



---

# Journal of Participatory Medicine

---

Advancing the understanding and practice of participatory medicine among health care professionals and patients

Volume 10 (2018), Issue 3 ISSN 2152-7202 Editors-in-Chief: Susan Woods, MD, MPH; Matthew F Hudson, PhD, MPH

---

## Contents

### Original Papers

Content-Sensitive Characterization of Peer Interactions of Highly Engaged Users in an Online Community for Smoking Cessation: Mixed-Methods Approach for Modeling User Engagement in Health Promotion Interventions ([e9](#))

Sahiti Myneni, Vishnupriya Sridharan, Nathan Cobb, Trevor Cohen. . . . . 2

Phase I of the Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties (DECADES) Study: Development of an Integrated Mental Health Care Model for Pediatric Gastroenterology ([e10655](#))

Stephanie Hullmann, Stacy Keller, Dustin Lynch, Kelli Jenkins, Courtney Moore, Brandon Cockrum, Sarah Wiehe, Aaron Carroll, William Bennett Jr. . . . . 12

Original Paper

# Content-Sensitive Characterization of Peer Interactions of Highly Engaged Users in an Online Community for Smoking Cessation: Mixed-Methods Approach for Modeling User Engagement in Health Promotion Interventions

Sahiti Myneni<sup>1</sup>, MSE, PhD; Vishnupriya Sridharan<sup>1</sup>, MS; Nathan Cobb<sup>2</sup>, MD; Trevor Cohen<sup>1</sup>, MBChB, PhD

<sup>1</sup>School of Biomedical Informatics, University of Texas Health Science Center at Houston, Houston, TX, United States

<sup>2</sup>Georgetown University Medical Center, Washington, DC, United States

**Corresponding Author:**

Sahiti Myneni, MSE, PhD

School of Biomedical Informatics

University of Texas Health Science Center at Houston

7000 Fannin Street, Suite 165

Houston, TX,

United States

Phone: 1 713 486 0115

Fax: 1 646 349 4081

Email: [Sahiti.Myneni@uth.tmc.edu](mailto:Sahiti.Myneni@uth.tmc.edu)

## Abstract

**Background:** Online communities provide affordable venues for behavior change. However, active user engagement holds the key to the success of these platforms. In order to enhance user engagement and in turn, health outcomes, it is essential to offer targeted interventional and informational support.

**Objective:** In this paper, we describe a content plus frequency framework to enable the characterization of highly engaged users in online communities and study theoretical techniques employed by these users through analysis of exchanged communication.

**Methods:** We applied the proposed methodology for analysis of peer interactions within QuitNet, an online community for smoking cessation. Firstly, we identified 144 highly engaged users based on communication frequency within QuitNet over a period of 16 years. Secondly, we used the taxonomy of behavior change techniques, text analysis methods from distributional semantics, machine learning, and sentiment analysis to assign theory-driven labels to content. Finally, we extracted content-specific insights from peer interactions (n=159,483 messages) among highly engaged QuitNet users.

**Results:** Studying user engagement using our proposed framework led to the definition of 3 user categories—conversation initiators, conversation attractors, and frequent posters. Specific behavior change techniques employed by top tier users (threshold set at top 3) within these 3 user groups were found to be goal setting, social support, rewards and threat, and comparison of outcomes. Engagement-specific trends within sentiment manifestations were also identified.

**Conclusions:** Use of content-inclusive analytics has offered deep insight into specific behavior change techniques employed by highly engaged users within QuitNet. Implications for personalization and active user engagement are discussed.

(*J Participat Med* 2018;10(3):e9) doi:[10.2196/jopm.9745](https://doi.org/10.2196/jopm.9745)

## KEYWORDS

user engagement; smoking cessation; text analysis

## Introduction

With the increasing recognition of the importance of participatory medicine in care delivery, researchers seek to improve traditional health care by placing the health consumer at the center of the system by means of “connected health” [1].

Biosensing devices, social media, big data analytics, treatment modalities, and patient engagement pathways define the infrastructure underlying connected health implementations [2,3]. The Web of intelligent communication and actionable insights can enable integrated care and better outcomes for health consumers [4]. Empowered and engaged health

consumers (and patients) in conjunction with technological advances can create a more streamlined and efficient system from the current health sector, which is chaotic and fragmented [1]. To this end, social media and online communities (often referred to as the “participative internet” [5]) are gaining popularity as venues for management of health and wellness. Traditionally, health care services and clinicians act as intermediaries in providing health consumers and patients with relevant and vetted health information. However, with the penetration of consumer-driven Web, these new generation platforms have been gaining popularity as predominant information sources where social contacts, collaborative tools (eg, content recommendation systems) and agents (eg, virtual assistants) guide health consumers and patients toward adoption and maintenance of positive health behaviors [6]. Accessibility, scalability, and affordability are key characteristics that can make these platforms effective public health interventions for health promotion and behavior change [7]. In order to achieve the full potential of these platforms, we need to address challenges related to adoption and sustained use [8-10]. Understanding the facets of user engagement in an online health community can help us drive acceptance and enhance utility of online social platforms in health care. Strong user engagement with a technology intervention may enhance outcomes [8]. Health consumers use internet-based resources differently than they do in-person and group programs, and hence, the characteristics of subpopulations must be assessed to determine the factors leading to sustained use [11]. Further, such nuanced understanding of patterns of use can help us optimize care pathways and personalize design of technologies to achieve long-term engagement [12].

There are multiple definitions of user engagement in health care settings [13-17]. As defined by Lalmas [17], user engagement is “the quality of user experience that emphasizes the desire of a user to use the application longer and in frequent intervals.” Traditionally, user engagement metrics are calculated by number of page views or time spent on specific activities [18]. In the context of a social platform, however, the volume of posts (also known as communication frequency) is the most used criterion to describe levels of user engagement in both short-term and long-term use. This quality of user experience can be described using a complex set of factors that are emotional, cognitive, and behavioral in nature [13]. Existing metrics do not capture this holistic view of user engagement with a technological resource such as an online social platform.

Previous studies on user engagement in online communities have focused on (1) enhancing user engagement through gamification and related techniques [19], (2) estimating the impact of personalization on engagement [20], (3) studying engagement from the perspective of the 3 main types of social support—informational support, emotional support, and companionship [21], (4) studying user engagement from the perspective of user roles such as lurkers [22,23] and user evolution across these roles [8], (5) estimating engagement through data logs [24], and (6) studying social bootstrapping and social curation as possible aspects of improved user engagement [25,26]. On the other hand, our prior research on online social platforms has highlighted the need to consider

content of user communication to better characterize peer interactions [27-30]. The content itself can have a strong influence on user engagement [27]. Also, sustained engagement is likely when the intervention offers ongoing learning and interactive opportunities. The extent to which these requirements are fulfilled can be understood by studying the content of communication from a theoretical perspective [30]. However, the dynamics of content-based attributes and user engagement in online communities has rarely been studied together.

In our study, we aimed to address these gaps by developing new methods inclusive of communication frequency and communication content, thus enabling the study of user engagement in online health communities. The relationship between these communication attributes and user engagement is detailed in the literature [5,20,31,32]. The methodology described in the paper takes an integrated approach from various user engagement models, some of which are specific to online communities for health behavior change [31,32]. We apply this proposed new model to analyze peer interactions in QuitNet, an online community for smoking cessation.

## Methods

### Materials

QuitNet is one of the first online communities for behavior change with historically over 100,000 new registrants per year [33]. Previous studies show that participation in QuitNet is associated with abstinence [34]. In this paper, we examined a data set from a version of QuitNet that ran until approximately 2015 where the primary mode of communication was threaded forums; in other words, peer conversations were initiated with an initial message and replies were displayed hierarchically. Each forum message is identified using a message ID, a thread ID, a sender ID, and a recipient ID. Participants set quit dates which represent abstinence from smoking and are preserved in historical logs if they change. This research project was reviewed and exempted by the Institutional Review Board at the University of Texas Health Science Center at Houston.

### Methods

#### *Characterization of QuitNet Users*

We defined 3 QuitNet user groups based on the frequency in which users engaged in peer interactions within QuitNet. Empirical cut points based on previous research were used to define the groupings as described below:

- Conversation initiators: users who initiated the highest number of threads
- Frequent posters: users who posted the highest number of messages to the forums
- Conversation attractors: users whose posts attracted the most replies

For the purpose of this study, our analysis included the top 3 QuitNet users within each user group (that is, 9 users in 3 groups in a given year) across the years 2000 to 2015, resulting in 144 unique users. Overall, 26,466 messages were exchanged by conversation attractors, 57,379 messages were exchanged by conversation initiators, and 75,638 messages were exchanged

by frequent posters. In total, these 144 highly engaged users exchanged 159,483 messages. Further, we analyzed the user demographics (age, gender) and self-reported smoking status where available in event logs. For users whose event logs were incomplete or unavailable (42.4% [61/144] of the users), we analyzed their messages manually, leveraging the fact that QuitNet users specify the number of days since they last smoked in every message as a form of tradition. From these data, we estimated user abstinence status across years and identified users as falling into one of the following categories: (1) abstinent for less than 3 months, (2) abstinent between 3 and 6 months, (3) abstinent between 6 months and 1 year, (4) abstinent between 1 and 2 years, (5) abstinent for more than 2 years, and (6) active smoker.

### ***Characterization of QuitNet Communication Content***

We analyzed 2.05 million messages generated by 102,005 unique users, exchanged between the years 2000 and 2015 for this purpose. Using a series of qualitative and automated text analysis methods, we categorized QuitNet messages into 16 themes.

### **Qualitative Analysis**

We selected 2000 messages at random to produce an annotated subset of QuitNet messages (Figure 1). These messages were manually coded using the taxonomy of behavior change techniques [35] by 2 independent coders. The taxonomy has 93 theoretically linked behavior change techniques clustered into 16 thematic categories that were developed by a team of behavior change experts and drawn from multiple behavior change theories such as social change theory and the health belief model. The list of techniques of the taxonomy with definitions and subcategories can be found in Michie et al [35]. Table 1 shows snippets of sample messages from QuitNet that correspond to a particular technique of the taxonomy. From the sample messages, it can be seen that a single message in QuitNet can be mapped to multiple techniques of the taxonomy. The interrater reliability was estimated at 0.76 for the 2 coders during annotation. Most disagreements were due to multiple labels assigned to each message. All coding conflicts were resolved through discussion before the manual annotation of QuitNet messages was finalized.

### **Automated Text Analysis**

All messages in the dataset were annotated by providing the QuitNet vector representations to a machine learning classifier trained on the manually annotated messages. The components of the process are represented in Figure 2. To generate vector representations of messages, we used neural word embeddings, specifically the Skipgram-with-Negative-Sampling (SGNS) algorithm developed by Mikolov and colleagues [36], as implemented in the open source semantic vectors [37] package for distributional semantics. With SGNS, a neural network is trained to predict the probability of encountering terms that occur in proximity to an observed term. For example, one might

anticipate a relatively high probability of observing the term “relaxing” in proximity to the term “hammock.” During the course of training, the neural network learns to predict higher probabilities for observing contextual terms that are observed in proximity to a term in the corpus than it does for those that are not observed in proximity to this term. Each term is associated with a set of weights—a weight vector—that encodes the terms that have been observed in proximity to it. Terms that occur in similar contexts will have similar weight vectors, and the similarity between the resulting weight vectors has been shown to correlate well with human estimates of the similarity between concept pairs. An advantage of this approach is that it permits the incorporation of background knowledge into a categorization model. For example, if 2 QuitNet users refer in messages to a concept such as “sadness” with different terms (such as “feeling blue,” “miserable today”), a classifier will be able to assign a category attached to one of these messages from the training set to the other previously unseen message because the words in these messages have similar representations, even though they are not identical words. Information of this sort can be learned by SGNS from a large unannotated general domain corpus.

For our research, Wikipedia was used as a background corpus. Our Wikipedia corpus contains 1.9 billion words in more than 4.4 million articles, and 500-dimensional Wikipedia-derived term vectors were obtained by applying the SGNS algorithm to the Wikipedia background corpus. This decision was motivated in part by the terse nature of the messages exchanged in QuitNet user forums, which often do not provide enough contextual information to train a distributional model [28]. However, there are ways in which the language used in QuitNet differs from that used in the Wikipedia. Of particular importance for the current research, QuitNet messages contain neologisms, community-specific terms such as “nicodemon” and “sickarettes.” While these terms are unlikely to appear in Wikipedia, within QuitNet they occur in the context of other terms for which robust representations have been learned from this larger corpus. As such, the distributional information learned from Wikipedia can be viewed as a form of prior knowledge, providing a starting point for the next phase—distributional modeling of the QuitNet corpus. This component of the training process used an iterative training procedure [38] in which term and message vectors are generated in succession.

Specifically, we first superposed (added together) the Wikipedia term vectors for the terms that occur in each QuitNet message to obtain Wikipedia-based QuitNet message vectors. We then composed term vectors for the terms that occur in QuitNet by adding QuitNet message vectors for each message in which a given term in QuitNet occurred. As such, these term vectors encode distributional information from Wikipedia and from QuitNet-specific contextual use of terms. Finally, QuitNet message vectors were generated by superposing these term vectors. This procedure is illustrated in Figure 2.

Figure 1. Methodological outline for content analysis.

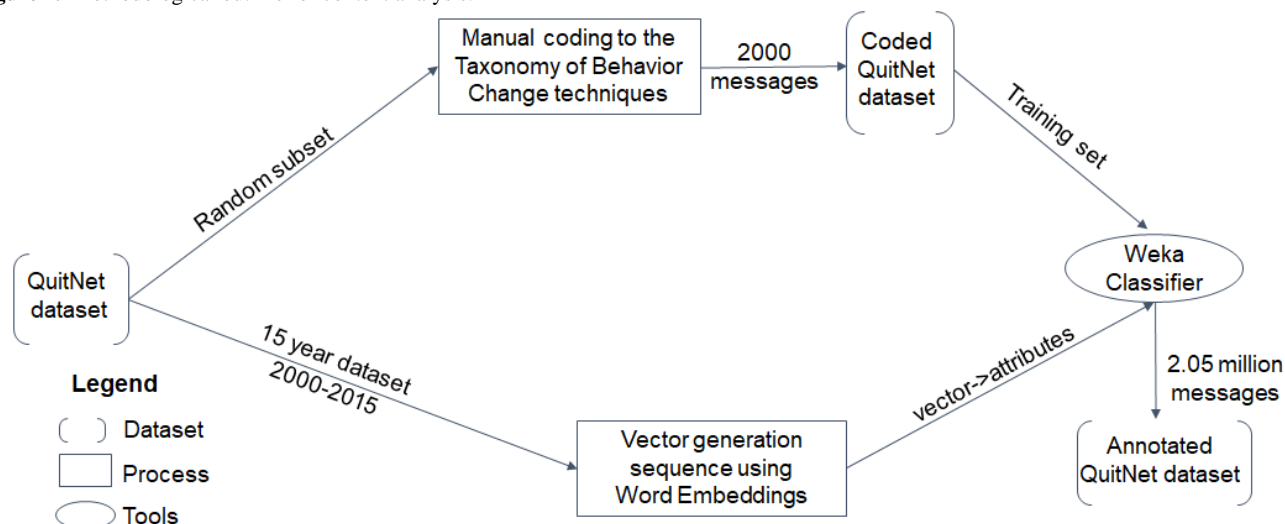
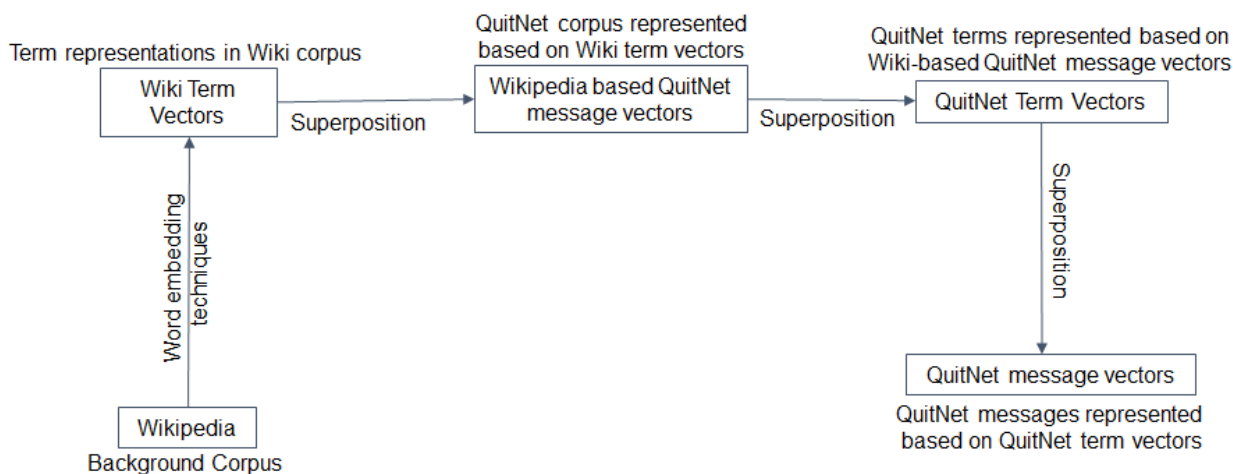


Table 1. Sample messages from QuitNet mapped to the thematic category in the taxonomy.

Taxonomy	Sample message snippets from QuitNet
Goals and planning	I pledge not to smoke today and extend my hand to the next quitter who drops by
Feedback and monitoring	////13 days, 23 hours, 47 minutes and 51 seconds smoke free. 280 cigarettes not smoked. \$56.98 and 2 days, 3 hours of my life saved! My quit date: 2/16/2007 10:00:00 AM
Social support	Awww! Sorry you're not feeling up to par. Hope you'll feel like joining in again soon!//Take care...////:J
Shaping knowledge	That "Demon Nic" article you copied is one/if not THE best thing I've ever read on the subject of quitting smoking - what an incentive!!
Natural consequences	To tell you the truth, it's a new experience for me NOT to cough (I smoked for 38 or so years - YUK!). Good luck to you
Comparison of behavior	Thanks for the hand and I extend mine to the next in line.////XXX
Associations	I am happy to add your 7500 cancer sticks to the fire! wwwooooosssshhhhhhhhhh Sit back and relax!
Repetition and substitution	Wow!!! xyxx is correct. You control your attitude. Deep breathing, chew gum, take a walk (or maybe a hike:-) Hang in there. This is not easy, your an addict.
Comparison of outcomes	At this point in your Quit it may be best to look at more immediate gains such as money saved or improved self esteem or better health. My dollar savings are \$5,293 and that is real and for now. My life saved is an unrealized 15 weeks and 20 minutes that may never happen.
Rewards and threat	Congratulations on your Quit. In the end YOUWIN...IWIN...WEWIN!
Regulation	If anxiety is an issue for you in general or you used smoking to alleviate it, using new coping tools and behaviors to help you relax and unwind will help this symptom fade quicker. The important thing is to keep going
Antecedents	I found this site before I quit also, and it made an incredible difference in my ability to be successful. Come over to the QuitStop Forum on this site and you will meet many people with all different stories about what worked for them and what didn't.
Identity	Great insight, YYY. But have been suffering a lot of depression type symptoms ....never occurred to me could be related to the smoking cessation. That actually helps me see things a little differently.
Scheduled consequences	Great News Also!!! After further Review, ZZZ it is now official! As of 6:00 AM you are on the Q Anni List so your 2 month quit is officially good now! The points will stay on the board! Keep up the great play calling! Hugs
Self-belief	What a change! But my not smoking wont change. My hand to you. Steve Indecision may or may not be my problem.
Covert learning	I'll be sending 33,657 unsmoked sick sticks to a blazing end. I don't want or need them!!!!/I need a shot of apricot brandy and a relaxing hammock to settle in

**Figure 2.** Vector generation sequence of QuitNet messages.

The components of the vectors generated in this way were used as feature vectors for supervised machine learning that was conducted using the widely used Waikato Environment for Knowledge Analysis open source package for machine learning [39]. Each of the techniques of the behavior change taxonomy was used as a target for classification. Ten-fold cross-validation was applied using the naïve Bayes classifier to evaluate a binary classifier for each of the themes. Each of the trained and validated classification models was then used to classify the entire set of 2.05 million messages. Given the highly engaged users in this paper, we focused on the manifestation of behavior change techniques within the messages exchanged by 144 users identified in the earlier step, thus limiting our analysis to 159,483 messages exchanged by these users.

### Sentiment Analysis

Sentiment analysis of user communication in QuitNet was performed using the open source software R (The R Foundation) on 159,483 messages exchanged by highly engaged users. Multiple packages were evaluated by comparing their output to manual annotation provided by 2 independent coders. Based on reliability measures, we chose the best performing package to ensure the suitability of the classification to QuitNet interactions. The SentimentAnalysis package [40] in R yielded the best results at 0.81 (average system-rater agreement measured using Cohen kappa) reaching good interrater agreement. This led to classification of messages by 144 users into the categories positive, negative, and neutral using the function `convertToDirection(sentiment$SentimentQDAP)`. The inbuilt dictionaries within the R package were used to assign a particular sentiment class to the QuitNet messages.

## Results

### Characterization of QuitNet Users

The average age of the 144 QuitNet users considered in this analysis was 49 (SD 9.4) years with 82.6% (119/144) female users. Among conversation attractors, 69% (33/48) were female users with an average age of 48 (SD 10.1) years. The remaining 31% (16/48) male users had an average age of 42 (SD 6.6) years. Of the conversation initiators, 85% (41/48) were female users

with an average age of 52 (SD 9.4) years. The remaining 15% (7/48) were male users with an average age of 46 (SD 6.8) years. Of the frequent posters, 94% (45/48) were female users with an average age of 49 (SD 8.6) years. The remaining 6% (3/48) were male with an average age of 51 (SD 10.2) years. Figure 3 provides the variations in smoking status across these user groups. Among conversation initiators, users who had been abstinent for more than 2 years accounted for 58% (28/48). The highest proportion of users among conversation attractors was individuals who were within 3 months of a quit attempt, with close to 42% (20/48) of the users in this category. Among frequent posters, QuitNet users with varying lengths of quit attempts had equal representation.

### Characterization of QuitNet Communication Content

Due to insufficient positive examples in the training set, we disregarded 8 of the 16 techniques of the taxonomy for final classification. For the remaining 8 techniques, the precision, recall, and f-measure for the cross-validation of the automated classification method using the naïve Bayes classifier were 0.80, 0.70, and 0.71, respectively. The themes considered for further analysis were goals and planning, feedback and monitoring, social support, natural consequences, comparison of behavior, comparison of outcomes, rewards and threat, and self-belief.

### Relationship Between Communication Content and QuitNet User Groups

#### Behavior Change Techniques

The average percentages of messages across different QuitNet user groups are shown in Figure 4. As seen in the figure, we observed manifestation of goals and planning and comparison of outcomes in 72.00% (19,056/26,466) and 41.00% (10,851/26,466), respectively, of the messages exchanged by conversation attractors. Among conversation initiators, the most exchanged techniques were rewards and threat and social support, in 63.00% (36,149/57,379) and 48.00% (27,542/57,379) of the messages, respectively. Among frequent posters, feedback and monitoring followed by goals and planning were embedded in 74.00% (55,972/75,638) and 49.00% (37,062/75,638) of the messages, respectively.

Figure 3. Percentages of users in each behavioral status.

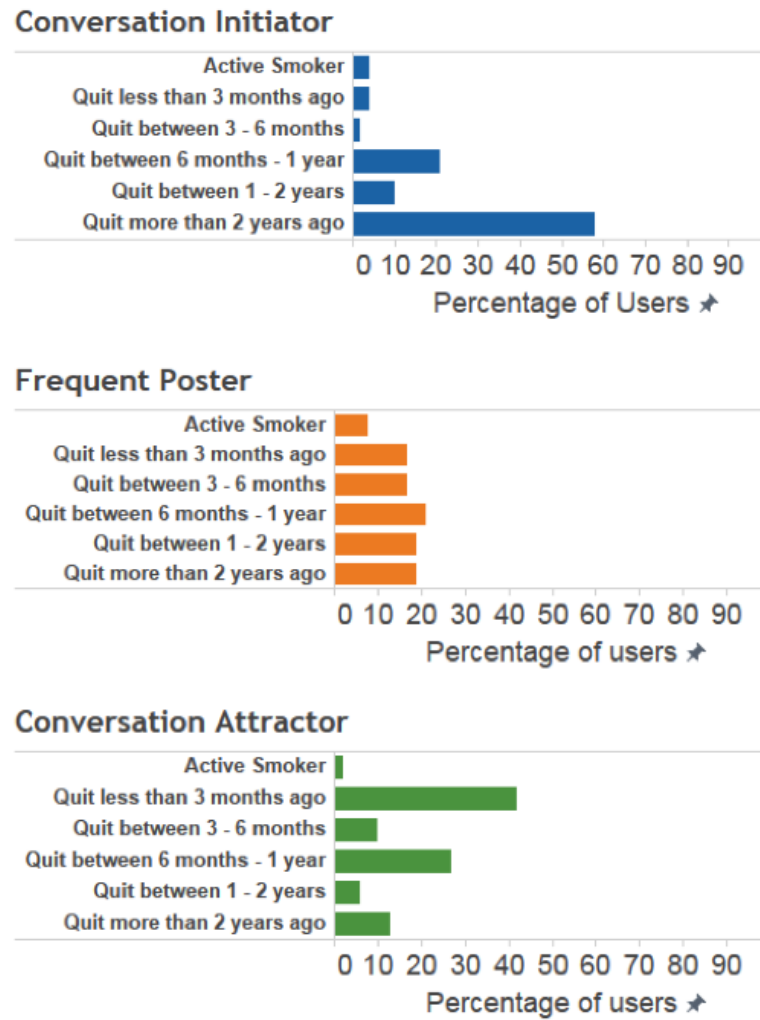
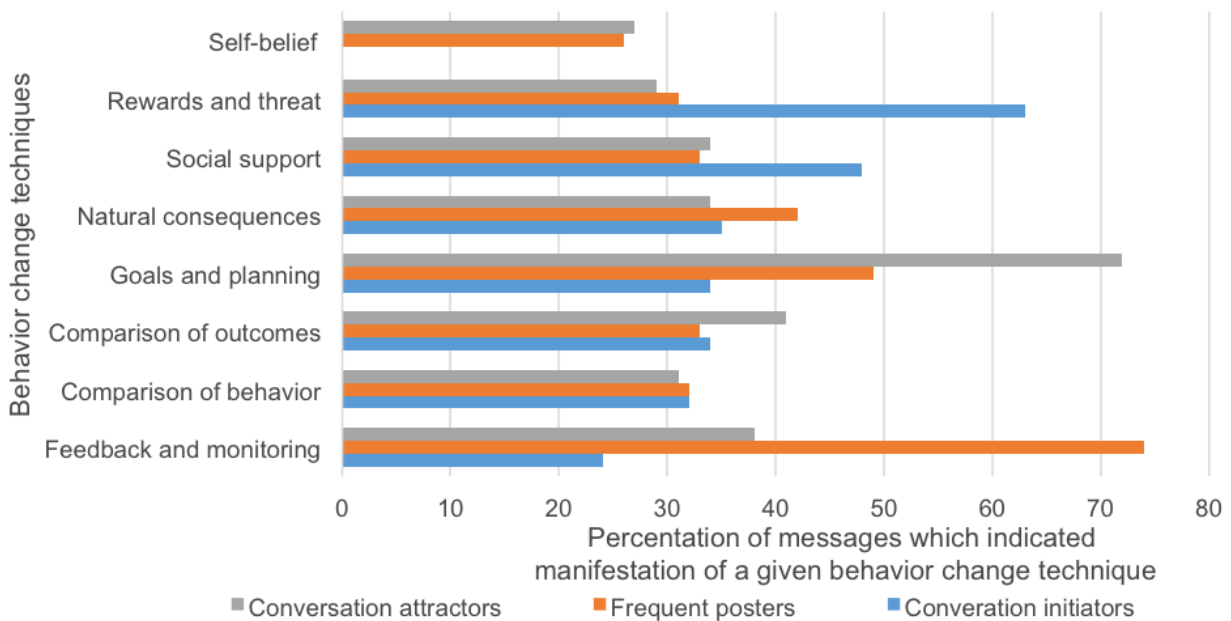
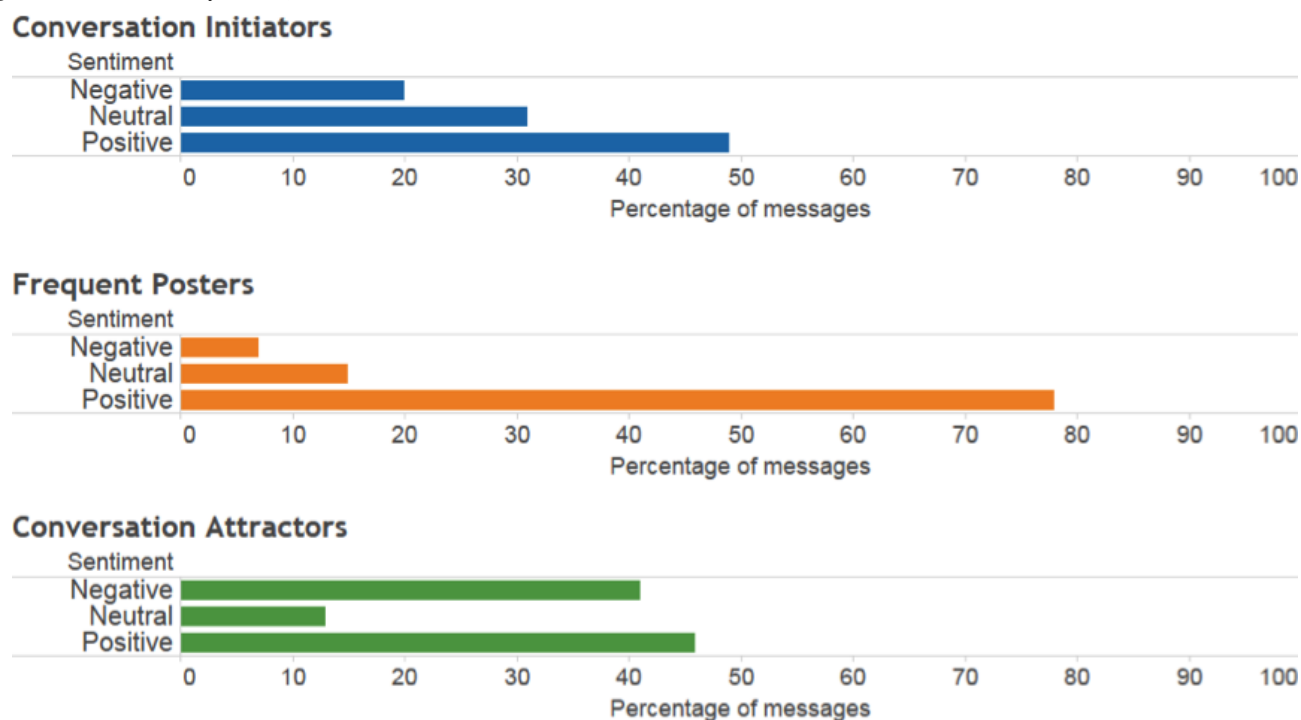


Figure 4. Most communicated themes among QuitNet user groups.



**Figure 5.** Sentiment analysis of QuitNet communication.

### Sentiments

Considering messages exchanged by conversation attractors (see Figure 5), 45.00% (11,910/26,466) of messages were found to be containing positive sentiments, while messages with negative sentiments accounted for 40.00% (10,586/26,466). Conversation initiators' posts were more positive, with 50.00% (28,690/57,379) of their messages classified as positive and about 23.00% (13,197/57,379) classified as negative. The frequent posters' discussions were also positive in nature, with 78.00% (58,998/75,638) of the messages classified as containing positive sentiments.

## Discussion

### Principal Findings

In this study, we developed a novel content plus frequency framework to identify highly engaged users across 3 social categories and identify each category's most common behavior change strategies. These methods and findings can help interventionists, technology developers, and health professionals (1) understand the techniques frequently used by highly engaged users in an online health community; (2) model, implement, and evaluate these known techniques to improve user engagement in other modalities and intervention programs; and (3) develop population health management strategies by considering the observed communication characteristics and behavioral attributes of highly engaged users.

Conversation attractors were predominantly recently quit users who appear to be facing difficulties after quitting and were seeking support from other users. They tend to discuss goals and planning and comparison of outcomes with tendencies toward negative sentiment, consistent with the communication

of difficulties in the acute cessation process. Conversely, conversation initiators on QuitNet were veteran users who had been abstinent for more than 2 years. Their long duration in the community, abstinence, and high percentage of messages covering social support and rewards and threat (with a positive sentiment trend) suggests that they serve as community elders, motivating and supporting the quit attempts of newer users. Frequent posters were overwhelmingly female (96%) with no specific trend in their smoking status. The majority of their messages were positive (78%) and tended to refer to popular traditions [27] within QuitNet (such as virtual bonfire events or pledging to not smoke). In QuitNet, these techniques manifest in the form of users sharing positive and negative consequences they have encountered after quitting and pledges to not smoke for the day. Internal norms, traditions, and celebrations form a central core of engagement within QuitNet [27] and other online behavior change platforms that emphasize social support. These results suggest that identification and engagement of conversation attractors in particular may allow intervention designers to modify and enhance or even create new norms and traditions for dissemination through a community.

### Limitations

There are a number of limitations to this study. Given our primary motivation was the development of new methods, we arbitrarily set thresholds for the top engaged users. Expansion of thresholds could change the characteristics of the findings. The manual coding process of behavior change techniques was limited to 16 high-level categories, which may not fully cover the array of techniques present in QuitNet or other programs. The automated text analysis methods can be improved using advanced word representation techniques (eg, convolutional neural networks [41,42]). Finally, we used off-the-shelf sentiment analysis tools, which can be improved with n-grams,



corpus-specific advanced machine learning classifiers, or specialized dictionaries [43,44].

## Conclusions

Sustained engagement with social support and effective behavior change programs remains the core principal of most online platforms that seek participation of patients in their own care. Support from peers, community-driven rituals, guidance from veteran users, and a safe and secure environment for open communication are a few motivational factors that have been hypothesized to drive engagement in QuitNet and are confirmed in this analysis. Insights from this study and future work using the same or similar framework may allow the implementation

of targeted recommendation engines [45-47] to promote meaningful affiliations with content (such as information about nicotine substitutes) and connections (such as connecting users who have quit recently to veteran users) personalized based on user characteristics (eg, age, gender, smoking status). Ultimately, achieving the promise of patient participation in online communities requires the platforms themselves to evolve in response to individual and network changes and preferences that develop over time. This study offers a potential framework to drive such observation, evaluation, and ultimate change to better serve users and close the loop between intervention providers and their participants.

## Acknowledgments

Research reported in this publication was supported by the National Library of Medicine and National Cancer Institute of the National Institutes of Health under award numbers R21LM012271 and R21CA220670. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

## Conflicts of Interest

None declared.

## References

1. Frist WH. Connected health and the rise of the patient-consumer. *Health Aff (Millwood)* 2014 Feb;33(2):191-193. [doi: [10.1377/hlthaff.2013.1464](https://doi.org/10.1377/hlthaff.2013.1464)] [Medline: [24493759](https://pubmed.ncbi.nlm.nih.gov/24493759/)]
2. Chouvarda IG, Goulis DG, Lambrinouadaki I, Maglaveras N. Connected health and integrated care: toward new models for chronic disease management. *Maturitas* 2015 Sep;82(1):22-27. [doi: [10.1016/j.maturitas.2015.03.015](https://doi.org/10.1016/j.maturitas.2015.03.015)] [Medline: [25891502](https://pubmed.ncbi.nlm.nih.gov/25891502/)]
3. Caulfield B, Donnelly S. What is Connected Health and why will it change your practice? *QJM* 2013 Aug;106(8):703-707. [doi: [10.1093/qjmed/hct114](https://doi.org/10.1093/qjmed/hct114)] [Medline: [23676416](https://pubmed.ncbi.nlm.nih.gov/23676416/)]
4. Fernandez-Luque L, Vilmarlund V, Borycki E, Schulz S, Kuziemyky C, Marschollek M, et al. Social media as catalyzer for connected health: hype or hope? Perspectives from IMIA working groups. *Stud Health Technol Inform* 2016;225:602-604. [Medline: [27332272](https://pubmed.ncbi.nlm.nih.gov/27332272/)]
5. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. *Health Promot Pract* 2013 Jan;14(1):15-23. [doi: [10.1177/1524839911405850](https://doi.org/10.1177/1524839911405850)] [Medline: [21558472](https://pubmed.ncbi.nlm.nih.gov/21558472/)]
6. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. *J Med Internet Res* 2008 Aug 25;10(3):e22 [FREE Full text] [doi: [10.2196/jmir.1030](https://doi.org/10.2196/jmir.1030)] [Medline: [18725354](https://pubmed.ncbi.nlm.nih.gov/18725354/)]
7. Wang X, Zuo Z, Zhao K. The evolution of user roles in online health communities: a social support perspective. *PACIS Proceedings* 2015;121.
8. Rothert K, Strecher V, Doyle L, Caplan W, Joyce J, Jimison H, et al. Web-based weight management programs in an integrated health care setting: a randomized, controlled trial. *Obesity (Silver Spring)* 2006 Feb;14(2):266-272 [FREE Full text] [doi: [10.1038/oby.2006.34](https://doi.org/10.1038/oby.2006.34)] [Medline: [16571852](https://pubmed.ncbi.nlm.nih.gov/16571852/)]
9. Glasgow RE, Boles SM, McKay HG, Feil EG, Barrera M. The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results. *Prev Med* 2003 Apr;36(4):410-419. [Medline: [12649049](https://pubmed.ncbi.nlm.nih.gov/12649049/)]
10. Eysenbach G. The law of attrition. *J Med Internet Res* 2005 Mar 31;7(1):e11 [FREE Full text] [doi: [10.2196/jmir.7.1.e11](https://doi.org/10.2196/jmir.7.1.e11)] [Medline: [15829473](https://pubmed.ncbi.nlm.nih.gov/15829473/)]
11. Schubart JR, Stuckey HL, Ganeshamoorthy A, Sciamanna CN. Chronic health conditions and internet behavioral interventions: a review of factors to enhance user engagement. *Comput Inform Nurs* 2011 Feb;29(2):81-92. [doi: [10.1097/NCN.0b013e3182065eed](https://doi.org/10.1097/NCN.0b013e3182065eed)] [Medline: [21164337](https://pubmed.ncbi.nlm.nih.gov/21164337/)]
12. Michie S, Yardley L, West R, Patrick K, Greaves F. Developing and evaluating digital interventions to promote behavior change in health and health care: recommendations resulting from an international workshop. *J Med Internet Res* 2017 Jun 29;19(6):e232 [FREE Full text] [doi: [10.2196/jmir.7126](https://doi.org/10.2196/jmir.7126)] [Medline: [28663162](https://pubmed.ncbi.nlm.nih.gov/28663162/)]
13. Attfield S, Kazai G, Lalmas M, Piwowarski B. Towards a science of user engagement. 2011 Presented at: WSDM Workshop on User Modeling for Web Applications; 2011; Hong Kong p. 9-12.
14. Barello S, Graffigna G, Vegni E, Bosio A. The challenges of conceptualizing patient engagement in health care: a lexicographic literature review. *J Participat Med* 2014 Jun 11;6(11).

15. Perski O, Blandford A, West R, Michie S. Conceptualising engagement with digital behaviour change interventions: a systematic review using principles from critical interpretive synthesis. *Transl Behav Med* 2017 Dec;7(2):254-267 [FREE Full text] [doi: [10.1007/s13142-016-0453-1](https://doi.org/10.1007/s13142-016-0453-1)] [Medline: [27966189](https://pubmed.ncbi.nlm.nih.gov/27966189/)]
16. Yardley L, Spring B, Riper H, Morrison L, Crane D, Curtis K, et al. Understanding and promoting effective engagement with digital behavior change interventions. *Am J Prev Med* 2016 Nov;51(5):833-842. [doi: [10.1016/j.amepre.2016.06.015](https://doi.org/10.1016/j.amepre.2016.06.015)] [Medline: [27745683](https://pubmed.ncbi.nlm.nih.gov/27745683/)]
17. Lalmas M, O'Brien H, Yom-Tov E. *Measuring User Engagement (Synthesis Lectures on Information Concepts, Retrieval, and Services)*. San Rafael: Morgan & Claypool Publishers; 2014.
18. Lehmann J, Lalmas M, Yom-Tov E, Dupret G. Models of user engagement. 2012 Presented at: Proceedings of the 20th international conference on User Modeling, Adaptation, and Personalization; 2012 Jul 16; Montreal p. 164-175.
19. Comello M, Qian X, Deal A, Ribisl K, Linnan L, Tate D. Impact of game-inspired infographics on user engagement and information processing in an eHealth program. *J Med Internet Res* 2016 Sep 22;18(9):e237 [FREE Full text] [doi: [10.2196/jmir.5976](https://doi.org/10.2196/jmir.5976)] [Medline: [27658469](https://pubmed.ncbi.nlm.nih.gov/27658469/)]
20. Dijkstra A, Ballast K. Personalization and perceived personal relevance in computer-tailored persuasion in smoking cessation. *Br J Health Psychol* 2012 Feb;17(1):60-73. [doi: [10.1111/j.2044-8287.2011.02029.x](https://doi.org/10.1111/j.2044-8287.2011.02029.x)] [Medline: [22106987](https://pubmed.ncbi.nlm.nih.gov/22106987/)]
21. Wang X, Zhao K, Street N. Social Support and user engagement in online health communities. 2014 Presented at: Smart Health: International Conference; 2014; Beijing.
22. Sun N, Rau P, Ma L. Understanding lurkers in online communities: a literature review. *Comput Hum Behav* 2014;38:110-117.
23. Zhang S, Elhadad N. Factors contributing to dropping-out in an online health community: static and longitudinal analyses. 2016 Presented at: AMIA; 2016; Chicago.
24. Morrison C, Doherty G. Analyzing engagement in a web-based intervention platform through visualizing log-data. *J Med Internet Res* 2014 Nov 13;16(11):e252 [FREE Full text] [doi: [10.2196/jmir.3575](https://doi.org/10.2196/jmir.3575)] [Medline: [25406097](https://pubmed.ncbi.nlm.nih.gov/25406097/)]
25. Zhong C, Salehi M, Shah S, Cobzarenco M, Sastry N, Cha M. Social bootstrapping: how Pinterest and Last.fm social communities benefit by borrowing links from Facebook. 2014 Presented at: World Wide Web Conference; 2014; New York.
26. Zhong C, Shah S, Sundaraviveelan K, Sastry N. Sharing the loves: understanding the how and why of online content curation. 2013 Presented at: Annual proceedings of ICWSM; 2013; Cambridge.
27. Myneni S, Fujimoto K, Cobb N, Cohen T. Content-driven analysis of an online community for smoking cessation: integration of qualitative techniques, automated text analysis, and affiliation networks. *Am J Public Health* 2015 Jun;105(6):1206-1212. [doi: [10.2105/AJPH.2014.302464](https://doi.org/10.2105/AJPH.2014.302464)] [Medline: [25880942](https://pubmed.ncbi.nlm.nih.gov/25880942/)]
28. Myneni S, Cobb N, Cohen T. , & Cohen, T. Content-specific network analysis of peer-to-peer communication in an online community for smoking cessation. 2016 Presented at: AMIA Annual Symposium Proceedings; 2016; Chicago.
29. Sridharan V, Cohen T, Cobb N, Myneni S. Characterization of temporal semantic shifts in peer-to-peer communication in a health-related online community: implications for data-driven for health promotion. 2016 Presented at: AMIA Annual Symposium Proceedings; 2016; Chicago.
30. Myneni S, Cobb N, Cohen T. In pursuit of theoretical ground in behavior change support systems: analysis of peer-to-peer communication in a health-related online community. *J Med Internet Res* 2016 Feb 02;18(2):e28 [FREE Full text] [doi: [10.2196/jmir.4671](https://doi.org/10.2196/jmir.4671)] [Medline: [26839162](https://pubmed.ncbi.nlm.nih.gov/26839162/)]
31. Mittler J, Martsof G, Telenko S, Scanlon D. Making sense of “consumer engagement” initiatives to improve health and health care: a conceptual framework to guide policy and practice. *Milbank Q* 2013 Mar;91(1):37-77 [FREE Full text] [doi: [10.1111/milq.12002](https://doi.org/10.1111/milq.12002)] [Medline: [23488711](https://pubmed.ncbi.nlm.nih.gov/23488711/)]
32. Short C, Rebar A, Plotnikoff R, Vandelanotte C. Designing engaging online behavior change interventions: a proposed model of user engagement. *Eur Psychol* 2015;17(1):32.
33. QuitNet LLC. URL: <https://quitnet.meyouhealth.com/> [accessed 2018-06-28] [WebCite Cache ID 70WWSQyMR]
34. Cobb N, Graham A, Bock B, Papandonatos G, Abrams D. Initial evaluation of a real-world Internet smoking cessation system. *Nicotine Tob Res* 2005 Apr;7(2):207-216 [FREE Full text] [doi: [10.1080/14622200500055319](https://doi.org/10.1080/14622200500055319)] [Medline: [16036277](https://pubmed.ncbi.nlm.nih.gov/16036277/)]
35. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Ann Behav Med* 2013 Aug;46(1):81-95. [doi: [10.1007/s12160-013-9486-6](https://doi.org/10.1007/s12160-013-9486-6)] [Medline: [23512568](https://pubmed.ncbi.nlm.nih.gov/23512568/)]
36. Mikolov T, Sutskever L, Chen K, Corrado G, Dean J. Distributed representations of words and phrases and their compositionality. 2013 Presented at: 27th Annual Conference on Neural Information Processing Systems; 2013; Lake Tahoe p. 5-8.
37. Widdows D, Cohen T. The semantic vectors package: new algorithms and public tools for distributional semantics. 2010 Presented at: Fourth IEEE International Conference on Semantic Computing (IEEE ICSC); 2010; Pittsburgh p. 9-15.
38. Cohen T, Schvaneveldt R, Widdows D. Reflective Random Indexing and indirect inference: a scalable method for discovery of implicit connections. *J Biomed Inform* 2010 Apr;43(2):240-256 [FREE Full text] [doi: [10.1016/j.jbi.2009.09.003](https://doi.org/10.1016/j.jbi.2009.09.003)] [Medline: [19761870](https://pubmed.ncbi.nlm.nih.gov/19761870/)]
39. Hall M, Frank E, Holmes G, Pfahringer B, Reutemann P, Witten I. The WEKA data mining software: an update. *IGKDD Explorations* 2009;11(1):10-18.

40. Sentiment analysis package. URL: <https://cran.r-project.org/web/packages/SentimentAnalysis/SentimentAnalysis.pdf> [accessed 2018-06-28] [WebCite Cache ID 70WX78xtB]
41. Zhang S, Grave E, Sklar E, Elhadad N. Longitudinal analysis of discussion topics in an online breast cancer community using convolutional neural networks. *J Biomed Inform* 2017 Dec;69:1-9 [FREE Full text] [doi: [10.1016/j.jbi.2017.03.012](https://doi.org/10.1016/j.jbi.2017.03.012)] [Medline: [28323113](https://pubmed.ncbi.nlm.nih.gov/28323113/)]
42. Zhang ML, Zhou ZH. Multilabel neural networks with applications to functional genomics and text categorization. *IEEE Transactions on Knowledge and Data Engineering* 2006;18(10):1338-1351.
43. Da Silva NF, Hruschka ER, Hruschka JER. Tweet sentiment analysis with classifier ensembles. *Decision Support Systems* 2014 Oct 01:66-69.
44. Pröllochs N, Feuerriegel S, Neumann D. Generating domain-specific dictionaries using Bayesian learning. In *ECIS 2015* May 29.
45. Pazzani M, Billsus D. Content-based recommendation systems. In: *The Adaptive Web*. Berlin: Springer; 2007:325-341.
46. Melville P, Raymond J, Nagarajan R. Content-boosted collaborative filtering for improved recommendations. 2002 Presented at: *Proceedings of the Eighteenth National Conference on Artificial Intelligence*; 2002; Edmonton p. 187-192.
47. Hannon J, Bennett M, Smyth B. Recommending twitter users to follow using contentcollaborative filtering approaches. 2010 Presented at: *Fourth ACM conference on Recommender systems*; 2010 Sep 26; Barcelona p. 199-206.

---

## Abbreviations

**SGNS:** Skipgram-with-Negative-Sampling

---

*Edited by S Woods, T Graedon; submitted 29.12.17; peer-reviewed by A Graham, H Brendryen, C Short; comments to author 01.02.18; revised version received 16.05.18; accepted 22.06.18; published 24.07.18.*

*Please cite as:*

*Myneni S, Sridharan V, Cobb N, Cohen T*

*Content-Sensitive Characterization of Peer Interactions of Highly Engaged Users in an Online Community for Smoking Cessation: Mixed-Methods Approach for Modeling User Engagement in Health Promotion Interventions*

*J Participat Med* 2018;10(3):e9

URL: <http://jopm.jmir.org/2018/3/e9/>

doi: [10.2196/jopm.9745](https://doi.org/10.2196/jopm.9745)

PMID:

©Sahiti Myneni, Vishnupriya Sridharan, Nathan Cobb, Trevor Cohen. Originally published in *Journal of Participatory Medicine* (<http://jopm.jmir.org>), 24.07.2018. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *Journal of Participatory Medicine*, is properly cited. The complete bibliographic information, a link to the original publication on <http://jopm.jmir.org>, as well as this copyright and license information must be included.

Original Paper

# Phase I of the Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties (DECADES) Study: Development of an Integrated Mental Health Care Model for Pediatric Gastroenterology

Stephanie E Hullmann<sup>1</sup>, PhD; Stacy A Keller<sup>2</sup>, MSN, CPNP; Dustin O Lynch<sup>3</sup>, BFA; Kelli Jenkins<sup>3</sup>, BFA; Courtney Moore<sup>3</sup>, BFA; Brandon Cockrum<sup>3</sup>, MFA; Sarah E Wiehe<sup>3</sup>, MD, MPH; Aaron E Carroll<sup>2</sup>, MD, MS; William E Bennett Jr<sup>2</sup>, MD, MS

<sup>1</sup>Division of Psychology, Department of Psychiatry and Behavioral Sciences, Indiana University School of Medicine, Indiana University, Indianapolis, IN, United States

<sup>2</sup>Center for Pediatric and Adolescent Comparative Effectiveness Research, Department of Pediatrics, Indiana University School of Medicine, Indianapolis, IN, United States

<sup>3</sup>Patient Engagement Core, Indiana Clinical and Translational Sciences Institute, Indiana University, Indianapolis, IN, United States

**Corresponding Author:**

William E Bennett Jr, MD, MS

Center for Pediatric and Adolescent Comparative Effectiveness Research

Department of Pediatrics

Indiana University School of Medicine

410 W 10th Street

HITS Building

Indianapolis, IN, 46202

United States

Phone: 1 3172786928

Email: [webjr@iu.edu](mailto:webjr@iu.edu)

## Abstract

**Background:** Children with gastrointestinal symptoms have a very high rate of anxiety and depression. Rapid identification of comorbid anxiety and depression is essential for effective treatment of a wide variety of functional gastrointestinal disorders.

**Objective:** The objective of our study was to determine patient and parent attitudes toward depression, anxiety, and mental health screening during gastroenterology (GI) visits and to determine patient and parent preferences for communication of results and referral to mental health providers after a positive screen.

**Methods:** We augmented standard qualitative group session methods with patient-centered design methods to assess patient and parent preferences. We used a variety of specific design methods in these sessions, including card sorting, projective methods, experience mapping, and constructive methods.

**Results:** Overall, 11 families (11 patients and 14 parents) participated in 2 group sessions. Overall, patients and their parents found integrated mental health care to be acceptable in the subspecialty setting. Patients' primary concerns were for the privacy and confidentiality of their screening results. Patients and their parents emphasized the importance of mental health services not interfering with the GI visit and collaboration between the GI physician, psychologist, and primary care provider.

**Conclusions:** Patients and their families are open to integrated mental health care in the pediatric subspecialty clinic. The next phase of the DECADES study will translate patient and parent preferences into an integrated mental health care system and test its efficacy in the pediatric GI office.

(*J Participat Med* 2018;10(3):e10655) doi:[10.2196/10655](https://doi.org/10.2196/10655)

**KEYWORDS**

qualitative research; patient-reported outcomes; depression; anxiety

## Introduction

The Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties (DECADES) study seeks to develop a model for integrated mental health care that is acceptable to pediatric gastroenterology patients and their families and to compare this model of care with standard care. The first phase of this study sought to develop an integrated mental health care model that is acceptable to both gastroenterology patients and their parents by exploring their attitudes and preferences using qualitative methods augmented by patient-centered design methods.

Depression and anxiety are 2 of the most common disorders occurring during childhood and adolescence [1-3], but they frequently remain unrecognized or untreated [4-6]. Rates of depression and anxiety are significantly higher in children with chronic illnesses [7,8], including gastrointestinal disorders [9-11], than those in the general population. Furthermore, children with depression or anxiety are far more likely to have somatic complaints and greater utilization of subspecialty care, especially in gastroenterology [12-14]. Efforts to recognize and treat mental health problems in children with chronic medical illness, such as gastrointestinal disorders, have been shown to improve adherence to therapy and other clinical outcomes [15,16]. More importantly, improving these mental health concerns may improve the outcomes patients care about the most.

Validated tools exist to screen for anxiety and depression in children, including the Screen for Childhood Anxiety Related Emotional Disorders (SCARED) [17] and the Patient Health Questionnaire (PHQ) [18]. Despite the established importance of depression and anxiety in the gastrointestinal health of children, few data-driven studies exist that describe the identification and management of anxiety and depression by pediatric gastroenterologists and how families or patients view the subspecialty office as the setting to detect or care for mental illness.

Patient engagement is a process by which patients, families, and health professionals work in partnership to improve health care [19], and it is a process for developing patient-centered care. When patients are engaged in the development of new models of care, it improves recruitment and retention to randomized clinical trials, and clinical care is more meaningful to patients and their families [20].

This study describes the development of an integrated mental health care model for pediatric gastroenterology as part of the larger DECADES trial. We sought to develop this model of care using patient-centered design methods to augment qualitative methodology and by directly engaging patients and their parents in the design process. The goals of this study are to determine patient and parent attitudes toward depression,

anxiety, and mental health screening during gastroenterology visits and their preferences for communication of results and referral to mental health providers after a positive screen.

## Methods

### Group Sessions

This study involves a series of qualitative group sessions in which standard qualitative focus group methodology has been augmented by patient-centered design methods. At the end of these sessions, we sought to develop a set of specific, actionable recommendations that could then be used to improve patient-centeredness in a subsequent randomized trial. As noted in Figure 1, the overall objective of the qualitative phase of the DECADES study was to develop a greater understanding of patient preferences related to mental health screening in a pediatric subspecialty office. This was accomplished by both individual interviews (the subject of a separate manuscript) and group sessions (the subject of this manuscript).

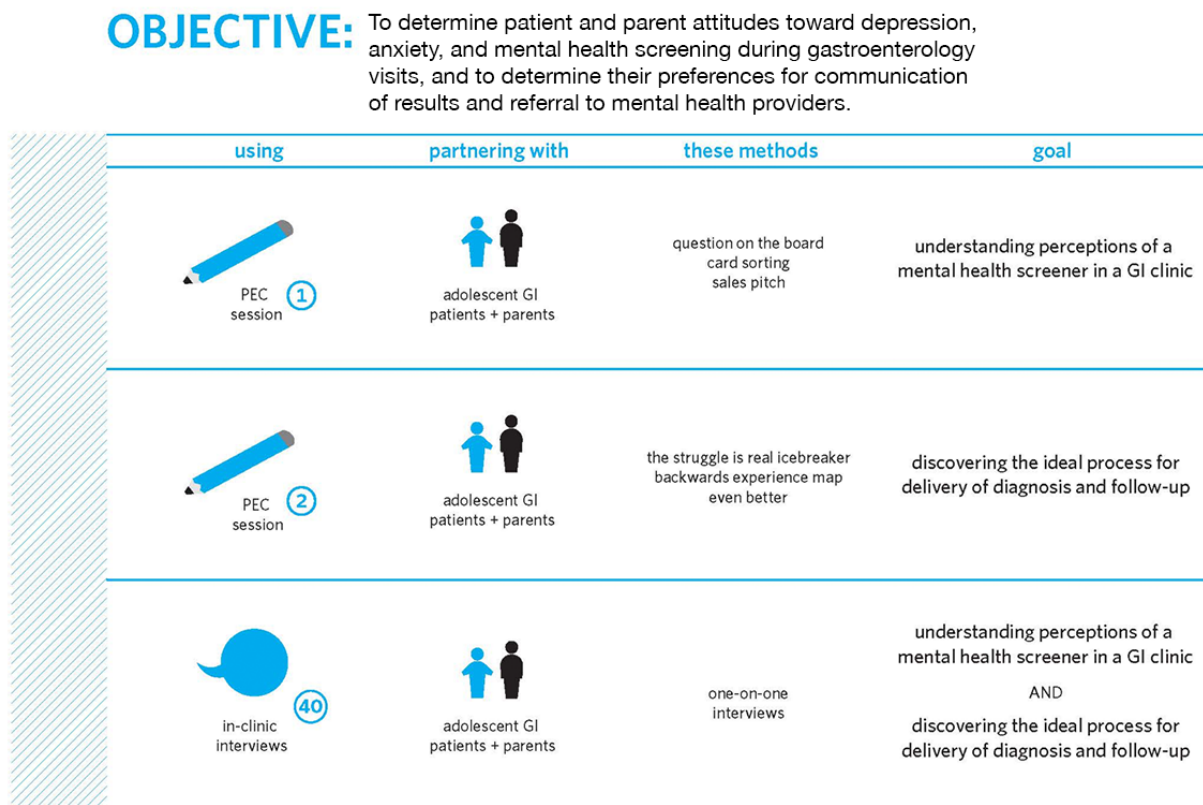
Patients were seeking care in a pediatric gastroenterology clinic and their parents were approached for enrollment in this qualitative study. Inclusion criteria were as follows: age 5-18 years, a parent or guardian who agreed to participate, and no diagnosed cognitive disabilities. Recruitment was conducted in the pediatric gastroenterology outpatient clinic at Riley Children's Health, part of Indiana University Health, in Indianapolis, IN. The principal investigator or study coordinator recruited all eligible patients. Permission to approach the patient was obtained from the gastroenterologist of record. Both new and established patients were enrolled.

### Overview of Group Sessions

Two group sessions were conducted with multiple families. Sessions were facilitated by design research specialists using patient-centered design research methods, which are enumerated below, and are based on established methodology in the design literature. Sessions lasted approximately 90 minutes and were audio recorded and transcribed for analysis. All families were compensated for travel to sessions and given a US \$30 gift card.

Group sessions used generative design research activities to engage the patients and their parents in codesigning the integrated mental health process [21-23]. Generative design activities tend to be open-ended and allow for a wide range of responses and response types to minimize bias and allow families to be as truthful as possible about their preferences. Sessions began with warm-up activities to encourage participation and collaboration [24]. We then used the following 2 specific types of generative design: projective methods, which are specifically designed to encourage participants to express their thoughts and feelings, and constructive methods to help with concept development [21].

**Figure 1.** Schematic of the Qualitative Phase of the DECADES Study. GI: gastroenterology; PEC: Patient Engagement Core.



**Specific Patient-Centered Design Activities During Group Sessions**

**Question on the Board**

The goal of this activity [24] was to establish participants’ baseline knowledge of anxiety and depression and understand how they express these concepts in their own words, informing how to present a screening tool to patients and their families. Participants were asked to answer the following questions on separate notecards: “What does depression mean to you?” and “What does anxiety mean to you?” Notecards were collected by study staff, and responses were not shared with the group.

**Card Sorting**

The purpose of the card sorting activity [25] was to identify concerns with the screener to help improve how we delivered the screener to patients. For this activity, families were divided into 2 groups (parents and patients) in separate rooms. Both groups were presented with the same stack of cards. Each card listed an item from brief versions of the SCARED and PHQ, the five-item SCARED-5 [17] or the four-item Patient Health Questionnaire [18]. Parents were asked to divide cards into the following 2 piles: “I would be concerned if my child said ‘yes’” and “I would not be concerned if my child said ‘yes.’” Patients were also asked to divide the cards into the following 2 piles: “I would have a hard time answering honestly” and “I would not have a hard time answering honestly.” Next, parents and patients were asked to imagine that they or their child answered all cards in pile #1 affirmatively, and they were asked to write what they would be concerned about happening next and how

they would want the results communicated to them. Then, the facilitator encouraged further discussion and elaboration.

**Sales Pitch**

The purpose of the sales pitch was to use projective methods [21] to inform the most acceptable sender, message, and environment for the mental health screener. Both patient and parent participants were asked to convince the person sitting next to them to take the anxiety and depression screeners. Then, they were asked to convince the person to be honest while taking the screener. After completing this exercise, the facilitator encouraged participants to discuss who they would like to explain the screener to them and where they would like to answer the screening questions. They also discussed what steps patients and their parents expected would occur if the patient’s responses yielded a positive screen as well as who would communicate the results of a positive screen.

**The Struggle is Real**

This projective technique was a cartoon completion test [26] used to define what “feeling better” means to patients and their families with regards to anxiety, depression, and gastrointestinal symptoms. Patients and parents sat at separate tables for this activity. Patients were presented with several recognizable memes and were asked to fill in the blanks and react to prompts, such as “My face when...” or “That feeling when...” Parents were presented with 3 different cartoon drawings with blank speech balloons. The first cartoon displayed a frowning child and neutral adult, the second showed a frowning child and happy adult, and the third showed a happy child and a happy adult. Parents were asked to fill in the speech balloons to describe a situation related to having and managing gastrointestinal

disorders. After completing the activity, the facilitator encouraged participants to share their responses among the group and facilitated discussion.

### **Backward Experience Map**

The backward experience map activity was intended to explore patients' preferred experience from the time they submit the screening questions to symptom improvement a year later [27]. Patients and parents completed this activity separately. There was a large sheet of paper on the wall with 7 equidistant points connected by an "s"-shaped curve. The beginning point and the last 3 points were subsequently identified (ie, "leaving," "three months later," and "one year later"). Participants were asked to identify steps toward getting "better" and fill in the appropriate points on the map. By identifying points that allow participants to get from point A to B, patterns begin to emerge. These patterns begin to uncover themes that establish patient preferences for the treatment experience, patient-centered outcomes, and what "better" means to them.

### **Even Better**

This activity used constructive methods [21] to define patient and parent preferences for the best possible sequence of events. Patients and parents completed this activity separately. Expanding upon the results of the backward experience map, participants mapped out their ideal integrated mental health clinic flow process. The facilitator initiated discussion by asking participants to determine what would be "even better" than the ideas that were generated during the backward experience map.

### **Analysis**

The results of all group session activities were analyzed and coded by the design research specialists who conducted the sessions. They synthesized data from pictures and written documentation (eg, note cards and maps), and they reviewed the audio recordings of the sessions. Data were organized into themes based on Ackoff's theory [28], which uses a grounded theory approach to distinguish between 3 levels of sense-making (data, information, and knowledge). This study was approved by the Indiana University Institutional Review Board. All patients and family members who participated signed informed consent or assent documents prior to participation.

## **Results**

### **Participants**

Overall, 11 families participated in the group sessions, which included 11 patients and 14 parents (Table 1); 5 families participated in the first group session and 6 families participated in the second group session. One family was present for both group sessions.

### **Depression and Anxiety**

Textbox 1 displays participants' responses to the question on the board activity. With regard to depression, they described emotional feelings of sadness, negative thoughts (eg,

worthlessness), and behaviors consistent with depression (eg, social isolation and withdrawal). Participants described symptoms of various anxiety subtypes (ie, generalized anxiety and social anxiety) as well as physiological symptoms of anxiety (ie, tachycardia, sweating, and nausea).

### **Mental Health Screening and Consultation in the Gastroenterology Clinic**

It was important to patients and their parents that patients still receive the gastroenterology (GI) care they intended to receive. Many participants stated that they could be traveling quite a distance for their appointment, and they stressed the importance of keeping their regularly scheduled appointment. One patient explained, "You should still have the GI appointment because that's what you were scheduled for and you still need that service."

They agreed that if the patient screened positive for depression or anxiety, they would like to discuss it with their doctor and consult with a psychologist, but it was important to them that this discussion did not interfere with their GI appointment.

### **Patient Comfort with Mental Health Screening**

Patients indicated that their level of comfort with completing mental health screening was related to how the screener was presented. In turn, their comfort would impact how honestly they would answer the questions. If patients felt a sense of control, they would be more likely to respond honestly; for example, patients indicated that if their parents were worried or if the screener was presented unexpectedly with no explanation, they would be more anxious about completing the screener. As a result, patients felt that they may rush through the screening questions or select the most desirable responses. Patients were clear that they would like to be prepared, and they requested to know how many questions are on the screener, how long it would take them to complete, and what would happen after taking the screener.

### **Privacy**

There was disagreement between parents and patients regarding the privacy of patients' screening results. When asked about whether parents should receive the results of the screener at the same time as their children, many parents acknowledged that their children would probably want privacy. However, because it is a health issue, parents wanted to be involved and aware of results. Most parents agreed that they had a right to their child's protected health information; therefore, they screening results should be shared with them. On the other hand, they acknowledged that their children may be less likely to answer questions honestly if they knew their parents would see their results.

*Some of the questions might be questionable. They may not want the parent to see. It's their privacy.*

[Parent 1]

*Right, but kids don't have that yet.* [Parent 2]

**Table 1.** Group session participant demographic characteristics.

Participants	Session 1	Session 2
<b>Patient</b>	<b>N=5</b>	<b>N=6</b>
Gender (female), n (%)	4 (80)	5 (83)
Age (years), mean (SD); range	15.8 (2.7); 11-17	13.8 (3.3); 9-17
<b>Race, n (%)</b>		
Caucasian	5 (100)	5 (83)
African American	0 (0)	1 (17)
Asian	0 (0)	0 (0)
<b>Ethnicity, n (%)</b>		
Hispanic	0 (0)	0 (0)
Non-Hispanic	5 (100)	6 (100)
<b>Primary gastroenterology complaint, &gt;n (%)</b>		
Irritable bowel syndrome	1 (20)	3 (50)
Abdominal pain	0 (0)	1 (17)
Vomiting	0 (0)	1 (17)
Crohn disease	1 (20)	0 (0)
Eosinophilic esophagitis	1 (20)	1 (17)
Peptic esophagitis	1 (20)	0 (0)
Celiac disease	1 (20)	0 (0)
<b>Insurance type, n (%)</b>		
Commercial	1 (20)	2 (33)
Public	3 (60)	4 (67)
Self-pay	1 (20)	0 (0)
<b>Parent</b>	<b>N=6</b>	<b>N=8</b>
Gender (female), n (%)	5 (83)	7 (88)
<b>Race, n (%)</b>		
Caucasian	6 (100)	4 (50)
African American	0 (0)	1 (13)
Asian	0 (0)	0 (0)
Unknown	0 (0)	3 (38)
<b>Ethnicity, n (%)</b>		
Hispanic	0 (0)	0 (0)
Non-Hispanic	6 (100)	5 (63)
Unknown	0 (0)	3 (38)



**Textbox 1.** Participant definitions of depression and anxiety.

<p>Patient definitions of depression</p> <ul style="list-style-type: none"> <li>• “Feeling worthless, being alone.”</li> <li>• “Living day to day feeling sad and not being able to function in the real world as you would like.”</li> <li>• “Sadness.”</li> <li>• “You’re 2 different people, the person on your good day and the person on your bad days.”</li> <li>• “Being sad.”</li> <li>• “Feelings of despair. Feeling like nothing goes right.”</li> </ul> <p>Parent definitions of depression</p> <ul style="list-style-type: none"> <li>• “An illness of the mind.”</li> <li>• “Inability to shake ‘the blues,’ feeling there’s something wrong with you that the rest of the world doesn’t ‘get’—that you don’t fit in.”</li> <li>• “A debilitating mental abnormality as defined by the majority of psychologists &amp; with my experience I would agree.”</li> <li>• “A feeling of being lonely, wanting to be by yourself, wanting to be left alone”</li> <li>• “Going to a very dark place in your life. Always feeling sad, not wanting to go anywhere or do anything but sleep all day.”</li> </ul> <p>Patient definitions of anxiety</p> <ul style="list-style-type: none"> <li>• “Strong feelings of fear that cause someone to lose normal rational behavior in extreme cases. Nervous or scared.”</li> <li>• “Shaking”</li> <li>• “You worry about everything, even the smallest details that don’t matter.”</li> <li>• “Struggling to go into a large crowd.”</li> <li>• “Having the feeling in the pit of your stomach that makes you feel nauseous. Fast heartbeat.”</li> <li>• “Feelings to get through an event where you can’t breathe, have sweats, feelings of being overwhelmed.”</li> </ul> <p>Parent definitions of anxiety</p> <ul style="list-style-type: none"> <li>• “Where you don’t want to be in a room with a bunch of people.”</li> <li>• “Tachycardia.”</li> <li>• “Also a debilitating mental abnormality, but I think of it more as worrying more often than you need.”</li> <li>• “Worrying, to the point that the stress caused by worry can sometimes become debilitating. A tight feeling in the pit of your stomach that just won’t go away.”</li> </ul>
--

Most patients did not want their parents to be aware of their screening results unless there was a serious concern. They described being more comfortable discussing these issues with their doctor than with their parents. This was also observed during group sessions. When the parents and patients were together for discussion, patients generally did not express their opinions, but when they were separated from their parents, patients contributed their opinions and actively engaged in discussion. However, there were a few patients who noted that they would feel more comfortable discussing screening results with a parent in the room. One patient explained, “I just feel more comfortable with people I know around.”

In both sessions, patients expressed that sharing screening results with their parents may make their parents anxious, and they did not want to worry them. One patient said, “I wouldn’t want her to have to deal with something unless it was like big or something...If I hadn’t told her about that, I wouldn’t necessarily want her to know.”

They acknowledged that not being transparent with their parents about screening results may also cause parents to be distressed. Patients agreed that parental worry was a major concern for them. Overall, they expressed that they wanted a choice about whether their parent was in the room while discussing the screening results.

### Communicating Results of Mental Health Screening

Patients agreed that they would not expect their screening results to suggest that they have anxiety or depression and taking a screener might cause some distress for them. Having conversations with their GI doctor and a psychologist would ease their worry about the screener. Most patients wanted their doctor(s) to talk to them without their parents right after taking the screener. All patients stated that they would like some kind of result and plan immediately after taking the screener. Although all patients said they would want some sort of feedback that day, only one said that they would like to get a diagnosis from the screener. Most patients wanted to talk to

their GI doctor and a psychologist at the same time right after taking the screener.

### The Best Clinic Experience

When asked what the order of events should be from the moment they completed the screener, patients and parents had little problem creating a process flow that was agreeable to the other participants within their own group but they had difficulty synthesizing a single agreed upon flow. The steps of the desired clinic flow for patients and their parents are included in [Table 2](#). Steps are numbered chronologically and “even better” steps are listed next to the initially desired step.

### Recommendations for the DECADES Study

Based on these results, our design team formulated the following recommendations, all of which have been incorporated in the protocol for the randomized controlled trial portion of the DECADES study.

1. Create a survey or worksheet for the parents to fill out while the patient is taking the screener to both educate and provide a parental distraction
2. Provide a handout that describes depression and anxiety and how it relates to GI symptoms
3. Use informational graphics to educate patients on the relationship between GI symptoms and mental health, as seen in [Figure 2](#)
4. Develop an introduction to mental health screening that includes how many questions will be included in the

screener, how long it will take, and what will happen after patients complete the screener

5. Use the following language to frame the screener:
  - a. Regarding the relationship between mental health and physical health: *“FACT: When your GI system is messed up, it can mess with your brain too, causing anxiety or depression. BONUS FACT: When you have anxiety or depression, it can mess with your GI system, causing all kinds of problems.”*
  - b. Regarding the brain-gut connection: *“Your GI system and your brain—like everything else in your body—are connected. When one is irritated, often so is the other.”*
  - c. Regarding privacy: *“The answers you give are CONFIDENTIAL. That means they can only be viewed by you and your doctor, unless YOU choose to share it.”*
6. Help patients develop a plan for care that addresses both their mental health concerns and their GI symptoms
7. Talk to the patient separately from the parent and ask patients if they would like their parents to be involved in the discussion
8. Have the patient meet with the GI physician and the psychologist at the same time initially; for example, the physician might say, *“This is (psychologist). She’s going to talk to you about the results of that screener you took. We’ll work together to make a plan for treatment of your depression or anxiety and how they might affect your GI issue.”*

**Table 2.** Steps of desired clinic flow according to patients and parents.

Step	Patient		Parent	
	Desired flow	“Even better” flow	Desired flow	“Even better” flow
1	Immediate feedback from the screener with animation	N/A <sup>a</sup>	Educational information about brain-gut connection, depression, and anxiety available in the waiting area and food provided	N/A
2	Discussion of results with GI <sup>b</sup> physician	N/A	GI physician gives the results of the screener	Parents and children receive screening results simultaneously; young children may even receive results from their parent
3	GI visit with physician	N/A	Provide additional educational materials	N/A
4	Choose whether or not parents are involved in conversation about screening results	Choose the therapist	Meet with the psychologist and GI physician together	Receive referral to a qualified psychologist close to home. Even better than that would be to be taught coping strategies to use until next appointment.
5	Reassurance and normalization of symptoms	N/A	The family, psychologist, and GI physician agree on a care plan.	Child is involved in care planning.
6	Patients, parents, and care team develop a treatment plan	N/A	Family and care team have a clear understanding of patient’s illness	N/A
7	GI symptom improvement	Being cured of GI symptoms	N/A	N/A
8	Self-management of symptoms with fewer visits to health care providers	N/A	N/A	N/A

<sup>a</sup>N/A: not applicable.

<sup>b</sup>GI: gastroenterology.

**Figure 2.** Graphic depicting brain-gut connection.



## Discussion

We conducted a qualitative study of patient and parent preferences regarding integrated mental health care in the GI office using patient-centered design methods to augment typical group session methodology. Our results suggest that this screening process is highly acceptable to patients and their families with the caveat that confidentiality remains intact, message delivery be customized to the patient or family member, and mental health services do not interfere with their GI visit.

This represents the first attempt, to our knowledge, to develop a set of clear criteria for effective mental health screening in a pediatric subspecialty office. These criteria were developed, not by expert consensus of clinicians as is often the case in similar studies, but by directly engaging with patients and their families who are already visiting this clinic. We believe this will result in a far more effective screening process that is much more acceptable to families and that increases the efficacy of subsequent mental health interventions. We plan to test this in the next, randomized controlled trial phase of the DECADES study.

There are several important limitations to this study. First, owing to the relatively small sample size and few male participants, it is difficult to ascertain broad generalizability of these findings. However, we attempted to recruit patients of various ages, gastrointestinal complaints, and insurance types to increase

generalizability to our larger clinic population. Second, the design methods used are novel in health-related research, but they have been well-established in service and product design. Third, results may be limited because adolescents were less likely to contribute to the patient-parent group discussions than their parents. However, patients engaged very well in discussion when they met as a separate adolescent group. Furthermore, the total number of subjects participating in the group sessions was low (11 families comprising 11 children and 14 adults), but these numbers are typical for this type of research, and larger groups tend to be less effective. Most of our subjects were female (both children and parents), which we believe reflects the higher rate of comorbid anxiety and depression in female adolescents as well as greater maternal engagement in child health. Finally, the subjects we recruited were a sample of convenience of nonconsecutive patients seen at our pediatric gastroenterology clinic, who were willing to participate in research, and may not represent a random sample of our patient population.

The next step in the DECADES project is to conduct a randomized comparative effectiveness trial. Patients in the gastroenterology clinic will complete depression and anxiety screening in accordance with the results and recommendations of this first phase of the study. Those who screen positive will be presented with their results and randomized to either standard care or consultation with a pediatric psychologist on the same day as the visit.

## Acknowledgments

We thank the Agency for Healthcare Research and Quality for generous support for this study through the Infrastructure Development Program in Patient-Centered Outcomes Research R24HS022434 (AEC, SEW, and WEB Jr) and the Patient Engagement Core, including Gina Claxton and Lisa Parks. The Patient Engagement Core is supported by the Indiana Clinical and Translational Sciences Institute funded in part by National Institute for Advancing Translational Science TR001107 (SEW).

We also thank the Indiana University Departments of Pediatrics and Psychiatry and Behavioral Sciences as well as the Indiana Clinical and Translational Sciences Institute.

### Conflicts of Interest

None declared.

### References

1. Costello EJ, Mustillo S, Erkanli A, Keeler G, Angold A. Prevalence and development of psychiatric disorders in childhood and adolescence. *Arch Gen Psychiatry* 2003 Aug;60(8):837-844. [doi: [10.1001/archpsyc.60.8.837](https://doi.org/10.1001/archpsyc.60.8.837)] [Medline: [12912767](https://pubmed.ncbi.nlm.nih.gov/12912767/)]
2. Kessler RC, Walters EE. Epidemiology of DSM-III-R major depression and minor depression among adolescents and young adults in the National Comorbidity Survey. *Depress Anxiety* 1998;7(1):3-14. [Medline: [9592628](https://pubmed.ncbi.nlm.nih.gov/9592628/)]
3. Polanczyk G, Salum G, Sugaya L, Caye A, Rohde L. Annual research review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. *J Child Psychol Psychiatry* 2015 Mar;56(3):345-365. [doi: [10.1111/jcpp.12381](https://doi.org/10.1111/jcpp.12381)] [Medline: [25649325](https://pubmed.ncbi.nlm.nih.gov/25649325/)]
4. Ani C, Bazargan M, Hindman D, Bell D, Farooq MA, Akhanjee L, et al. Depression symptomatology and diagnosis: discordance between patients and physicians in primary care settings. *BMC Fam Pract* 2008 Jan 03;9:1 [FREE Full text] [doi: [10.1186/1471-2296-9-1](https://doi.org/10.1186/1471-2296-9-1)] [Medline: [18173835](https://pubmed.ncbi.nlm.nih.gov/18173835/)]
5. Ferreiro F, Seoane G, Senra C. Gender-related risk and protective factors for depressive symptoms and disordered eating in adolescence: a 4-year longitudinal study. *J Youth Adolesc* 2012 May;41(5):607-622. [doi: [10.1007/s10964-011-9718-7](https://doi.org/10.1007/s10964-011-9718-7)] [Medline: [21965131](https://pubmed.ncbi.nlm.nih.gov/21965131/)]
6. S S, Nair C, L S R. A Study On Prevalence Of Anxiety Disorders Among Higher Secondary School Students. *jemds* 2015 Mar 27;4(26):4473-4478. [doi: [10.14260/jemds/2015/646](https://doi.org/10.14260/jemds/2015/646)]
7. Pinquart M, Shen Y. Depressive symptoms in children and adolescents with chronic physical illness: an updated meta-analysis. *J Pediatr Psychol* 2011 May;36(4):375-384. [doi: [10.1093/jpepsy/jsq104](https://doi.org/10.1093/jpepsy/jsq104)] [Medline: [21088072](https://pubmed.ncbi.nlm.nih.gov/21088072/)]
8. Ferro MA, Boyle MH. The impact of chronic physical illness, maternal depressive symptoms, family functioning, and self-esteem on symptoms of anxiety and depression in children. *J Abnorm Child Psychol* 2015 Jan;43(1):177-187. [doi: [10.1007/s10802-014-9893-6](https://doi.org/10.1007/s10802-014-9893-6)] [Medline: [24938212](https://pubmed.ncbi.nlm.nih.gov/24938212/)]
9. Engström I. Mental health and psychological functioning in children and adolescents with inflammatory bowel disease: a comparison with children having other chronic illnesses and with healthy children. *J Child Psychol Psychiatry* 1992 Mar;33(3):563-582. [Medline: [1577899](https://pubmed.ncbi.nlm.nih.gov/1577899/)]
10. Hyams J, Burke G, Davis P, Rzepski B, Andrulonis P. Abdominal pain and irritable bowel syndrome in adolescents: a community-based study. *J Pediatr* 1996 Aug;129(2):220-226. [Medline: [8765619](https://pubmed.ncbi.nlm.nih.gov/8765619/)]
11. Fond G, Loundou A, Hamdani N, Boukouaci W, Dargel A, Oliveira J, et al. Anxiety and depression comorbidities in irritable bowel syndrome (IBS): a systematic review and meta-analysis. *Eur Arch Psychiatry Clin Neurosci* 2014 Dec;264(8):651-660. [doi: [10.1007/s00406-014-0502-z](https://doi.org/10.1007/s00406-014-0502-z)] [Medline: [24705634](https://pubmed.ncbi.nlm.nih.gov/24705634/)]
12. de BA, Sprangers M, Bartelsman J, de HH. Predictors of health care utilization in patients with inflammatory bowel disease: a longitudinal study. *Eur J Gastroenterol Hepatol* 1998 Sep;10(9):783-789. [Medline: [9831274](https://pubmed.ncbi.nlm.nih.gov/9831274/)]
13. Wong W, Lai K, Lam K, Hui W, Hu W, Lam C, et al. Prevalence, clinical spectrum and health care utilization of gastro-oesophageal reflux disease in a Chinese population: a population-based study. *Aliment Pharmacol Ther* 2003 Sep 15;18(6):595-604 [FREE Full text] [Medline: [12969086](https://pubmed.ncbi.nlm.nih.gov/12969086/)]
14. Cunningham NR, Jagpal A, Peugh J, Farrell MK, Cohen MB, Mezoff AG, et al. Risk Categorization Predicts Disability in Pain-associated Functional Gastrointestinal Disorders After 6 Months. *J Pediatr Gastroenterol Nutr* 2017 May;64(5):685-690 [FREE Full text] [doi: [10.1097/MPG.0000000000001342](https://doi.org/10.1097/MPG.0000000000001342)] [Medline: [27437930](https://pubmed.ncbi.nlm.nih.gov/27437930/)]
15. Mackner LM, Crandall WV. Oral medication adherence in pediatric inflammatory bowel disease. *Inflamm Bowel Dis* 2005 Nov;11(11):1006-1012. [Medline: [16239847](https://pubmed.ncbi.nlm.nih.gov/16239847/)]
16. Keerthy D, Youk A, Srinath AI, Malas N, Bujoreanu S, Bousvaros A, et al. Effect of Psychotherapy on Health Care Utilization in Children With Inflammatory Bowel Disease and Depression. *J Pediatr Gastroenterol Nutr* 2016 Dec;63(6):658-664 [FREE Full text] [doi: [10.1097/MPG.0000000000001207](https://doi.org/10.1097/MPG.0000000000001207)] [Medline: [27035372](https://pubmed.ncbi.nlm.nih.gov/27035372/)]
17. Birmaher B, Brent D, Chiappetta L, Bridge J, Monga S, Baugher M. Psychometric properties of the Screen for Child Anxiety Related Emotional Disorders (SCARED): a replication study. *J Am Acad Child Adolesc Psychiatry* 1999 Oct;38(10):1230-1236. [doi: [10.1097/00004583-199910000-00011](https://doi.org/10.1097/00004583-199910000-00011)] [Medline: [10517055](https://pubmed.ncbi.nlm.nih.gov/10517055/)]
18. Kroenke K, Spitzer RL, Williams JBW, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics* 2009;50(6):613-621. [doi: [10.1176/appi.psy.50.6.613](https://doi.org/10.1176/appi.psy.50.6.613)] [Medline: [19996233](https://pubmed.ncbi.nlm.nih.gov/19996233/)]
19. Carman K, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)* 2013;32(2):a-31.
20. Domecq J, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014 Feb 26;14:89 [FREE Full text] [doi: [10.1186/1472-6963-14-89](https://doi.org/10.1186/1472-6963-14-89)] [Medline: [24568690](https://pubmed.ncbi.nlm.nih.gov/24568690/)]

21. Martin B, Hanington B. Universal methods of design ways to research complex problems, develop innovative ideas, and design effective solutions. In: *Universal Methods of Design: 100 Ways to Research Complex Problems, Develop Innovative Ideas, and Design Effective Solutions*. Beverly, MA: Rockport Publishers; 2012.
22. Prahalad C, Ramaswamy V. *The future of competition: Co-creating unique value with customers*. Boston, MA: Harvard Business Press; 2004.
23. Sanders E, Stappers P. *Convivial toolbox: Generative research for the front end of design*. Amsterdam, Netherlands: BIS; 2012.
24. Michalko M. *Thinkertoys: A handbook of creative-thinking techniques*. Berkeley, CA: Ten Speed Press; 2010.
25. Cataldo E, Johnson R, Kellstedt L, Milbrath L. Card sorting as a technique for survey interviewing. *Public Opinion Quarterly* 1970;34(2):202-215.
26. Bellenger D, Bernhardt K, Goldstucker J. *Qualitative research in marketing*. Decatur, GA: Marketing Classics Press; 2011.
27. Adaptive Path. *Adaptive Path's Guide to Experience Mapping*. San Francisco, CA: Blurb, Inc; 2015.
28. Ackoff R. From data to wisdom. *Journal of applied systems analysis* 1989;16(1):3-9.

## Abbreviations

**DECADES:** Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties

**GI:** gastroenterology

**PHQ:** Patient Health Questionnaire

**SCARED:** Screen for Childhood Anxiety Related Emotional Disorders

*Edited by A Powell, T Graedon; submitted 30.03.18; peer-reviewed by S Stones, C Chen, P Sossai; comments to author 11.05.18; revised version received 19.06.18; accepted 22.06.18; published 10.09.18.*

*Please cite as:*

*Hullmann SE, Keller SA, Lynch DO, Jenkins K, Moore C, Cockrum B, Wiehe SE, Carroll AE, Bennett Jr WE*

*Phase I of the Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties (DECADES) Study: Development of an Integrated Mental Health Care Model for Pediatric Gastroenterology*

*J Participat Med* 2018;10(3):e10655

URL: <http://jopm.jmir.org/2018/3/e10655/>

doi: [10.2196/10655](https://doi.org/10.2196/10655)

PMID:

©Stephanie E Hullmann, Stacy A Keller, Dustin O Lynch, Kelli Jenkins, Courtney Moore, Brandon Cockrum, Sarah E Wiehe, Aaron E Carroll, William E Bennett Jr. Originally published in *Journal of Participatory Medicine* (<http://jopm.jmir.org>), 10.09.2018. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *Journal of Participatory Medicine*, is properly cited. The complete bibliographic information, a link to the original publication on <http://jopm.jmir.org>, as well as this copyright and license information must be included.

---

Publisher:  
JMIR Publications  
130 Queens Quay East.  
Toronto, ON, M5A 3Y5  
Phone: (+1) 416-583-2040  
Email: [support@jmir.org](mailto:support@jmir.org)

---

<https://www.jmirpublications.com/>