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Getting Ready for Adult Healthcare: Designing a Chatbot to Coach Adolescents with Special Health Needs Through the Transitions of Care



Jeremy Beaudry, Lead Health Care Experience Designer^a, Alyssa Consigli, Project Director^b, Colleen Clark^c, Keith J. Robinson, MD, Director of Quality Improvement^{c,d,*}

^a hiCOLab, University of Vermont Health Network Medical Group, United States of America

^b Vermont Child Health Improvement Program, Larner College of Medicine at the University of Vermont, United States of America

^c University of Vermont Medical Center, United States of America

^d University of Vermont Children's Hospital, United States of America

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ABSTRACT

Objective: The AAP, AFP, and ACP have authored statements and recommendations to clinicians about the importance of the transition from pediatric to adult care. The Got Transition program provides a framework and resources based on AAP, AFP and ACP recommendations to promote skill attainment in self-care. Engaging adolescents along the transition journey has proven challenging. Use of smartphones, text messaging, and social media are prevalent among teenagers, offering a unique opportunity to engage teenagers in their preferred channel to provide tools and resources to help them successfully transition to adult focused care.

Methods: A multidisciplinary team of clinicians, quality improvement facilitators, and human-centered designers at the University of Vermont (UVM) Children's Hospital designed tools for teens with chronic conditions that support the Got Transition recommendations. Using a co-creative design process, we created a novel tool to increase engagement among teenagers. We conducted a pilot study of 13 teenagers with a chronic medical condition using a text messaging platform (chatbot) with scripted interactions to increase engagement and deliver educational content according to Got Transition.

Results: Mean engagement was 97% during the study period. Qualitative feedback from study participants suggests our chatbot should be extended and shows promise to help teenagers attain self-care skills on the transition journey.

Conclusions: A scripted text messaging platform is feasible and appears to be well-received by patients and caregivers. Furthermore, our approach emphasizes the need to engage teenagers through multiple platforms to effectively serve as “coaches” during the transition to adult care.

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Introduction

Adolescents and young adults face significant challenges when transitioning their care from pediatric to adult providers. Poor medication adherence, inadequate understanding of medical problems and treatments, reduced quality of care and increased healthcare utilization are common among teenagers making the transition to adult care (Lemke, Kappel, McCarter, D'Angelo, & Tuchman, 2018; McManus et al., 2013). These problems are often compounded for children with special health care needs (CSHN) and their families. As the number of CSHN living into adulthood increases (Lebrun-Harris, McManus, Ilango, et al., 2011), so does the need for health care teams to develop

a structured team-based approach to foster independence and self-care skills.

The American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) released a joint statement in 2011 describing the ubiquitous problem of adolescent transition to adult care (AAP, AAFP, & ACP, 2011). In 2018, the workgroup from the AAP, AAFP and ACP revised the statement to emphasize quality improvement, infrastructure, education and research (AAP, AAFP, & ACP, 2018). The “Six Core Elements of Health Care Transition” was released shortly after the 2011 statement to provide a practical framework for clinical teams trying to optimize the transition process for their patients (AAP, AAFP, & ACP, 2011). These core elements have become the foundation of the “Got Transition” program from the National Alliance to Advance Adolescent Health. Transition readiness is one of the “Six Core Elements of Health Care Transition” and involves assessing self-care skill attainment. Increasing engagement with

* Corresponding author.

E-mail address: keith.robinson@uvmhealth.org (K.J. Robinson).



Fig. 1. A patient creating their own visual map to a successful transition of care journey.

adolescent transition to adult care has been shown to lead to self-care skill attainment (Sebastian, 2014).

The use of smartphones, text messaging, and social media are nearly ubiquitous among teenagers, with the Pew Research Center reporting in 2018 that access to a smartphone among teens was at 95% (Pew Research Center, 2018). The Associate Press-NORC Center for Public Affairs Research, a partnership between the Associated Press and NORC at the University of Chicago, presented a report in 2017 that found 91% of teens using native text messaging to communicate (The Associated Press-NORC, 2017). Given the saturation of this technology, it is not surprising that health care providers have attempted to use these channels to engage teens in promoting healthy behaviors, from smoking cessation to obesity reduction (Hingle, 2013; Mason, Campbell, Way, & Keyser-Marcus, 2015). These trends present a unique opportunity to engage teenagers in their preferred communication channel to provide tools and resources to help them successfully transition to adult focused care.

The primary objective of this pilot study was to test the feasibility of a novel texting platform aimed at increasing engagement—measured by the response rate to text messages—among teenagers while teaching essential self-care skills. We also sought to develop unique partnerships with quality improvement and human-centered design specialists to create educational and coaching tools to prepare adolescents and families for the transition of care process in selected pediatric specialty clinics. Both objectives were inspired by the joint consensus statements and the Got Transition framework to address Transition Readiness, one of Got Transition's Six Core Elements.

Methods

Design approach

Vermont Child Health Improvement Program (VCHIP) is the oldest running national improvement partnership (Shaw, Norlin, Gillespie, Weissman, & McGrath, 2013). VCHIP established the organizational infrastructure that brought together several stakeholders including the Vermont Department of Health (VDH), the University of Vermont (UVM) Medical Center, UVM Children's Hospital, and hiCOLab (Healthcare Innovation Collaboratory), a design and innovation lab embedded in the UVM Health Network Medical Group. We built important relationships between these different organizations that included leaders and partners from pediatric and adult specialty clinics and primary care practices, hospital operations, the Patient and Family

Advisory Council, and the VCHIP Youth Health Advisory Council. Our design process created a clear structure for meaningful participation with the work that was action-oriented, energizing, and productive.

With greater frequency, health care organizations are building internal human-centered design teams to improve existing services and systems as well as create new models for health care delivery (Molloy, 2018; Kachirskaia et al., 2018). Human-centered design (HCD) is a collaborative and creative process focused on understanding the implicit and explicit needs of end users (Brown, 2008). HCD engages patients, families, providers, and staff to actively participate in the co-creation of healthcare services. Our project united clinicians trained in quality improvement and the Institute for Healthcare Improvement (IHI) Model for Improvement and designers with expertise in the human-centered design process championed by hiCOLab. Both methodologies (quality improvement and human-centered design) involve developing clear and measurable aims using an iterative process for brainstorming different ideas, designing and prototyping the strongest ones, and testing them with patients and clinicians. Our team facilitated a participatory research and co-design process to explore how we might better help adolescents with chronic conditions transition successfully to independence in managing their own health care. This highly collaborative approach brought several key partners closer together, catalyzing the creation of innovative responses to address the problem of transition readiness in our patient population.

The project team conducted semi-structured interviews with and observations of over 60 stakeholders including patients, caregivers, providers, and other clinical staff. (Fig. 1) We reviewed relevant scholarly research and case studies to establish a broader context for pediatric healthcare transitions. These research activities yielded nuanced detail and richness to aid our understanding of the complex issues adolescent patients face as they transition, while engaging our stakeholders as participants in the design process.

Working with the principles and methods of co-design, we facilitated several co-creative workshops with patients. In small peer groups, patients created large, wall-sized timelines of their individual transition of care journeys, sharing their experiences, past frustrations and successes, as well as hopes and fears about the future. Building off the

Table 1
Age breakdown of participants at time of enrollment.

| 14 years | 15 years | 16 years | 17 years |
|----------|----------|----------|----------|
| 2 | 1 | 9 | 1 |



Fig. 2. The chatbot coaching a teenager about transition.

insights from this exercise, the participants brainstormed, sketched, and built their own ideas for products and services that might help patients like them meet the challenges of health care transitions. These generative research tools helped our team learn more about what resources young people wish they had to help them along the transition of care journey.

Our clinical partners told us that there are certain skills that adolescents need to know to successfully manage their own health care, such as being knowledgeable about their illness and treatment, following care guidelines (medications, self-care, and other treatments), and taking an increasing responsibility for their health care. We learned that self-advocacy, one of the most crucial yet difficult skills, needs to be built and practiced over time and reinforced through a range of interactions such as coaching.

Our collaboration with adolescent patients confirmed published reports on technology usage trends: a native digital format optimized for a smartphone to access information is expected by default by young people. We used all the insights from the research to design new tools and resources for adolescent patients on the transition of care journey. This led to the rapid creation and subsequent iteration of a novel transition of

care readiness program for adolescent patients that included an introductory workshop and a text messaging platform (chatbot) to help them meet specific goals along their journey in preparation for entering the adult health care environment. Topics for the chatbot were inspired by the previously mentioned clinician interviews.

In order to better understand the how the chatbot would be most impactful, quality improvement facilitators engaged subspecialists, nurse clinicians, and support and administrative staff to evaluate and build the content of the chatbot. Later, we engaged a youth advisory council to test the chatbot to refine content, persona and tone of the messages. Collaborating with these stakeholders helped our team learn more about the tools, technology, and coaching strategies care teams might need to successfully support adolescents and young adults throughout the transition journey.

Intervention

We conducted an IRB-approved six-month pilot study of our program, which included 13 patients between the ages of 14 and 17 who are seen in our Pediatric Inflammatory Bowel Disease, Cardiology, and Type I Diabetes specialty clinics (see Table 1). Nurse clinicians and physicians were integral partners in our study. As the primary health care clinicians working with adolescents and families, nurse clinicians and physicians recruited patients within their clinic and encouraged them to participate in the research study. After obtaining consent from parents and assent from adolescent patients, the participants completed the introductory workshop and interacted with the text messaging chatbot built with the Twilio (San Francisco, CA) and Motion.ai (HubSpot, Cambridge, MA) platforms. Our goals were to determine the feasibility and acceptance of the program and to measure the efficacy of the tools for building confidence and skills necessary for the transition of care journey. To evaluate the program, we administered surveys to patients, throughout the study, and captured usage data of the text message interactions. As an incentive, adolescents were offered \$25 cash debit card to attend the introductory workshop, and then another \$50 cash debit card for completing the post-project survey.

The introductory workshop was developed to orient teens to the transition of care journey through peer-to-peer learning and creative activities. Workshop participants created autobiographical collages describing themselves, mapped and discussed their personal transition

Table 2
Schedule of message topics.

| Month/week | Topics | Module |
|------------|------------------------------------|---|
| Week 1 | Know your health condition | Understanding your health condition |
| Week 2 | Know your health condition | Reminder |
| Week 3 | Know your health condition | Talking with others about your health condition |
| Week 4 | Know your health condition | Reminder |
| Week 5 | Know your medical history | Know your medical history |
| Week 6 | Know your medical history | Reminder |
| Week 7 | Know your medications | List your meds / side effects |
| Week 8 | Know your medications | Medication reminders |
| Week 9 | Know your medications | Reminder |
| Week 10 | Know your medications | Dosages |
| Week 11 | Know your medications | Medication consistency |
| Week 12 | Know your medications | Order refills |
| Week 13 | Know your medications | Reminder |
| Week 14 | Preparing for your appointments | Getting Ready |
| Week 15 | Preparing for your appointments | Reminder |
| Week 16 | Preparing for your appointments | Meeting Alone |
| Week 17 | Preparing for your appointments | Reminder |
| Week 18 | Preparing for your appointments | Reporting Ineffective Treatments |
| Week 19 | Preparing for your appointments | Reminder |
| Week 20 | Contacting your doctors and nurses | Scheduling appointments |
| Week 21 | Contacting your doctors and nurses | Knowing when to call |
| Week 22 | Contacting your doctors and nurses | Reminder |
| Week 23 | Health Insurance | Learn more about insurance |
| Week 24 | Health Insurance | Reminder |

of care timelines with each other, learned about some of the most important skills needed for a successful transition, and created PSA-style posters advocating for these skills. The workshop was also used to introduce teens to the text messaging chatbot and enroll them in the program.

The chatbot (Fig. 2) was designed to send weekly text messages on Wednesday evenings to adolescent patients to begin to prepare them for the transition of care journey. A platform using basic text messaging was selected because it did not require an app to download – it is portable across virtually every mobile phone – and it is one of the most dominant communication channels among teens. The messages invite interaction by asking patients about different aspects of their health care each week (Table 2), including topics like understanding one's chronic condition and medical history, ordering prescription medication refills, contacting a doctor's office, and preparing for doctor's appointments. Based on how the user responds to these questions, the chatbot then replies with appropriate encouragement, tips, and links

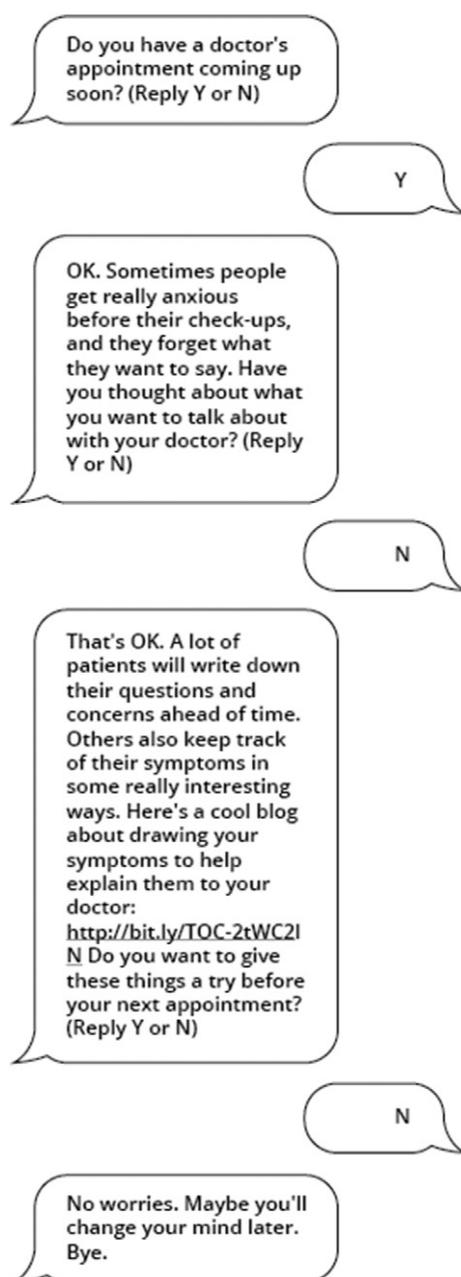


Fig. 3. An example of a chatbot text message interaction.

to additional online resources. An example of one of these interactions is given in Fig. 3.

Results

Data collected included analytics from the text messaging software, and surveys designed to measure user behavior, including knowledge gained, satisfaction of the materials and workshop, and usability of the technology. Surveys were deployed to adolescents at the following intervals: at the beginning of the study, before and after the introductory workshop, and at the close of the study. Thirteen adolescents completed the initial survey and twelve completed the final survey; all 13 participants were counted when measuring engagement throughout the duration of the text messaging program.

Quality improvement methodology using statistical process control charts evaluated the engagement rate. Over the course of the six-month period of the chatbot, the overall weekly response rate to the messages (rate of engagement) showed a mean of 97% on a statistical process control chart (Fig. 4). This corresponded with what patients reported in the final survey: they overwhelmingly agreed that text messaging was the right channel for them, and they indicated that the rate of one message per week was preferred. They reported being motivated to respond to the texts because of its "ease of use" and "friendly" persona. Participants stated that they would more likely than not recommend the text messaging program to their peers.

Analysis of the pre and post project surveys revealed an increased patient participation in many important activities needed for successful health care transitions, like managing medications, ordering prescription refills, and proactively contacting providers about health-related concerns (Figs. 5–7). However, study participants did not feel more confident with the "softer" skill of self-advocacy. Participants reported that they do not understand health insurance and would benefit from more education on that topic. Study participants reported that they appreciate the peer-to-peer interactions of the transition of care workshop and they indicated a strong interest in more opportunities to connect with young adults who can provide mentorship along the transition of care journey. Two thirds of the participants reported that the workshop was helpful in teaching them transition related topics.

Total number of participants: $n = 12$.

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Discussion

Our pilot study confirmed it is feasible to use a novel text messaging platform with scripted messages to increase engagement – measured by the response rate to text messages – among adolescents with chronic illnesses. During our 24-week study period, the mean response rate was 97%. This suggests that engagement with adolescents may be increased with a text messaging platform and offers an opportunity to use this digital format to impart knowledge or teach skills. Our text messaging platform had little financial cost, which will reduce barriers for clinicians. While the technical cost was relatively low, there was a significant investment of time from the project team to develop and maintain the program. Costs related to the time and maintenance of the program will need to be quantified in further studies.

Interpretation of the engagement rate among adolescents in the study may be confounded by incentives to enroll in the study. However, the incentives were linked to completion of the pre and post study survey, not responding to the chatbot. Future studies should test the chatbot in larger populations without the use of incentives to better understand how the chatbot can be used routinely in the clinical setting.

A trend suggesting skill attainment was seen in 3 areas: tracking medications, completing medication refills, and contacting a provider's office with questions. While our sample size was small and not intended to show statistical significance, we are optimistic that some teenagers

Response Rate to SMS Messages by Week September, 2017 - March, 2018

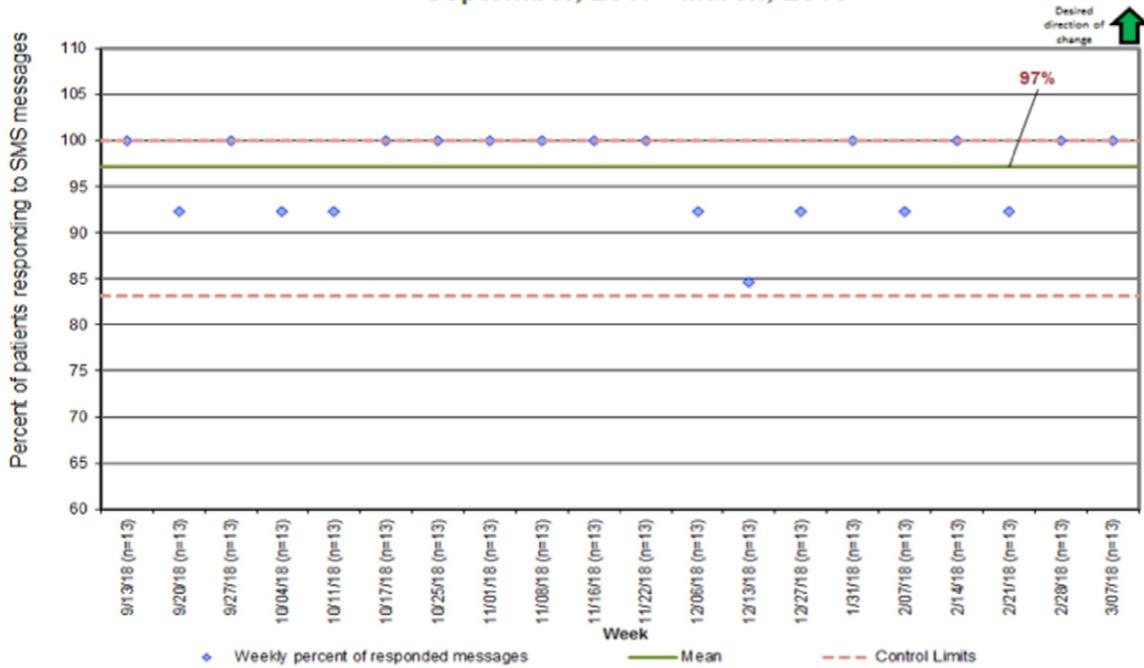


Fig. 4. A statistical process control chart (P chart) of weekly teen engagement with the texting platform. The percent of responses to the text messages is on the Y-axis.

retained information from the modules and were able to affect change. We recognize that the timing of our post pilot survey deployment may not have allowed the amount of time necessary to practice these new skills. Additionally, skill attainment should be assessed longitudinally which would require a system and data collection tool. (Baker, Riekert, Sawicki, & Eakin, 2015; Wood, 2014) Our interpretation of the pilot, even with its limitations, is that the digital formats are appealing to adolescents and young adults and provide another vehicle to coach skills and convey important information in the transition journey. This format may be considered when programs address Transition Readiness as part of the Got Transitions Six Core Elements framework.

We speculate that the workshop was an equally important tactic for creating high engagement throughout the duration of the pilot because it created an energizing social experience among a group of peers, and it provided a structured onboarding experience. Unfortunately, we are not able to continue the workshop due to resources required from clinic

staff, patients and families. Consistent with existing literature, we would like to engage and develop roles for nurse clinicians, social work case managers and physicians. Young adults indicated on their post pilot surveys that they value their health care clinician's role in providing education and counseling on health care topics and view them as a key partner. Moving forward, we envision nurse clinicians taking a more active role in facilitating similar workshops.

Finally, our project combined two different but similar methodologies (quality improvement and human-centered design) to develop and test a novel intervention. These methodologies generated a deeper understanding of how clinicians approach the process of transitions, the patient and family experience of preparing for the transition, engagement with key stakeholders, change management, and rapid prototyping/rapid cycle improvement. In our experience, the combined methodology resulted in an innovation aimed at solving a notoriously challenging problem while delivering a richer experience for the project



Fig. 5. Pre and post results of medication tracking after our text messaging pilot. Gray icons represent patients not performing the task. Orange icons represent patients completing the task.

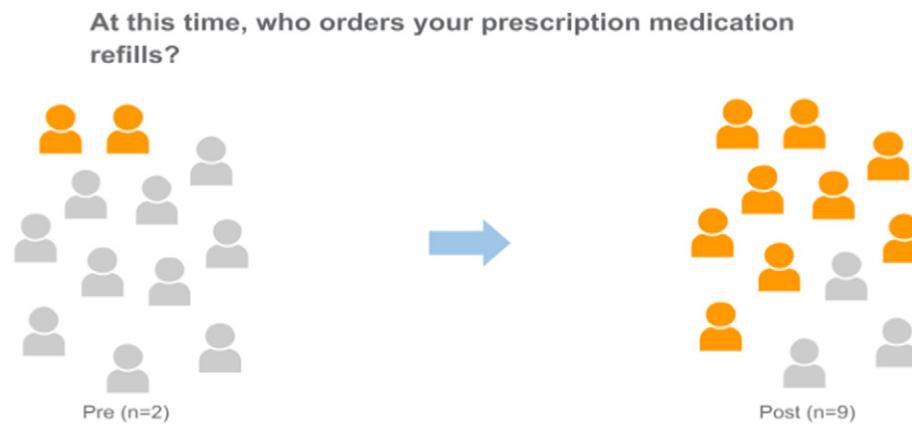


Fig. 6. Pre and post results of medication refills after our text messaging pilot. Gray icons represent patients not performing the task. Orange icons represent patients completing the task.

team. We plan to sustain our partnership to encourage innovation and a deeper understanding of complex systems that impact our patients and families.

An important limitation of our study is the use of a digital format relying on text messaging. Our project required study participants to have a cellular phone with reliable and affordable service, which introduces selection bias. Furthermore, our study period was relatively short and might not be long enough to detect changes in cellular phone numbers or lapses in cellular service that would be a barrier to this tool. Future studies should investigate how differences in geography, race, gender, socio-economic status impact engagement and effectiveness of the program.

The transition from pediatric to adult care is fraught with numerous challenges to adolescents, parents, caregivers and clinicians. Ideally, the transition process would evolve over time with the focus on developing self-care skills for the adolescent (Tuchman, Schwartz, Sawicki, & Britto, 2010). In order for this to occur, the adolescent requires a strong support network with effective engagement to “coach” the development of self-care skills. As digital media use continues to increase among teenagers, we believe healthcare teams should leverage technology such as text messaging and related formats to increase engagement.

Conclusion

Our pilot study tested the feasibility of a text messaging platform to increase engagement. While we showed promise to increase

participation in a transition program, we do not think that relying solely on digital formats is sufficient to impart knowledge and teach skills necessary for a successful transition to adult care. Future work must integrate clinical workflows, clinical champions and peer interactions as outlines in the joint AAP, ACP and AAFP statements. As stated in the 2018 consensus statement, encouraging innovation and improvement methodology are essential to advancing the challenging field of adolescent transition (AAP, AAFP, & ACP, 2018).

CRedit authorship contribution statement

Jeremy Beaudry: Conceptualization, Software, Investigation, Resources, Writing - original draft. **Alyssa Consigli:** Conceptualization, Investigation, Resources, Writing - review & editing, Project administration. **Colleen Clark:** Software, Investigation. Conceptualization. **Keith J. Robinson:** Conceptualization, Methodology, Formal analysis, Investigation, Supervision, Writing - review & editing.

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Fig. 7. Pre and post results of contacting your doctor's office after our text messaging pilot. Gray icons represent patients not performing the task. Orange icons represent patients completing the task.

References

- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley, W. C., & Sagerman, P. J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *128*(1), 182–200. <https://doi.org/10.1542/peds.2011-0969>.
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, White PH, Cooley WC. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018; *142*(5):e20182587. (2019). *Pediatrics*, *143*(2), e20183610.doi:<https://doi.org/10.1542/peds.2018-3610>.
- Baker, A. M., Riekert, K. A., Sawicki, G. S., & Eakin, M. N. (2015). CF RISE: Implementing a clinic-based transition program. *Pediatric Allergy, Immunology, and Pulmonology*, *28*(4), 25–254. <https://doi.org/10.1089/ped.2015.0594>.
- Brown, T. (2008). Design thinking. *Harvard Business Review*, *86*(6), 84 Retrieved from <https://hbr.org/2008/06/design-thinking>.
- Hingle, M. (2013). Texting for health: The use of participatory methods to develop healthy lifestyle messages for teens. *Journal of Nutrition Education and Behavior*, *45*(1), 12–19. <https://doi.org/10.1016/j.jneb.2012.05.001>.
- Kachirskaia, I., Mate, K. S., & Neuwirth, E. (2018, June 28). *Human-centered design and performance improvement: Better together*. NEJM Catalyst Retrieved August 11, 2019, from <https://catalyst.nejm.org/hcd-human-centered-design-performance-improvement/>.
- Instagram and Snapchat are Most Popular Social Networks for Teens; Black Teens are Most Active on Social Media, Messaging Apps | APNORC.org | APNORC.org (Ed.). (2017). Retrieved August 9, 2019, from [apnorc website. http://apnorc.org/PDFs/Teen%20Social%20Media%20Messaging/APNORC_Teens_SocialMedia_Messaging_2017_FINAL.pdf](http://apnorc.org/PDFs/Teen%20Social%20Media%20Messaging/APNORC_Teens_SocialMedia_Messaging_2017_FINAL.pdf).
- Lebrun-Harris, L. A., McManus, M. A., Ilango, S. M., et al. (2011). Transition planning among US youth with and without special health care needs. *Pediatrics*(4), *142* (doi:e20180194).
- Lemke, M., Kappel, R., McCarter, R., D'Angelo, L., & Tuchman, L. K. (2018). Perceptions of health care transition care coordination in patients with chronic illness. *Pediatrics*, *141*(5), e20173168. <https://doi.org/10.1542/peds.2017-3168>.
- Mason, M. J., Campbell, L., Way, T., & Keyser-Marcus, L. (2015). Development and outcomes of a text messaging tobacco cessation intervention with urban adolescents. *Substance Abuse*, *36*(4), 500.
- McManus, M. A., Pollack, L. R., Cooley, W. C., McAllister, J. W., Lotstein, D., Strickland, B., & Mann, M. Y. (2013). Current status of transition preparation among youth with special needs in the United States. *PEDIATRICS*, *131*(6), 1090–1097. <https://doi.org/10.1542/peds.2012-3050>.
- Molloy, S. (2018, April 20). Innovation labs in healthcare - a review of design labs as a model for healthcare innovation [MRP]. Retrieved August 11, 2019, from <http://openresearch.ocadu.ca/id/eprint/2364/>
- Sebastian, R. A. (2014). Measuring youth health engagement: Development of the youth engagement with health services survey. *Journal of Adolescent Health*, *55*(3), 334–340. <https://doi.org/10.1016/j.jadohealth.2014.02.008>.
- Shaw, J. S., Norlin, C., Gillespie, R. J., Weissman, M., & McGrath, J. (2013). The National Improvement Partnership Network: State-based partnerships that improve primary care quality. *Academic Pediatrics*, *13*(6), S84–S94. <https://doi.org/10.1016/j.acap.2013.04.001>.
- Teens, Social Media & Technology 2018 | Pew Research Center. Retrieved August 9, 2019, from <https://www.pewinternet.org/2018/05/31/teens-social-media-technology-2018/>(2018, May 31)..
- Tuchman, L. K., Schwartz, L. A., Sawicki, G. S., & Britto, M. T. (2010). Cystic fibrosis and transition to adult medical care. *PEDIATRICS*, *125*(3), 566–573. <https://doi.org/10.1542/peds.2009-2791>.
- Wood, D. L. (2014). The transition readiness assessment questionnaire (TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics*, *14*(4), 415–422. <https://doi.org/10.1016/j.acap.2014.03.008>.