Table 1 shows the demographic and clinical characteristics of the sample. Mean age of the parent participants was 39 (SD 5.8) years. Mean age of the patients was 9 (SD 2.9) years. Among the parent participants, 92%, were female, and 58% of the patients were female. Mean patient A1C in the study was 8.0 % (SD 1.0). The average duration of diabetes was 3.4 years (SD 2.3). Among the parent participants 97%, were Caucasian, 3% were African American, and none were categorized as other. Among the patients, 97%, were Caucasian, 4% were African American, and none were categorized as other. 42% of the patients used subcutaneous insulin infusion pumps. Income distribution demonstrated 4% reported income =<\$20,000, 10% reported income \$20,001-\$40,000, 26% reported income \$40,001-\$70,000, and 60% reported income >70,001. 99% of the parent participants were married, and 91% had completed some college.

Non-responders

Table 1 shows the demographic and clinical characteristics of the patients whose caretakers were invited to complete the questionnaire but did not respond (non-responders). Mean age of the patients was 9.2 (SD 2.6) years. 51% of the patients were female. Mean A1C was 8.3 (SD 1.6). 76% of patients were Caucasian, 13% were African American, and 26% were categorized as other. Income distribution (estimated by using patient's addresses and data from the US Census American Community Survey) demonstrated 1% given income =<\$20,000, 1% given income of \$20,001-\$40,000, 69% given income of \$40,001-\$70,000, and 30% given income of >70,001. Race, A1C, and household income demonstrated differences with p<0.05 between the participant respondent population and the non-responder population.

	Parent	Child	Controls (n=248) Non-responders
Variable (n=73)	Mean(SD) or n(%)	Mean(SD) or n(%)	Mean(SD) or n(%)
Age	38.9 (5.8)	9.1 (2.9)	9.2 (2.6) p=0.539
Female	67 (92%)	42 (58%)	121 (49%) p=0.183
Race (multi-select)		_	p=0.008
Caucasian	71 (97%)	71 (97%)	189 (76%)
African American	2 (3%)	4 (5%)	33 (13%)
Others			26 (11%)
Pump User		31 (42%)	
Duration Diabetes (years)		3.4 (2.3)	
A1C		8.0% (1.0)	8.3 (1.6) p=0.025
Household Income		-	p=0.044
<\$20,000	3 (4%)	_	0 (0%)
\$20,001-\$40,000	7 (10%)		2 (1%)
\$40,001-\$70,000	19 (26%)		171 (69%)
>\$70,001	44 (60%)		75 (30%)
Insurance			p=0.001
Private	55 (75%)		136 (55%)
Medicaid	18 (25%)		112 (45%)
Parent Education			
High school or GED	7 (9%)		
2-year college	21 (29%)	_	
4-year college	26 (36%)		
Master's degree	14 (19%)	_	
Doctoral or professional degree	5 (7%)		
Parent Relationship to child		_	
Mother	66 (90%)	_	
Father	6 (9%)		
Grandparent	1 (1%)		
Parent Marital Status			
Single	6 (8%)		
Married	66 (91%)		
Long-term relationship	1 (1%)		

Table 1: Demographic and clinical characteristics of study participants and non-responders (Controls)

Barriers

Figure 1 shows the medical and psychosocial barriers and adherence challenges selected by the parents who completed the survey. The top selected medical barriers included 'how certain foods affect blood sugar,' 'what to do when sick,' and 'how exercise affects blood sugar.' The top selected psychosocial barriers included 'keeping a close eye on things when busy,' option for free text response,' and 'cost and finances.'

Free text responses about barriers were provided by 33% of participants. 55% of the given free text responses were mapped to existing presented medical or psychosocial barriers, particularly "arguments with child about diabetes." The main free text responses that did not map well to the existing barriers included concerns about hypoglycemia and parent expressions of feeling overwhelmed with the daily rigor of the regimen.

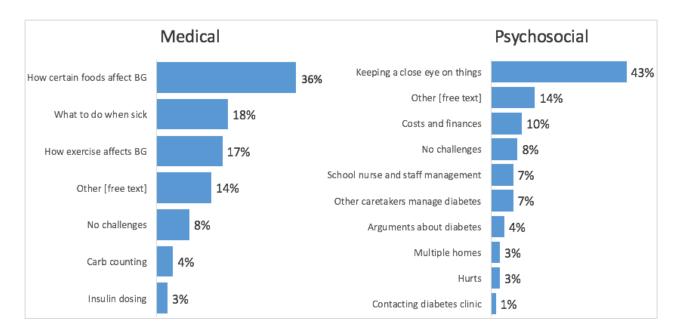


Figure 1: Medical and psychosocial barriers and adherence challenges selected by participants

Provider Qualitative Interviews

16 providers were interviewed to provide feedback about their experience using the generated interval history summary notes. Mean age of the providers was 45 (SD 11) years. Average years of practice was 12 (SD 11) years. The majority of the providers were female (69%). The average number of half-days of clinic a week was 4 (SD 2). Providers were questioned about whether they preferred to type their clinical notes on a computer during their patient encounter or not. 56% of providers stated that they always documented on the computer while in the room with the patient, 31% of providers stated they sometimes documented in the room with the patient, and 13% of the providers stated they never documented on a computer while in the room with the patient (Figure 2).

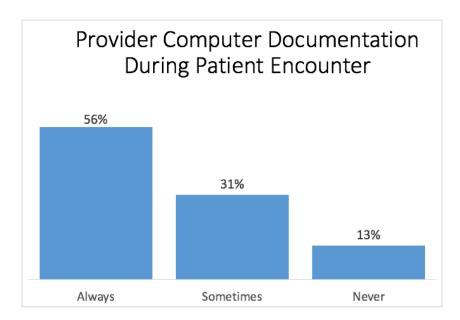


Figure 2: Provider documentation in exam room with patient

When the providers who preferred to document in the room were asked about their motivations, the two main stated reasons were 1) efficiency: because they felt it was more efficient to capture that information while they were there with the patient than writing down notes on paper and having to retype the notes later, and 2) memory: because it would be easier to remember the information shared at that time than having to recall it afterwards. The top reasons given by the providers that preferred not to document in the room while they were with their patient were 1) efficiency: because it was too inefficient to try to type up a clinic note accurately during the encounter, and 2) poor patient engagement: because it was challenging to maintain patient engagement while working simultaneously in the EHR.

Provider Perspectives on notes as Clinical Decision Support

- 1) Right information: 13/16 (81%) of providers desired notes less than one week old, 2/16 (12%) of the providers desired notes less than two weeks old, and 1/16 (7%) of the providers would allow for a note up to 4 weeks old. Sentiments such as "accurate" and "true and current" were used to describe the relevance of a note in association with the duration since it was completed. Providers expressed concerns that information completed too far in advance was subject to change, thus potentially rendering the generated summary inaccurate.
- 2) To the right person: All providers, 16/16, found it useful to direct barrier information to them. Providers expressed that patient barrier and adherence challenges were information they would like to have about their patients but can be time prohibitive to acquire. A poignant quote from the interviews that best captured the majority sentiment was a comment by a provider who stated, "[we do] not often get into this... in the short time that we have." This statement expresses that barrier information is content providers often desire to have but are often too time constrained to collect.
- 3) In the right intervention format: 11/16 (69%) of providers stated that the generated paragraph prose version of the note was the optimal format to save the note in final form to communicate information to others. One provider statement that captured the overall sentiment was, "it's the role of sentences to mimic conversation between two individuals. And I think it would be a more appreciated version for a primary care physician or a referring physician. I know, myself, I would prefer to get something like this... rather than a bulleted thing. It somehow lends a more personal touch." 12/16 (75 %) of the providers stated that a bulleted version of the note would be an optimal form to review the notes because the data could be easier gleaned in that manner. One provider

statement that captured the overall sentiment was "would be great to... have in the room to review with the patient and knowing that it would match this, you know, would be nice."

- 4) Through the right channel: 15/16 (94%) of providers desired a feature to auto-import the generated summary into their note so it would be available for them to review and edit within the channel they were working. Some providers expressed frustration about forgetting to access the generated summary before their clinical encounter. Although the generated summary was visible in the patient's chart, providers could still overlook it because it was not directly linked to their documentation: "[I was] kicking myself when I noticed it was there and I didn't use it."
- 5) At the right time in the workflow: All providers, 16/16, found it useful to have access to their patient's barrier information before encountering the patient that day. One provider's statement that captured the overall sentiment was "sometimes you might learn; I mean I guess I'm thinking, I've been blindsided sometimes going into a room and there's been a divorce or some kind of major life event, Dad died. You would want to know that before you walk into the room, I think."

Provider Generated notes

Intervention and Control Notes

Table 2 shows the results of coding for barriers and adherence challenges documented in the provider notes. A total of 204 notes were coded to determine how frequently the provider documented patient adherence problems and barriers, and how frequently the provider documented plans to address those adherence problems and barriers.

Adherence documentation: 7 of 131 (13%) of control notes had adherence problems coded, and 18 of 73 (25%) of intervention notes had adherence problems coded (p=0.03). In 14 of 131 (11%) of the control notes providers documented plans to address the patients' adherence problems, and in 14 of 73 (19%) of the intervention notes providers documented plans to address the patients' adherence problems (p=0.09).

Barrier documentation: 19 of 131 (15%) of control notes had barriers coded, and 14 of 73 intervention notes (19%) had barriers coded (p=0.38). In 15 of 131 (11%) of control notes providers documented plans to address the patients' barriers, and in 6 of 73 (8%) of intervention notes providers documented plans to address the patients' barriers (p=0.46).

	Control N = 131	Intervention N = 73	Combined N = 204	
Adherence				$\chi_1^2 = 4.5, P = 0.034^1$
not documented	87% (114)	75% (55)	83% (169)	
documented	13% (17)	25% (18)	17% (35)	
Barrier				$X_1^2 = 0.76, P = 0.385^1$
not documented	85% (112)	81% (59)	84% (171)	
documented	15% (19)	19% (14)	16% (33)	
Adherence_and_or_Bar	rrier			$\mathcal{X}_1^2 = 0.95, P = 0.331^1$
not documented	79% (103)	73% (51)	76% (156)	
documented	21% (28)	27% (20)	24% (48)	
Adherence Plan				$\mathcal{X}_1^2 = 2.85, P = 0.091^1$
not documented	89% (117)	81% (59)	86% (176)	
documented	11% (14)	19% (14)	14% (28)	
Barrrier Plan				$X_1^2 = 0.53, P = 0.467^1$
not documented	89% (116)	92% (67)	90% (183)	
documented	11% (15)	8% (6)	10% (21)	
AdhPlan_and_or_BarPla	an			$\mathcal{X}_1^2 = 0.28, P = 0.599^1$
not documented	82% (108)	79% (58)	81% (166)	
documented	18% (23)	21% (15)	19% (38)	
TotalScore	0.000 0.000 0.000 (0.496±1.055)	0.000 0.000 1.000 (0.712±1.275)	0.000 0.000 0.000 (0.574±1.140)	$F_{1,202} = 1.07, P = 0.303^2$
Copied_interval_hx_by	_note			$X_1^2 = 24.9, P < 0.001^1$
not documented	100% (131)	82% (60)	94% (191)	
documented	0% (0)	18% (13)	6% (13)	
Copied_interval_hx_by	_provider			$X_1^2 = 0.05, P = 0.819^1$
not documented	57% (75)	59% (43)	58% (118)	
documented	43% (56)	41% (30)	42% (86)	

a b c represent the lower quartile a, the median b, and the upper quartile c for continuous variables. $x \pm s$ represents $X \pm 1$ SD. Numbers after percents are frequencies. Tests used: Pearson test; Wilcoxon test

Table 2: Coding results for adherence challenges and barriers in provider intervention and control notes

a b c represent the lower quartile a, the median b, and the upper quartile c for continuous variables. $x \pm s$ represents $X \pm 1$ SD. Numbers after percents are frequencies. Tests used: Pearson test; 2^{NVikoxon} test

Table 3 shows the results of coding for barriers and adherence challenges in the 204 provider notes comparing notes that incorporated the generated interval summary into their note, compared to notes that did not:

Adherence documentation: 28 of 191 (15%) of notes that did not incorporate the generated interval history had adherence problems coded, and 7 of 13 (54%) of notes that did incorporate the generated interval history had adherence problems coded (p<0.001). In 23 of 191 (12%) of notes with no incorporated interval history providers documented plans to address the patients' adherence problems, and in 5 of 13 (38%) of notes with an incorporated interval history providers documented plans to address the patients' adherence problems (p=0.02).

Barrier documentation: 28 of 191 (15%) of notes that did not incorporate the generated interval history had barriers coded, and 5 of 13 (38%) of notes that did incorporate the generated interval history had adherence problems coded (p<0.02). In 18 of 191 (9%) of notes with no incorporated interval history providers documented plans to address the patients' barriers, and in 3 of 13 (23%) of notes with incorporated interval history providers documented plans to address the patients' barriers (p=0.11).

	Incorporation of Generated Hx	No Incorporation of Generated Hx	Combined	Test Statistic
	N = 13	N = 191	N = 204	
Adherence not documented	46% (6)	85% (163)	83% (169)	$\mathcal{X}_1^2 = 13.2, P < 0.001^1$
documented	54% (7)	15% (28)	17% (35)	
Barrier				\mathcal{X}_1^2 = 5.09, P = 0.024 ¹
not documented	62% (8)	85% (163)	84% (171)	
documented	38% (5)	15% (28)	16% (33)	
Adherence _and_or_Barrier				$X_1^2 = 7.09, P = 0.008^1$
not documented	46% (6)	79% (150)	76% (156)	
documented	54% (7)	21% (41)	24% (48)	
Adherence Plan				$X_1^2 = 7.17, P = 0.007^1$
not documented	62% (8)	88% (168)	86% (176)	
documented	38% (5)	12% (23)	14% (28)	
Barrier Plan				\mathcal{X}_1^2 = 2.46, P = 0.117 1
not documented	77% (10)	91% (173)	90% (183)	
documented	23% (3)	9% (18)	10% (21)	
AdhPlan_and_or_BarPlan				$\mathcal{X}_1^2 = 6.94, P = 0.008^1$
not documented	54% (7)	83% (159)	81% (166)	
documented	46% (6)	17% (32)	19% (38)	
TotalScore	0.000 _{2.000} 3.000 (1.538±1.613)	0.000 _{0.000} 0.000 (0.508±1.075)	0.000 _{0.000} 0.000 (0.574±1.140)	$F_{1,202} = 8.55, P = 0.004^2$

a b c represent the lower quartile a, the median b, and the upper quartile c for continuous variables. $x \pm s$ represents $X \pm 1$ SD. Numbers after percents are frequencies. Tests used: Pearson test; Wilcoxon test

Table 3: Coding results of adherence challenges and barriers in notes that incorporated the generated interval history compared to those that did not incorporate the generated interval history

Note word count

The average word count of the clinic note's interval history section where the providers incorporated the generated summaries in their notes was 68 (SD 47) words. The average word count of the clinic note's interval history section where the providers did not incorporate the generated summaries in their notes was 137 (SD 74) words. This relationship was statistically significant p=0.003 (Figure 3).

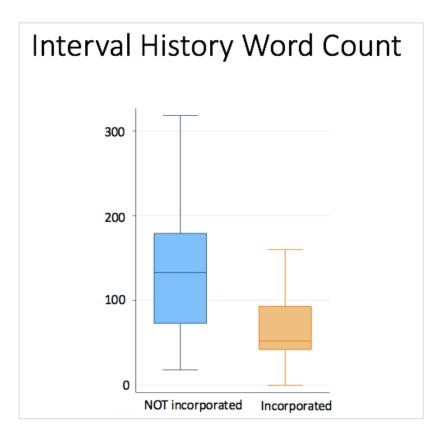


Figure 3: Average number of words typed by providers in the interval history portion of the clinic note when a) generated summaries were not incorporated in the documentation (blue) compared to number of words typed when b) generated summaries were incorporated in the documentation (orange)

Parent Participant Post Visit Evaluation

68 of the 73 participants that completed the BVQ completed the post visit questionnaire after their clinical encounter. 80% of participants completing the post visit questionnaire either agreed (35%) or strongly agreed (45%) that the BVQ helped them feel more prepared for their clinic visit (Figure 4). 79% of participants completing the post visit questionnaire either agreed (38%) or strongly agreed (41%) that the system improved their clinic visit (Figure 5). While the majority (69%) of participants indicated that they would have discussed at least one of their primary barriers with their provider, 31% of participants were either unsure they would have discussed their primary medical or psychosocial barrier (29% | 18%) or would certainly not have discussed their primary medical or psychosocial barrier (2% | 8%) with their provider without having completed the BVQ (Figure 6).

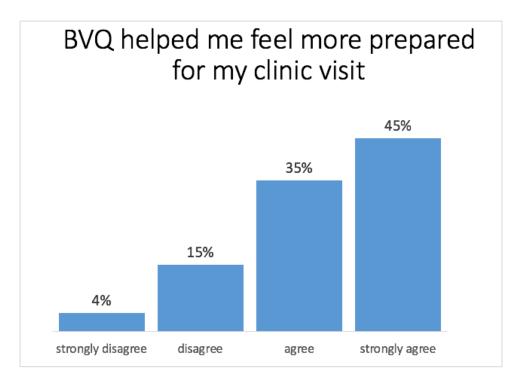


Figure 4: Post visit response from participant- BVQ impact on clinic preparation

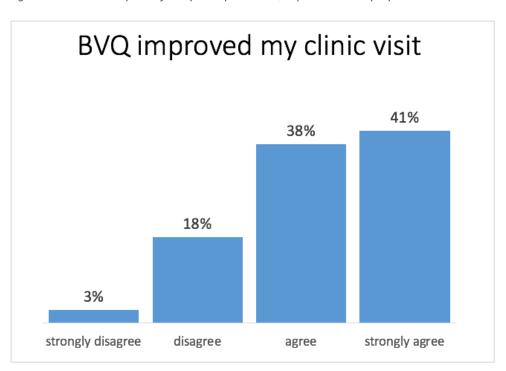


Figure 5: Post visit response from participant- BVQ improvement of clinic encounter

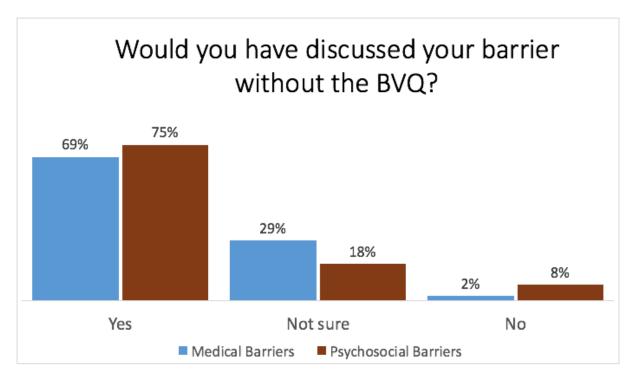


Figure 6: Post visit response from participant- BVQ facilitation of barrier discussion

V. Conclusion & Discussion

Barriers faced by patients with diabetes can prevent them from adhering to their prescribed plan of care. An aspect of the clinical encounter that detracts from patient-provider engagement is the work required for a provider to collect and document a patient's interval medical history. A workflow that allows patients to complete a computerized BVQ prior to their clinic visit can support communication during a clinical encounter by highlighting the patient's barriers to adherence and using the patient's responses to facilitate provider documentation. We created a patient facing BVQ to collect information about patients' histories and barriers in a format that could generate a summary note for their provider. In this study, we found that BVQs were acceptable to both providers and patients, increased documentation of adherence problems, barriers, and plans to address adherence problems, and may have facilitated discussion about challenges for about 30% of patients. While the majority of studies with patient questionnaires focus on assisting data collection for clinical encounters in acute care settings [9-14], the BVQ is unique in addressing and communicating barriers in chronic disease management.

The majority of patients agreed that the BVQ had a positive impact on their clinical encounter by helping them identify and communicate their barriers to their provider before their next clinic visit. This was an encouraging finding. It may even be possible to further augment this communication by using this tool as a way to log and track the course of a patient's concerns on a regular basis leading up to their clinical encounter. Additionally, this tool can serve as a platform for patient education and shared decision making by giving patients access to actionable educational modules based on responses entered in the questionnaire.

The study highlights the relevance of patient expressivity using free text comments. One-third (33%) of patients provided free text responses regarding their barrier concerns. Of those responses, 55% could be mapped to the available selection options. Future work will be done to explore the content of the free text comments provided by the participants along with those participants to better understand why the available options did not satisfy their communication needs. The free text responses that do not map to the existing options may be incorporated into future questionnaires. Although it is beneficial for the research team to collect barrier information as structured content for analysis, it will likely always be equally important to allow patients to communicate their thoughts freely to acknowledge their concerns. Sentiment analysis of the free text responses can also be explored in the future as a means to develop additional alerts to the medical team about any concerning patient sentiments.

The ability of the BVQ to capture most barriers in a structured way will have downstream benefits for the patient's care. For example, if a patient expresses a barrier raising financial concerns, decision support may then produce a question asking the patient if they would like to see a social worker at their next clinical encounter, then subsequently facilitate scheduling of a social work consult for the patient. Collecting this barrier and interval history information about patients longitudinally will also allow patients and providers to evaluate how effectively the patient's barriers are being addressed. Over time this aggregate information can allow the medical team to anticipate certain barriers in certain scenarios and potentially pre-empt the consequences of these barriers.

For providers, the benefit of having a generated interval summary that could facilitate communication with their patients was well received. Timeliness of the information was an important feature of the generated summary. The majority of providers (81%) desired summaries less than one week old, or the accuracy beyond that point would become more questionable due to the dynamic nature of diabetes. The majority of providers desired the ability to auto-import the summary directly into their clinical note so it would be within the channel where they were documenting. In addition to presenting the patient's barriers to the providers as a summary, there may also be an opportunity to incorporate prompting in the assessment and plan section of the note that will encourage action by the provider to document a plan to address the patient's barriers thoroughly.

Insightful formatting considerations for the rendering of the interval summary as prose vs. bullets resulted from the provider interviews. The majority of providers preferred the prose version of the note as the optimal version for saving in a final form (69%). However, the majority of the providers (75%) also viewed the bulleted version of the note as the preferable form to review when gathering information. Fortunately, one of the benefits afforded by an electronic record system is the ability to modify the rendered version of the note to best suit the information needs of the user. A design consideration could be a toggle feature that may allow a user to easily navigate between the different versions of the note to efficiently satisfy their workflow needs.

Exploration of provider's considerations of the concept of efficiency in this study was interesting. When the providers who preferred to document were asked why they preferred to do so, the two primary stated reasons were the efficiency associated with getting their task completed in a timely fashion, and the ability to recall information related to that task accurately. The top reasons given by the providers that preferred not to document in the room while they were with their patient were that it was more efficient to bypass some of the cumbersome aspects of the EHR documentation process and that bypassing the EHR would allow them to maintain better patient engagement, which was a high priority. The concept of task efficiency presented by the providers who preferred to document in the room versus the situational efficiency presented by the providers who preferred to not document in the room is an interesting dynamic. Ultimately though, both sets of priorities could benefit from the workflow that presents the provider with a generated interval summary for the patient prior to their clinical encounter. Both sets of providers will find that there is less documentation required of them since the majority of all relevant information to be documented would have already been captured. In the study, providers who copied the generated summary into their note typed 50% fewer words describing the patient's history, because the generated summary already contained the rest of the content. This workflow could also satisfy the providers who are concerned about the EHR interfering with patient engagement. Capturing the patient's concerns prior to the encounter and reviewing the responses together with the patient during the encounter may increase patient engagement. The perspective of providers who stated they never document in the room may evolve if this tool is leveraged as a discussion aid that may now serve to facilitate patient engagement during their encounter.

Patient completed BVQs have the potential to change the way patients and providers communicate in a positive manner. The way providers currently communicate with patients and document in the clinic is an area that is rich for disruption, and this is a simple strategy that has demonstrated efficacy and acceptability to both parties. We have shown that patients will willingly contribute to their medical record using electronic questionnaires and that patients ultimately believe that this benefits them. It is time to revisit

the standard workflow of the clinic paper clipboard forms that are currently used to collect information from patients and allow them to share their information in a structured and reusable manner that can trigger further actions. This research demonstrates that this workflow can improve communication between patient and providers and decreases the work of documentation for a provider which can lead to more patient engagement. This study challenges existing paradigms of clinical documentation practice and demonstrates that engaging patients in their health by allowing them to contribute to their medical documentation can improve their care delivery.

This study has several limitations. This data was obtained from a single subspecialty clinic, so external validation is necessary. Additionally, there were notable differences between our respondent and non-respondent population in the demographic categories of race, income and glycemic control which limits the generalizability of the outcomes. The quasi-experimental nature of the intervention study also poses limitations. Examination of evidence of communication about barriers based on provider documentation may not have been the most specific method to assess the impact of the BVQ on patient-provider communication. It is possible that conversations about barriers might have occurred during the clinical encounter without the provider fully documenting that exchange. However, in medicine, documentation serves an important role in communication and as evidence of the work done. In future studies, audio or video recording of clinical encounters may provide a more sensitive and specific means of capturing this information. It will also be beneficial in future studies to collect long-term follow-up data from patients about how well the provider addressed their barriers and to correlate that with clinical outcomes such as A1C. Extension of this research to other medical conditions beyond diabetes will also be important for motivating future initiatives for the incorporation of general patient generated content into clinical documentation. EHR systems that can support the collection of patient entered data in a manner that can be integrated into clinical notes will also be important in the scalability of this methodology. As this form of patient-provider communication emerges, EHR systems that offer this functionality will be desirable to practices interested in improving patient engagement and provider efficiency.

A. Before Visit Questionnaire

Before-Visit Questionnaire 3/19/17, 7:06 AM

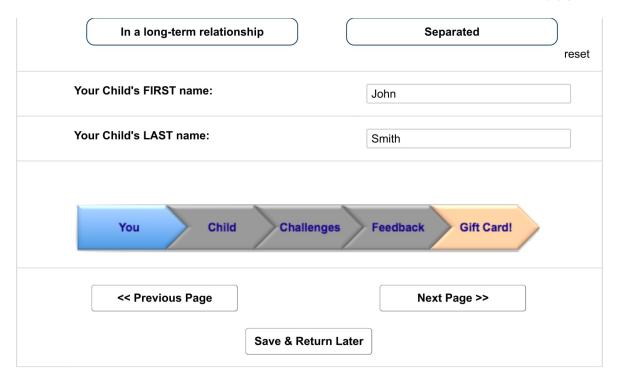
Before-Visit Questionnaire	Resize font:
Basics About You	
	10%
You Child Challenges	Feedback Gift Card!
40	u
Your FIRST name:	Jill
Your LAST name:	Smith
Your email address (e.g., parent@email.com)	sailermune@aol.com
(will be used to send your *payment* and log back in):	(*You can use your email address to log back in later)
Your phone number:	(362) 939-2938

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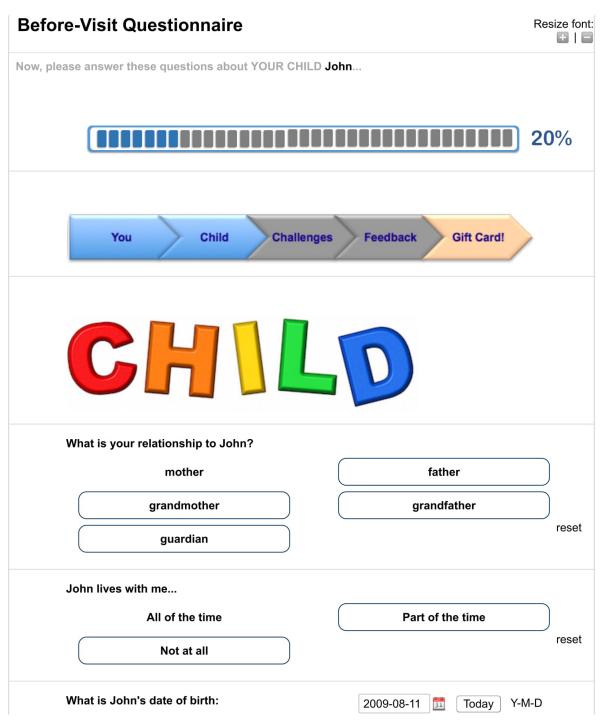
Page 1 of 3

Your age:	33
Your gender:	male female reset
Your race:	
(select all that apply)	
White/ Caucasian	African American
Native American	Pacific Islander
Asian	Other
Are you Hispanic?	Yes No reset
What is the highest level of education you have co	ompleted?
Less than high school	High school or GED
2-year college	4-year college
Masters degree	Doctoral or professional degree (MD, JD)
	reset
What is your total household income?	
Under \$20,000	\$20,001 - \$40,000
\$40,001 - \$70,000	More than \$70,001
How would you describe your current relationship	reset
Single	Married

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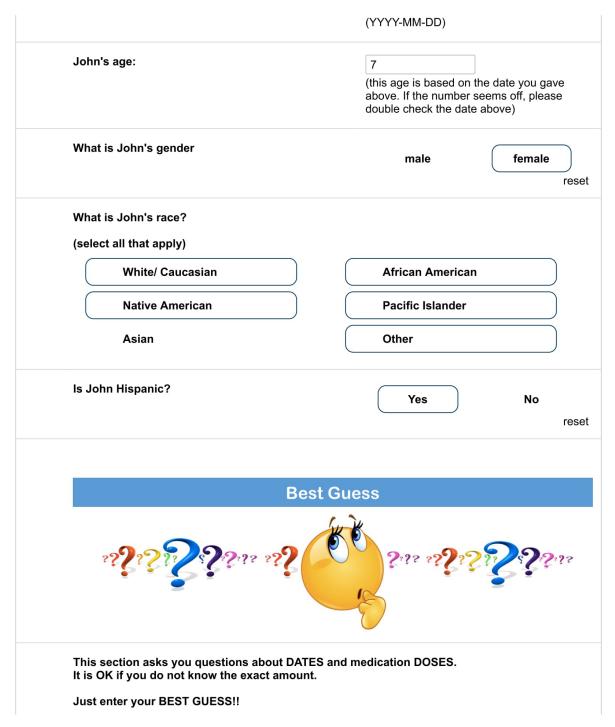


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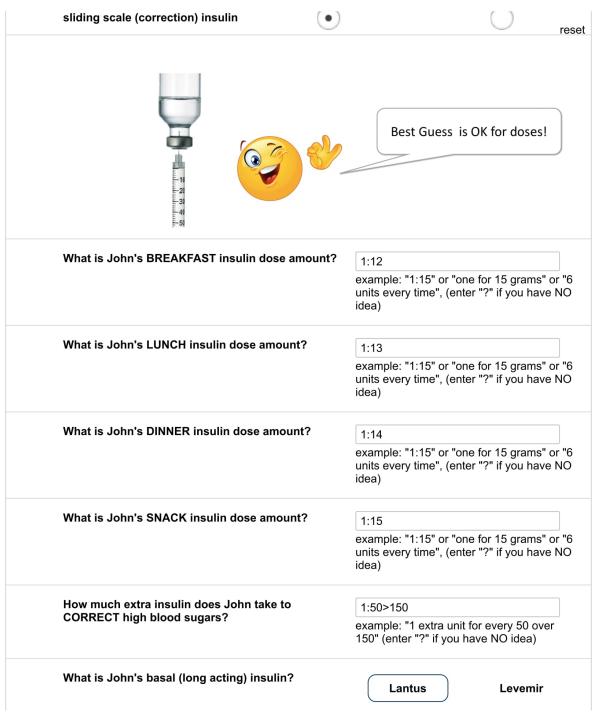
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Do you know the exact date John was diagnosed w	ith diabetes?
I know the the exact date	I know around which week
I know around which month	I know around which year
I know within 2 years	I do NOT know within 2 years
	reset
Around what DATE was John diagnosed with diabetes?	2013-08-12
(your best guess is alright)	
This is the number of years John has had diabetes based on the date you gave:	3.6 (this number of years is based on the date you gave above. If the number seems off, please double check the date above)
What kind of insulin does John take for meals (fast	acting insulin)?
novolog	humalog
apidra	reset
Have you made any changes to John's insulin since	e your last clinic visit?
have made changes	have NOT made any changes
	reset
Are you comfortable making changes to John's ins diabetes clinic?	ulin on your own, without help from the
diabetes office.	um on your own, manout noip noin tho
NOT comfortab	le making
NOT comfortab	es comfortable making changes
NOT comfortab change meal insulin (short acting	le making

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Jill, here is a summary of what we will share with your provider so far based on the answers you entered above:



SUMMARY SO FAR

Your child John is a 7 year old male patient with Type 1 Diabetes diagnosed 3.6 years ago. John uses insulin injections to manage his diabetes. He uses Levemir as his basal insulin and takes 8 units in the morning.

John takes novolog as his rapid insulin for meals. His breakfast insulin ratio is 1:12, lunch ratio is 1:13, dinner ratio is 1:14, and snack ratio is 1:15. John's correction factor is 1:50>150.

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Since the last clinic visit you have made changes to John's insulin regimen. At this time you are comfortable making changes to John's meal insulin, you are comfortable making changes to John's basal insulin, and you are NOT comfortable making changes to the sliding scale insulin between diabetes clinic visits.



You can make changes to this summary by scrolling up and changing the information you entered above.

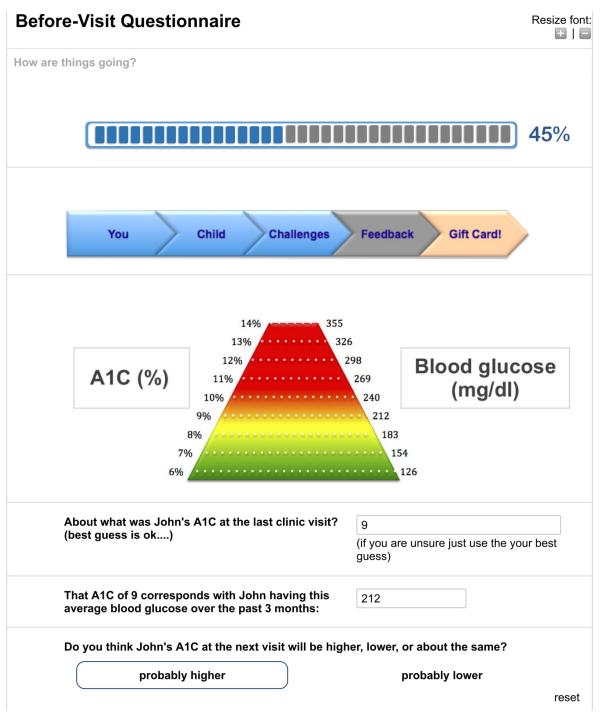
If you need to make any changes please make them now.



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probably about the same	
Did you know that John's goal A1C is 7.5? That go ~169?	es along with an average blood sugar of
yes, I already knew that	I did not know
Since the last clinic visit, how many times (number of episodes) has John had glucagon, OR was unresponsive, OR had a loss of	
no episodes	one or more episodes () reset
Since the last clinic visit, how many emergency department visits, or urgent for diabetes? no emergency department visits, or urgent care visits, or hospitalizations for diabetes	one or more emergency department visits, or urgent care visits, or hospitalizations for diabetes (
How well do you think you have done with John's diabetes since the last clinic visit (scale from 0-100)?	not great ok pretty great 65 reset

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Medical Challenges Life Challenges **Challenges Medical** A: Medical Challenges: What is the ONE HARDEST thing about managing John's diabetes? carb counting insulin dosing how certain foods affect John's how exercise and activity affects blood sugar John's blood sugar figuring out the best time to check feeling uncomfortable giving blood sugars and give insulin injections or checking blood sugars what to do when John is sick other challenges including reset actually have no challenges with diabetes care Do you want to select more than one medical yes no

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challenge? (select more from the new list below)

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reset

Select additional Medical Life Challenges from list below





A: Medical Challenges (Multiple Select):

What are ALL the things that make it hard to manages John's diabetes?

carb counting

how certain foods affect John's blood sugar

figuring out the best time to check blood sugars and give insulin

what to do when John is sick

actually have no challenges with diabetes care

insulin dosing

how exercise and activity affects John's blood sugar

feeling uncomfortable giving injections or checking blood sugars

other challenges including

Life



Challenges

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keeping a close eye on things when it is busy	keeping a close eye on things because of multiple homes
how John's school nurse and staff manage diabetes	how John's other caretakers manage diabetes
transportation	costs and finances
contacting diabetes clinic when I need to	arguments with John about diabetes
it hurts John to check blood sugars and give insulin	actually, no challenges with diabetes care
other challenges including	
Do you want to select more than one life challenge? (select more from the new list below)	yes no
Does John need any prescription refills at this next	clinic appointment?
does not need refills	needs refills for
Would you like to talk to your diabetes provider aborlinic visit?	out anything in particular at John's
will not need to talk about anything in particular	would like to talk about "puberty"

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puberty

Expand

YOUR SUMMARY

Jill, here is a summary of what we will share with your provider so far based on the answers you have entered:



Your child John is a 7 year old male patient with Type 1 Diabetes diagnosed 3.6 years ago. John uses insulin injections to manage his diabetes. He uses Levemir as his basal insulin and takes 8 units in the morning.

John takes novolog as his rapid insulin for meals. His breakfast insulin ratio is 1:12, lunch ratio is 1:13, dinner ratio is 1:14, and snack ratio is 1:15. John's correction factor is 1:50>150.

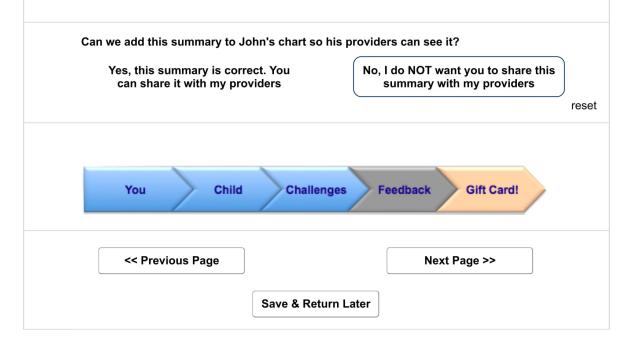
Since the last clinic visit you have made changes to John's insulin regimen. At this time you are comfortable making changes to John's meal insulin, you are comfortable making changes to John's basal insulin, and you are NOT comfortable making changes to the sliding scale insulin between diabetes clinic visits.

https://redcap.vanderbilt.edu/surveys/index.php?s=tVRPtEromi

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Since the last clinic visit John has had no episodes of severe hypoglycemia/low blood sugars that lead to either unconsciousness, seizure, or required glucagon. John has had no emergency department visits, or urgent care visits, or hospitalizations for diabetes since the last clinic visit. You think that on a scale from 1 (not great) to 100 (pretty great) you have done about a 65 with John's management since his last visit. You expects John's a1c to be probably lower at the next clinic visit.

The most challenging medical part of managing John's diabetes regimen since the last visit for you has been "what to do when John is sick." The most challenging non-medical part of John's diabetes management since the last visit has been "how John's school nurse and staff manage diabetes." During the clinic visit you would like to talk about "puberty". John does not need refills during the clinic visit.



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[Branching logic exists]

This interval history was generated from patient provided information using the Pediatric Dlabetes Before-Visit Questionnaire. If you have any questions regarding the Before-Visit Questionnaire please contact yaa.kumah@vanderbilt.edu.

This interval history was completed by [name] [ptlname]'s [relationship] [parentname] [parentlastname] on [survey_completion_date].

[name] is a [age] year old [gender] patient with Type 1 Diabetes diagnosed [duration] years ago. [name] uses [insulin_delivery] to manage his diabetes. He uses [basal] as his basal insulin and takes [basal_units] units in the [basal_time].

[name] takes [rapid_insulin] as his rapid insulin for meals. His breakfast insulin ratio is [insulin_breakfast], lunch ratio is [insulin lunch], dinner ratio is [insulin dinner], and snack ratio is [insulin snack]. [name]'s correction factor is [correction].

Since the last clinic visit [name]'s [relationship] says that they [any_dose_adjustments] to [name]'s insulin regimen. At this time they are [matrix1] to [name]'s meal insulin, they are [matrix2] to [name]'s basal insulin, and they are [matrix3] to the sliding scale insulin between diabetes clinic visits.

Since the last clinic visit [name] has had [hypo_male] of severe hypoglycemia/low blood sugars that lead to either unconsciousness, seizure, or required glucagon. [name] has had [ed_hospital_visits] since the last clinic visit. [name]'s [relationship] thinks that on a scale from 1 (not great) to 100 (pretty great) they have done about a [management] with [name]'s management since his last visit. [name]'s [relationship] expects [name]'s a1c to be [next_a1c] at the next clinic visit.

The most challenging medical part of managing [name]'s diabetes regimen since the last visit for [name]'s [relationship] has been "[difficulties_manage_single]." The most challenging non-medical part of [name]'s diabetes management since the last visit has been "[difficulties_social_single]." During the clinic visit [name]'s [relationship] [talk_to_provider]. [name] [refill] during the clinic visit.

C. Generated Interval History: Provider Template (Blank)

This interval history was generated from patient provided information using the Pediatric Diabetes Before-Visit Questionnaire. If you have any questions regarding the Before-Visit Questionnaire please contact yaa.kumah@vanderbilt.edu.

This interval history was completed by 's Yaa Kumah on
is a year old female patient with Type 1 Diabetes diagnosed years ago uses insulin injections to manage her diabetes. She uses as her basal insulin and takes units in the afternoon.
takes as her rapid insulin for meals. Her breakfast insulin ratio is, lunch ratio is, dinner ratio is, and snack ratio is 's correction factor is
Since the last clinic visit's says that they to's insulin regimen. At this time they are to's meal insulin, they are to's basal insulin, and they are to the sliding scale insulin between diabetes clinic visits.
Since the last clinic visit has had of severe hypoglycemia/low blood sugars that lead to either unconsciousness, seizure, or required glucagon has had one or more emergency department visits, or urgent care visits, or hospitalizations for diabetes () since the last clinic visit 's thinks that on a scale from 1 (not great) to 100 (pretty great) they have done about a 19 with 's management since her last visit 's expects 's a1c to be at the next clinic visit.
The most challenging medical part of managing's diabetes regimen since the last visit for's has been "" During "" The most challenging non-medical part of's diabetes management since the last visit has been "" During the clinic visit.

D. Generated Interval History: Provider Template (Completed)

This interval history was generated from patient provided information using the Pediatric Diabetes Before-Visit Questionnaire. If you have any questions regarding the Before-Visit Questionnaire please contact yaa.kumah@vanderbilt.edu.

This interval history was completed by John Gant's mother Sally Gant on 10-05-2016.

John is a 10 year old male patient with Type 1 Diabetes diagnosed 1.2 years ago. John uses insulin injections to manage his diabetes. He uses Lantus as his basal insulin and takes 8 units in the bedtime.

John takes novolog as his rapid insulin for meals. His breakfast insulin ratio is 1:25, lunch ratio is 1:25, dinner ratio is 1:20, and snack ratio is 1:20. John's correction factor is 0.5 extra unit for every 50 over 200.

Since the last clinic visit John's mother says that they have NOT made any changes to John's insulin regimen. At this time they are comfortable making changes to John's meal insulin, they are comfortable making changes to John's basal insulin, and they are comfortable making changes to the sliding scale insulin between diabetes clinic visits.

Since the last clinic visit John has had no episodes of severe hypoglycemia/low blood sugars that lead to either unconsciousness, seizure, or required glucagon. John has had no emergency department visits, or urgent care visits, or hospitalizations for diabetes since the last clinic visit. John's mother thinks that on a scale from 1 (not great) to 100 (pretty great) they have done about a 91 with John's management since his last visit. John's mother expects John's a1c to be probably about the same at the next clinic visit.

The most challenging medical part of managing John's diabetes regimen since the last visit for John's mother has been "what to do when John is sick." The most challenging non-medical part of John's diabetes management since the last visit has been "costs and finances." During the clinic visit John's mother will not need to talk about anything in particular. John does not need refills during the clinic visit.

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