ISSN 2564-0127 (Print)
ISSN 2564-0135 (Online)

Canadian Journal of Medicine 7(2025) 73-85

Canadian Journal of Medicine

WWW.CIKD.CA

journal homepage: https://www.cjm.cikd.ca

Original Research

Exploring Digital Platforms for the CLEFT-Q®

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Keywords:
CLEFT-Q, Patient reported outcome measures, Cleft lip and/or palate, Qualitative interviews

Received
19 June 2025
Received in revised form
05 August 2025
Accepted
12 August 2025

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ABSTRACT

The CLEFT-Q® is a validated Patient Reported Outcome Measure (PROM) for patients aged 8 to 29 years with Cleft Lip and/or Palate (CLP). This study aims to determine if using animations and colors in the presentation of the CLEFT-Q will affect the overall experience and questionnaire responses. The CLEFT-Q® was administered in two different software platforms: REDCap and Tickit. Focus groups or individual interviews were used to obtain participant feedback. Responses to the CLEFT-Q® questions were compared between the software platforms. Setting: Pediatric tertiary care center. Individuals aged 8-29y with cleft lip and/or palate living in British Columbia. Twenty out of 26 participants preferred Tickit. Participants described Tickit as a more engaging platform; they felt that the use of colours and animations made the questionnaire less intimidating, which made it easier to answer emotionally charged questions. Participants felt that looking at one question at a time on Tickit allowed them to answer more honestly. Conversely, some participants appreciated the simplicity and efficiency of having all the questions on one page in REDCap. 76% of participant responses were the same on each platform. Using different software for administering the CLEFT-Q® can affect a patient's experience. Most participants preferred the Tickit version; they felt that the layout was more engaging and less intimidating. These results support further development and validation of the CLEFT-Q® in Tickit.

Cleft lip and cleft palate are amongst the most prevalent congenital birth defects at 6.4 per 10,000 births [1]. To ensure better treatment and greater accuracy in managing patient expectations, it is important to assess not only the clinical outcome of cleft care but also the patient's perspective and overall satisfaction with their treatment outcome. Patient-Reported Outcome Measures (PROMs) are instruments that measure the outcomes that are important to

patients. The CLEFT-Q® is a cleft-specific PROM rigorously developed by Klassen et al. that has been tested across multiple countries and treatment centers for reliability and validity [2]. Using the CLEFT-Q® within clinical practice may allow for an increased objective understanding of what patients are concerned with and enable comparisons of treatment approaches through patient generated information.

In order to optimize data collection from patients, if PROMs are being administered, it is in the best interest of healthcare practitioners to determine the least imposing and most enjoyable way of gathering data. A previous study amongst adult participants suggested a more colorful and animated questionnaire design felt informal and potentially confusing, but it did not assess the difference in answers or accuracy from one platform to another [2]. The CLEFT-Q® has the potential to be administered on different software platforms yet the type of interface preferred by patients and whether the software platform can affect a patient's responses has not been studied.

The objective of the study was to assess the effect of illustrations on patient perception of the CLEFT-Q® via two different interfaces. This was done by [1] obtaining patient feedback on their preferences for two different CLEFT-Q® questionnaire designs: a REDCap version, and a version designed by Tickit using colors, icons, and interactive sliders, and [2] comparing whether the responses are the same or different between each version of the CLEFT-Q®. The findings from this study may inform clinicians about patients' preferred method of completing the CLEFT-Q® and provide preliminary data regarding the potential validation of Tickit for collecting CLEFT-Q® outcome measures.

Method

Study Design

This study was designed as a prospective study with in-person and online focus groups and online interviews. Ethics approval was obtained from the University of British Columbia Children's and Women's Clinical Research Ethics Board (H18-03582).

Recruitment

Patients were identified from the British Columbia Children's Hospital (BCCH) Cleft Palate – Craniofacial Clinic database. Individuals aged 8-29 years old, living in British Columbia with non-syndromic or unspecified cleft lip and/or palate (CLP), who had the ability to complete the questionnaire by themselves and attend an in-person or online focus group/interview were included. Eligible participants for in-person focus groups were selected using purposive sampling in consideration of driving distance to the hospital. Eligible participants for online focus groups/interview were selected using randomized sampling. Given that the CLEFT-Q® is offered in English, exclusion criteria was difficulty with the English language. Invitations were sent by mail and potential participants were later contacted by phone to provide further information and/or schedule a focus group or interview. Informed consent was obtained prior to any focus groups/interviews. Recruitment continued until thematic saturation was reached and no new insights were evident. Participants were provided with a CAD $20 gift card to acknowledge their time.

Focus Groups/Interviews

In-person focus groups took place at BCCH in January 2019 and were conducted by TO. In order to limit in-person contacts during the COVID-19 pandemic, participants who agreed to participate from July - September 2020 did so virtually from their homes; either as a focus group or an individual interview via the University of British Columbia's Zoom software with VS. For in-person and virtual focus groups, participants were organized by age category (children 8-13 years old, adolescents 14-18 years old, and adults 19-29 years old). For children and adolescents, parents could participate in the focus group/interview to help their child navigate the software to answer the CLEFT-Q® if necessary. In the focus group/interview, participants were asked to fill out select modules (Appearance and Psychological Function) from the CLEFT-Q® questionnaire on two different interfaces: (1) Tickit, a Canadian for-profit online software for building and administrating PROMs and (2) REDCap (Research Electronic Data Capture), a well-established online web application used to build and manage online surveys and databases, adapted for individual research centers [3,4]. The Tickit interface allows for a flexible design (colors, animations, emoticons), and shows one question per page with a "next" button to move on to the next question. The emoticons and animations may correspond to the types of answers, i.e., a sad face emoticon for a more negative answer, or a thumb turning to face upward for a positive answer (Figure 1). The REDCap version of the questionnaire is mostly black and white form with minimal images, and consists of one page with all the questions (Figure 2). The parts of the CLEFT-Q® selected for participants were on appearance of the face, with questions worded as "how much do you like […]" and response options ranging from "not at all" to "very much", as well as questions on psychological wellbeing with questions about how participants feel about themselves with response options ranging from "never" to "always".

Figure 1. Screen capture of Tickit showing two questions presented to participants.

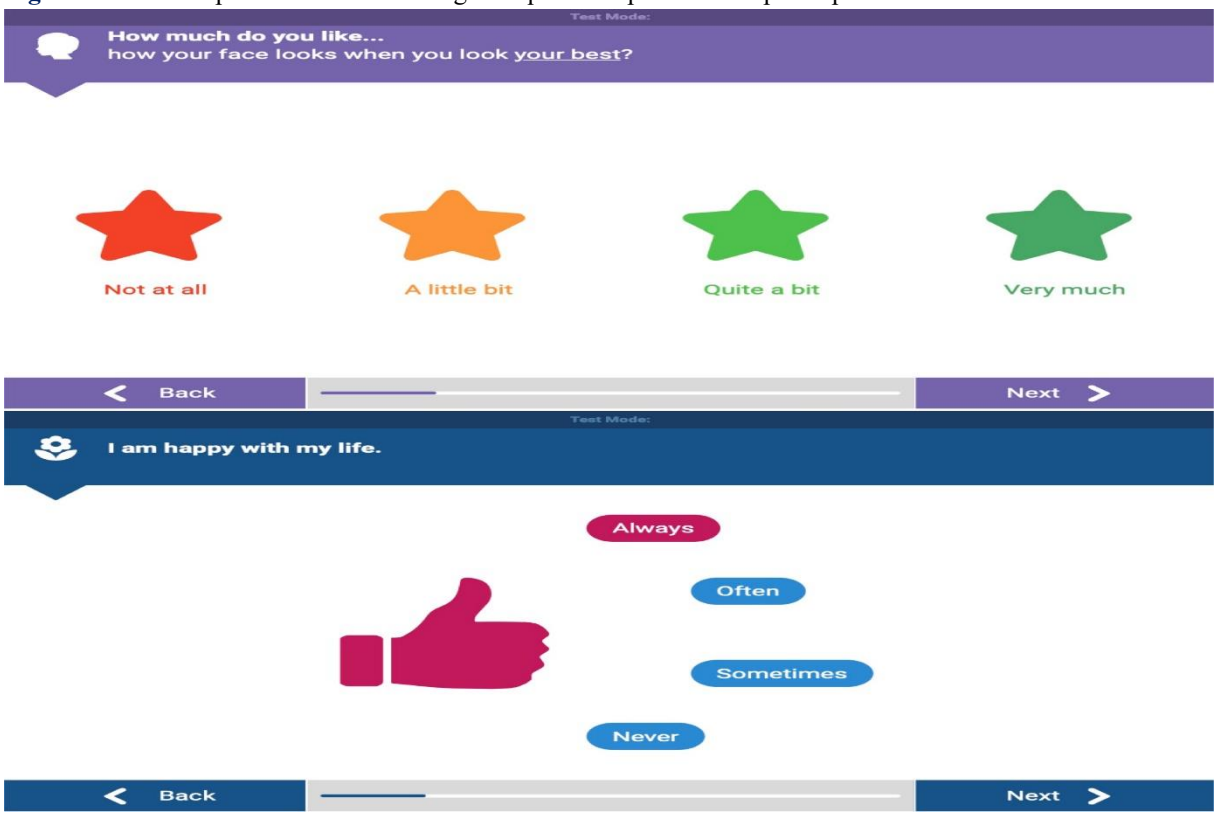
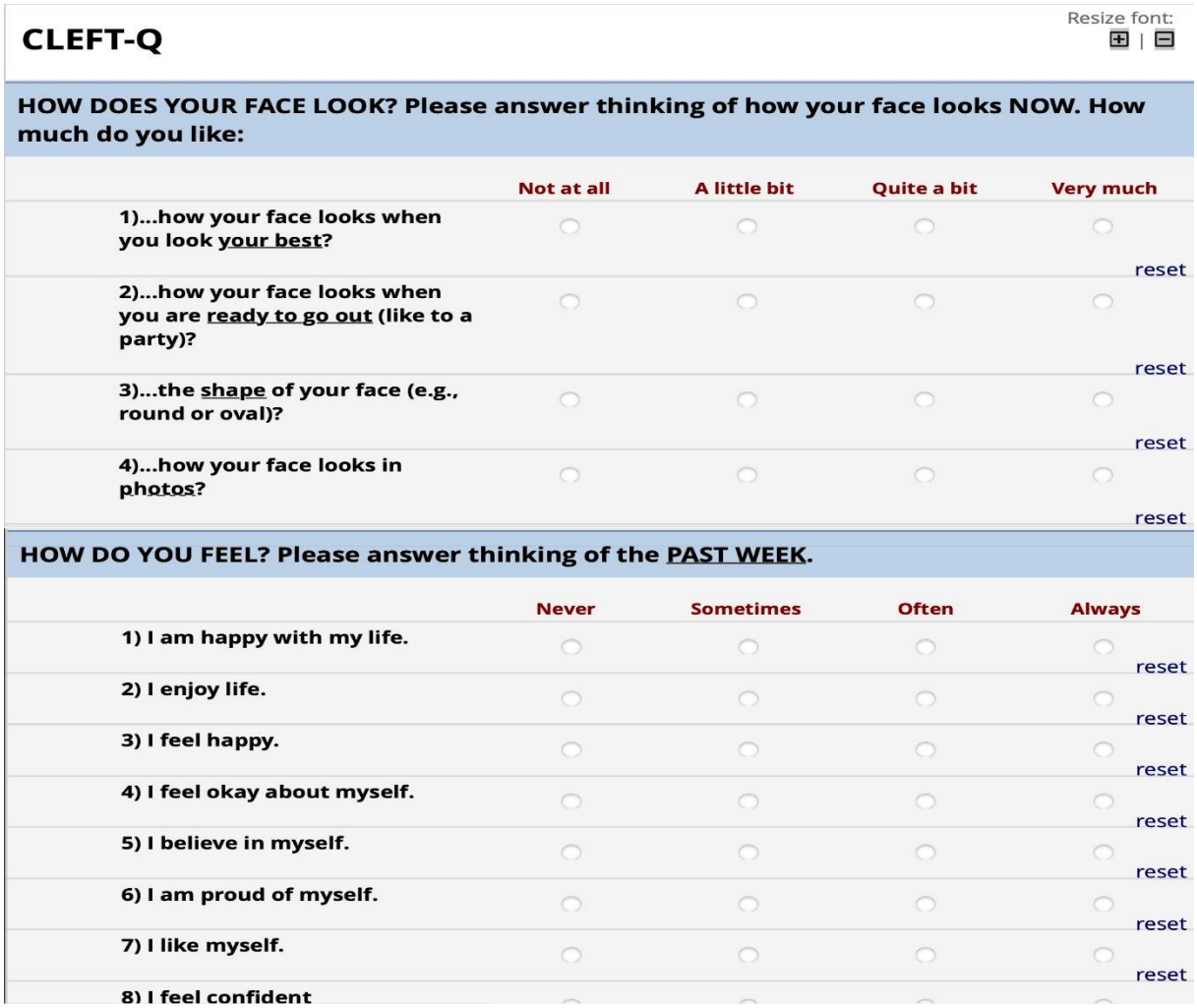


Figure 2. Screen capture REDCap's layout presented to participants.



Randomization

For the first focus group, all participants were assigned to group 1. Participants in group 1 answered the CLEFT-Q® using REDCap first, followed by Tickit®. For the second focus group, all participants were assigned to group 2 and answered the CLEFT-Q® using Tickit® first, followed by REDCap. This alternating pattern continued for the duration of the study until recruitment concluded. No blinding was done.

The primary outcome of the study was participant preference of each software platform. To measure this, participants were asked to reflect on their experiences answering the questions on both interfaces. The questions used to guide a semi-structured focus group or interview can be found in Table 1. Participants were asked to answer the questions in relation to the design of the questionnaires (e.g., color, layout, animation if applicable). Participants were also asked which software platform they preferred overall.

Table 1. Questions used to guide focus groups and interviews.

Question Number	Question
1	What did you think about answering these questions?
2	What did you like about answering questions using each version?
3	What didn't you like about answering questions using each version?
4	What made the question easy to answer?
5	What made the question hard to answer?

The secondary outcomes of the study were to compare each participant's responses to each questionnaire design version, as well as compare the distribution of total scores between each platform.

Data Analysis

Focus groups and interviews were audio-recorded and transcribed, with patient names replaced with a non-identifying study ID, in order to analyze participant feedback using a line-by-line approach. The text was explored inductively using content-analysis to develop themes and sub-themes. The method described by Bree and Gallagher [5] was used to organize and analyze the focus group transcripts.

Participant responses to the CLEFT-Q® were compared between software platforms, to assess whether the questionnaire design affected their answers. A value was assigned to each response choice (4 points for the most positive answer, 1 point for the least positive answer, and 0 points for an unanswered question). Participant responses in Tickit were compared to their responses in REDCap to determine the frequency of different responses for the same question.

For each participant, a score was calculated per platform for each module (appearance, psychological function). A total score was also calculated per platform (appearance and psychological function combined). The difference between scores for each platform was calculated and the distribution of score differences was analyzed. The ordinal data for each module was analyzed and compared across platforms using a Mann-Whitney test. Time for questionnaire completion was also recorded and compared between the two platforms. Statistical significance was set at $p = .05$.

Results

Study Participants

Ninety-six patients were invited to participate. A total of twenty-six participants were included (12 female, 14 male, mean age 16 years, range 8-28 years). There were three in-person focus groups, one with five participants aged 9-20, one with two participants aged 8 and 13, and one with 3 participants aged 10, 15, and 24. Six participants' diagnoses were of unspecified cleft lip and/or palate, three were of cleft palate, two were of bilateral cleft lip and palate, seven were of unilateral cleft lip and palate, and five were of unilateral cleft lip (all non-syndromic). There were 3 virtual focus groups, one with three adult participants, one with two adult participants, and one with two children/teenagers aged 11 and 14. The rest of the participants (n = 9) did a virtual individual interview. Eleven participants, all 11 years old or younger, had parents present during their interview or focus group.

Twenty-six participants aged 8 to 28 years completed select modules from the CLEFT-Q® on both REDCap and Tickit. Overall, 20 out of 26 participants preferred completing the CLEFT-Q® using Tickit software. Comments from participants described Tickit as a more engaging platform; they felt that the use of colors and animations made the questionnaire less intimidating, which made it easier to answer emotionally charged questions about themselves. Participants also felt that looking at one question at a time on Tickit allowed them to answer more honestly without comparing their answers. Conversely, some participants appreciated the simplicity and efficiency of having all the questions on one page on the REDCap version, and

described Tickit as "distracting". Of the six participants (four female, two male) who preferred REDCap, two were children, two were teenagers, and two were adults.

Software Platform Preferences

The main themes identified were question presentation, authenticity, clarity, engagement, overall focus and attention, and comfort.

Question Presentation

Tickit presents one question per page, with a 'next' button to move to the next question; REDCap, which looks like a paper questionnaire, has all the questions continuously, across three pages. The majority of participants specifically mentioned that they preferred seeing only one question at a time (Tickit format), versus three participants who liked seeing all their questions at once (REDCap format) to get a general idea of how they were answering. Two subthemes were found: authenticity and clarity.

Authenticity

Nine participants said that they felt more honest while answering the questions on Tickit because they could focus on one question at a time, and move on once they had answered. Six participants felt they wanted to or did change their answers on REDCap when they could see that they were answering the same thing too often:

> *"It's kind of like writing a test, you put too many D's or too many C's and you're like "oh I gotta switch it up"" –Participant #22, 27-year-old male, cleft lip and palate: unspecified.*
>
> *"With the, like, isolated questions I feel like I'm going to be more honest than when I saw them all and I was like OK I'm picking one answer too many times, I wanted to change my answer" –Participant #23, 22-year-old female, unilateral cleft lip and palate: non-syndromic.*

Certain comments from participants also deemed their Tickit answers more honest because they felt more relaxed while answering the questions, and consequently more comfortably answering how they truly felt:

> *"The colorful one is closer to the truth because it's a more relaxed environment because you can say more of what you want to." – Participant 5, 20-year-old-male, unilateral cleft lip and palate: non-syndromic.*

Conversely, three people said they questioned their answers less on REDCap because the questionnaire felt more straightforward and consequently, their answers felt more definitive. These people stated that being able to focus less on the individual questions made their response choice more honest as they would not dwell on their answers.

Clarity

Multiple comments from six participants were made about the Tickit layout being clearer and easier to follow because there were less words and more space on each page:

> *"I personally liked the layout of the first survey [Tickit], they were easier to look at, more colorful than the second one and it just overall looks, I guess, nice. It seemed easier to read the layout" - Participant 24, 18-year-old female, cleft lip: unspecified*

"I just like the clarity of it and how it was big and easy to follow and there was more space and like organized a bit better."-Participant 33, 25-year-old female, cleft lip: unspecified.

The REDCap layout was described in one instance as "congested" (Participant 33, 25y/o female), and two other participants mentioned not liking having to scroll down and potentially lose their place, rendering them less focused on the actual questions. One 9-year-old girl mentioned that the words would 'jumble up' on REDCap and she couldn't understand the questions as well. She said it was easier for her to 'not make a mistake' on Tickit. Another participant criticized the REDCap font for being too small to read comfortably.

Engagement

Overall, participants felt they were interacting more, and were more engaged with the Tickit platform because of the colors and designs. Five children or adolescents mentioned they appreciated the colors and icons in Tickit because instead of explicitly reading the answer options, they were guided by common color/icon associations, ex: green represents a more positive answer versus red representing a more negative answer, a smiley face represents a more positive answer versus a sad face for a more negative answer:

"You just have to click instead of going through them and pick the right one, you memorize the colors and just click the colors without having to read each one" – Participant 3, 9-year-old male, unilateral cleft lip and palate: non-syndromic.

One parent of a young boy echoed this sentiment, and said that he could see his son interacting with the Tickit layout more, paying more attention to the questions, and finding it easier to choose his answer due to the icons. Ten participants referred to the REDCap questionnaire feeling like a school test or a standardized test:

"The REDCap one felt more like a test, kinda like a [..] test where you're just marking things down with no interaction whatsoever." –Participant 26, 14-year-old male, unilateral cleft lip and palate: non-syndromic.

Overall Focus and Attention

A common trend amongst participants was the mention of Tickit keeping their attention better. Many of the children expressed simply liking the colors and patterns as their reasoning for why they preferred Tickit, and one 10-year-old boy explicitly mentioned that "your attention went straight there" when the colors "popped up". At least two participants explicitly mentioned that they went through the REDCap questionnaire faster to get it over with, not interacting with the questionnaire at all.

In contrast, five participants commented that Tickit was more distracting because of the colors and animations:

"I like the simplicity of the other one 'cause it's just straightforward there, instead of having to click on it and then have the fancy graphics go, I mean it's nice but sometimes it's just a bit jarring that it goes like that"- Participant 21, 23-year-old female, cleft lip: unspecified.

"I just like it when it's all laid out and not as many colors. It's easier to focus on the actual questions rather than the colors" - Participant 27, 10-year-old female, unilateral cleft lip: non-syndromic.

One participant made the following comment about the design feeling unnecessarily intricate in Tickit:

> *"It kind of felt like random the ways that each answer was presented like a slider or the thumb […] it just kind of felt like colorful and playful for its own sake" – Participant 28, 19-year-old male, unilateral clef lip and palate: non-syndromic.*

Comfort

In general, participants felt that the Tickit layout was more inviting; they felt it made the experience more comfortable. Although six participants preferred REDCap, their comments were related to preferring the layout simplicity, or finding Tickit distracting; no comments were made about finding REDCap inviting/comfortable. Two of the adults who preferred REDCap mentioned in their explanation that they were used to working with long lists, and were not the type to prefer extra colors/animations in any situation. In contrast, over 30 positive comments were made related to Tickit feeling "inviting" and "comfortable", or along similar lines.

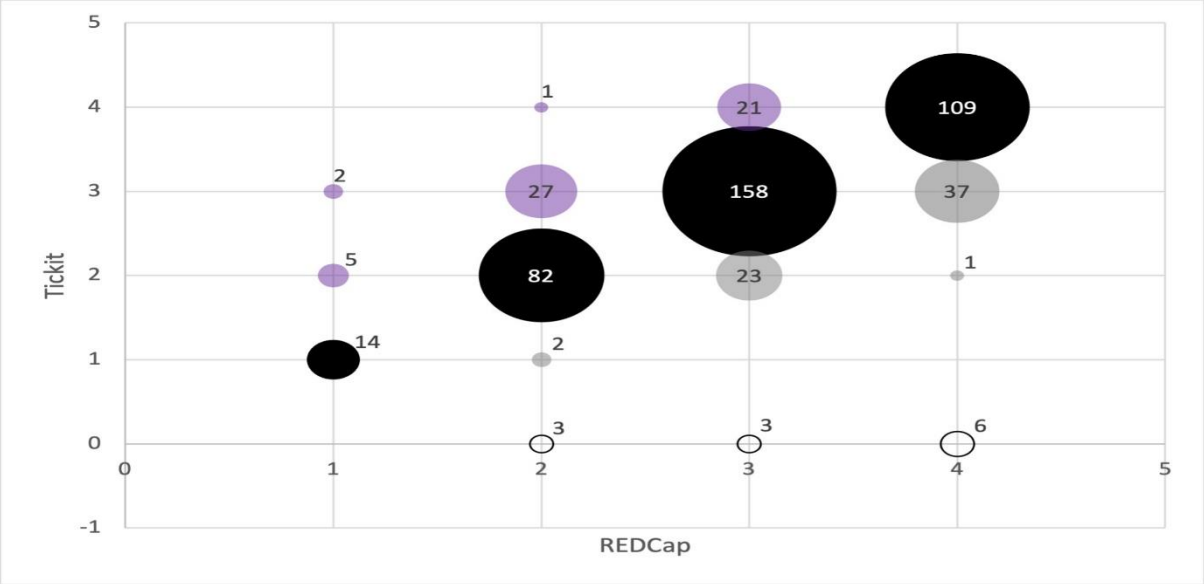
Five participants said the REDCap layout felt too serious and impersonal, which made them less comfortable. On three instances, participants said that the REDCap survey made them feel like they were being studied, like the survey was looking for data rather than to help patients. One participant mentioned that they felt more stressed doing the REDCap survey because it felt like their answers would determine their future course of treatment. One participant made the following comment about REDCap:

> *"I didn't like how close together and like formal and it looked like it lacked empathy. […] it seems like there's more empathy with colors involved"* and continued to say about Tickit, *"Since it looks friendlier I kind of felt more relaxed when answering […] it seems warmer like I think it's like a personal sort of situation and it's for me just like warmed it up and made it seem friendlier and more genuine"- Participant 33, 25-year-old female, unspecified cleft lip.*
>
> Another participant made the following comment:
>
> *"I thought the Tickit one was better, it just made it feel less like a research thing like it just makes you feel more comfortable when you're taking it […] made it so approachable and as opposed to like the REDCap one, the standardized test one"- Participant 26, 14-year-old male, Unilateral cleft lip and palate: non-syndromic.*

CLEFT-Q® Responses

The majority of responses were the same in REDCap and Tickit for the same question (n = 363, 73%) (Figure 3). There were 53 instances of a higher (more positive) answer in Tickit, and 63 instances of a more positive response in REDCap. There were twelve instances of the questionnaire being submitted with questions left unanswered, all of which were on Tickit.

Figure 3. Comparing responses in Tickit versus REDCap for the same question. More positive answer in Tickit shown in purple (n=56); more positive answer in REDCap shown in grey (n=63, unanswered in Tickit not included); same answer in Tickit and REDCap shown in black; unanswered in Tickit outlined in black.



Linear regression analysis was used to examine the distribution of total scores between each platform. The difference between REDCap and Tickit scores was within 3 points for 96% of participants in the appearance module and for 88% of participants in the psychological function module. The difference between total scores was within 3 points for 73% of participants (Figure 4). Statistical significance was set to $p = .05$. The total scores from each platform were found to be strongly correlated for appearance ($r = .97$, 95% CI [.94, .98], $p = .0001$) and for psychological function ($r = .91$, 95% CI [.82, .96], $p = .0001$). Mean ranks for each module by platform were not statistically different, $p = .8181$ for appearance and $p = .54$ for psychological function (Table 2). Paired sample comparison for order of platform and module experience are reported in Table 3, although none were statistically different.

Figure 4. Total score difference summary between Tickit and REDCap.

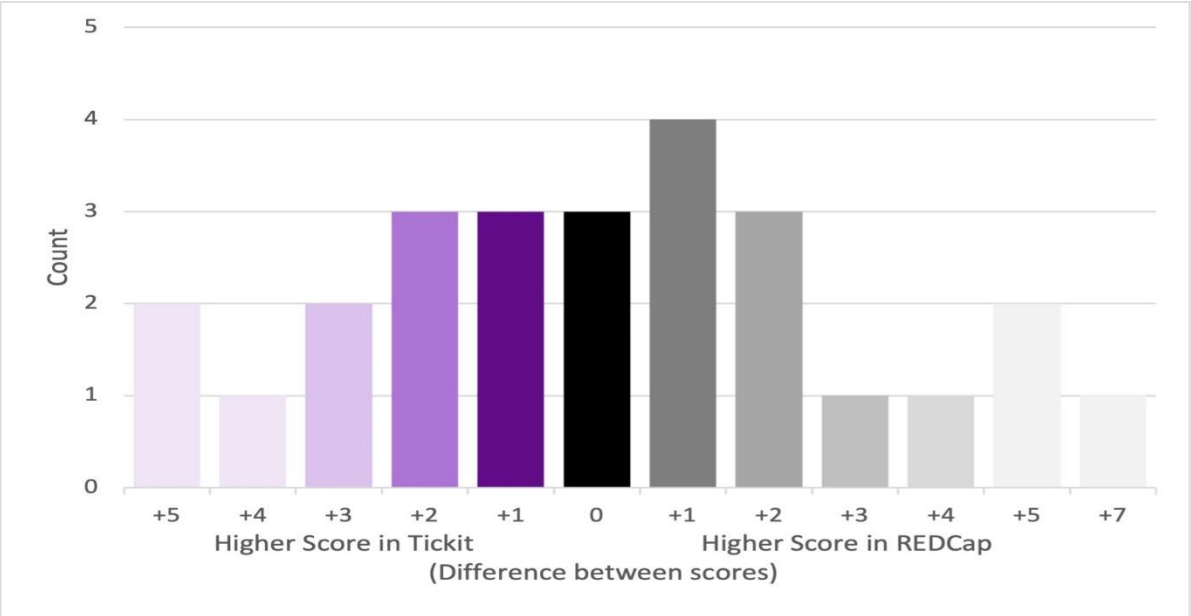


Table 2. Comparison of questionnaire responses for each module.

Module	Platform	Mean Rank	U	z-score	p-value
Appearance	REDCap	26.0	351	-0.23	0.8181
	Tickit	27.0			
Psychological Function	REDCap	27.8	304.5	0.60	0.5485
	Tickit	25.2			

Table 3. Paired samples comparison for order of platform and module experience.

Platform	Module	Order of Completion	Mean Rank	U	z-score	p-value
REDCap	Appearance	First	13.4	85.5	-0.05	0.9601
		Second	13.6			
	Psychological Function	First	15.1	103.5	-0.98	0.3271
		Second	12.1			
Tickit	Appearance	First	13.1	90	-0.28	0.7795
		Second	14			
	Psychological Function	First	11.9	107	-1.16	0.2460
		Second	15.4			

Time

Participants took, on average, 34 seconds longer to complete the CLEFT-Q® on Tickit (mean 2m55s, range 1m21-6m04) compared to REDCap (mean = 2m21s, range 49s-6m23), however, this difference was not statistically significant (p = 0.0562).

Discussion

The results of this study showed the majority of participants preferred completing the CLEFT-Q® using Tickit software, with reasons related to question presentation, engagement and comfort; these themes and subthemes are related to end-user experience, a term generally used in software development that encompasses the software factors that will affect a user's overall experience with the software.

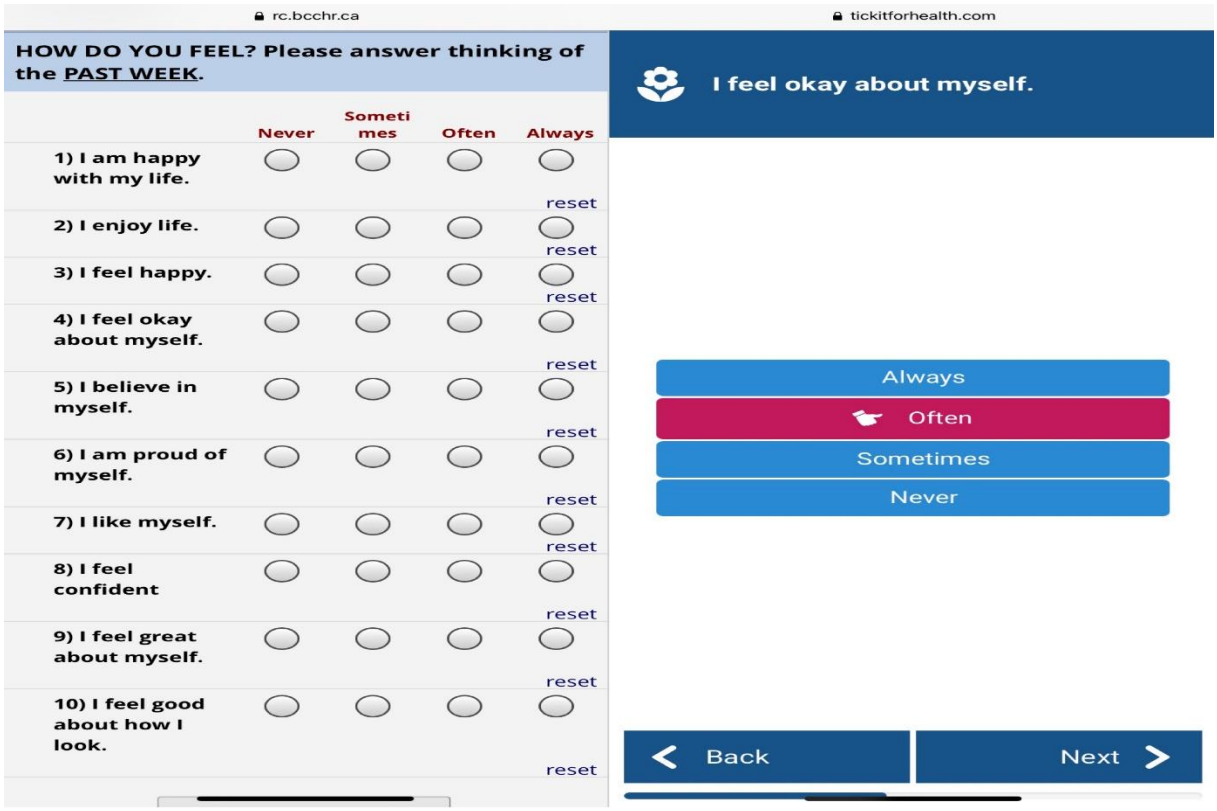
Despite the use of colours or designs with emotional connotations, we found that Tickit did not result in more positive responses, and that 73% of answers were the same in REDCap and Tickit for the same question, which indicates that a different design is not likely to introduce bias; the CLEFT-Q® could be administered both ways. There was no statistically significant difference in mean ranks between the order of platform completion. Moreover, there were no differences between the first and second module responses. This suggests that neither platform affected how participants responded to the questionnaire. Additionally, the range of times for completion on REDCap vs. Tickit was similar, which would indicate that there is no efficiency gained from using one layout versus the other. We were surprised to find that the ages amongst the participants who preferred the simple REDCap layout came from every category (child, adolescent, adult). This indicates that the user experience for each individual is subjective. In contrast to the findings reported by Kaur et al. [2], who also compared REDCap to Tickit, no participants in our study commented that the Tickit survey appeared unprofessional or lacked scientific credibility; however, our mean participant age range was younger (8-29 versus 18-83 years).

It has been shown that electronic administration of PROMs is more effective for medical institutions and patients, and leads to greater patient compliance within the context of a clinical

trial [6]. Implementing the CLEFT-Q® longitudinally throughout patient care, as described in a study by Cano et al [7] in which patients completed the BREAST-Q® at various points in their breast care, is an efficient way to directly address the issues that are important to the patients. This incorporates the patient's opinion at every stage of their care and can improve the overall quality/approach to patient care. In practice, implementing the CLEFT-Q® on either Tickit or REDCap would require a secure server, discussion on whether the patients complete the questionnaire on their own devices (within the clinic, before, or after their appointment), data storage, and how to use the data to assess patient care.

Our study was limited in terms of module choice and participant device control. While our sample size is comparable to other studies in the cleft-population [8-11], the results from our single-centre design may not be generalizable to other pediatric hospitals or geographic regions. Additionally, participant recruitment continued until data saturation was achieved, yet true saturation may only occur once the whole population has been sampled. A future larger sample size with participants from multiple sites may corroborate the conclusions we have drawn. Additionally, only select modules of the CLEFT-Q® were used and may not represent a comprehensive assessment of the CLEFT-Q® on each digital platform. Furthermore, we did not have control over what device participants used to answer the questionnaires in the second round of virtual focus groups/interviews. However, participant responses did not seem to change from the in-person focus groups, where participants were all provided an iPad. Both software platforms are responsive on mobile devices (Figure 5), and one participant, whom we know, participated from a mobile phone, commented on REDCap looking 'congested'. Thus, not having a standard device for the administration of the CLEFT-Q® may have introduced bias as different screen sizes and device familiarity may affect task performance.

Figure 5. Mobile versions of REDCAP (left) and Tickit (right).



In summary, the findings from this study have implications for clinicians, researchers, and patients using the CLEFT-Q®. Participants felt they answered the CLEFT-Q® on Tickit more honestly, and we did not find that the preferred questionnaire design of Tickit biased participants' responses compared to REDCap. If the CLEFT-Q® is to be used consistently throughout the cleft care for these patients, ensuring the best possible user experience will lead to greater compliance and more reliable data. Overall, the practical use of the CLEFT-Q® as well as the application of this study's findings will rely on further investigation in the clinical setting, individual preference, and logistical planning of individual care centers.

Conclusion

The REDCap version of the CLEFT-Q® has been previously validated, and our study has shown that patients find the Tickit platform to be of equal or preferred interest with no loss of data quality. Considering patient preference is important to ensure their comfort and involvement with their treatment plans, which can ultimately increase their overall satisfaction with their medical care. To further corroborate these results, we plan on having the entire CLEFT-Q® developed on Tickit to be used in the clinical setting and report the outcomes and logistics of its use.

Declarations

Acknowledgements

The authors would like to thank Marija Bucevska for her support with this project.

Disclosure Statement

No potential conflict of interest was reported by the authors.

Ethics Approval

Not applicable.

Funding Acknowledgements

VS's effort contributing to this manuscript was funded by a Summer Studentship from the Office of Pediatric Surgical Evaluation and Innovation.

Citation to this article

Sebag V, Omeis T, Courtemanche R, Courtemanche DJ. Exploring digital platforms for the CLEFT-Q®. Canadian Journal of Medicine. 2025 Aug 12;7(2):73-85. doi: 10.33844/cjm.2025.6050

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