

Investigating and Supporting Sensemaking within
Online Health Communities

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ABSTRACT

Investigating and Supporting Sensemaking within Online Health Communities

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This dissertation focuses on understanding and supporting individual and collective sensemaking within online health communities (OHCs). This major goal was achieved in three aims. In Aim 1, this dissertation contributes a rich descriptive account of collective sensemaking in OHCs forums by describing how it occurs and develops, what triggers it, what elements constitute collective construction of meaning, and what conversational moves positively contribute to this process. Further, it describes how collective sensemaking in OHCs is impacted by the interplay between informational and socio-emotional needs of OHCs members. Moreover, it examines how design of different social computing platforms influences OHCs members' ability to meet their informational and socio-emotional needs and engage in collective sensemaking. In Aim 2, this dissertation explores the design space of tools for supporting individual sensemaking through optimized information access. Through the design and evaluation of a prototype DisVis it examines the impact of such tools on OHCs members' ability to understand information within discussion threads. In the final Aim 3, this dissertation proposes a novel approach for meeting the three main needs identified in Aims 1 and 2: promoting individual sensemaking, while at the same time encouraging collective sensemaking, and facilitating development of social awareness and ties among community members. The design and evaluation of the novel solution for visualizing discussion threads that synergistically addresses these three needs—dSense—provides insights for future research and design of interactive solutions for supporting individual and collective sensemaking within OHCs.

Table of Contents

List of Tables	xiii
List of Figures	xv
CHAPTER 1: INTRODUCTION	1
1.1 Problem statement	1
1.2 Background and knowledge gaps	2
1.2.1 OHCs as environments for social support, knowledge production and collective sensemaking	2
1.2.2 Solutions for supporting sensemaking in OHCs	5
1.3 Dissertation Aims	8
1.4 Aim 1	11
1.5 Aim 2	13
1.6 Aim 3	15
1.7 Significance	18
CHAPTER 2: LITERATURE REVIEW	22
2.1 Sensemaking support tools in OHCs	23
2.2 Collective sensemaking in OHCs	24
2.3 Influencers on collective sensemaking in OHCs	25
2.3.1 The importance of the social component of OHCs to the collective sensemaking process	27

CHAPTER 3: AIM 1 – GENERATING A RICH DESCRIPTION OF COLLECTIVE	
SENSEMAKING IN OHCS FORUMS AND ITS INFLUENCING FACTORS	29
3.1 Study A1.1 - Understanding of collective sensemaking in OHC forums	29
3.1.1 Related work and knowledge gaps	30
3.1.2 Methods.....	31
3.1.3 Results.....	32
3.1.3.1 Patterns of engagement	32
3.1.3.2 Discussion types and level of collective sensemaking.....	33
3.1.3.3 Collective sensemaking elements.....	35
<i>Lateral engagement between participants</i>	35
<i>Reaction to previous perspectives</i>	36
<i>Transformation of ideas</i>	36
3.1.3.4 Conversational moves of collective sensemaking.....	37
3.1.3.5 Collective sensemaking triggers.....	40
<i>Contentious topic</i>	40
<i>Contentious posts</i>	41
<i>Generalizing personal problems</i>	41
<i>Involvement of core members</i>	42
3.1.3.6 Collective sensemaking dimensions	42
3.1.3.7 Impact of the social computing platform on collective sensemaking	44

	<i>Making suboptimal contributions to the collective sensemaking process</i>	44
	<i>Strategies for making sense of new threads</i>	46
3.1.4	Implications of the results.....	46
3.1.5	Summary of Study A1.1	49
3.2	Study A1.2 – Coexistence of informational and socio-emotional needs in OHCs forums and their influence on collective sensemaking.....	50
3.2.1	Related work and knowledge gaps	50
3.2.2	Methods.....	52
3.2.3	Results.....	54
3.2.3.1	Focused discussions versus free socializing	55
3.2.3.2	Seeking diversity versus looking for homogeneity	57
3.2.3.3	Favoring authority versus “every voice counts”	58
3.2.3.4	Attention to contributions versus attention to the authors.....	61
3.2.4	Implications of the results.....	63
3.2.4.1	Staying focused and going off-topic	65
3.2.4.2	Homogeneity and diversity	66
3.2.4.3	Credibility without undue influence.....	68
3.2.4.4	Providing context while respecting privacy	69
3.2.4.5	Designing for balance: the urban life of online health communities	71
3.2.5	Summary of Study A1.2	75

3.3	Study A1.3 – Importance of the social context in OHCs on sensemaking and the role of social computing platforms in creating it.....	77
3.3.1	Related work and knowledge gaps	77
3.3.2	Methods.....	78
3.3.3	Results.....	81
3.3.3.1	The platforms involved in the migration.....	81
3.3.3.2	Improving information management in the forum.....	83
	<i>Information generation</i>	84
	<i>Community feedback</i>	85
	<i>Information organization</i>	86
	<i>Information access</i>	87
3.3.3.3	Disruption in identity management and building strong ties between members	87
	<i>Personal profiles</i>	88
	<i>Forming “friendship” relationships</i>	89
	<i>Blogs</i>	90
	<i>Groups</i>	91
	<i>Members’ roles and trust</i>	91
3.3.3.4	Changes in the community.....	92
3.3.4	Implications of the results.....	94
3.3.5	Summary of Study A1.3	99

3.3.5.1	Enabling collective sensemaking at the cost of community building	99
3.4	Summary of results for Aim 1	101
CHAPTER 4: AIM 2 – EXPLORING OF THE DESIGN SPACE FOR SENSEMAKING		
SUPPORT TOOLS FOCUSED ON INFORMATION ACCESS		
4.1	Study A2.1 – Designing, developing and evaluating a sensemaking support prototype for OHC forum discussions, DisVis.....	104
4.1.1	Related work and knowledge gaps	104
4.1.2	Methods.....	105
4.1.2.1	Design.....	105
	<i>Discussion overview</i>	107
	<i>Finding topics of interest</i>	108
	<i>Summary of opinions</i>	109
	<i>Usage scenario</i>	110
4.1.2.2	Development	112
4.1.2.3	Evaluation study	113
4.1.3	Results.....	117
	<i>Performance</i>	117
	<i>Perceptions and design feedback from community members</i>	119
	Overall assessment of the DisVis tool.....	119
	Exploratory browsing	121

Focused information search.....	123
4.1.4 Implications of the results.....	125
4.2 Summary of results for Aim 2.....	129
CHAPTER 5: AIM 3 – EXPLORING THE DESIGN SPACE FOR SENSEMAKING SUPPORT TOOLS THAT FOCUS ON INFORMATION ACCESS, WHILE PROMOTING COLLECTIVE SENSEMAKING AND SOCIAL AWARENESS AND CONNECTIONS	
5.1 Designing and developing a holistic sensemaking support tool for OHCs forum discussions, dSense	132
5.1.1 Related work and knowledge gaps	132
5.1.2 Identifying user needs and formulating design goals	134
5.1.2.1 Identifying user-centered design requirements	134
5.1.2.2 Balancing the competing forces generated by the needs of OHC members through design goals	135
<i>Precision in formulating information needs vs. the need for light-weight interactions</i>	136
<i>Individual vs. collective sensemaking in a discussion.....</i>	138
<i>Information access vs. social fabric in OHCs.....</i>	139
5.1.3 Defining relevant content through similarity	142
5.1.3.1 Defining relevance in the context of OHCs forum discussions	142
<i>Different types of relevance.....</i>	142
<i>Assessing relevance in OHCs forum discussions context</i>	143
<i>Assessing topical relevance in OHCs forum discussions context</i>	144

5.1.3.2	Finding relevance between two texts based on similarity.....	147
	<i>Evaluation of suite of algorithms for text similarity</i>	148
	<i>Results of the evaluation</i>	150
5.1.3.3	Calculating similarity between a highlighted continuous text segment and a post	152
5.1.4	Iterative design of dSense	153
5.1.4.1	Design phase 1: Operationalizing the design goals and developing initial design sketches	154
	<i>Conceptualization of the design for accessing relevant information</i>	156
	Design Goal 1: Provide members with efficient access to information of personal interest	156
	Design Goal 2: Foster collective sensemaking and construction of new knowledge	158
	<i>Conceptualization of the design for stimulating social interactions</i>	159
	Design Goal 3: Contribute to stimulating awareness of community members and social interactions	159
	<i>User study</i>	160
	<i>Participants</i>	160
	<i>Procedures</i>	161
	<i>Analysis</i>	163
	<i>Results</i>	163
	<i>Design implications</i>	164

5.1.4.2 Phase 2: Technical feasibility and detailed design features.....	165
<i>Updates in the design</i>	167
<i>User study</i>	169
<i>Participants</i>	169
<i>Procedures</i>	169
<i>Analysis</i>	171
<i>Results</i>	171
<i>Design implications</i>	173
5.1.4.3 Phase 3: High fidelity mockups feedback for full functionality of dSense	173
<i>Updates in the design</i>	174
<i>Algorithmic support for the Post Card and the Reading Support</i>	176
Identifying relevant text segments.....	178
Identifying text overlaps based on key phrases	179
Post summary based on key phrases.....	182
<i>User study</i>	183
<i>Procedures</i>	184
<i>Analysis</i>	189
<i>Results</i>	189
Highlighting.....	189
Exploration	190

Reading.....	196
Synchronization and search history	198
<i>Design Implications</i>	198
Summary of the results	198
Updates to the design.....	200
5.1.4.4 Phase 4 - The final design of dSense	201
<i>Additional design changes</i>	203
<i>Reinforcing the author-relevant content links</i>	205
<i>Meeting the needs for the Post Card</i>	206
<i>Meeting the needs for the Reading Support</i>	207
5.1.5 Implementation of dSense as a Chrome Extension to the Discourse platform.....	208
5.1.5.1 The architectural framework of the dSense system	208
5.1.5.2 Communication for securing high responsiveness of the dSense system	209
5.1.5.3 Use case based on the implementation of dSense	210
5.2 The evaluation study of dSense.....	224
5.2.1 Approach and assessment measures	226
5.2.1.1 Assessing impact on individual sensemaking.....	226
<i>A cognitive model for discussion sensemaking in OHCs and points for tool support</i> .	226
<i>Adapting the sensemaking framework for dSense evaluation</i>	229
5.2.1.2 Assessing impact on collective sensemaking.....	235

5.2.1.3	Assessing impact on social connections.....	237
5.2.2	Study materials.....	239
5.2.2.1	Selecting a discussion for the evaluation	239
5.2.2.2	Developing the gold standard for the evaluation	239
5.2.3	Study design.....	241
5.2.3.1	Participants	241
5.2.3.2	Procedures	242
5.2.4	Data analysis	243
5.2.4.1	Individual sensemaking.....	243
	<i>Presentation</i>	244
	<i>Hypothesis</i>	244
	<i>Schema</i>	245
5.2.4.2	Collective sensemaking.....	245
	<i>Structure</i>	245
5.2.4.3	Social connections.....	246
5.2.5	Results.....	247
5.2.5.1	Individual sensemaking.....	247
	<i>Confidence in the sensemaking process</i>	248
	<i>Confidence in the Presentation and Hypothesis</i>	249
5.2.5.2	Collective sensemaking.....	249

5.2.5.3	Social awareness and connections.....	251
5.2.5.4	Sensemaking behaviors using dSense.....	252
	<i>Defining information needs</i>	252
	Highlight as a socializing tool	252
	<i>Discussion exploration behaviors</i>	253
5.2.6	Discussion.....	253
5.2.6.1	Assessing the impact of dSense	254
	<i>Individual sensemaking</i>	254
	<i>Collective sensemaking</i>	255
	<i>Social awareness and connections</i>	256
5.2.6.2	Reasoning about the sensemaking behaviors using dSense.....	257
	<i>Defining information needs</i>	257
	<i>Discussion exploration behaviors</i>	258
5.2.6.3	Sensemaking support tools design implications.....	258
	<i>Integrating typed search and highlighting</i>	259
	<i>Tracing the sensemaking process</i>	260
5.2.6.4	Evaluating sensemaking support tools	260
	<i>Suitability of the current evaluation</i>	260
5.2.6.5	Limitations	262
5.3	Summary of Aim 3.....	263

CHAPTER 6: CONCLUSIONS	265
6.1 Summary of work.....	265
6.2 Contributions.....	266
6.3 Limitations	268
6.4 Future work	269
6.4.1 Relevance in OHC forum discussions	269
6.4.2 Discussion exploration.....	270
6.4.3 Going beyond a single discussion.....	270
6.4.4 Evaluation of sensemaking support tools for OHCs.....	271
REFERENCES	273
APPENDIX.....	303

List of Tables

Table 1. Types of contributions to a discussion; 6-10 specifically indicate contributions to collective sensemaking.....	38
Table 2. Information management and community building features of the two platforms: Ning (A) and Discourse (B).....	82
Table 3. Categories of questions asked to the participants for the evaluation of the tool on accuracy and time to answer.	115
Table 4. Average time to answer and average score of answers for a set of questions and all questions overall. Significance tested with Mann-Whitney U Test.....	118
Table 5. The performance of the individual algorithms for similarity between an Anchor and a Candidate Post as measured by nDCG@5, nDCG@10, nDCG@15.	150
Table 6. Mapping the core design goals to solutions that rely on visual representations.....	155
Table 7. Mapping the design goals to solutions that rely on visual representations tested for technical feasibility. The design solutions that are bolded are the new additions to the previous design.	166
Table 8. Sensemaking tasks.....	170
Table 9. Mapping the design goals to solutions that rely on visual representations present in the high-fidelity mockups. The design solutions that are bolded are the new additions to the previous design.	175
Table 10. Mapping the design goals to solutions that rely on visual representations in the final design. The design solutions that are bolded are the new additions to the previous design.....	202
Table 11. Probing questions to elicit individual's Schema.....	234

Table 12. Contributions to a discussion that serve as building blocks for collective sensemaking.	236
Table 13. Contextualizing questions for obtaining additional signal relevant to collective sensemaking.....	237
Table 14. Question for social awareness after the sensemaking process.....	238
Table 15. The overlap in key points between the gold standard developers about each of the questions from the individual sensemaking stage of the dSense evaluation.	240
Table 16. Individual sensemaking performance.	247
Table 17. Individual sensemaking performance for the Schema sub-section.....	248
Table 18. Confidence in the Presentation and Hypothesis.	249
Table 19. Collective sensemaking performance.	250
Table 20. Social awareness and connections	251
Table 21. The questions at each of the stages of the sensemaking process.	303

List of Figures

Figure 1. Existing knowledge gaps for understanding OHCs as environments for collective sensemaking and social support.....	5
Figure 2. Existing knowledge gaps for building successful sensemaking support solutions in OHCs (tied to the previously mentioned knowledge gaps)	7
Figure 3. The knowledge gaps the thesis addressed in three Aims	8
Figure 4. Knowledge gaps addressed in Aim 1.	11
Figure 5. Knowledge gaps addressed in Aim 2.	14
Figure 6. Knowledge gaps addressed in Aim 3.	16
Figure 7. Knowledge gaps addressed in Aim 1.	29
Figure 8: Patterns of engagement: a) number of users in a discussion; b) number of replies in a discussion; c) average number of replies per user; d) posts per user per discussion; e) discussion longevity; f) time to first response.....	33
Figure 9. The knowledge gap addressed after the completion of Study A1.1 from Aim 1.	49
Figure 10. The knowledge gaps addressed after the completion of Study A1.2 from Aim 1.....	76
Figure 11. The knowledge gaps addressed after the completion of Study A1.3 from Aim 1.....	99
Figure 12. Knowledge gap addressed in Aim 2.....	103
Figure 13. Logical and functional division of DisVis.....	106
Figure 14. Features that support forming an overview of the entire discussion thread (blue). ..	107
Figure 15. Features that support forming an overview of the entire discussion thread (blue) and finding prevalent topics within a discussion (red).....	108

Figure 16. Features that support forming an overview of the entire discussion thread (blue), finding prevalent topics within a discussion (red) and summarizing different opinions in regards to the prevalent topics (green).....	110
Figure 17. A snapshot of the DisVis user interface in use with functionality markers.	111
Figure 18. DisVis evaluation study design.	113
Figure 19. The knowledge gap addressed after the completion of Aim 2.	129
Figure 20. The knowledge gap addressed in the first part of Aim 3.....	132
Figure 21. The Anchor Post contains the highlighted text segment to serve as a search query and the Relevant Post contains text segments that are similar to the highlighted text and are above a certain threshold.....	147
Figure 22. The sliding window for calculating similar content.	152
Figure 23. The steps involved in the iterative user-centered design of dSense.	154
Figure 24. The first step in the design process (Phase 1) – getting feedback on the core functionality of dSense.	155
Figure 25. Left: Highlighted continuous text segment that represents a search query (orange) from the text of the Anchor Post of interest (gray), Right: the visual rendering of the relevant posts in the discussion color coded for relevance (the darker the green the more relevant).	156
Figure 26. Holistic mental model of a discussion while at the same time supporting information needs.	158
Figure 27. Providing personal information about the post author at the point of exploration and explicit links between posts’ relevance and authors.	159
Figure 28. dSense design sketches.....	162

Figure 29. The second step in the design process (Phase 2) – testing the technical feasibility of the design for dSense.	166
Figure 30. The implementation of the core features of dSense within the Discourse platform .	168
Figure 31. The third step in the design process (Phase 3) – obtaining feedback on the design with full functionality of dSense.	174
Figure 32. A Relevant Post with inner structure containing text segments relevant to the highlight and others that aren't.....	177
Figure 33. Identifying similar segments from the post to the query.	178
Figure 34. Explaining the quality of the relevance by identifying overlap between the post or the post segment and the highlight and the rest of the important content of the post not relevant to the highlight.	179
Figure 35. The intersection between the relevant post or a post segment and the highlight represented with top three similar key phrases.	181
Figure 36. The part of relevant post or a post segment that is important, but not immediately relevant to the highlight, represented with top three key phrases.	182
Figure 37. Conceptual representation of the summary of the post or the post segment based on the key phrases that represent the overlapping with the highlight and the other important information which that piece of text is covering.	183
Figure 38. A) The highlighting stage, B) Exploration by relevance and C) Exploration by author.	185
Figure 39. A) The Post Card for a post of interest, B) The Profile Card for the author and C) The Reading Support after inspecting the Post Card and deciding to read the full content.	187

Figure 40. The search history bar with two tabs, one for each executed query in the context of the post it belongs to.	189
Figure 41. The design alternatives for the Post Card.....	195
Figure 42. The design alternatives for the Reading Support.	197
Figure 43. The final step in the design process (Phase 4) – consolidating the feedback from the previous design phases for dSense.....	201
Figure 44. The final design of the dSense tool with the Heat Map with the Slider (A), the Post Tiles discussion segment (B) and the Participants Panel for that discussion segment (C), together with the author-relevant information reinforcements in the Participants Panel (D) and the Search History Bar (E).....	204
Figure 45. The Post Card in the final design.	207
Figure 46. The Reading Support in the final design.	208
Figure 47. The dSense system architecture: Chrome Extension with a client for fast rendering and server side for resourceful processing.....	209
Figure 48. The detailed client-server architecture.	210
Figure 49. The implementation phase of dSense.	211
Figure 50. The Discourse discussion before the activation of dSense.....	212
Figure 51. Initial state of the tool immediately after the sensemaker has landed on a discussion.	212
Figure 52. Highlighting a text to serve as a query.	213
Figure 53. Rendering of the discussion based on the highlighted text to provide an overview of the distribution of the relevant content.	214
Figure 54. Using the Slider to focus on a particular segment of the discussion.	215

Figure 55. Jumping to a post of interest for reading its integral content.	216
Figure 56. Following the relevance of the post in the reading mode.....	217
Figure 57. Selecting a user to see their posts.	217
Figure 58. Moving the Slider to encompass the most of the contributions from a given user. ..	218
Figure 59. Personal information about a discussion participant contained in the Profile Card..	219
Figure 60. Expanding the Post Card to see a summary of the post of interest.	220
Figure 61. Reading Support provided for lengthy posts.	220
Figure 62. Selection of a new highlight within a Relevant Post.	221
Figure 63. Queries are stored in the Search History.	222
Figure 64. Browsing of the queries is allowed by clicking on the tiles associated with them. ..	222
Figure 65. Executing a query from the Search History.	223
Figure 66. The knowledge gap addressed in the second part of Aim 3	224
Figure 67. Assessing the impact of dSense at three key processes for OHCs forums: individual sensemaking, collective sensemaking and community building.	225
Figure 68. Sensemaking loop for intelligence analysts adopted for OHCs	227
Figure 69. The sensemaking model for intelligence analysts adapted for the OHC forum discussion sensemaking.	229
Figure 70. The flow of the evaluation and the hypotheses at each of the stages of the individual sensemaking process.	230
Figure 71. The hypothetical friend persona represented with the attributes of a specific case. ..	231
Figure 72. Providing a recommendation based on the specified knowledge gap, the given discussion and the friend’s case.	232

Figure 73. Delving into more specific question about each of the attributes for the friend's case.
..... 235

Figure 74. The evaluation study design. 242

Figure 75. The knowledge gap addressed after the completion of Aim 3. 263

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Dedication

I dedicate this dissertation to my parents Stela and Predrag. They helped me grow intellectually and creatively since very early age and taught me about the values of hard work and respecting others. I'm strongly convinced that my achievements are a direct consequence of those values for which I am forever grateful.

I also dedicate this dissertation to the game of basketball. Very early in my life, this beautiful game taught me how to be positive, adjust to new situations quickly and never give up to reach my goals. It also taught me the value of collaboration, devotion to the team and respecting people around me that contribute in reaching my goals, and opened the world to me through numerous travelings and international competitions at a very young age. This early exposure to the world helped me to embark on my PhD journey outside of my home country, which brought me new friends and experiences beyond any comparison.

CHAPTER 1: INTRODUCTION

1.1 Problem statement

In recent years, online health communities (OHCs) have emerged as an important complement to the traditional health care [6,62]. They have become an important source of informational and emotional support for individuals with a variety of health challenges and conditions, as well as their family caregivers [132]. In response, there emerged a large number of OHCs such as breastcancer.org, TuDiabetes.org, and PatientsLikeMe.com. Typically, each OHC features a discussion forum where members can share information and socialize. These discussion forums have become valuable repositories of information and opinions about issues related to health and various diseases [31]. Because the majority of OHCs do not provide editorial appraisal of the members' contributions, discussion threads often represent vastly different positions expressed by members with different backgrounds, levels of knowledge about and experience with the disease, as well as different motives for participating. Further, overtime discussion threads can accumulate a considerable number of posts, in which topics transition and shift, including both agreement and heated debates among members, where informational posts are interwoven with off-topic social interactions. *As a consequence, members of OHCs often feel overwhelmed by the information they encounter in these forums and experience difficulties in making sense of that information, which can lead to frustration and disengagement, and, on some occasions, to suboptimal health choices.*

1.2 Background and knowledge gaps

1.2.1 OHCs as environments for social support, knowledge production and collective sensemaking

For the purposes of this dissertation, I will define an OHC as any group of individuals that are unified by a set of shared values in regards to health in general or a specific health challenge in particular and utilizes a social computing platform to support their communication. Some OHCs use social computing platform dedicated to online forums, such as Ning and Discourse among others, other OHCs organize as sub-groups within larger communities, for example Groups within Facebook [125], or sub-Reddits within Reddit [45].

Previous research on OHCs explored the underlying dynamics within these forums and identified two essential types of social support: *informational* and *socio-emotional* [113,157,169]. Informational support helps in satisfying *informational needs* related to finding advice or learning about others' experiences with diseases and different health challenges [40,113]. From the information needs perspective, previous research often considered OHCs as information repositories that store vast amounts of information that could be mined and analyzed for important trends and patterns by both forum participants and researchers [24,53,72,170]. On the other hand, socio-emotional support helps satisfying *socio-emotional needs*. This often includes *companionship*, which is accomplished through chat, humor, and discussions on general life topics, outside of the disease, and *emotional support*, which is related to understanding, encouragement and empathy, among others [136,157,168]. From the socio-emotional perspective, researchers painted OHCs as social spaces where individuals come to seek emotional support and socialize through spontaneously meeting new people with similar or

different medical profiles and health challenges [104,144]. Related to the importance of informational and socio-emotional support, previous research has also shown that the existence of both types of support is essential for the survival of OHCs [48]. Moreover, investigators have found that matching members' needs with the appropriate support affects their satisfaction and commitment to the community [154,159,160].

Yet another way to conceptualize OHCs is through the lens of knowledge production. Previous research has observed OHCs as social spaces that produce knowledge [39,78] and noted that social dynamics among their members play a significant role in the knowledge production [174]. Researchers have shown that the density of the social network and the trust developed among their members affect the amount and quality of the produced knowledge [173]. In addition to this, previous work suggested that one of the underlying mechanisms critical for the production of new knowledge in groups is collective sensemaking [51,118], typically defined as construction of meaning through collective efforts. Collective sensemaking is closely tied to individual sensemaking, which describes the process through which individuals make sense of information and the world around them; however, collective sensemaking extends it to social settings when multiple individuals produce meaning together. Both concepts are related to the iterative phenomenon of sensemaking which involves closing individuals' knowledge gaps by estimating the *relevance of socially constructed artifacts* and utilizing them accordingly. Based on some research traditions, *individual sensemaking* is related to processes taking place in the individual's mind in order to make sense of a particular situation within a given context and in order to move to the new desired state [115]. On the other hand, *collective sensemaking* is related to understanding how individuals construct meaning together based on each others' knowledge, which involves observation and interpretation of collectively constructed artifacts that represent

a particular situation within a context in order to allow individual participants to move to the next desired state [74,109]. Given this, these two phenomena are closely tied together and heavily influence each other: *the way an individual makes sense of the information contributes to the collective sensemaking process, and the way the collective sensemaking evolves influences the individual sensemaking.*

This is strongly emphasized in OHCs forums. In this context, forum discussions are often initiated by their members who experience knowledge gaps in regards to a specific health-related issue, and seek information and advice from the community [154]. Other members then contribute posts they deem relevant to the discussion topic and its initiator, helping them to close their information gap [154,159]. Because health management is complex, discussion participants are often compelled to ask clarifying or contextualizing questions in order to enrich their own individual sensemaking regarding the topic of the discussion, and to arrive at more insightful contributions [78]. Through this engagement with questions and answers, clarifications, and refutations, they engage in the back and forth of collective sensemaking, thus enriching their own understanding of the issue at hand, and potentially together producing new knowledge, not previously possessed by any single participant of the discussion. In addition, as the content builds over time, the back and forth of collective sensemaking captured in a discussion thread becomes a resource not just for the initiator of the thread, but for other members who may visit it at a later time. This positions OHCs as a fertile ground and domain for studies of individual and collective sensemaking as pertains to health and disease.

Thus far, collective sensemaking has been explored within organizational sciences [164], crisis management [74], and in clinical setting [4]. Despite these ongoing efforts, there remain important knowledge gaps in our understanding of both individual and collective sensemaking in

the OHCs and the way these processes influence each other, and consequently, in our ability to identify solutions for improving individual and collective sensemaking within these communities. *First, while previous authors suggested that collective sensemaking is an important activity in knowledge production, few specifically examined this phenomenon within OHCs (Figure 1, top). Second, while previous studies focused on either informational or socio-emotional needs, few specifically examined the interplay between them and their coexistence, and how those influence the collective sensemaking process (Figure 1, bottom).*

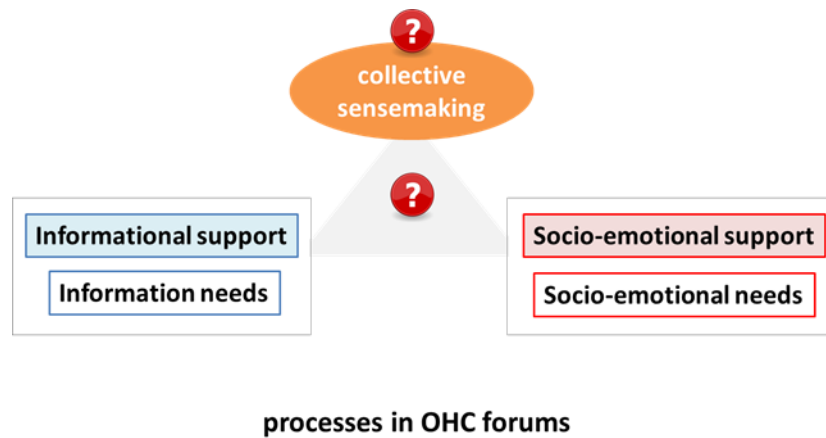


Figure 1. Existing knowledge gaps for understanding OHCs as environments for collective sensemaking and social support.

1.2.2 Solutions for supporting sensemaking in OHCs

Previous research generated a number of solutions to support sensemaking through optimized information access in online forums [3,35,47,58,76,114,140] and other channels for asynchronous group communication, such as email threads [153] and news groups [151]. Because of the complexity, richness and volume of information and the dynamically changing user needs, previous solutions for supporting sensemaking have relied on interactive

visualizations rather than more classical information retrieval techniques [58,140]. These solutions mainly explored approaches to computationally identifying and visualizing prevalent topics within discussion threads and posts [47] and included posts' sentiment in order to establish author-sentiment-post connections for opinion inference [76], or utilized posts' levels of moderation to inform content reliability [47,114]. These tools often rendered a discussion in a single view and provided both a high-level overview of the discussion, as well as means for dissecting its topical space for easier navigation and synthesis of positions about a topic of interest. Notably, the majority of these solutions considered a given post as a monolithic structure freed from any rhetorical units that could be related or unrelated between each other and cover more than one topic or idea. Given that typical posts in the discussion threads are complex, multifaceted and cover a number of topics, this assumption may have limited these solutions' ability to support individual sensemaking. At the same time, these previous efforts often conceptualized a discussion thread as a "bag of posts", essentially abstracting the thread from the process through which it was created and the underlying relationships between posts. As a result, these solutions may have limited the access to the most relevant information contained in interdependent posts and inadvertently disrupted collective sensemaking within these communities, and their potential of generating new knowledge. Finally, these existing tools were deployed in communities that differed from OHCs in their expression of the informational and socio-emotional needs, and that were less concerned with their impact on social dynamics and cohesiveness within the communities they target. Neglecting this impact might pose risks to interrupting the social fabric in the community and thus carry some potential threats to the knowledge production and collective sensemaking that takes place in it.

Similar questions have been previously explored within Computer-Supported Cooperative Work (CSCW) and, particularly, groupware. According to Grudin [64], groupware, such as OHC platforms, should be able to support the needs of the individual and the group simultaneously, which is often challenging and requires careful design process and evaluation. To be successful, these platforms need to allow OHC members to contribute to the group efforts without excessive burden and with results that benefit the individual and the group at the same time. In the context of OHCs, this translates into the need for OHCs platforms and tools that specifically focus on promoting sensemaking to help individual members to satisfy their information needs and thus promote individual sensemaking, while at the same time encouraging them to contribute to the group efforts to construct new meaning together thus promoting collective sensemaking. Also, these tools should pay attention to satisfying the socio-emotional needs of the individual, but at the same time encourage the building of social fabric critical for the survival of the community.

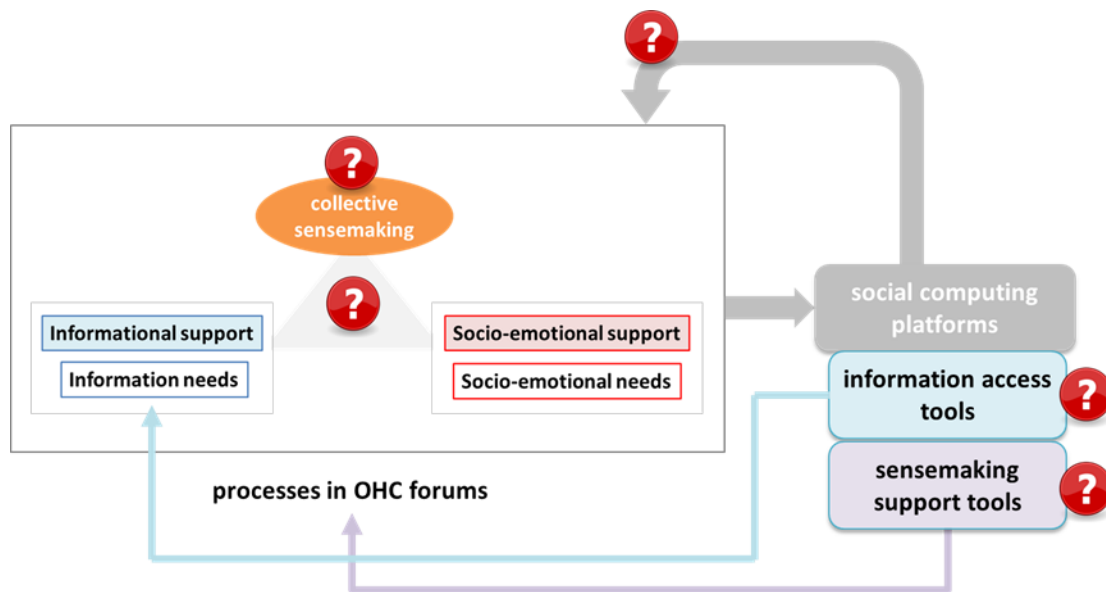


Figure 2. Existing knowledge gaps for building successful sensemaking support solutions in OHCs (tied to the previously mentioned knowledge gaps)

In summary, while there are multiple interactive visualization solutions for supporting individual sensemaking through optimized information access within discussion forums, there is a lack of understanding how transferable those solutions are to the OHCs and the specific informational and socio-emotional needs of OHCs members (Figure 2, information access tools). Further, there is a lack of understanding how different features of social computing platforms that host OHCs, especially the ones which embed such tools or include advanced features for information management, influence the main processes in the community (Figure 2, social computing platforms). Consequently, few previous sensemaking support solutions took a holistic view of the group processes in OHCs and specifically focused on optimizing information access while at the same time promoting collective sensemaking and the development of social connections within communities (Figure 2, sensemaking support tools).

1.3 Dissertation Aims

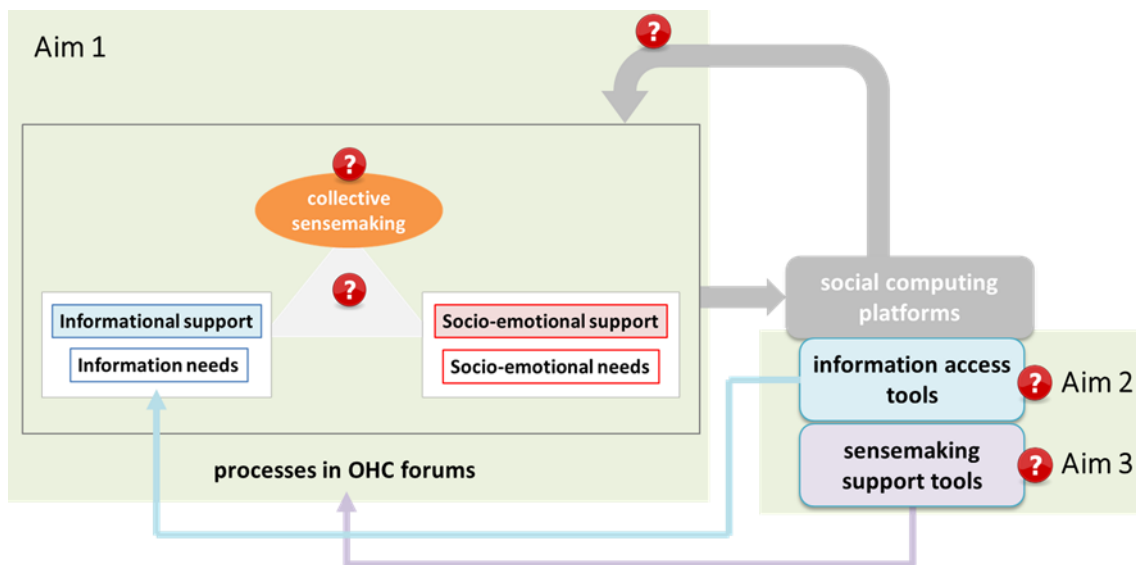


Figure 3. The knowledge gaps the thesis addressed in three Aims

The goal of this dissertation is to close the knowledge gaps described above through developing rich descriptive accounts of collective sensemaking within OHCs and to identify novel approaches for facilitating collective sensemaking within OHCs that can be integrated with the existing OHC platforms. In order to fulfill its purpose, this dissertation pursued the following aims (Figure 3):

Aim 1: Develop a rich descriptive account of collective sensemaking within OHCs and factors that contribute to it (Figure 3, Aim 1).

In Aim 1, I conducted several studies that examined different properties of collective sensemaking within OHCs. The contributions of this aim include the following:

- a) *Described the main characteristics of collective sensemaking in OHCs: how it occurs and develops, what are its triggers, elements and building blocks [101].*
- b) *Described the main characteristics of the environment in which collective sensemaking occurs: how do informational and socio-emotional needs coexist in OHCs [111].*
- c) *Described the interaction between informational and socio-emotional needs and the collective sensemaking process: how the coexistence of informational and socio-emotional needs shapes and influences the collective sensemaking process [110,111].*
- d) *Examined features of social computing platforms that host OHCs and these features impact on their ability to support sensemaking and socio-emotional needs in a balanced way: how different features that are translated from other social computing domains affect the well-being of the OHCs and what should these features be designed for when applied to OHC context [110].*

AIM 2: Explore the design space for sensemaking support tools focused on information access (Figure 3, Aim 2).

In Aim 2, I designed, developed and evaluated a novel interactive tool for visualizing discussion threads within OHCs that focused on enhancing individual sensemaking, DisVis [112]. The main contributions of Aim 2 include the following:

- a) *Examination of new design features for promoting individual sensemaking within OHCs using interactive visualizations of discussion threads.* Specifically, the evaluation study conducted within this aims helped to examine both the acceptance of specific design features by members of OHCs and their preference for different features.
- b) *Examination of the possible impact of interactive visualizations of discussion threads on individuals' comprehension of information within the thread:* the impact of the proposed features on the members' capacity to understand information within a discussion thread as measured by their ability to accurately answer questions and the time required to answer such questions.

AIM 3: Explore the design space for sensemaking support tools that focus on information access, while promoting collective sensemaking and social awareness and connections in the OHCs (Figure 3, Aim 3).

Based on the knowledge obtained from Aim 1 and Aim 2, I designed and developed dSense—an interactive tool that takes a holistic approach to advancing sensemaking for OHCs forums by supporting individual sensemaking through providing efficient access to information of interest in a way that is sensitive to the collective sensemaking and the social context of the OHCs. The main contributions from this Aim 3 include:

- a) *Design principles for tools that facilitate sensemaking in OHCs*: what features can promote different types of sensemaking, individual and collective, and how these features should coexist in the complex OHC ecosystem of informational and socio-emotional support.
- b) *Framework for evaluating sensemaking support tools for OHCs*: a novel approach to evaluating sensemaking support tools for OHCs.

In the following sections I further expand on the three aims and summarize their main accomplishments. For all studies that involve human subjects, an approval was obtained from Columbia University Medical Center IRB Office.

1.4 Aim 1

Aim 1: Characterize collective sensemaking within OHCs: develop a rich descriptive account of collective sensemaking within OHCs and factors that contribute to it (Figure 4, green rectangle).

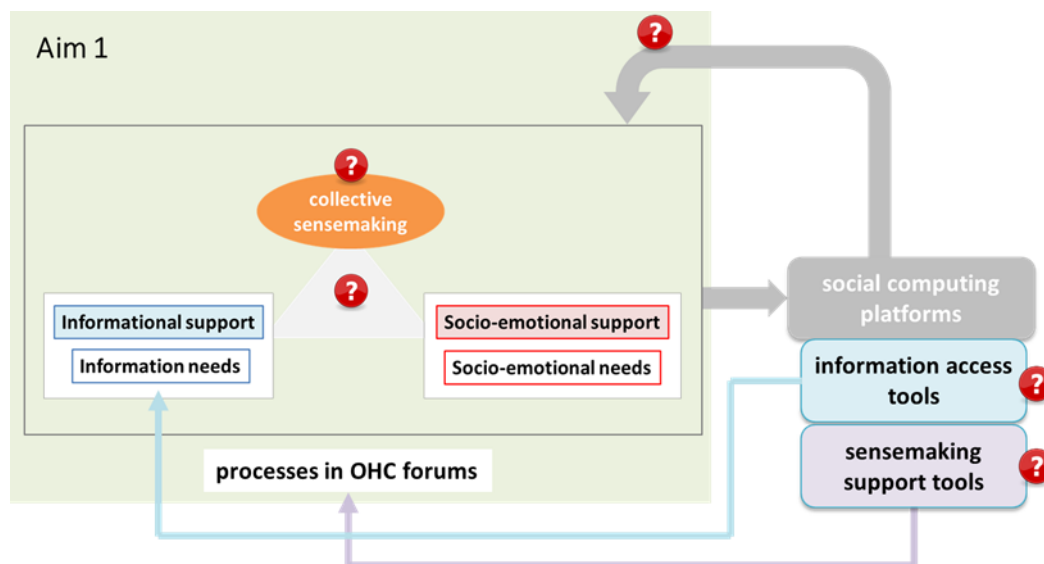


Figure 4. Knowledge gaps addressed in Aim 1.

In Aim 1, I conducted three complementary studies that focused on different processes and characteristics within OHCs, which have not received sufficient examination in previous work: 1) *collective sensemaking* (Study A1.1), 2) *coexistence between informational needs and socio-emotional needs and their impact on collective sensemaking* (Studies A1.2 and A1.3), and 3) *designing features in social computing platforms that host OHCs and support the key values of the community: informational and socio-emotional support* (Study A1.3).

While much research has been dedicated to the phenomenon of knowledge production in different online communities, including Wikipedia [89,90,146,177], StackOverflow [100], Quora [155] and OHCs [174], the phenomenon of collective sensemaking received considerably less attention. Knowledge production in a group is an iterative process in which individuals have to make sense of the contributions from other members of the group and build on them to produce their own contribution [55,145]. Previous research argued that collective effort to construct meaning together, often referred to as *collective sensemaking* (CSM), is one of the fundamental underlying knowledge production mechanisms [51,118]. Notably, in collective sensemaking, the main objective is often achievement of multiple perspectives for individual decision making support, rather than reaching a consensus [74,78]. The phenomenon of collective sensemaking has been explored in many domains such as organizational behavior [164,165], military [142], education [42], crisis management [74] and clinical setting [4], but less so in OHCs. Yet, deep understanding of collective sensemaking within OHCs is essential as it provides both a richer understanding of the OHC environment and a foundation for the design of tools that can support the process. *For these reasons, in Aim 1 I conducted an observational study of collective sensemaking within an OHC (Study A1.1) and developed a rich descriptive account of this*

phenomenon. The findings of this study led to better understanding of the mechanisms that enable collective sensemaking and ways it shapes discussions within OHCs.

On the other hand, previous research has shown that knowledge production is deeply impacted by the social dynamics within a community and, in particular, by the trust developed among community members [173]. This suggests that a positive social environment in the community is an important contributor to knowledge production [174]. However, the interplay between socio-emotional and informational needs that shape the socio-emotional and informational support in the community, as well as the relationships between these forms of support and collective sensemaking remain poorly understood. In fact, understanding how to design features in social computing platforms that host OHCs that would be respectful for both of these needs, especially when struggling with information overload, was not well developed. *For these reasons, the second Study A1.2 and the third Study A1.3 in this Aim 1 investigated the coexistence of informational and socio-emotional needs in OHCs and their impact on collective sensemaking within these communities, as well as social computing platform features that might affect the social fabric in the community on which this process heavily depends. The findings of these studies helped to better understand the impact of different technical solutions on both informational and socio-emotional support within these communities, as well as on their well-being and the collective sensemaking that takes place in them.*

1.5 Aim 2

Aim 2: Develop and evaluate new approaches to supporting sensemaking within OHCs:
design, develop and evaluate a prototype informatics solution for supporting individual

sensemaking within online health forums through improved access to information (Figure 5, green rectangle).

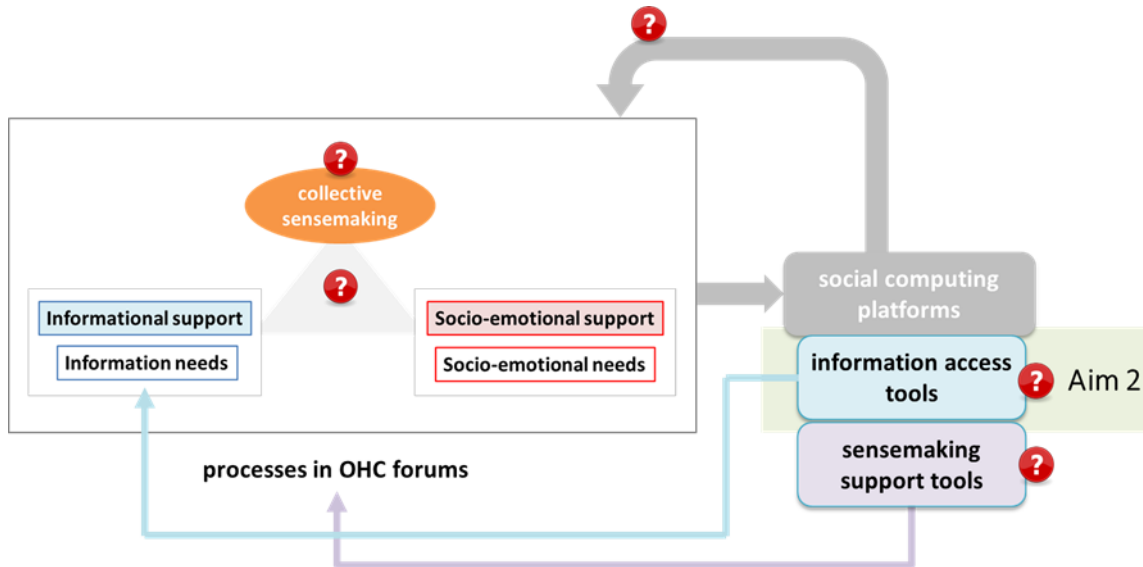


Figure 5. Knowledge gaps addressed in Aim 2.

Many solutions that optimize access to information for improving individual sensemaking in asynchronous group communication have been proposed. These relied on the visual analytics approach due to the multifaceted nature of the content produced by these communities and to the dynamically changing user needs. As a consequence, the predominant approach to designing such solutions is through interactive data visualizations, rather than the more traditional information retrieval techniques that rely on discussion search engines [58,140] and recommendations [1,3,35]. While some of the solutions focused on e-mail exchange [152,153] and news groups [151], others explored discussions in forums [47,76,93,94,114]. However, the vast majority of the solutions developed thus far were outside of the OHCs domain. Moreover, visual analytics solutions that specifically focused on OHC forums did not focus on single discussion threads (which could be very long and significantly complex), had limited

interactivity, were mainly intended for answering research questions (rather than satisfying user information needs) [8,29,30,32], and were specifically designed for community moderators rather than regular members [93].

For these reasons, in this Aim 2 I designed, developed and evaluated an informatics solution that strives to improve the access to information in a single OHC forum discussion through interactive visualization approach. *The evaluation study of the solution allowed to: a) investigate attitudes towards interactive visualizations for improving access to information within discussion threads among members of an OHC; b) investigate how members of an OHC engage with different features for improving access to information, and c) investigate the impact of the proposed features on the members' capacity to understand information within a discussion thread as measured by their ability to accurately answer questions and the time required to answer such questions. The findings of this study increased our knowledge regarding the feasibility and potential usefulness of different design features for supporting individual sensemaking through improving access to information within discussion threads and suggested future design directions for such tools.*

1.6 Aim 3

AIM 3: Use knowledge collected within previous aims to further extend the design space for supporting sensemaking within OHCs: design, develop and evaluate a novel informatics solution for supporting individual sensemaking through improving access to information within a discussion, while at the same time fostering collective sensemaking and promoting social awareness and connections in the community (based on the knowledge gaps addressed in Aim 1 and Aim 2, Figure 6 - green rectangle.

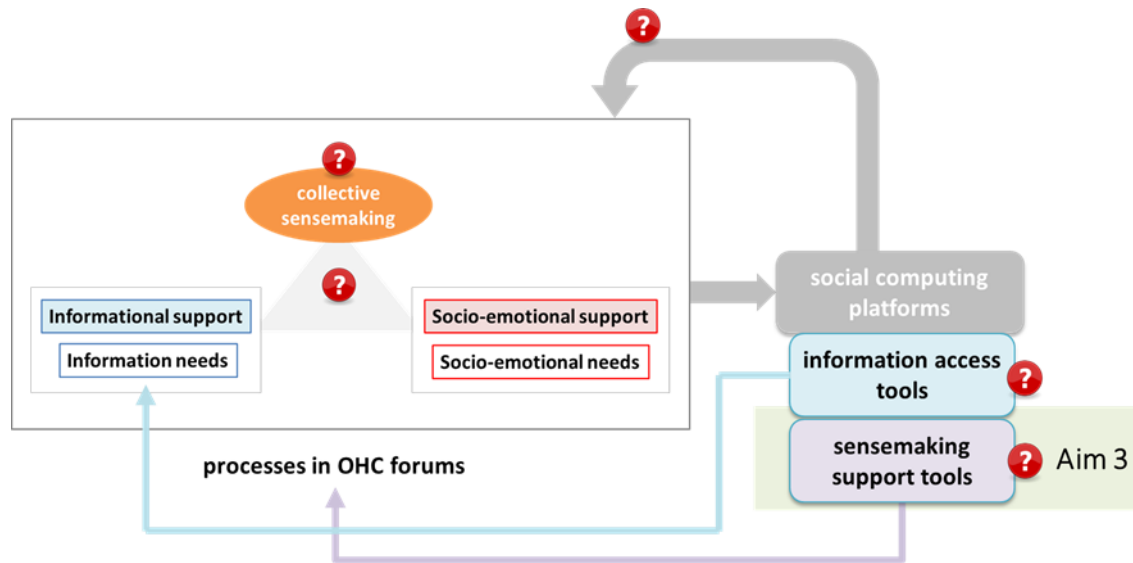


Figure 6. Knowledge gaps addressed in Aim 3.

Previous research suggested many visual analytics solutions for improving access to information in forum discussions. These solutions focused on showing overview of discussions’ topics [47,76,77,93], displaying connections between topics, sentiment and authors [76,93], and filtering posts by topicality, similarity and levels of moderation [47,76,93,114], all within a single view discussion representation. Many of these tools provided both an overview of a discussion and means for dissecting its topical space for easier navigation and opinion synthesis. However, these approaches have a number of limitations. First, they generally consider a given post as a monolithic structure. In contrast, in my previous work from Aim 1 and based on Rhetorical Structure Theory (RST) [103], I found that posts in real-world discussions are complex and often constructed from many rhetoric units that could be related or unrelated with each other and potentially cover multiple topics or ideas. This mismatch could potentially lead to lower accuracy in retrieving information of interest to the users and lead to suboptimal user experiences. Second, current solutions rely on a view of each discussion as an unstructured collection of posts (“bag of posts”). In contrast, my preliminary studies suggested that there exist

important rhetorical relationships between individual posts, which also contribute to the emergence of new meaning and to collective sensemaking. Third, current solutions have ignored social identities of individuals who created posts in a discussion and relationships between them, thus contributing to the gap between information within discussion threads and the social dynamics in the community. In contrast, my preliminary work highlighted the importance of the social context under which making sense of information is taking place and social computing platform (SCP) features that are responsible for building the social fabric that creates that context. To address these limitations of existing solutions, in this aim I developed new mechanisms that allow for: *1) more flexible definition of user's information needs in the context of complex posts, thus addressing the need to identify sub-focus of interest within them, 2) improved user access to information of interest based on similar textual content that is sensitive to the overall flow of the discussion, thus promoting collective sensemaking at the same time, and 3) explicitly integrated informational and social aspects of the posts of interest, thus promoting and maintaining social connections while satisfying users' information needs.*

Using these mechanisms, I designed, developed and evaluated a novel tool for supporting sensemaking within OHCs, dSense. Further, evaluation of tools that support individual and collective sensemaking is non-trivial; the majority of previously proposed solutions focused on information comprehension, rather than their broader impact on sensemaking. To address this, I have developed a set of methods for evaluating the impact of novel solutions on individual and collective sensemaking. Finally, I conducted initial evaluation of dSense and explored its impact on individual sensemaking, an individual's ability to contribute to collective sensemaking, and on an individual's awareness of the participants in the discussion. *The results of this aim can help to generate new insights for the design of future informatics solutions that take holistic*

approach to supporting sensemaking within OHCs and gravitate around finding relevant content in a discussion, as well as means for evaluating them.

1.7 Significance

This dissertation makes contributions to the scientific knowledge and has the potential to make a practical impact.

This work generated new knowledge regarding collective sensemaking in OHCs and different factors that contribute to this phenomenon. First, it articulated the multiple factors that trigger collective sensemaking, including reference to a contentious topic, contentious or strongly expressed opinion, statement of a personal question in generic terms, and involvement of core members of the community. Further, it described the elements that constitute collective sensemaking within OHCs, such as lateral engagement between participants, reflection on previously stated perspectives, and transformation of ideas through the posts in the thread. Moreover, it outlined conversational moves that enable collective sensemaking, such as agreement/disagreement with previously stated position, presenting argument for/against previously stated position, further developing previously stated position, personal reconciliation, and synthesis of previously stated perspectives. These results can provide a firm foundation for the development of a more formalized definition and description of collective sensemaking within OHCs. In the future, this formalization of collective sensemaking could serve as a basis for computational approaches to detecting and measuring the intensity of collective sensemaking in online discussions that could potentially lead to improved information retrieval and construction of meaning in groups. This knowledge was contributed through several in-depth studies of collective sensemaking that takes place in OHCs and its relationship to the interplay

between informational and socio-emotional needs that are manifested in this setting. By understanding these relationships we can assess the importance of the social component for collective sensemaking and OHCs well-being more accurately and design accordingly for the specifics of this environment.

Further, this dissertation explored the design space for interactive solutions that support the three main processes in OHCs: providing support for informational and socio-emotional needs of their members, and creating new knowledge through collective sensemaking. Along these lines, I have proposed and evaluated two novel design solutions that extend previous work and that were explored with DisVis and dSense. First, I identified and developed a novel way of helping individuals meet their informational needs using two complementary components: 1) fast and granular articulation of information needs through selection of a segment of text in a discussion post, and 2) using this selection as a query to identify posts that contain similar text. Next, I proposed a new way of integrating individual and collective sensemaking via a visual representation of a discussion thread that both preserves its general structure, as well as highlights posts of potential interest and allows for easy exploration of the discussion. Moreover, I proposed new ways of promoting social awareness as part of the information access by visually coupling posts in the discussions with social identities of their authors and allowing easy access to their summarized profiles. Finally, I provided a scalable approach to visually representing discussion threads that can accommodate up to a 1000 posts contributed by hundreds of participants, and by some adjustments in the visualization parameters, based on user's preference, scale even further. This is important because long discussions that accumulate large numbers of posts, although relatively uncommon, typically focus on topics that generate considerable interest within the community, such as controversial topics with highly polarized

opinions, new questions for which little is known, and topics that elude consensus. Consequently, these long discussion threads present the main need and opportunity for introducing support for both individual and collective sensemaking.

This dissertation generated a set of design principles and preferred features for sensemaking support tools in OHCs that facilitate optimized information access. These design principles can potentially inform and inspire future research on sensemaking in OHCs and on supporting it with novel social computing platforms.

Finally, this dissertation produced a framework for evaluating sensemaking support tools for OHCs forum discussions that attempt to improve individual sensemaking through optimized information access, but are at the same time respective to the collective sensemaking processes in the discussion and the social fabric in the community.

In addition to these scientific contributions, I expect that this dissertation will have a significant impact on current practices within OHCs. Due to the information overload in OHCs forums, tools that support optimized information access are in high demand. However, because of the complexity and interdependency of the information in forum discussions that are a consequence of the collective sensemaking efforts in these communities, such tools need to go beyond the classical information retrieval approach. The dSense tool that I developed in Aim 3 combines information retrieval from the perspective of collective sensemaking and data visualization techniques to achieve more efficient sensemaking of the information in a given discussion. I anticipate that dSense can help the OHC members more effectively and efficiently close their knowledge gaps, and reduce their frustration due to the inefficient information search and confusion that arises from the fragmented information. Indirectly, by improving members'

ability to make sense of information within a discussion thread, dSense may contribute to production of new knowledge. In addition, because of the specific focus on the interplay between collective sensemaking and socio-informational support within OHCs, the proposed solution may stimulate new social interactions, in addition to supporting the sensemaking process. Consequently, this solution may have a positive impact not only on individual members, but on the social dynamics within OHCs and its well-being.

CHAPTER 2: LITERATURE REVIEW

In recent years, online health communities (OHCs) such as breastcancer.org, TuDiabetes.org, and PatientsLikeMe.com, have established themselves as an important complement to the traditional health care [6,62]. Close to a third of all American adults had accessed social media for questions related to health [179] and more than a half of e-patients (patients relying on online medical services) living with chronic disease consume user-generated health information [180]. Of these, almost a fifth participate in generating that type of information [180]. Consequently, discussion forums where most of this information is generated and made accessible to OHC members have become valuable repositories of information and opinions about issues related to health and various diseases [16,40,79]. Traditionally, OHCs have relied on relatively simple discussion forums in which members post their questions and stories and receive replies from others [157]. However, as the membership of these communities grew, so did the information traffic, resulting in high volumes of information collected within their forums [83,120]. As a consequence, making sense of this information became increasingly difficult [25,113]. This could be mainly contributed to the fact that current forum solutions promote continuing growth of the discussion threads, which often results in long discussions, in which topics transition and shift, including both agreement and heated debates among members, where informational posts are interwoven with off-topic social interactions [124]. As a consequence, the discussions often cause OHC members to feel overwhelmed by the information they contain and present difficulties in making sense of that information, which can lead to frustration and disengagement, and in some occasions to suboptimal health choices.

2.1 Sensemaking support tools in OHCs

Previous research found that the members' ability to extract useful information from the forum positively affects individual's empowerment, but is becoming increasingly harder to achieve that task [5,10,149]. Recognizing these issues, Nambisan suggested the need to focus on developing tools that make information seeking more effective and efficient [113]. However, despite these calls for building solutions for optimized information access, little work has been done in the OHCs domain. The solutions that currently exist took the visual analytics approach and were mainly intended for answering research questions, rather than satisfying dynamically changing user information needs [8,29,30,32] or were specifically designed for community moderators rather than regular members [93].

On the other hand, overcoming information overload is a broader challenge that concerns not only OHCs, but also many other online communities. Consequently, previous research outside of the healthcare domain generated a number of solutions to support sensemaking through optimized information access in online forums [3,35,47,58,76,114,140] and other channels for asynchronous group communication, such as e-mail threads [152,153] and news groups [151]. Because of the complexity, richness and volume of information and the dynamically changing user needs in these contexts, these solutions relied on interactive visualizations [47,76,114] rather than the more classical information retrieval techniques relying on search engines [58,140] and recommendation [1,3]. *However, few of these tools for supporting sensemaking in online forums through visual approaches to optimized information access were specifically designed and tested in the context of OHCs. Therefore, open questions remain as to these solutions' ability*

to meet the unique needs of OHC members, their suitability to this new environment, and the levels of preference for their features in this new setting.

There are two major reasons why previous solutions developed outside of the OHCs context may have limitations when applied to OHCs: 1) *lack of understanding how OHCs members collectively make sense of the information in their forums, and 2) lack of understanding what are the influencers to that process typical for those environments.*

2.2 Collective sensemaking in OHCs

The majority of the existing sensemaking support solutions conceptualize a discussion thread as a “bag of posts”, essentially abstracting the thread from the process through which it was created and from the underlying relationships between the posts. To overcome this limitation and to design more reliable and complete solutions, there is a need to investigate and conceptualize the driving processes of the knowledge production in the OHCs forum discussions and incorporate that formalization in the design of tools for facilitating individual and collective sensemaking. Previous research argued that *collective sensemaking* is one of the fundamental underlying mechanisms of knowledge production within communities of practice and organizations [51,118]. Collective sensemaking is related to understanding how individuals construct meaning together: building on each-others knowledge about the situation under a given context through observations and interpretations of others contributions with the purpose to support independent individuals to move in the new desired state [74,109]. Thus far, collective sensemaking has been explored within organizational sciences [164,165], crisis management [142], and in clinical setting [4], but less so within OHCs. Previous studies of collective sensemaking as a mechanism behind knowledge production in online communities were conducted primarily in the context of

Wikipedia, one of the better known communities for collaborative production of knowledge. There, researchers explored mechanism such as construction of facts [146], leadership coordination [176,177], negotiation and resolution of differences in opinions [90], patterns of contributions [65,89] and transformation of members' contributions to the community knowledge [18]. Similarly, in the healthcare domain, researchers investigated how diabetes OHCs members help one another find individualized strategies for managing diabetes [78], and how competing viewpoints in online content affect patients recently diagnosed with Lyme disease with their understanding about the condition [102]. *While these studies developed initial descriptive accounts of collective sensemaking, much remains unknown in regards to how collective sensemaking occurs and what factors promote and inhibit it and what informatics solutions can facilitate collective sensemaking within OHCs.*

2.3 Influencers on collective sensemaking in OHCs

Aside from abstracting the discussion thread from any underlying generating processes, previous sensemaking support solutions also did not pay attention to the social fabric in the community and how it influences the collective sensemaking process. While collective sensemaking is primarily attributed to making sense of information with group efforts, it is inherently a social process and it can't be detached from the social context under which it takes place [74,109,118]. Consequently, deep understanding of the environment in which it takes place is of great importance for designing sensemaking support tools.

Strongly tied to this notion is the fact that previous research suggested that OHCs can be observed as informational repositories that store valuable information regarding individuals' experiences with different health conditions and diseases [39,73,78], but also as social spaces

where members spontaneously meet and mingle [144] and establish friendships and deep social connections [99,136]. Indeed, there are two main reasons for which people join these communities and two forms of social support that members seek and receive: informational and socio-emotional support. Informational support helps satisfying *informational needs* related to finding advice or learning about others' experiences with diseases and different health challenges [40,113]. On the other hand, socio-emotional support helps satisfying *socio-emotional needs*. This often includes *companionship*, which is accomplished through chat, humor, and discussions on general life topics, outside of the disease, and *emotional support*, which is related to understanding, encouragement and empathy, among others [136,157,168].

Researchers have previously investigated the relationship between informational and socio-emotional support. Studies pointed out that matching members' needs with the appropriate form of support (informational or socio-emotional) is essential for membership retention [154,159,160] and that the type of support provided depends on the seniority in the community and levels of engagement [137]. Therefore, the ways in which these two types of needs that drive the social support in the community coexist together could potentially influence the way members perceive the OHCs and engage in collective sensemaking. *However, the interplay between socio-emotional and informational needs that shape the socio-emotional and informational support in the community, as well as the relationships between these forms of support and collective sensemaking remain poorly understood.*

2.3.1 The importance of the social component of OHCs to the collective sensemaking process

As a consequence of the delicate interplay between informational and socio-emotional needs in OHCs, new solutions for supporting sensemaking should consider how the social environment, which is a major component of the OHCs, affects the community's well-being and shapes the collective sensemaking process.

Research has shown that over half of the reasons why people participate in health related online communities is for obtaining socio-emotional support through chat, humor, and empathy and building friendships [136,157]. Further, being able to socially integrate in the community is related to the quality of socio-emotional support received [43,75]. In addition, the knowledge production in OHCs is deeply impacted by the social dynamics within the community and, in particular, by the trust developed among community members [173]. This suggests that a tightly knit positive social environment in the OHC is an important contributor to the knowledge production and wellbeing of its members [174]. Tools that detach information access optimization from the social component of the community and do not account for and are not sensitive to the important dependencies between collective sensemaking and social ties of the community members may inadvertently disrupt the social fabric within the OHCs and possibly hurt the way members collectively construct meaning. As a result, it is important that solutions for promoting sensemaking focus not only on members' informational needs, but also on the social eco-system in the OHCs and on supporting their members' socio-emotional needs. *However, there exist few guidelines as to how to incorporate social awareness and support for*

building social relationships into the design of tools and solutions for improving access to information in online communities in general, and OHCs more specifically.

In summary, previous research provided a rich description of OHCs as spaces for social support (informational and socio-emotional) and for collective production of knowledge, and offered broad spectrum of solutions for tools that can support sensemaking in forum discussions. However, these tools were designed and evaluated with online communities outside of the healthcare domain, which have different expression of informational and socio-emotional needs and dynamics between them. In addition, these tools didn't account for the underlying process behind the generation of the information in the discussions i.e. collective sensemaking and how the interplay between informational and socio-emotional needs in the particular community of practice might affect it. Moreover, they didn't consider the social aspects of the communities they were developed for - the social ecosystem established between their members, and how tools that try to support collective sensemaking should be appreciative of that and even support it.

In the following Aims, I will try to address each of these gaps in order to: *a) provide deep understanding of the collective sensemaking process in OHCs and factors that influence it specific for that environment, and b) produce principles and guidelines, as well as a set of desirable features for sensemaking support tools design for OHCs, which take into account collective sensemaking and are respective of the social fabric of the community.*

CHAPTER 3: AIM 1 – GENERATING A RICH DESCRIPTION OF COLLECTIVE SENSEMAKING IN OHCS FORUMS AND ITS INFLUENCING FACTORS

The goal of Aim 1 was to characterize collective sensemaking within OHCs through developing a rich descriptive account of collective sensemaking and factors that contribute to it. This was achieved in three studies: Study A1.1, Study A1.2, and Study A1.3 (Figure 7).

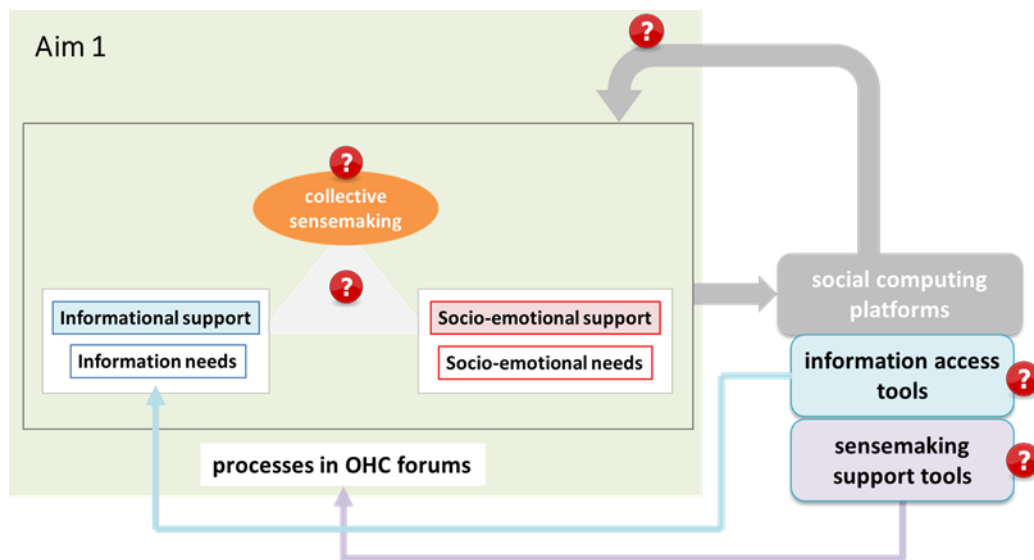


Figure 7. Knowledge gaps addressed in Aim 1.

3.1 Study A1.1 - Understanding of collective sensemaking in OHC forums

In this study I developed a rich descriptive account of collective sensemaking within OHCs and factors that contribute to it.

3.1.1 Related work and knowledge gaps

The phenomenon of collective sensemaking has been explored in many domains such as organizational behavior [164,165], military [142], education [42], crisis management [74] and clinical setting [4], but rarely in OHCs. While research generally agrees that in collective sensemaking the main objective is often achievement of multiple perspectives for individual decision making support, rather than reaching a consensus [74,78], there is a need for a more detailed and robust understanding about how that happens in online communities, especially in OHCs. Research tangible to collective sensemaking that goes deeper in describing mechanisms behind knowledge production in online communities was conducted in Wikipedia. There, researchers explored mechanism such as construction of a fact [146], leadership coordination [176,177], negotiation and resolution of differences in opinions [90], patterns of contributions [65,89] and transformation of how members contribute to the community knowledge [18]. Similarly and in the healthcare domain, Huh and Ackerman investigated how diabetes OHC members help one another find individualized strategies for managing diabetes [78]. Also, Mankoff et al. explored how competing viewpoints in online content affect patients recently diagnosed with Lyme disease with their understanding about the condition [102]. *However, there remain many questions as to how collective sensemaking occurs, what steps are involved in this process, what triggers it, and what factors facilitate and inhibit it.* To address this knowledge gaps, I asked the following research questions:

1. *How OHC community members share information and learn from each other?*
2. *How can we recognize and describe the quality of the collective sensemaking process?*
3. *What are the building blocks of the collective sensemaking process?*

3.1.2 Methods

To answer the research questions from above, I conducted a mixed-methods study with the TuDiabetes.org online health community for diabetes self-management. The study took place in the spring and summer of 2014. To answer RQ1 and get a better grasp of the members' involvement in the TuDiabetes forum discussions I first quantitatively analyzed patterns of members' engagement with the forum based on 20,000 discussions (out of 22, 180 available at that time in the forum). In addition, I conducted qualitative open-ended interviews with 9 administrators and active users of the TuDiabetes.org forum. Questions were asked related to individuals' experiences with the community, characterization of discussions that resulted in new knowledge and insights, issues of trust, and the impact of the platform on users' engagement, among others. To answer RQ2, I conducted thematic analysis of 30 of the most popular threads with the specific focus on patterns of participants' engagement. Based on my working definition of collective sensemaking, which understands it as a back and forth negotiation of meaning between multiple actors, I assigned labels to the most popular threads for having high, medium or low level of collective sensemaking. Then, I examined what other attributes differed between threads exhibiting different degrees of collective sensemaking. Finally, to answer RQ3, I conducted a detailed discourse analysis of two threads from the list subject to the previous analysis and inductively coded each post based on its contribution to the discussion and with respect to collective sensemaking.

To preserve the participants' identity used P1-P9 to refer to the participants of the interviews, and M1-M9 to refer to members who contributed to the discussion threads I analyzed.

3.1.3 Results

In this study I developed a rich descriptive account of collective sensemaking within OHCs and factors that contribute to it. I identified patterns of engagement in the discussions, discussion types and levels of collective sensemaking they contain. I also defined the elements of collective sensemaking as well as the factors that trigger it. Then, I determined the building blocks of collective sensemaking. Finally, I described how the social computing platforms influence the sensemaking process.

3.1.3.1 Patterns of engagement

The analysis of the discussions showed patterns consistent with much of the previous research on online communities that roughly follow Exponential-Logarithmic (EL) distribution with high failure rate and long tail. For example, most of the discussions included only a few members (between 1 and 10, including the initiator of the thread) and only a small percentage of the discussions had more than 30 participants (Figure 8A). Similarly, most of the discussions had between 0 and 30 replies, however, several reached over 1K replies (Figure 8B). Most users posted only once, fewer contributed between 2 and 6 posts, and only a few posted on a regular basis; their contributions could amount to tens of thousands of posts during their membership with the community (Figure 8C). Similarly, when examining posts per user within discussions, most users contributed to a given discussion only once (Figure 8D). However, a fair number contributed between 2 and 8 posts, and a few individuals contributed more than 8 posts to a given discussion. Most of the discussions did not stay active beyond the first day; a fair number stayed active for about a week, and the oldest still active discussion was initiated almost 6 years

ago (Figure 8E). Also, TuDiabetes was a very active forum – almost 90% of the initial posts received their first reply within the first day (Figure 8F).

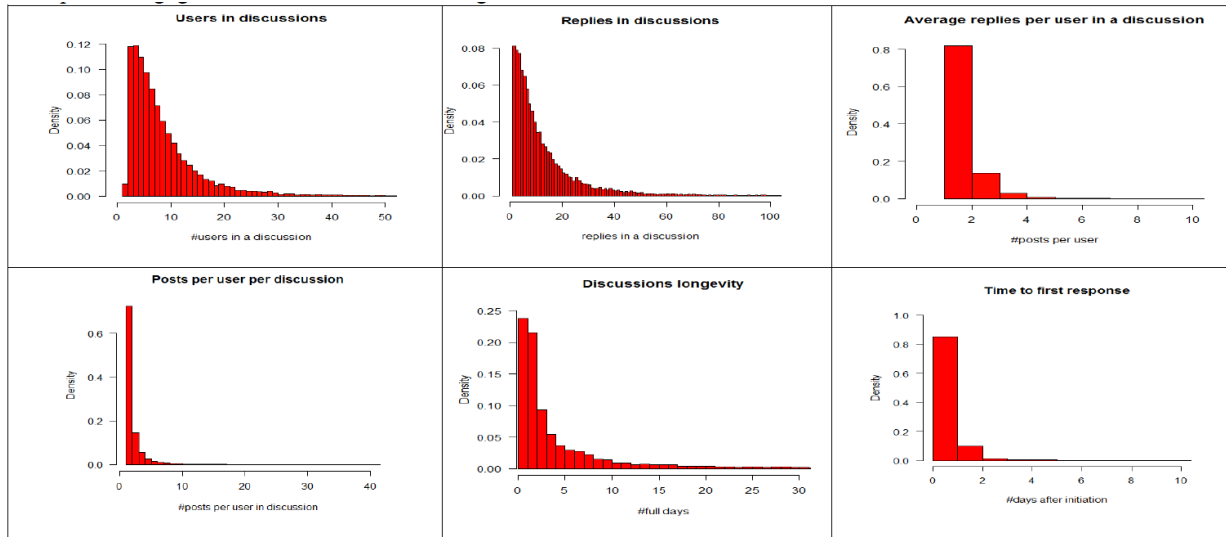


Figure 8: Patterns of engagement: a) number of users in a discussion; b) number of replies in a discussion; c) average number of replies per user; d) posts per user per discussion; e) discussion longevity; f) time to first response.

3.1.3.2 Discussion types and level of collective sensemaking

In this study, my goal was to identify discussion types and the level of collective sensemaking they carry. The qualitative analysis of 30 of the most popular discussion threads on TuDiabetes revealed several distinct categories of discussions: a) *opinion/experience polls* (n=13) started with posts that sought opinions or experiences of others on a topic of interest; b) *statement of strong opinion* threads (n=2) started with posts that stated a strong opinion about a certain issue; c) *ice-breakers* represented games usually not related to diabetes (n=7); d) *bonding* threads (n=3) asked individuals to share their general experiences related to diabetes, rather than focusing on any aspect of it in particular; e) *personal issue* threads (n=3) were initiated by individuals

seeking advice in regards to a specific personal issue, and f) *announcements* of new events from TuDiabetes leadership (n=2) usually led to a roll call with members responding and committing to participating.

These popular threads varied greatly in their longevity (from 3 days to over 6 years), the number of posts (from 64 to 24,193), and in the reply rate, from 1 post every 5 days to 91 posts per day (on average). I found an interesting metric to be a ratio of views to replies, which indicated both the level of interest in the topic among members of the community, and the effort required for participation in the discussion. For example, many ice-breakers had low view/reply ratio, suggesting that most members who viewed this thread posted their own reply. In contrast, opinion polls, particularly on controversial topics had a very high view/reply ratio with many people viewing the thread, but only few replying to it.

Using a working definition for collective sensemaking, I labeled the discussions as having high, medium or low collective sensemaking. Discussions where individuals engaged in deep discussion with each other, examined different perspectives, and sought consensus on an issue of common interest were considered to have high degree of collective sensemaking. Based on this, I classified 8 of the threads as “high collective sensemaking”, 7 threads as “medium collective sensemaking” and 13 threads as “low collective sensemaking”. Most of the community building threads (ice-breakers and bonding) were classified as having a low degree of collective sensemaking; opinion/experience poll threads were almost evenly split between “high collective sensemaking” and “medium collective sensemaking”, as were personal issue threads.

3.1.3.3 Collective sensemaking elements

After labeling the discussion with high, medium and low level of collective sensemaking, I tried to investigate in more detail what characteristics those that have high collective sensemaking have in common. By qualitatively analyzing these forum discussions I identified 3 constituting elements of collective sensemaking: 1) *lateral engagement between participants*, 2) *reflection on previously stated perspectives*, and 3) *transformation of ideas through the posts in the thread*.

The first one is related to the involvement of a variety of members in the process of meaning negotiation through dense conversational turns. The second one is related to approving or disapproving of previous statements. The third one is related to taking a statement from someone else and developing it further. For the collective sensemaking to be present each of the three elements has to be observed.

Lateral engagement between participants

One of the most obvious indicators of collective sensemaking was the depth of the replies in the thread. Multiple levels of replies usually indicated that participants not only expressed their own individual perspectives but also engaged in the back and forth negotiation of meaning. For example, in many of the opinion/experience polls, individuals often interrogated each other's perspectives, weighting evidence or sharing relevant experiences. In contrast, many ice-breakers included only first-level replies, and showed no engagement between participants. Importantly, however, level of depth was not always a sufficient indicator of collective sensemaking. When most of the back and forth discussions occurred between the person who initiated the discussion and those who responded, individuals' ideas and recommendations rarely developed beyond their original form. In contrast, when different respondents engaged with each other, their exchanges often focused on clarifying, enriching, and otherwise developing their initial ideas.

Reaction to previous perspectives

Many posts in the threads with a high degree of collective sensemaking began with reflection on previously stated perspectives. For example, below are two replies in the “How Soon to Insulin?” thread, one that reinforces a previously proposed solution, and another that contradicts it:

M1: *“I agree with what everyone else has said; you need to be antibody tested to see if you are T1.”*

M2: *“I second everything that has been said here ... except the criticism of Humulin.”*

These simple references placed new posts in the context of other contributions and helped to move the discussion forward. In contrast, in “At the End of the Rope...” most of the new posts lacked such reference and seemed independent from each other, often leading to high redundancy in the thread. Any similarity in opinions and recommendations could only be recognized through critical reading and comparison.

Transformation of ideas

Perhaps most importantly, many posts within high collective sensemaking threads not only reflected on the previously proposed perspectives, but also developed those ideas beyond their original form. Consider the following sub-discussion from the thread “How Soon to Insulin!” that focused on comparative advantages and disadvantages of a particular type of insulin, Humulin. This sub-thread began when the initiator of the original post mentioned that she was prescribed Humulin taken at bedtime. This choice, however, was quickly called into question:

M3: *“I wonder at her decision to put you on Humulin rather than using one of the newer insulins.”*

Many subsequent posts took a similarly skeptical view of Humulin; however, instead of simply restating their disagreement with the endocrinologist's choice, each of them contributed a new perspective on Humulin's specific limitations, for example its unpredictability and its ability to lead to hypoglycemia (low blood glucose levels).

Yet, another replies highlighted its positive aspects, for example its ability to "handle" high-protein meals:

M2: *"It may not be the flashiest and newest thing around, but it definitely has its valid uses. I haven't found anything else that handles high-protein meals anywhere near as well."*

In our analysis I found that all three of these characteristics are necessary to recognize collective sensemaking; absence of either one of them puts collective sensemaking into question. For example, lack of lateral exchange between participants in a thread de-emphasizes the possibility of any shared understanding among participants. Absence of reflection on the previously stated perspectives obscures connection between posts, turning a thread into a list of unconnected opinions and recommendations. And finally, if there is no transformation of ideas, and each new post simply agrees or disagrees with previously expressed perspectives, the thread becomes an elaborate way of community voting more typical for Q&A sites, or a debate between individuals holding opposing positions, rather than richer forms of collective sensemaking.

3.1.3.4 Conversational moves of collective sensemaking

With regards to finding the building blocks of collective sensemaking I used discourse analysis of two of the most popular 30 threads that I previously used for analysis and identified 10 conversational moves - different types of contributions each individual post made to the overall

discussion (Table 1). Importantly, individual posts were rarely limited to a single move and often included multiple moves simultaneously.

Table 1. Types of contributions to a discussion; 6-10 specifically indicate contributions to collective sensemaking.

Conversational move	Example
1. Asking a question	Anyone else in a similar situation or have any advice?
2. Statement of a perspective	I think it is perfectly fine to move to insulin.
3. Reframing the problem	I strongly encourage you to ask for a full panel of antibody testing and a c-peptide test to determine if you are Type 1
4. Introducing new topic	Btw, even with insulin I still have to eat a low carb diet to keep my bg as stable as possible, you may end up having to do that anyway.
5. Suggesting resources	Gary Scheiner's "Think Like a Pancreas" and John Walsh's "Using Insulin" are good resources.
6. Agreement/disagreement with previously stated position	I agree with what everyone else has said, you need to be antibody tested to see if you are T1
7. Presenting argument for/against previously stated position	There was a study I saw a note about in a Diabetes Forecast "sidebar" that showed that T2 put straight onto insulin had better control or something to that effect
8. Further developing previously stated position	Humulin R may have a role as a supporting player or even as a primary insulin if cost is the issue but it is being prescribed for use before bed rather than before meals
9. Personal reconciliation	Dear, im sorry if i offended you
10. Synthesis of previously stated perspectives	You have gotten some excellent advice here at TuD, and I am glad you have an appointment with your endo. It is important to get testing to see if you have Type 1 diabetes, but the most important thing is getting excellent treatment and care.

Five of the identified conversational moves were those through which collective sensemaking is manifested and takes form (moves from 6 – 10 in Table 1): 1) *agreement/disagreement with previously stated position*, 2) *presenting argument for/against previously stated position*, 3) *further developing previously stated position*, 4) *personal reconciliation*, and 5) *synthesis of previously stated perspectives*. I will further elaborate on these conversational moves below.

Many discussion threads began with a post that *asked a question*. These types of posts, however, could appear anywhere in the conversation, when members sought new information or clarification of previous positions. Often, questions were replied to with posts that *stated different perspectives* on the topic of interest. Notably, these could take a form of an opinion (for example, “it’s never too early to start on insulin”) or a recommendation (for example, “I think you should ask your endo for insulin right away”). At times, however, instead of directly answering the question, answers attempted to *reframe the problem* in somewhat different terms. For example, instead of answering whether early introduction of insulin is appropriate, this type of post could suggest correctness of diagnosis as a more important question. Other posts suggested a *new topic for discussion* that was related to the original question, yet took the discussion in a different direction. For example, in a thread about early introduction of insulin, one of the replies mentioned low carb diet as a way to stabilize blood glucose (BG) levels in addition to medication. Other posts *suggested resources*, such as useful websites or books, often without stating their authors’ opinion on the topic of interest.

While the five categories above focus on the nature of the individual posts, the next five categories focus more on the relationships between posts. The first category includes moves that express direct *agreement or disagreement* with previously stated perspectives. These moves can often be complemented by presenting an *argument or evidence* for a previously stated

perspective; however, often I found that individuals continued presenting new arguments long after the perspective was stated. When differences in opinions created conflicts, individuals often attempted to *reconcile differences*, make amends, or to phrase their opinions in milder terms. In some cases, individuals, often community moderators, attempted to *synthesize and summarize previously stated perspectives*.

3.1.3.5 Collective sensemaking triggers

In addition to the three collective sensemaking elements and conversational moves through which those are achieved, I also identified several triggers to collective sensemaking. The study suggested four main factors that appeared to be associated with collective sensemaking: *1) reference to a contentious topic; 2) contentious or strongly expressed opinion; 3) statement of a personal question in generic terms; and 4) involvement of core members of the community.*

Contentious topic

There are a number of contentious topics that almost inevitably provoke engaged discussion within the community. The appropriateness of low carbohydrate diet for diabetes self-management, the nature and significance of differences between T1 and T2 and which of these conditions is “worse”, and advantages and shortcomings of early introduction of insulin therapy – these questions are continuously debated within TuDiabetes and healthcare community at large. Some participants became wary of these ongoing debates that often involve emotional reaction from members, but rarely get resolved or lead to any consensus.

M2: *“There are certain topics that apparently must be debated and redebated endlessly. Every few months this discussion starts up again. Everyone restates their positions, nobody changes their mind, and everyone jockeys to have the last word. Broken records. Makes me tired.”*

However, new members of the community often felt that these debates were enormously educational, exposed them to many diverse opinions, and often inspired them to try new approaches in their own self-management.

M6: *“I know it's been discussed and debated in the past, but just reading through these 8 pages over lunch, I've gleaned a lot of new information that is great!”*

Contentious posts

In addition to contentious topics, posts that expressed strong opinions even on mundane topics tended to generate a lot of discussion:

P1: *“I think for a lot of people, you know, you see a thread and you chime in with what you want to say about it and then you're kind of done with it unless you're mad, and then you say what you want to say and then you wait 15 minutes and go see if anybody replied so that you can reply again.”*

However, in both of these cases, intensive back-and-forth engagement between participants did not always lead to collective sensemaking, for example if their posts did not include transformation of ideas.

Generalizing personal problems

Third, I found that the framing of the question in the post initiating the discussion had a significant impact on the patterns of engagement between participants. This became particularly apparent in threads in which the initiating post presented a personal challenge and asked for advice. For example, initial posts in both “At the End of the Rope...” and “How Soon to Insulin” asked for advice on a specific personal challenge. However, in “At the End of the Rope...”, the initial post presented the problem in a rather idiosyncratic way, which made it difficult to

construct a more general question of interest to others. In contrast, the initial post in the “How Soon to Insulin” thread formulated a more general question: whether it is appropriate to introduce insulin as the first treatment option. This generalization inspired others to not only respond to the original question, but also engage in negotiation of a more generalizable answer.

Involvement of core members

Finally, I found that while the topic and the framing of a question had a significant impact on the patterns of engagement among participants, ultimately it often came down to who posted the question, and who was involved in the discussion. As many other online communities, TuDiabetes has a core group of members who actively contribute to blogs and forums and who often recognize each other’s names. These individuals are usually highly opinionated and outspoken; their voices were persistent in all of the threads included in my analysis. Moreover, they have a level of comfort and familiarity with each other that often leads to a deeper engagement.

P2: *“If a person is plugged into a site, that is they are common posters in that area, they are far more likely to get more and more comments back. The more plugged in you are, the more regulars will comment back to you.”*

3.1.3.6 Collective sensemaking dimensions

Together with persistent patterns, there were also considerable differences between threads with a high degree of collective sensemaking. I discuss these differences along two different but related dimensions: whether these threads included exchange of information or personal experiences, and whether they sought consensus or diversity in opinions.

Information-driven threads often evolved around general concepts of high interest to the community, for example, the appropriateness of severe reduction of carbohydrates for individuals with diabetes. In these threads, most of the back and forth negotiation of perspectives focused on presenting and critiquing new arguments and evidence supporting either of the contrasting positions:

M7: *“Here are some studies to look at: 1) Link between obesity and inflammation. 2) Link between chemicals secreted by fat tissue and insulin resistance. 3) Another study along the same lines as the one above, but regarding different inflammatory chemicals.”*

M8: *“The first link has a lot of “could” in it...”*

In contrast to this, most of the posts in *experience-driven threads* included descriptions of individuals’ personal experiences related to the topic of interest. For example, in a different thread with the focus on low carbohydrate diet, the participants mostly shared their personal stories, and what worked and did not work for them. In these situations, the participants use similar back and forth mechanisms to relate to each other’s experiences and point similarities and possible explanations.

M9: *“I like to be in the upper 80s because after 8:30, I start to climb to 120ish until 11:00 when it magically goes down and stays down if I eat right. If I start out in the 80s it doesn't climb as high. So I have dawn phenomenon but it doesn't kick in until after 8:30?”*

M10: *“M8, same thing happens to me. If I don't eat & inject right away, up, up & away. Not a morning person either.”*

Perhaps as a result, these two threads exhibited different attitudes towards consensus. In the first one, individuals holding different perspectives presented new information and evidence, trying to convince other members to agree with their point of view. In contrast, in the second thread, a consensus, even temporary, was neither sought, nor deemed necessary. Instead of trying to convince each other, participants of this thread shared different perspectives and experiences, together creating a rich and multifaceted picture of this complex issue.

3.1.3.7 Impact of the social computing platform on collective sensemaking

At the time of this study, TuDiabetes was hosted by Ning – a commercially available social networking platform that featured a discussion forum. This forum had a number of distinct features that appeared to have an impact on how the discussions unfold and hence the collective sensemaking taking place in them. Most importantly, it supported sub-threading of discussions by allowing participants to reply to each other at great level of depth (up to 9 levels). This allowed individuals to explore issues of mutual interest in greater depth, and enabled that back and forth that was perceived as indicative of collective sensemaking. However, this sub-threading approach also has a few limitations that often led to suboptimal comprehension of the discussions and contributions to the collective sensemaking process taking place in the discussions.

Making suboptimal contributions to the collective sensemaking process

First, because all of the posts in a thread are made in a textual form with no meta-data users must read the entire thread to understand how each individual post contributes to the discussion, which may present a challenge for threads with a large number of posts. Second, because the initial post in a discussion thread is immediately followed by a “Reply” button with an open text field, users

often felt compelled to compose their own reply before reading the existing discussion. However, after engaging with the discussion for a little while, many users restated their perspective as a response to a particular post. This often resulted in redundant posts that made the thread longer, but contributed little to collective sensemaking. For example, collective sensemaking was triggered about aspects of topics that were already addressed elsewhere in the discussion, or the collective sensemaking moves such as agreement or disagreement with previously stated position, presenting argument for or against previously stated position, and further developing previously stated position were simply repeated. Third, the platform imposes a limit of 9 replies within a sub-discussion and removes the option to continue the sub-thread beyond that. As a result, additional replies were sometimes added not to the last post in the sub-thread, but to the previous posts, essentially putting replies out of order.

In regards to thread presentation, all the posts in a thread are displayed in chronological order, but within their original sub-discussion structure. As a result, when reading through the thread, individuals could read posts added to subdiscussions several years later before seeing posts added to the main thread much earlier.

These limitations, combined with a rather ineffective search function, made it difficult to peruse discussion threads with over 20 or 30 posts, which was noted in many of the interviews. Those who actively participated in a discussion could follow its structure by seeing it unfold in real time. However, synthesizing the main topics and opinions in a discussion they were not a part of was both labor-intensive and time-consuming.

M8: *“Well, the challenge is the amount of words you have to read in order to find the consensus. ... so if I go on and I want to know if there is a discussion that is going on, it's easy for me to*

follow it, hour by hour, minute by minute but if I want to look at it even one month later, it's very very difficult to figure it out because you have to read it all.”

Strategies for making sense of new threads

The participants mentioned several different strategies to exploring threads they did not participate in. Some started reading from the beginning of the thread (in chronological order) and read until they “got bored” or reached a point of saturation. Others read in the reverse chronological order, starting with the most recent posts and going backwards. Yet the most common strategy appeared to be random sampling. In this strategy, the participants skimmed through the thread, reading a few messages from the beginning of the thread, a few from the middle, and a few more from the end. Many participants who reported relying on this strategy felt that it gives them an idea of how the thread evolved over time. However, this common strategy made it difficult to benefit from the rich back and forth of collective sensemaking, and could result in a fragmented or skewed perspective on the opinions in the community.

3.1.4 Implications of the results

The study suggested that currently available discussion boards are ill-suited to supporting collective sensemaking. The rich back and forth negotiation among members is often buried in the volume of posts in the threads, and is usually only apparent to those who participated in the discussion. The random sampling method for reviewing long discussion threads, common among members of the community, breaks internal structures of meaning and can lead to a distorted or incomplete perspective on the topic of the discussion. Given the limitation of the discussion boards, one might wonder whether such platforms as Wikipedia, or Stack Overflow present a more suitable alternative to the traditional discussion boards. The results presented here suggest

that there are indeed many similarities between the types of engagement I observed on TuDiabetes, and others observed within Wikipedia [146] and Stack Overflow [100]. Similarly to the members of these communities, members of TuDiabetes often engaged in deep discussions, back and forth negotiation of meaning, and resolution of conflicts in opinions. In addition, individuals together created shared artifacts, as their negotiated opinions left permanent traces in the discussion threads. In a way, these traces fulfill Wenger's requirement for reification through construction of shared artifacts [166].

However, together with these similarities, there are also deep epistemological differences between Wikipedia, Stack Overflow, and TuDiabetes. Wikipedia's style of engagement implies that knowledge is socially constructed through active collaboration between individuals. Somewhat in contrast to this, the design of Stack Overflow implies that knowledge is a property of an individual, and the role of the community is to recognize the "best answer", rather than collectively construct it. Further, both Wikipedia and Stack Overflow value consensus and lead their users towards agreement through collaborative writing and editing or through voting. At the end, there is only one Wikipedia article on any given topic, and one most popular answer on Stack Overflow, however unstable it might be. Similarly to Wikipedia, the style of engagement in TuDiabetes implies that knowledge is distributed among many individuals, and is often brought into existence through active back and forth negotiation of different perspectives. However, members of TuDiabetes value both diversity of opinions and agreement among members. Often the main benefit of the forum is in exposing individuals to the richness and multiplicity of different perspectives, which help them to construct their own personal views. Based on this, it is likely that there is something unique that discussion boards bring to the

collective sensemaking process that might be lost if we think about replacing them with platforms that share features close to Wikipedia or Stack Overflow.

As a result of our analysis, I propose that tools for facilitating collective sensemaking in online health communities could take several different forms. First, they can help individuals to engage in a more explicit collective production of shared artifacts in a way that encourages negotiation, yet does not require consensus. Instead, as a result of my analysis, I propose that tools for facilitating collective sensemaking in online health communities could take several different forms. First, they can help individuals to engage in a more explicit collective production of shared artifacts in a way that encourages negotiation, yet does not require consensus. In recent years, shared content collections, such as Pinterest, gained substantial popularity [181]. In a similar way, members of TuDiabetes could create collages of content related to topics of mutual interest that reflect their perspectives and views. Such collectively constructed collages could serve as shared artifacts and further reinforce reification. Second, computing tools can help individuals to be more explicit about how their posts contribute to the overall discussion thread. For example, using the taxonomy of collective sensemaking contribution types from this study, members can be more explicit on whether they present a new perspective, agree or disagree with others, provide evidence or recommend new resources by assigning it an appropriate tag. Moreover, these tools could also facilitate polling opinions of others through voting, making distribution of opinions more apparent. Finally, there is a significant and growing body of work on using computational approaches, such as natural language processing (NLP), data mining, and machine learning, to computationally analyze text within discussion threads. In computational linguistics, new methods focus on the design of novel statistical models for tasks such as event detection [14], sentiment analysis [121], and modeling of the topics of discussions [138] as well

as predicting the structure of discourse [156]. Taking these trends further, Hoque et al used a combination of NLP and data visualization techniques to visualize salient properties of discussion threads, such as topics discussed and sentiment towards these topics [76]. The framework suggested in this Study A1.1 can provide foundation for new approaches to facilitating collective sensemaking using computational text analysis and interactive visualizations (exactly the approach that was taken in this thesis for the development of a sensemaking support tool). Specifically, the three main attributes of collective sensemaking proposed here—lateral engagement between participants, reflection on previous perspectives, and transformation of ideas—can suggest new directions for computational analysis of text. Some of these methods already exist (e.g. detection of agreement and of topic transformation) [44]; others still need to be developed. These methods can then be used to inform visualizations of discussion threads that draw individuals’ attention to areas of debate, or to areas where discussion pivots and may warrant further examination.

3.1.5 Summary of Study A1.1

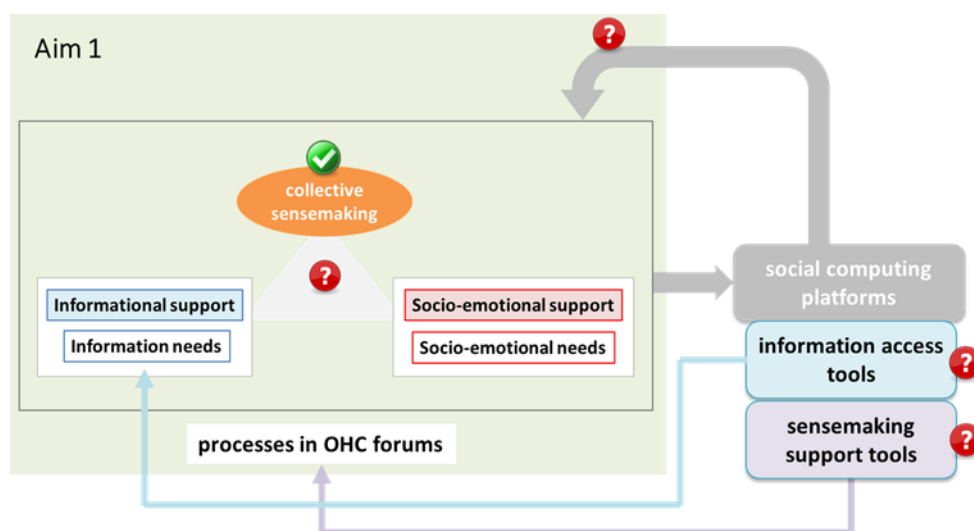


Figure 9. The knowledge gap addressed after the completion of Study A1.1 from Aim 1.

The findings from Aim 1 contributed to better understanding of the mechanisms that enable collective sensemaking, ways it shapes discussions within OHCs and how it is influenced by the technological affordances of the platform where it takes place (Figure 9). This deep knowledge about the dependencies between the contributions in a discussion with respect to collective sensemaking and the technological platform affordances that constrain it will help in the development of more reliable information access algorithms for collective sensemaking support tools and ways to make the process more apparent to the discussion participants.

The main findings that are relevant for the design of the holistic sensemaking tool in Aim 3 are: a) individual posts in a discussion exhibit a variety of complex dependencies with other posts in the discussion as a consequence of collective sensemaking; b) the collective sensemaking should be made more apparent as compared to what a typical discussion platform can provide to enable more optimal contributions by discussion participants.

3.2 Study A1.2 – Coexistence of informational and socio-emotional needs in OHCs forums and their influence on collective sensemaking

In this study I investigated the coexistence of informational and socio-emotional needs in OHCs which dictate the context under which collective sensemaking takes place.

3.2.1 Related work and knowledge gaps

Collective sensemaking is a process in which a group makes an effort to contribute to the process of making sense about certain topic of interest in order to close a knowledge gap i.e. satisfy an

information need for individual members [74]. However, making sense of information in a group is highly driven by the group's social context [118,164]. In the OHCs setting, this social context is in turn dictated by the satisfaction of socio-emotional needs of community members, which typically takes the form of providing companionship and emotional support [99,154,160]. Therefore, there is a need for a deeper understanding of the interplay between informational and socio-emotional needs, as two major pillars in OHCs, as it can have an important impact on the design of new tools for supporting collective sensemaking in these communities. Previous research pointed that informational and socio-emotional needs have intricate and complex relationships. For example, Vlahovic et al. found that users expressed higher levels of satisfaction with their experience when their information needs were matched with information, but less satisfaction when they sought informational support and received emotional support [154]. Similarly, Wang et al. found that members exposed to more emotional support were less likely to leave the community; however, informational support did not have the same strong effects on their commitment [160]. Other researchers suggested that there may be relationships between members' engagement and experience within the community and their orientation towards information and socio-emotional support. Specifically, they found that members form the core of the community are more likely to engage in socio-emotional interactions among themselves than with more peripheral members to whom they provided mostly informational support [137]. *However, the interplay between socio-emotional and informational needs that shape the socio-emotional and informational support in the community, as well as the relationships between these forms of support and collective sensemaking remain poorly understood.* To address this knowledge gap, I asked the following research questions:

1. *What relationships exist between individuals' social and emotional needs and their need for information?*
2. *How those relationships shape members' perception of the OHC and their attitudes towards it?*
3. *What are design implications for future sensemaking support tools for OHC that are sensitive to the different needs and priorities of its members?*

3.2.2 Methods

For the purpose of answering these questions, I conducted a secondary analysis of the data collected from three different studies previously conducted with TuDiabetes. This diabetes self-management community has an active forum that includes over 30,000 members. At the time of these studies the forum utilized a commercial social network platform Ning, which included such features as discussion forums, blogs, and live chat, among others. Members of TuDiabetes could form groups based on shared interests, create public profiles, and subscribe to posts by others whose opinions they find interesting.

The studies included in this analysis were conducted in 2014 and 2015 and had different focal points; however, all three studies included open-ended interviews in which participants were invited to reflect on their experiences and perceptions about their participation in the forum discussions and when trying to make sense of the complex OHC forum environment. The first study was the previous study of this Aim 1 - Study A1.1 that was trying to deeply understand and characterize the collective sensemaking process in OHCs forums. From the Study A1.1 dataset (2014), I only reused the interviews with 9 participants (administrators and members), which was an exploratory study of members' general experiences with the forum. In these interviews the

participants were asked to talk about their habits and practices participating in the forum and approaches to reading and comprehending discussions. The second study was the Study A2.1, from the following Aim 2. This study included assessment of a new discussion visualization tool impact on participants' performance in answering discussion related questions and open-ended interviews to obtain in-depth feedback for the tool. From the Study A2.1 dataset (2015), I only reused the qualitative feedback provided by the 10 participants, which were asked to openly talk about their experience with the tool and give unrestricted suggestions for improvement. The third study (Summer 2015) was a small informal brainstorming session with 6 experienced members of the community (who eventually became its moderators) regarding new ways to facilitate information seeking and sharing within the community. This brainstorming was conducted over email in which participants and researchers exchanged messages and replied to each other's ideas.

As a result, a total of twenty five (N=25) participants were included in the three studies. Pulled together, the participants of these studies were mostly regular users, with only a few occasional ones. Most of them were also experienced members in the community, with membership of several years, some even from the early beginnings of the community. There were few relatively new members with membership of less than a year who were actively using the forum. The majority of the participants were diagnosed with Type 1 diabetes, but there were several with Type 2. All of the participants were familiar with the disease having lived with it from 5 years to more than thirty: only few had it for less than 5 years and more than half had it for more than 20 years. While neither of these studies specifically focused on interpersonal relationships, these issues emerged as a strong recurring theme, which served as a motivation for conducting this secondary analysis.

The data for the secondary analysis included: the full set of interviews from Study 1; the interviews for collecting feedback on the discussion visualization tool from Study 2; and the text of e-mail messages exchanged during Study 3. During the data analysis, all the transcripts (and written messages) were analyzed using inductive thematic analysis, but with a particular focus on relationships between informational needs and socio-emotional needs, how these needs manifested themselves, whether and how they were met, and whether and how they influenced members' perceptions of the forum. I and my thesis advisor (Dr. Mamykina) first read through the transcripts, independently for all three studies, to form general impressions. These were discussed in a meeting to refine the research questions. This was followed by inductive coding, in which we identified meaningful units of discourse in the transcripts and assigned them labels. This was done independently by the two researchers. In the following axial coding, we grouped similar categories and identified several recurring themes in the data. This was done collaboratively and through a discussion for building consensus, relying on the previous independent open coding.

3.2.3 Results

In this study, I found several tensions in the participants' attitudes towards the community, and in their expectations as to what they can accomplish within the forum. I argue that to a large degree these tensions arise due to the need to balance informational and socio-emotional needs of community members. While both of these needs were universal to all study participants, the participants differed in whether they placed a higher importance on one or the other. I also found that these different needs can translate into different and sometimes contradictory expectations from the forum. In this section, I present my findings along four different continuums that are

related to 1) *the perceptions regarding the appropriate topic of discussion*; 2) *the need for diversity*; 3) *distinguishing authority*; and 4) *the role of identity of contributors*.

To distinguish between participants and studies, I identify each quote by its study number (S1-S3) and the participant ID within the study (P1-P10). To illustrate my findings I include representative quotes from 8 different participants from the three studies: S1 with 4 participants and 11 quotes, S2 with 2 and 2, and S3 with 2 and 4. The relatively balanced distribution of quotes between the studies and the participants suggests that the findings were consistent across the studies. Below I present our findings along four continuums that illustrate these tensions.

3.2.3.1 Focused discussions versus free socializing

The first tension identified in this study was related to significant differences in participants' expectations for how focused the discussions within the community should be and whether these discussions should be focused exclusively on diabetes. Some participants valued the opportunity to discuss a variety of diabetes-related topics in great depth; something they were rarely able to do outside of the forum. This was particularly the case for individuals with Type 1 diabetes, who present the largest sub-group of TuDiabetes members. Despite the high overall prevalence of this disease, Type 1 diabetes is considerably less common than Type 2. As a result, the vast majority of individuals with Type 1 did not have any friends or relations with the disease in their immediate surroundings, which often led to a rather lonely existence and the feeling of isolation. In a way, these individuals often felt "alone in a crowd" – having a common disease, but not having anybody else with this disease to share their ideas and experiences. These individuals took every opportunity to engage in discussions on a variety of topics related to diabetes, comparing and contrasting different opinions:

S2.P10 (regular [3 years], type 1 [3 years]): *“You know, it's just a way of reading that other people are similar in their answers, have different experiences but it gives me a broader feeling of community because I am the only, well I should say, up until Christmas, I was the only type 1 I knew in my area.”*

In contrast, many others, particularly with Type 2, grew up witnessing diabetes affecting their family members, due to its strong hereditary component. For these individuals, having a community of others with diabetes was not a novelty. Instead, they appreciated the opportunity to look beyond the disease and to have a community of friends to socialize with and to discuss topics related to art, entertainment, politics, and many others:

S1.P3 (regular [8 years], type 1 [40 years]): *“As I said that was just not my experience but I think the majority of people out there feel that they are very isolated. I will tell that was not my experience [] I never viewed diabetics as having a life outside of diabetes. When I met diabetics that's what we talked about was diabetes and I was over it. I mean I was just finished with it but TuDiabetes allowed me to start a subgroup about movies, something I am passionate about, so it's pretty cool”.*

Possibly as a result of these different social experiences, I found a tension between the need for accessibility, clarity, relevance and cohesiveness of information and the desire to socialize through chatting, humor and talking about non-disease topics. Some participants were hungry for any information on diabetes self-management, as well as for sharing experiences regarding what it feels like to have the disease. Others valued an opportunity to socialize with others on topics unrelated to diabetes. Interestingly, however, both of these groups of participants often

complained of information overload within the forum and of the difficulties related to finding what they came to seek.

3.2.3.2 Seeking diversity versus looking for homogeneity

I also found that participants had important differences in regards to how they approached similarity and divergence in opinions of others. Some study participants were more interested in exploring opinions and experiences of members that had different life situations and different ways of looking at things:

S1.P1 (community manager [3 years], type 1 [lifetime]): *“So the perspectives are good because they give me a point of reference for figuring out, for making my own decision, really choosing among their decisions”.*

In some situations, new perspectives caused members to think about their own questions and challenges in a different way and have their attention drawn to issues they haven't considered important or interesting previously. In that regard, they often valued contributions from new members:

S1.P3 (regular [8 years], type 1 [40 years]): *“At the time when I started, I was not using the pump and I didn't really seek out pump information from TuDiabetes but the number of pump users on the site helped me gain courage, I guess, to explore the pump... So stuff like getting a pump was influenced by TuDiabetes but I didn't really go there for information about pumps in particular.”*

Yet other participants actively sought out members whose opinions they shared and whose personal experiences they could relate to:

S1.P3 (regular [8 years], type 1 [40 years]): *“...if somebody tells me that red cars are better than blue and I like red cars a lot, then it's human tendency that I am probably going to favor their point of view more than the person who says blue cars are better, that's just a human tendency...”*

These individuals valued personal bonds over exposure to new information and diverse opinions. They tended to create small and informal sub-communities, or even cliques, members of which felt stronger engagement with each other, than with a greater TuDiabetes community:

S3.P2 (moderator): *“If there is a way to support that so that you can see posts from people with whom you have established a social connection (like looking at their posts, profiles or messages) that might be a way of encouraging the formation of small supportive social networks in the face of a vast sea of 100,000 members.”*

As a result, I suggest that there exists a tension between the need for diversity in opinions that could increase objectivity and lack of bias in the information, and members' tendency towards homophily that helps to establish relevance of the information, and also serves to reinforce social connections between members. According to the study participants, the optimal experience lies in the careful balance between having a small group of likeminded virtual friends, and a way to sample perspectives in a larger community; yet establishing this balance is nontrivial.

3.2.3.3 Favoring authority versus “every voice counts”

Yet another tension was found in the participants' perceptions of authority and importance of identifying authoritative voices. Many participants felt overwhelmed with the amount of information and differences in opinions among the members, and expressed concerns about lack of indications as to whose opinion can be trusted:

S3.P2 (moderator [6 years], type 2 [10 years]): *“I want answers from members who are considered competent and objective. I want answers from members that other members trust.”*

This was a particular concern for newcomers, who may often feel overwhelmed and need guidance. While most of the participants in my studies were experienced members of the community, they all remembered how it felt like to be a newbie and not know who to trust:

S2.P1 (regular [8 months], type 1 [10 years]): *“...but if you are new and maybe also have no idea about diabetes, you are open to every advice and then you might follow advice that this is really nice or not really doing very good and if you can see Oh! this person doesn't really give often good advice, then I can't follow.”*

Yet for others, the main reason for their sustained commitment to the community was its welcoming and friendly nature. For these individuals, creating a nurturing environment where each member felt welcomed, heard, and understood was among their top-most priorities:

S1.P4 (regular [5 years], type 1 [7years]): *“So, somebody who needs some kind of help that I feel that I have to offer; somebody who is emotionally struggling or in need of support or just an interesting discussion about a topic that's related to diabetes or even not that related.”*

For these participants, any initiative within the community that promoted the sense of inequality between members was at odds with its spirit of comradery and companionship:

S1.P4 (regular [5 years], type 1 [7years]): *“I don't like, I might be getting off the topic so I will be just brief, I don't like the popularity contests like when they give awards every year, even though I have been the recipient of some I don't like the fact that they do that, I think everybody*

contributes something, I openly say 'thank you for selecting me but I think everybody has something great to contribute.'

Similarly, these individuals resisted the idea of using visual features (for example different font size) to indicate common contributors or otherwise distinguish between members based on their contributions:

S3.P2 (moderator [6 years], type 2 [10 years]): *"I like the leveling aspect of everyone having the same font. If we start sizeism, it seems likely that people will end up with virtual antlers and use it to take over the herd."*

Particularly in the context of a diabetes self-management community that values supportive and welcoming atmosphere, these kinds of differentiators were perceived as potential contributors to increased emotional distress, and decreased confidence:

S3.P4 (moderator [5 years], type 1 [31 years]): *"I think the problem would be non-antlered being intimidated by big names, like on the "tu [TuDiabetes] isn't as friendly as it used to be..." thread. I don't agree with that but diabetes grinds people down and some people are less confident than others. I think the community provides its own regulation through conviviality and kibbitzing."*

As a result, I suggest there exists a tension between members' need for assessing authority, credibility and trustworthiness of the information and their socio-emotional tendency for belonging to a group and need for affirmation, empathy and sympathy. The participants often felt overwhelmed by the amount of information in the forum and wanted to distinguish opinions of members deemed trusted and reliable. At the same time, equal footing between members and welcoming and embracing culture that values members regardless of their contributions was of

great importance to many participants and something that in their eyes distinguished TuDiabetes from other online diabetes communities.

3.2.3.4 Attention to contributions versus attention to the authors

Finally, I found that participants had different degrees of interest in learning more about other members and their identity outside of the community, in contrast to focusing only on their contributions to TuDiabetes. For some participants, the most important characteristics of a member that rendered them credible and reliable were this member's contributions to the forum. For these individuals, such characteristics as frequency of a member's posts, the diversity of topics they discussed, and clarity and insightfulness of their contributions were defining factors in establishing an individual's credibility:

S1.P1 (community manager [3 years], type 1 [lifetime]): *"...after all you have to see well, this person replies a lot and also see how other people respond to this opinion."*

For these individuals, the actual identity of the authors of posts was less important than their contributions. Consequently, these participants often wished for features that could make levels of members' activity within the forum more explicit, but did not expect to learn much about the authors' lives and identity outside of the forum.

Moreover, many participants also acknowledged that different members have different perceptions of privacy and of how much personal data they were willing to share on the forum. These considerations further reinforced these members' desire to focus exclusively on members' contributions to the forum:

S1.P4 (regular [5 years], type 1 [7years]): *“There is one guy on there that we think very similarly and he said, it's so scary how much we think alike, but he is a very private person and I have been aware of the fact that I have no idea and I know how old he is, he has mentioned that, but I have no idea if he is married, if he is retired, what he did for a living, he is just a private person.. I know about his diabetes, and that's a personal choice.”*

They felt that requirements to share personal experience could present barriers for more privacy conscious individuals and prevent them from becoming more active participants in the forum. Other participants, however, paid particular attention to the personal characteristics of individuals who authored the posts they were reading, and not just the posts themselves:

S1.P3 (regular [8 years], type 1 [40 years]): *“Yeah, if I know the person I will have a – I will have great weight on what they might be saying... And the more I know a person, then the more credibility I add to that.”*

For example, seeing sense of humor, positive attitude towards life in general and disease in particular, played a role in determining whose opinions to rely on:

S1.P5 (regular [9 months], type 1 [20 years]): *“I think the humor and the clarity, and the...everybody obviously deals with a chronic situation differently and I find some people to be much more stalwart and have humor about it, and kind of take things as they come which is more of my style, and I think some people, it is much more of a burden and their writing tends to be a little darker or a little more problematic.”*

These individuals tried to learn more about the authors of posts they found interesting by looking at these authors' profiles. This was particularly the case for posts whose authors were new members of the community:

S1.P4 (regular [5 years], type 1 [7years]): *“...when I am responding to someone I do like to know a little bit about them because sometimes people will just say, I am new, I don't know how to handle my diabetes and it's the best way they can post their question but it's not enough information. So I will go to their page and I will look and see, are you type 1 or are you type 2? how long ago were you diagnosed? What is your A1c?”*

As a result, I propose that there is a tension between the need for accuracy, reliability and utility in the information and the socio-emotional need for privacy. While some members wished to focus on individuals' contributions to the forum, regardless of who the authors of the posts really are, others were interested in the identity of the contributors. Moreover, there were varying degrees of sensitivity to disclosure of personal information with some individuals being more private about their lives outside of TuDiabetes than others.

3.2.4 Implications of the results

In this study I examined perceptions and attitudes of members of an online community dedicated to diabetes self-management, TuDiabetes, with a particular focus on the interplay between informational and socio-emotional needs of its members. Overall, the study suggested that there exist different perceptions regarding the purpose of the community and important differences in what its members considered a positive and desirable experience. Some placed utmost importance on the social ties and emotional support among its members, and valued the community mostly for its warm and welcoming character. Others were primarily concerned with their ability to effectively and efficiently search for information and considered everything else a distraction from their primary purpose.

These findings are consistent with previous studies that pointed out a similar dichotomy in members' perceptions. For example, Brzozowski et al., explored public Google+ communities and found that these communities were perceived as “plazas” to meet new people by some, and as “topic boards” to discuss common interests by others [19]. Similarly, studies of Twitter posts found two major modes of behavior: an information-driven one, and one based on reciprocated social ties, where the prevalence of the two depends on the age of the user's account [108]. In my work I further build upon these previous findings, and not only suggest that there exist tensions between informational and emotional needs of community members, but also identify several different dimensions for how these tensions manifest themselves in individuals' expectations from the forum. More closely, I identified four types of tensions: 1) *staying focused and going off-topic*, 2) *homogeneity and diversity*, 3) *credibility without undue influence*, 4) *providing context while respecting privacy*.

- *staying focused and going off-topic*: related to the members' desire to discuss a variety of diabetes related topics, which was in contrast to their will to freely socialize and talk about topics outside of the disease scope.
- *homogeneity and diversity*: related to the members' need to be exposed to different opinions, which was opposing the need to find like-minded people with similar experiences and form homophilous cliques.
- *credibility without undue influence*: related to the members' drive to find indicators as to whose opinion can be trusted, where such explicit indicators were perceived as “member labeling” and conflicting with the idea of equal chance for everybody to be heard and understood in the community.

- *providing context while respecting privacy*: related to members' preference of having more contextual information based on personal information for more reliable communication, which was in tension with the variety of privacy perception among members in the OHC.

Below I discuss these dimensions in further detail, and draw implications for the design of future platforms for online health communities. While few of the studies referenced below specifically focus on OHCs, their findings are consistent with my observations and, as such, are of high relevance for my claims.

3.2.4.1 Staying focused and going off-topic

The first of the tensions identified in my study focused on the contrast between the desire for focused discussion and free socializing. Given the focus of TuDiabetes, it is not surprising that diabetes and its self-management are the glue that connects the members and keeps the community together. Many participants of my studies placed particular importance on keeping the discussions focused and were less supportive of topics that could increase information overload and, consequently, make finding desired information more challenging. Yet for others, discussions about wine, coffee, and movies were just as valuable as those related to diabetes self-management, because they helped them build social relationships with other members and increase the sense of belonging to the community. These findings are consistent with previous studies that examined the dichotomy between focused and broad discussion topics and their impact on member engagement. For example, studies of Twitter showed that users who have narrow focus of topics in their early tweets, ultimately attract higher number and more tightly knit followers [161]. On the other hand, Postmes et al. showed that restricting conversations to specific domains makes a community less appealing to people who want to learn more about

other members, whereas a policy of encouraging off-topic conversation can undercut identity-based attachment [147]. To overcome this tension, Kraut and Resnick proposed the notion of “going off-topic together”—a situation where something that is normally considered off-topic becomes on-topic, at least temporarily. They suggested that “going off-topic together” can increase both identity based commitment and bonds-based commitment [91]. Moreover, off-topic conversations can help members discover additional common interests and share personal information, thus enhancing interpersonal bonds [91]. In regards to computational solutions for addressing focused and broad discussion, many of them use computational methods that automatically match discussion initiators’ needs with the comments provided by others [159,160]. Others distinguish between factual and conversational discussions [68] and detect evolution and semantical distance between topics over time [44,163]. However, few of these solutions provide recommendations as to how to handle conversational and off-topic conversations once they are identified.

3.2.4.2 Homogeneity and diversity

The second tension contrasted members’ interest in diversity and their desire for homogeneity and belonging to a group. TuDiabetes has a highly diverse international membership with over 30,000 participants from all over the world who have diverse experiences and knowledge in regards to diabetes and its self-management. Many of its members considered this diversity to be one of the forum’s most valuable assets. Yet others felt overwhelmed by the multiplicity of opinions and felt the need to find a smaller group of members they could identify with. As these participants pointed out, it is human nature to trust those whose perspectives and life experiences are similar to one’s own, and to be suspicious of opinions of strangers. Previous research depicts the positive and negative sides of both perspectives. For example, past studies identified

correlations between profile similarity, shared interests and trust [60]. However, restricting one's interactions to a small circle of similar friends may introduce bias in interpretation of the information and distort true credibility [162], prevent users from exposure to diversity in perspectives [123] and opinions that can have important benefits like triangulation for validity, power of cooperation [128] and lateral thinking which is known to contribute to creativity in problem solving [135]. Additionally, this approach of recommending similar users may further reinforce existing cliques and lead to new members feeling excluded and disenfranchised. Moreover, while it may promote development of strong ties between few members, it may prevent development of weak ties among larger groups that could be instrumental to dissemination of novel approaches to self-management of diabetes. Granovetter suggested that social networks with weak ties among individuals who share fewer common characteristics are more conducive to diffusion of information than more homogeneous groups with stronger ties among their members [61]. Many participants in this study were aware of the importance of diversity of opinions in exposing one to new ideas and original approaches to the management of diabetes. In regards to the computational solutions explored thus far, many of them focused on helping members of online communities to connect with others based on shared interests. Researchers worked on subdividing a larger community into clusters of participants who are similar to each other [69], discovering social circles in ego-networks [105] and predicting the strength of social ties [59]. Topic modeling techniques were used to identify the important themes in a discussion [27,84], and automatic methods for detecting opinion leaders [17] and comparing opinions [96] were developed. In addition, many mechanisms have been proposed for helping people stay connected with those they interacted with in the past, or with similarity in profiles, interests, and social proximity [33]. These are particularly common in social networks

like Twitter for example [66], but are also present in OHCs, where PatientsLikeMe members can locate others with similar circumstances and with shared medical experiences based on manually entered detailed profiles [57]. Going one step further, researchers automatically extracted person-generated health data from posts and reconstructed profiles for peer mentor matching along three dimensions: health interests, language style and demographics [72].

Once again, while these proposed approaches provide novel solutions to the question of connecting members based on similarity and shared interests, it is not clear what impact they would have on promoting diversity of opinions, and promoting weak ties that can greatly enhance dissemination of information within the community.

3.2.4.3 Credibility without undue influence

The next tension identified in this study focused on the members' need to establish authority and credibility of information, and their desire for democracy, and for equal footing for all. TuDiabetes is a lively and active community; most of the questions posted by its members are answered within the first day [101]. Moreover, many questions receive a great variety of answers that may reflect deep differences in opinions among members. As a result, the participants of the studies who prioritized information needs often wished for an easy way to identify credible posts that came from trusted and authoritative members. Given that many members come to TuDiabetes to ask for advice on critical issues related to diabetes self-management, distinguishing between trusted sources and unsupported opinions was important. For some participants, a member's past contributions to the forum, their quality and whether others found these contributions useful were among the most important questions [141]. This information was often used to gauge credibility and trustworthiness of this member's future contributions. In

addition, these individuals often wished for a better ability to see members' aggregate contributions to understand their views and opinions. However, other participants were highly skeptical of introducing any explicit cues as to the credibility and trustworthiness of members, because of their potential to give these members a higher degree of influence in the community. For example, they feared it may enable strong-willed and opinionated individuals to establish dominance within the community, and to help them "grow antlers", in the words of one of my participants. These findings are consistent with previous research on the impact of competence on social influence, which showed that individuals perceived as more competent have a higher influence on judgment of others [49]. However, these authors were also concerned that creating highly competitive environment may inhibit less knowledgeable, experienced and vocal members from participating. There exist emerging computational solutions relevant to this problem. For example, previous work proposed methods for computationally identifying credible posts [107], finding authorities [86] and experts [39,41] and estimating trust among members [60]. Yet, few previous studies examined the impact of these approaches on the power dynamics within the communities and on inclusion of novices.

3.2.4.4 Providing context while respecting privacy

The final tension identified in this study focused on the members' desire to contextualize information in experiences and identity of its authors, and their need to maintain privacy. As is typical for many online communities, most members of TuDiabetes know each other only through the forum; few have any personal encounters in the real world, or communicated outside of the community. In these circumstances, the impressions members form of each other are mostly based on the information available within the forum [39,41,71]. For some participants, and similar to findings of other studies [71], additional information on contributors' life

circumstances, specific diagnosis and disease trajectory, and other aspects of their lives that could show them the person behind the posts was of great importance. It could help them to build a closer relationship with the person, and construct more reliable and meaningful discussions around their questions and challenges. These participants wished for richer profiles that complement and expand what was manually entered in the members' profiles [71], which could include personal stories, photographs, and information on their disease history. Yet these desires were sometimes met with skepticism due to different attitudes in regards to privacy issues; while some were comfortable disclosing intimate personal details, others remained guarded about their life outside of TuDiabetes. Both of these sides of the argument have their support in existing literature. For example, previous research argued that context is crucial in a quest for health-related information, for example when building a query [38] or asking a question [171]. Others suggested that search results should be personalized based on a user's medical history [38]. Other solutions in this area proposed incorporating searchable profiles that reflect an individual's treatments, side effects, lifestyle information, strength of social ties and their social roles, as well as type and level of health-related knowledge [39]. However, all types of information are not universally treated. A study showed that there is more willingness to share clinical information than other forms of demographic and daily life information [57] and that sharing is highly context-dependent on what type of information is shared, to whom, and for which purpose [116]. On the other hand, there is a body of research that promotes awareness of the potential harms due to the disclosure of personal information [9] and advocates the importance of privacy [54,158]. Existing solutions in this space focus around user modeling [172] for content recommendation in Twitter [2] and learning users interests from Facebook profiles and activities [15], formulating aggregated and multi-domain user profiles [119] extracting patients' personal information from

the social web [54,97] and several categories of health interests: health problems, treatments, diagnostics and tests, and provider care [72]. A recent study in PatientsLikeMe showed that when such detailed profiles are made available for social use, they are often utilized for constructive purposes: asking advice of a user with a particular experience, offering advice to a user with a specific symptom or health problem, and fostering relationships based on shared attributes [56]. However, the implications of these new capabilities on the discourse and dynamics within the communities still remains poorly understood.

3.2.4.5 Designing for balance: the urban life of online health communities

Given the seemingly irreconcilable nature of the tensions identified in this study, the question remains as to whether and how these tensions can be addressed in the design of new platforms for online health communities? While the review of the solutions provided previously is far from comprehensive, it suggests that new solutions increasingly favor informational needs and focus on optimizing effective and efficient access to information. From using novel topic modeling methods to flag “off-topic” discussions, to using computational methods to identify clusters of individuals based on shared interests, to automatically detecting trustworthiness of individual members, to automatically reconstructing individuals’ profiles, these solutions can indeed address the challenge of information overload and make it easier to navigate the richness and complexity of the modern discussion forums.

However, these solutions may also lead to unintended consequences. In a way, the tensions identified in this study carry a resemblance with a long-standing argument in regards to the interplay between efficiency and community building in urban planning. In her book “The Death and Life of Great American Cities” Jane Jacobs [82] identified segregation of function and

disproportional focus on purpose and efficiency as one of the root causes of the decline of urban life in the United States. Jacobs suggested that the desire for clean organization of neighborhoods by their purpose created cities that included residential quarters, business districts, and commercial zones, each with their dedicated purpose. However, such cities lacked places where people of different walks of life could mingle, socialize, and build a community. As a result, this segregation led to a degree of sterilization of urban life and to a large degree destroyed its vibrant spirit. Conversely, neighborhoods that managed to preserve a synergistic and at times chaotic mix of commerce, business, and residential life, maintained their resilience and community spirit even in the face of economic hardships. Jacobs describes the struggle between community activists in New York City (herself included) to prevent construction of a four-lane highway (a functional unit) through Washington Square Park (a social interaction unit), the cultural heart of progressive New York that gathered artists, musicians, activists, and protesters [182]. As a result of this movement the highway plans were abandoned; moreover the park was closed for all traffic, which helped preserve the vibrant Greenwich Village neighborhood.

The analogy with urban planning and Jacobs' characterization of urban life has several implications for the design of future online health forums. I envision that these platforms build upon the new technical innovation in automated text analysis and information retrieval, while at the same time promoting social engagement among community members. First, the analogy points to potential pitfalls of enabling customizable experiences for different individuals based on their identified needs and preferences. Given the differences in opinions between community members, customization may seem an attractive, if not inevitable option. However, while customization can meet individuals' needs in the short term, over time it may potentially lead to a growing disconnect between community members and reduced sense of common ground

between them. If each person experienced a city in their own unique way, they would have fewer opportunities for community building. I envision that future platforms for OHCs can help their members meet their individual needs while at the same time reinforcing shared experiences. For example, they can further enhance members' ability to create and maintain personalized content collections by subscribing to particular authors or threads or by automatically detecting content of interest, while at the same time enabling easy traversing between the selected content and discussion threads it originated from. Second, it advises against going too far in promoting efficiency in satisfying information needs at the expense of social interactions. For example, if a search engine focused only on informational needs of an individual and efficiently retrieved information that matches those needs, it may discourage this individual from posting to the forum and thus contributing to social interactions within it. Overtime, this may reduce the amount of new searchable content available to others. And while browsing through multiple discussions within a forum may seem inefficient, it could nonetheless expose an individual to unexpected perceptions and highlight the multitude of opinions. Moreover, if search results are presented in a way that disconnects them from the informational and social context in which they were created, it may have a negative impact on the individual's ability to fully understand the topic, and also to prevent them from contributing their own perspectives. Instead, I suggest that future platforms further reinforce the connection between the content and its authors and the social setting in which it was created and uses every information request as an opportunity to promote social interaction among members. Moreover, I suggest that these forums focus not only on addressing individuals' immediate informational needs, but also create opportunities for their members to be exposed to the breadth of perspectives within the community. Finally, it suggests the need to complement research on optimizing information seeking in the online communities

with research on new technical solutions to promoting social interactions and engagement. While many previous studies suggested the importance of community building for the survival of online communities, typically, such efforts fall into human domain. For example, a recent study of StackOverflow highlighted the active role of this forum's founders in energizing the community, attracting new members, and maintaining its active functioning [100]. Similarly, in TuDiabetes, forum's founders and moderators work tirelessly on organizing new community-building activities. Yet computational solutions to promote and enhance these efforts are limited. I propose that new computational methods could be used to not only facilitate access to information, but also to monitor wellbeing and pulse of the community and for creating new opportunities for members to engage and socialize. For example, such increasingly popular methods as sentiment analysis could be used to detect emerging negative attitudes within a community towards a subject or between members, or identify members in distress and help community organizers and moderators better focus their efforts.

However, all the design recommendations mentioned here need to be further examined and evaluated on their actual impact on the social dynamics within online health communities. Taken together, the findings presented here paint a complex picture of highly divergent priorities and expectations expressed by different members of TuDiabetes, particularly in regards to whether they prioritized information needs as opposed to valuing an ability to socialize and build a community. These different priorities are not mutually exclusive but form complex intertwined relationships and have impact on each other in often unexpected ways. While perhaps not surprising, these findings highlight how challenging it is to strike the right balance between these competing priorities, and how easy it is to disrupt the social fabric of the community by favoring one set of needs over the other with focused technical solutions. This research focused

specifically on online health communities and examined forces that may contribute to their longevity or inadvertently disrupt them. The question remains, however, to what degree the phenomena uncovered in our study apply specifically to communities that focus on health and wellness, and to what degree they generalize to other online communities and social media platforms. In previous work Mamykina et. al examined an online question and answer forum for software developers, Stack Overflow, and found that these communities have somewhat different set of values and priorities [100]. For a professionally-oriented community that focuses on efficiency in finding the right information, features that promoted competition and rewarded expertise were highly successful and beneficial to the growth of the community's popularity. This suggests that different communities of practice may have different sets of values and priorities that may require different sets of features to reflect these values.

This study has a number of limitations. Most importantly, it only included a small fraction of members of TuDiabetes and as such may not generalize to all members. In addition, it relied on a convenience sample of volunteers who in their majority overrepresented experienced members of the community. As such, these findings may underrepresent the experiences and perceptions of new members and are not sensitive to possible differences in opinions among them and the more experienced members.

3.2.5 Summary of Study A1.2

These results contributed to our understanding that steps involved in collective sensemaking such as: staying within the boundaries of a topic under which meaning is collectively negotiated and constructed, being exposed to multiple perspectives, assessment of reliability of the information with respect to the trustworthiness of the source and the context under which it is provided, could

be in tension with the social drivers that knit the fabric in the community and hold it together (Figure 10). These findings yielded careful design approach for tools that have the tendency to support collective sensemaking through focusing on optimized information access in which social aspect of the OHC must be taken into serious consideration.

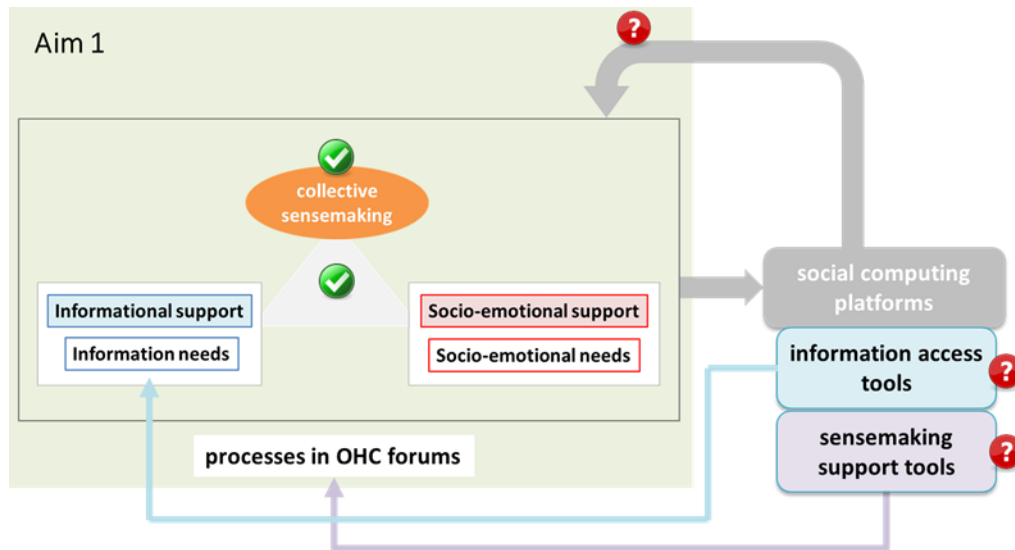


Figure 10. The knowledge gaps addressed after the completion of Study A1.2 from Aim 1.

The main finding that is relevant for the design of the holistic sensemaking tool in Aim 3 is that collective sensemaking support tools should be appreciative of the social fabric in the community.

3.3 Study A1.3 – Importance of the social context in OHCs on sensemaking and the role of social computing platforms in creating it

In this study I aimed to understand the importance of the social context under which making sense of information is taking place and social computing platform (SCP) features that are responsible for building the social fabric that creates this context.

3.3.1 Related work and knowledge gaps

Previous research often considered OHCs as information repositories that store vast amounts of disease related information that if efficiently accessed can positively affect members' empowerment [5,10,149]. On the other hand, researchers saw value in OHCs as social spaces where individuals come to seek socio-emotional support and socialize through spontaneously meeting new people with similar or different medical profiles and health challenges [104,144]. Related research explored the dynamics of online group interactions and the relationship between the participation in an OHC and individuals' off-line life and found that participation in these strongly knit communities positively affects the life outside of the virtual space [99]. On the other hand, previous research has also shown that knowledge production in OHCs is deeply impacted by the social dynamics within a community and, in particular, by the trust developed among community members [173]. This suggests that a positive social environment in the community is an important contributor to knowledge production [174]. *However, the relative importance of the socialization features responsible for community building under the presence of information management features for supporting efficient sensemaking of information is less*

understood. To address this knowledge gap I observed a community migrate to a new platform, and asked the following research questions:

1. *What were the community's values with respect to informational and socio-emotional support provision?*
2. *What were members' perceptions regarding the role of different platform features in their ability to obtain/provide informational and socio-emotional support?*
3. *What were the effects of some of those features to the social dynamic in the community and its wellbeing?*

3.3.2 Methods

To answer these questions, I observed an OHC platform migration from a social computing platform with emphasis on community building features to another one with emphasis on information management ones. The community I observed was again TuDiabetes - a peer-to-peer OHC for diabetes self-management for adults with over 30,000 members. According to the community leadership, members of this community predominantly include individuals diagnosed with different types of diabetes, with a higher prevalence of Type 1, but also caregivers, such as parents and significant others. Unlike many other OHCs, this particular community was not moderated by healthcare professionals but rather by volunteer moderators recruited among community members. Much of the information collected within this community is publically available in the discussion forum and is generated by registered community members.

My goal in this study was to provide an in-depth account of a specific case of platform migration in order to gain insights for future design and research in OHC platforms that may generalize to other scenarios. Consequently, and similarly to the approach in [67], I used a case-study method.

In order to address my research questions, I conducted an in-depth semi-structured interview with a member of the community leadership and a semi-structured focus group session with three moderators that were heavily engaged in the transition process. The member of the community leadership was responsible for supervising and coordinating the moderators, and planning and devising strategies for promoting and growing the community. The main goal of this interview was to learn more about the reasons for the migration and the leadership's perceptions regarding the impact of this event on the community. The moderators were experienced members of the community, with the general responsibility of promoting community values among the members, carrying out new initiatives and helping the community maintain its lively and friendly spirit. I selected these participants because they could speak not only to their own personal experiences with the two platforms but also to the opinions and perceptions of other members of the community and thus could be considered opinion leaders. The goal of the focus group was to learn more about the moderators' impressions regarding the response to the migration from the community members and their perceptions of the two platforms, and members' experiences with their respective features. Both the in-depth interview and the focus group were audio-recorded and transcribed for further analysis. To complement the perspectives of these participants with opinions of regular community members, I analyzed 59 discussion threads identified within the forum that focused on issues related to the platform migration. The discussion threads covered close to 1, 000 posts and came from 108 members. My analysis of the contributors' profiles showed that these discussions included a diverse selection of members including both regulars and occasional posters, experienced members and newcomers, those with decades of experience with the disease and those recently diagnosed with diabetes. The discussions spanned from November 2014 (migration was officially announced) through April 2015 (it took place) and

until December 2015 (the last discussions focusing on the migration). I used the following inclusion criteria to create my dataset: the initial post of the discussion needed to be related to the timeline of the transition, features of either of the platforms, or to include soliciting feedback related to the transition. These three different sources helped our team examine different angles of bias and subjectivity, and gain different perspectives on the transition from multiple time points.

During the data analysis, all the transcripts and written messages from the discussion threads were analyzed using inductive thematic analysis. First our research team (including myself and my thesis advisor, Dr. Mamykina) read through the transcripts and discussions to form general impressions. This was followed by the first cycle of coding—inductive coding, in which I identified meaningful units of discourse in the transcripts and assigned them labels. The coding was reviewed by both investigators, and all disagreements were discussed and clarified. In the second cycle of coding, we collaboratively grouped the codes in categories and similar categories into themes. Through a collaborative consensus building process the themes were discussed in a group meeting with other qualitative researchers in the healthcare domain for prioritization and focus of the findings. In addition, the codes from the 59 discussions served as a source of reevaluation and potential enrichment of the themes obtained from the interview and the focus group. However, all of the key themes pertinent to my research questions were covered in all three data sources. Other themes that emerged in these sources were only marginally relevant to my research questions, which led me to the conclusion that we have successfully reached data saturation in the analysis.

3.3.3 Results

In this study I provided deep understanding of the importance of the social context under which making sense of information was taking place in an OHC and a social computing platform's (SCP) features that were responsible for building the social fabric that creates that context.

3.3.3.1 The platforms involved in the migration

The purpose of this study was to investigate the impact of platform migration on social dynamics and behaviors within an OHC. The two platforms discussed in this paper are both widely available and popular not only among OHCs, but also among many diverse online communities. The first platform, Ning [178], launched in October 2005, started as a highly customizable platform for open-source social applications; however, it later transitioned to a commercial platform primarily focused on hosting a variety of social networks. The main features used by the community in this study included customizable user profiles, an open discussion forum where registered users could initiate new discussions and reply to posts submitted by others, live chat, and blogs, among several others. The second platform, Discourse [183], was introduced in 2013 with an explicit goal of improving user experience with online forums. Discourse, which remains open source, introduced a number of innovative features to help users manage increasing amount of information within the forum, including scrolling through discussions posts, updates on new content and direct replies, improved search, and many others.

Table 2. Information management and community building features of the two platforms: Ning (A) and Discourse (B).

FEATURES	A	B
Information Management		
Information access		
<i>effective search engine</i>	no	yes
<i>members badges</i>	no	yes
<i>open discussions</i>	yes	yes
Information generation		
<i>discussion generation: one level of reply depth, citations, referencing (contributors and other discussions), discussion forking</i>	no	yes
<i>new content tracking</i>	no	yes
Community feedback		
<i>“like” button</i>	no	yes
Information organization		
<i>autocomplete: similar discussions suggestion</i>	no	yes
<i>forking discussions</i>	no	yes
<i>high granularity in categorization</i>	no	yes
Community Building		
Identity management		
<i>members badges</i>	no	yes
Identity management and self-expression		
<i>rich profiles</i>	yes	no
<i>blogs</i>	yes	no
Trust and close relationships		
<i>friendship relationship</i>	yes	no
<i>closed groups</i>	yes	no
Identity management and self-expression, and trust and close relationships		
<i>personal pages</i>	yes	no

The analysis identified three major themes, which included: 1) *improvements in information management*; 2) *disruption in identity management and close ties within the community*, and 3) *changes in the dynamics of the community and the nature of interactions among members due to the transition*. To help contextualize my findings, I include a comparison of platform features that emerged as important from the data analysis (Table 2). Notably, since my questions were directed towards members' perceptions regarding these features' usefulness and effectiveness, this table and other characterizations of the platforms discussed in this study represent members' perspectives rather than results of my own analysis. As one can see from the table, the two platforms: the old one (Platform A – Ning) and the new one (Platform B – Discourse) varied considerably in the prominence of features for information management versus community building. In the rest of the results section I further elaborate on these perceptions.

To illustrate my findings I included 20 representative quotes from 10 different participants from the full dataset: 1 community manager, 3 moderators and 6 members. For clarity of the quotes, I labeled the roles in the community with *CM* for the member of community leadership, *MODI-MODX* for the moderators and *MEMI – MEMXX* for a member. I labeled the data sources the quotes came from with: *Interview*, *FocusGroup* and *Forum*. For example, the same person who is a moderator and participated in the focus group and a discussion was labeled as *MODX_FocusGroup* and *MODX_Forum*, respectively. I represent the detailed results below.

3.3.3.2 Improving information management in the forum

One of the main reasons for the migration was to improve members' access to information collected within the ever-growing forum and their ability to quickly identify information of interest. The results of the study showed that members did perceive multiple improvements in

the efficiency of information organization and access. These improvements fell into one of the four main categories: a) *information generation* – the way the discourse was conducted and discussions updated and presented; b) *community feedback* – the way the community could evaluate the quality of the contributions; c) *information organization* – the way discussions could be classified and interconnected and d) *information access* – the capabilities to search for a particular piece of information.

Information generation

One of the main reasons for the migration was confusing organization and structure of discussions that presented significant challenges to the members' ability to find information of interest and to follow discussion threads. According to the participants of the study, much improvement has been made in the way discussions were presented for enhanced readability. Replacing pagination with scrollable pages that listed the entire discussion was universally perceived as an important improvement. In addition, abandoning the hierarchical structure of discussions with multiple levels of replies and enabling a flat structure mitigated disruptions in the discussion flow:

MEM1_Forum: *“One thing I absolutely HATED about the old system was how difficult it was to tell who was responding to whom in longer discussion threads. As soon as it got past a page or two--and breaking them into pages was itself a totally obsolete and misconceived piece of interface design--you had no idea to what earlier statement a given comment was responding or by which member unless mentioned by name.”*

These improvements were particularly well-received because they preserved members' ability to provide replies to individual posts without disrupting the flow of the discussion. Moreover,

participants shared that the new platform allowed members to tag persons to whom the reply was directed, and cite a portion of a post to which the new post or a reply was attached. Additionally, the new platform provided members with various notifications on updates to discussions of interest and with features to visually distinguish between old and new content. This helped members track new content easily and in a timely manner, and as a result helped them engage in discussions in a more meaningful way:

MOD3_Forum: *“I can see any new topics added since my last visit, and any new replies to topics I've read or have been following. If there's new replies, it remembers where you last stopped reading, so you don't have to go through PAGES, a def improvement imo.”*

While many of the new features were found to be useful, some others had unanticipated negative impact. For example, restricting the minimum post length to 20 characters, which was assumed to aim at improving discussions' quality and eliminating meaningless posts, prevented members from quickly reporting on their self-monitoring data and participating in light-weight socializing, such as word association games, a very popular social activity in the community.

Community feedback

Another perceived limitation of Platform A was lack of features that allowed members to express their agreement or disagreement with posts of others in a way that could be aggregated across members. These features were highly desired because they were perceived as enabling the community to collectively curate the information collected within the forum and simplifying access to perspectives held by majority of community members. In response to this, Platform B included a feature relatively common to social media platforms that allows members to collectively evaluate the quality of content, specifically, the “Like” button. However, after the

transition and initial experience with the feature, it received mixed reviews from the members. Some participants felt that the “Like” button could be very useful and could serve as a form of quick acknowledgement and other members questioned this feature’s real value and applicability to OHCs. Moreover, the introduction of the “Like” feature had an impact on how discussion threads were summarized, with posts receiving more “Likes” being more likely to be included in the summary. Awareness of this relationship led some participants to use this feature with caution.

Information organization

To eliminate possible redundancies in the content, the new forum offered a feature to automatically detect similar discussion starters as the member was initiating a new discussion. The purpose of this feature was perceived as to remind members that there might be already an answer to their problem and creating a new discussion will only introduce duplication in the system. In addition, the new platform offered an option to reply to a post by starting a new discussion. This was perceived as a tendency to keep the discussions on-topic. Similarly, participants also felt that the new forum offered more granular structuring of the discussion threads by breaking them into different categories:

CM_Forum: *“[The new platform] allows for much more granular and specific organization than our current platform. The goal for us is to create categories that make it as easy to post in the forum as possible, AND as easy as possible to find other people's posts, based on your interests.”*

All these new features were perceived as having a positive impact on members’ ability to find information and meet their information needs.

Information access

Participants reported on significant improvement in finding desired content in the new platform:

MEM2_Forum: *“I have found [Platform A] to be one big PITA in terms of finding discussions. (Nothing is linked!) Yes, there is search capability. But except for the occasional times when your search is so specific that it takes you almost immediately to the post you are looking for, you usually have to do a lot of post search sifting & winnowing. And you STILL may not be able to track down what you thought you remembered. This is much easier in [Platform B]. In some cases it can be jaw droppingly easy as in a single click gets you the context you wanted to reference.”*

The new search engine incorporated numerous options that could more precisely define the query and order and narrow down the relevant results. It also included different facets of information that could be searched for like time, author, and location in discussion, among others.

3.3.3.3 Disruption in identity management and building strong ties between members

The results presented in the previous section suggest that the migration to the new platform was successful as far as improving members’ ability to more efficiently follow and engage in the discussions and find information of interest faster is concerned. However, together with these improvements, study participants discussed several unintended consequences of the migration that for some of them erased or at least significantly reduced the gains. Most importantly, these consequences were related to the members’ ability to construct their online identities and develop more intimate ties with selected others in addition to participating in a larger forum. In my study, these changes were most often associated with several features that lost their richness

or were completely lost in the migration. These included: *personal profiles*, an ability to declare certain members as *friends*, an ability to *form groups*, and ability to create and maintain *personal blogs*. Instead, the new platform assigned explicit members' roles by earning badges with active participation:

MOD1_FocusGroup: *“And the transition ended up with a different system where certain things came over and so you had to do the same sorts of social interactions, but other social interactions we lost. And I don't know how others feel, but I kind of feel like we mourn that that some of our community actually that was kind of the primary thing they did. And so that was part of the difficulty we had.”*

Personal profiles

One of the main losses of the migration lamented by the community leadership and moderators, but also most of the community members in the study was in relation to member's ability to create a personal profile page. Members used this page to create their own personal space in the community, or “my little house” as one of the participants described it:

CM_Interview: *“A lot of our members have really come to feel like their profile page was their little house. It's my little front porch and you can stop by and post a picture on my profile page and say hi and people really did think of it as visiting each other.”*

The ability to post text, images and videos, as well as create one's own theme of the profile page highly contributed to members' presentation of self, managing identity and coping:

MEM8_Forum: *“I hope that the page decorating is still an option. I have gotten over many lows changing my page layout.”*

These personalization capabilities also helped members learn about personalities of other members, which often served as a foundation for deeper social connections and support. One strongly valued feature in promoting bonding between members was the option to post on somebody's profile page. Those postings, that often started conversations, were on a more intimate level and were judged less appropriate for the forum. Related to bonding, the loss of personal profiles was deeply felt by all study participants who missed their ability to learn more personal details about others:

MOD1_Forum: *“One of the things we really miss is personal profiles, a way of clicking on someone's picture, seeing a summary of who they are, seeing the stories they have shared, their pictures, their videos and to leave personal comments.”*

One participant was worried that the lack of a rich and active profile page might “numb” the community:

MEM9_Forum: *“Clearly the personal images in the profiles tell something personal about the users. There is undeniably a bonding effect associated with these personal nuggets people are sharing here. The effect might be that [the OHC] becomes just one of those discussion sites we have more than plenty of. Perhaps some of those abandoned [Platform A] features even make [the OHC] so special or unique - have you considered that?”*

Forming “friendship” relationships

Another feature that was lost in the transition and was important for building the social scaffolding in the community was the ability to declare certain other members as “friends”. Some members pointed that one of the most important consequences of the loss of the “friend”

feature was that it removed members' ability to form smaller, more intimate circles and share information more privately:

MOD1_Forum: *"You are correct, the "Friends" concept didn't come over. But that was really not the biggest change, the biggest change is the model of privacy. And in fact "Friends" in the old [OHC] wasn't really about a positive social network it was about privacy. Only friends could msg or if you wished only friends could see your profile or blog."*

Moreover, the "friend" feature didn't only have socializing purpose, but also served as an index to reliable content of interest:

MEM10_Forum: *"Friends" made it much easier to find the people whose posts I always check out. At the moment, I just roam around hoping I'll run into them somewhere. I with Holger on this...."*

Blogs

Blogs were used as a place to share stories, feelings, and personal experiences as well as perspectives and opinions. It was regarded as a strong tool for self-expression and a form to represent one's identity to the community. Hence, it was also regarded as a way to connect to other bloggers in the community more intimately:

MEM10_Forum: *"So many of our blog posts move me deeply and feel like a bridge to our shared humanity"*

Because of that, many members were disappointed about the loss of blogging feature in the new platform.

Groups

Groups were used as places where people with special interests could come together to discuss a topic. Groups were of closed characters and a member required an approval to join. Similarly to the “friend” feature, groups presented a safe place to discuss highly intimate and sensitive topics:

MOD3_FocusGroup: *“We had two groups men sexuality and women’s sexuality group, it worked in every amm... I think men used it more, because, you know, there was a place for men to talk about diabetes, to talk about having a an erectile dysfunctions. And there is – we don’t have any place like that where that’s sort of private, but—.”*

In addition, the groups did not only provide a safe place for sharing sensitive stories, but also served as a very reliable tool for solving problems as members would have some form of shared mental model already established. In contrast, not all members considered groups to be as valuable since they believed they led to fragmentation in the community. However, most participants agreed that loss of an ability to form groups further contributed to the loss of intimacy in the forum and resulted in a more open, impersonal atmosphere:

MEM2_Forum: *“There are some very personal stories I would like to share. It doesn't feel safe to do so here anymore. The one I would like to delve into at the moment, I would have posted in the Bernstein Group on the old site—a place where there was a baseline agreement on a starting place, no long explanations needed of where one is coming from.”*

Members’ roles and trust

In addition to lamenting loss of the features participants valued in the old platform, the new platform introduced a number of new features that further contributed to members’ frustration.

For example, in order to highlight individual members' contributions to the forum, the new platform introduced the concept of badges. Badges were awarded depending on the activity and engagement in the community which would define someone's role in the community. A single user could have multiple badges, in some occasions even more than 10. While badges are a common feature of many social platforms, they were viewed as deeply inconsistent with the non-competitive spirit of this particular OHC:

MEM10_Forum: *"I, too, find badges offensive and would very much like to disengage from all such competitiveness garbage. It actually makes me want to NOT participate in anything"*

A related feature that was introduced with the new platform included the trust levels of members. While some study participants acknowledged its ability to assist with moderating discussions and to recognize and intercept intruders, many members felt that such explicit means were inconsistent with the spirit of the community that mostly relied on social moderation and peaceful ways of reinforcing community values.

3.3.3.4 Changes in the community

As a result of these transformations, the participants of the study shared common perceptions of the changes in the nature of social dynamics in the forum. Most study participants characterized this OHC as being a warm and welcoming environment where people can freely express their feelings and opinions. Members of the community shared intimate stories and experiences and formed true friendships:

MEM10_Forum: *"The old OHC felt like Home because it felt intimate. I would share personal highs and lows there, especially the lows when I needed a boost---things I would never post on a place like FB---at least not with any detail"*

The community encouraged diversity in opinions and members were inevitably exposed to a variety of them. In some occasions this exposure was positive for the learning experience. With the transition to the new platform, much of this old spirit was lost:

MOD1_FocusGroup: *“And people become – people you know only actually established social fabric if they sort of learn about each other, know each other intimate. Instead of just being sort of talking heads online. And so one of the things I kind of mourn about what we have was that we had a much better ability to like express who we were as people.”*

Some members drew clear connections between the perceived changes in the community and design philosophies of the two platforms:

CM_Interview: *“Really the thing is that the guys who created Platform B, they really value the sharing of content and ideas and the folks who created Platform A really value sharing identity. And so the two platforms reflect that a lot. I mean you really got to manage your identity to put up pictures of yourself and you could write problems about yourself or about your family and post them on your profile page and all the stuff. I think combination of the two would be ideal.”*

All these changes ultimately led some of the members to change their levels of engagement:

MEM12_Forum: *“... you know, I'm not here very much anymore. I miss some features on the old site--a special place for blogs, my favorite groups, and most of all the ability to talk to others on their Profile Pages. Now it all seems so darn impersonal, not friendly at all. Oh well.”*

One of the community moderators reflected on the overall impact on the community membership:

MOD2_FocusGroup: *“I think a lot of people still have that issue because we’ve retained a lot of— we lost some good members in the process. We’ve retained a few you know. We’ve retained probably 60 to 70% of them mostly. I don’t know how many we’ve lost, but some people still mourn that loss today. Some of our regular members just sort of left, and so in a way I’d rule out I think where evolves in everybody else, but use those functions, ‘cause we lost some of the sociability of the site by doing this.”*

3.3.4 Implications of the results

In this study I examined implications of a platform migration on perceptions, attitudes, and social dynamics within a popular diabetes self-management OHC. While the specifics of the migration may be unique to the community I studied, it presents an insightful case study that can enhance our understanding of social dynamics within OHCs, values and priorities of their members, as well as ways these values impact and are in turn impacted by technical affordances of social computing platforms that host these communities. Overall, the study showed that all participants had a shared vision regarding the *core values* of the community: *providing a warm and inclusive social space, where members can easily navigate through the information space to satisfy their interests*. The participants also had a shared perception of which *behaviors* were consistent with these community values: *construction of social identity, development of close and intimate social relationships, giving everyone a chance to be heard, and contribution of useful and actionable information that could be easily accessed*. The study also suggested that there were direct connections between these behaviors and platform *features* that enabled them. For example, rich customizable profiles and blogs were critical for identity management, building self-image and self-expression. Similarly, marking others as “friends” and the ability to create small closed

discussion groups were essential for building trust and close social ties through discussions on intimate topics.

These findings are consistent with previous studies that examined the impact of different design features on community building and membership retention (i.e. identity and bond-based commitment), and, consequently, the wellbeing of online communities [91,92,133,134]. However, my study also led to several new observations not highlighted by the previous research. First, it suggests that while some of the connections between design features and social behaviors were relatively direct and straightforward, others were less obvious, and at times not apparent to either the members or the leadership of the community. For example, the ability to post private messages and engage in small group discussions turned out to be critical to supporting social connections and providing socio-emotional support. However, prior to the migration, these abilities were perceived by some as limiting an unrestricted flow of information within the forum; their true importance was recognized only after they were lost. Second, the study suggested that some features introduced within the new platform for improving information management had unintended consequences that negatively affected self-expression and building of social connections. For example, the feature for detecting similar discussion starters has clear benefits of preventing unnecessary duplication of content and redundant discussions. At the same time, this feature was met with criticism from the members who viewed it as censorship of content that may prevent members from freely expressing their views and experiences. Similarly, limiting posts' length to fewer than 20 characters has a potential to reduce noise in discussions and stimulate deeper engagement. However, in this study, it was often perceived as preventing quick self-monitoring updates, expressing empathy and playing social bonding games that require very short utterances. Finally, the study suggested that some

features that were successful in other communities and settings did not produce the expected positive impact, often because they did not match community values. For example, badges and an ability to “like” posts by others, while widely popular and successful in many social media sites, were perceived as introducing competitiveness and exclusivity both of which were at odds with the spirit of the community.

Combined, these three findings highlight the idiosyncratic and at times unpredictable impact of different design choices on social behaviors. Previous research on online communities often focused on producing knowledge regarding the impact of different design solutions that may generalize across communities and settings [91]. Complementary to this view, my study showed that identifying connections between design features and value driven behaviors can be non-trivial due to unpredictability of technology appropriation [50]. This is particularly relevant for OHCs that often have to maintain a careful balance between providing informational and socioemotional support [111]. For example, according to previous research, positive feedback on user’s engagement and carefully tailored rewards typically stimulate contributions by members [91]. However, my study showed that both the feedback and rewards could be highly specific to the culture within a community. However, my study showed that both the feedback and rewards could be highly specific to the culture within a community. Similarly, previous research emphasized the importance of closed small groups on identity and bond-based commitment, essential for building the social fabric in the community [91]. However, in a fact oriented community that primarily values free information flow, small closed groups might not be of high priority to users and might not have the desired effect on member commitment [100]. As a consequence, while previous work established a solid foundation for promoting user engagement within social computing platforms, my study suggests that such generalizable knowledge may

need to be complemented with innovative solutions that allow communities to discover what design choices work in their concrete settings and fine-tune affordances of their platforms to align with community values.

I propose that these new solutions can fall within two broad categories. First, they can include new tools for easy customization of platform configuration that do not require high level of technical skills. For the vast majority of contemporary social computing platforms, platform customization requires a certain level of technical expertise and, typically, involvement of platform technical teams. This may prevent small non-technical communities from fine-tuning their platform affordances to better meet their members' need. In contrast, new platforms can provide moderators with easy to use visual interfaces for turning different features on and off, and for dynamically changing their parameters. These abilities have been shown critical to the success of such communities as Stack Overflow, whose creators tuned its design through multiple iterations and continuous feedback cycle with its users [100]. Related to this, and given the richness of existing knowledge on online communities in general and OHCs in particular, these interfaces could alert moderators to the possible social impact of different features, based on their previously documented successes. The real innovation, however, could come in the form of tools to help community leaders and moderators more fully examine connections between different design features and social behaviors within their community. Most of the monitoring tools for online communities proposed thus far have focused on analyzing content contributed by members to detect abnormal behaviors [26,34,117,143] or help moderators understand the flow and structure of the discussions [36,93,176]. However, little research has focused on helping communities to discover and understand the relationships between value driven social behaviors of their members and features of their platforms, as well as these features' impact on community

wellbeing [46]. To start tackling this problem we could rely on the work that reveals patterns of interactions by integrating interaction logs and social networks analysis [122,167,175] and combine it with computational content analysis. For example, by conducting a detailed graph analysis of social and topical networks on Quora, researchers were able to establish connections between positive behaviors in the community that were responsible for creating valuable content and features of the platforms [155]. Similar approaches could be applied within an OHC setting. For example, in my study, noticing high utilization and frequent updates to user profiles could have alerted the moderators of the high value placed on identity expression. Similarly, high volume of private messages with positive sentiment could suggest the importance of small-group interactions. These computationally derived mappings could be further used as probes for surveying the community to validate discoveries and arrive at new ones. These new approaches can greatly increase the ability of OHCs to adapt their platforms to the unique needs and values of their members and enable communities to evolve their platforms overtime. This could also reduce the need for migrating between platforms, thus avoiding associated threats to community wellbeing. Moreover, if such migration is unavoidable, as can be the case if a platform is no longer supported, it could help the leadership identify the most valued and utilized features and make informed choices in regards to selection of a new platform.

This study had several limitations. First, in our study, I relied on OHC members' perceptions to infer associations between platform features and social behaviors, their relative importance and their impact on the social dynamics in the community and its wellbeing. However, making more explicit claims about the impact of specific features on social behaviors would require additional analysis of feature utilization logs and produced content which were not available in this study. Second, the study mostly reflects perspectives of members who joined the community prior to

the migration, rather than new members who may have different opinions regarding the affordances of the new platform. Third, it is possible that some of the changes in the community were due to these other factors related to the migration process, rather than to differences in platform affordances.

3.3.5 Summary of Study A1.3

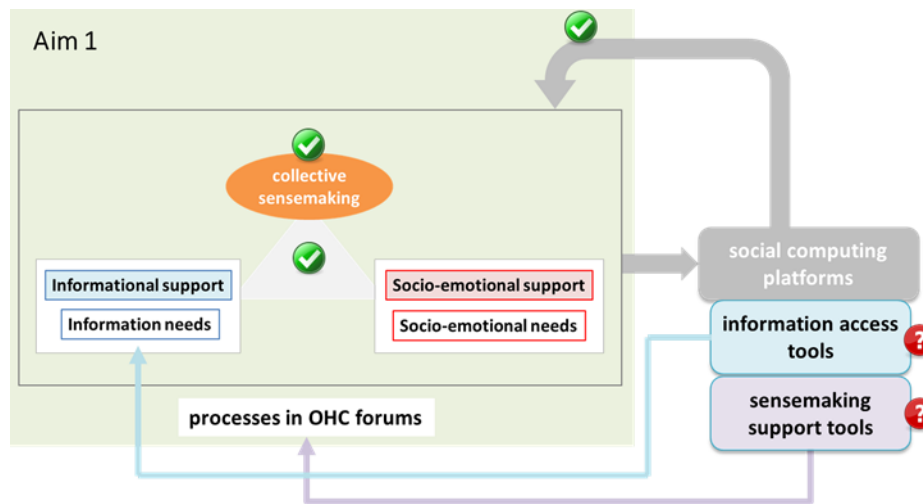


Figure 11. The knowledge gaps addressed after the completion of Study A1.3 from Aim 1.

This study led to several important observations (Figure 11). First, it suggested that while some of the connections between platforms’ features and value driven social behaviors were relatively direct and straightforward, others were less obvious, and at times not apparent to either the members or the leadership of the community.

3.3.5.1 Enabling collective sensemaking at the cost of community building

Second, some features introduced within the new platform for improving information management had unintended consequences that negatively affected self-expression and building of social connections. These observations are highly likely to be the root cause for the positive

intentions to enable collective sensemaking by opening the flow of information, eliminating redundancy and inhibiting unmeaningful contributions actually ending up hurting the social fabric in the community. The ability to post private messages and engage in small group discussions turned out to be critical to supporting social connections and providing socio-emotional support. However, prior to the migration, these abilities were perceived by some as limiting an unrestricted flow of information within the forum; their true importance was recognized only after they were lost. Also, the feature for detecting similar discussion starters has clear benefits of preventing unnecessary duplication of content and redundant discussions. At the same time, this feature was met with criticism from the members who viewed it as censorship of content that may prevent members from freely expressing their views and experiences. Similarly, limiting posts' length to fewer than 20 characters has a potential to reduce noise in discussions and stimulate deeper engagement and contributions to the collective sensemaking process. However, in this study, it was often perceived as preventing quick self-monitoring updates, expressing empathy and playing social bonding games that require very short utterances. These findings deliver two important messages for designing sensemaking support tools for OHCs:

- SCP features that support satisfying socio-emotional needs of community members are of high importance for the community's wellbeing and could be possible that are thus sensemaking enablers on par as the features that support satisfying informational needs, which are generally primarily associated as being of ultimate importance for sensemaking.
- Along the lines with the findings from Study A1.2, SCP features can sometimes have dual roles, usually unintended by design, that satisfy informational needs, but conflict with satisfying socio-emotional needs, which may threaten the community's wellbeing.

These results contributed to better understanding of the importance of socializing features of SCPs and the need for incorporating these features in the tools that attempt to support collective sensemaking in OHCs by paying careful attention on the possible “spill-over” of information management features’ functionality that may threaten the satisfaction of socio-emotional needs. These results contributed to better understanding of the importance of socializing features of SCPs and the need for incorporating these features in the tools that attempt to support collective sensemaking in OHCs by paying careful attention on the possible “spill-over” of information management features’ functionality that may threaten the satisfaction of socio-emotional needs. Future OHC platform designs should strive to mitigate the dichotomy I observed in this study: enabling collective sensemaking at the cost of community building. Future research should examine lessons learned from other platform migration examples or design efforts that were able to successfully overcome this dichotomy.

In summary, this study suggested that sensemaking tools that specifically focus on improving information management in the community should also employ features that at least preserve the social fabric in the community or even reinforce old and stimulate new social interactions.

3.4 Summary of results for Aim 1

The completed work for this Aim 1 enriched our understanding of the collective sensemaking process that takes place in OHCs forum discussions and how the discussions evolve through this process, revealing important dependencies between discussion posts with respect to this phenomenon. This Aim1 also led to better understanding of the importance of the social context under which collective sensemaking is unfolding, focusing our attention on the importance of social computing platforms features that stimulate social connectedness in the OHCs in the

presence of features that improve access to information. *These findings call for sensemaking sensemaking support tools for OHCs forum discussions that: 1) optimize the individual's information access in a fast and efficient way, 2) make collective sensemaking transparent while preserving the inner structure of and dependencies between posts, and 3) respect the social fabric in the community and possibly stimulate social interactions.*

CHAPTER 4: AIM 2 – EXPLORING OF THE DESIGN SPACE FOR SENSEMAKING SUPPORT TOOLS FOCUSED ON INFORMATION ACCESS

The purpose of Aim 2 was to develop new approaches to supporting sensemaking within OHCs through designing, developing and evaluating a prototype informatics solution for supporting individual sensemaking within online health forums through improved access to information (Figure 12).

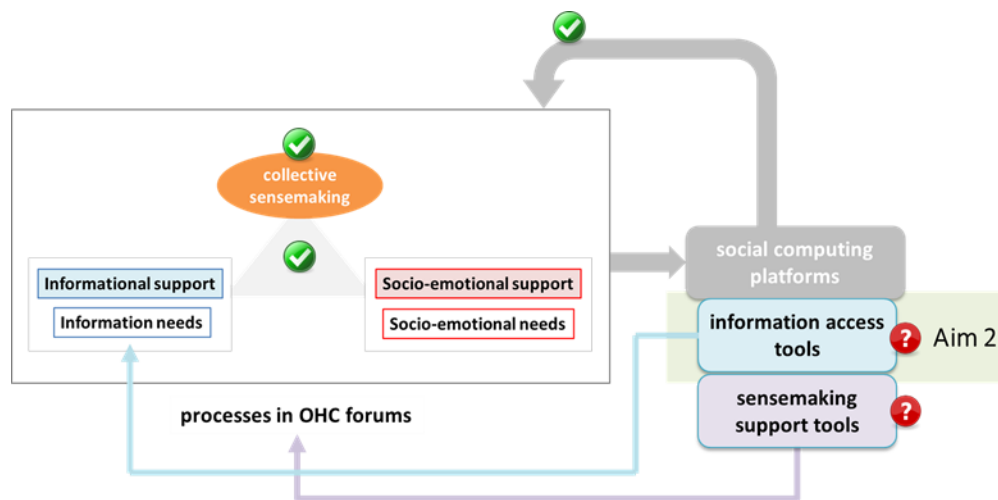


Figure 12. Knowledge gap addressed in Aim 2.

4.1 Study A2.1 – Designing, developing and evaluating a sensemaking support prototype for OHC forum discussions, DisVis

4.1.1 Related work and knowledge gaps

Many solutions that optimize access to information in asynchronous group communication have been proposed. A sizeable portion of these solutions took the visual analytics approach due to the multifaceted nature of the content produced by the communication in groups and highly variable user needs. As a consequence, many previous solutions utilized interactive data visualizations, rather than the more traditional information retrieval techniques that rely on discussion search engines [58,140] and recommendations [1,3,35]. While some of the solutions focused on e-mail exchange [152,153] and news groups [151], others explored discussions in forums [47,76,93,94,114]. The multifaceted nature of data produced is also typical for OHCs: identities and social dynamics, sentiment and information [169]. In addition to this, OHC members have complex and dynamically changing user needs [78,104], which makes it highly suitable for relying on visual pattern detection when trying to make sense of information. *However, the vast majority of the solutions developed thus far were outside of the OHCs domain. Moreover, solutions that specifically focused on OHCs did not focus on a single discussion thread, had limited interactivity, were mainly intended for answering research questions, rather than satisfying user information needs [8,29,30,32] and were specifically designed for community moderators rather than regular members [93].* To address this knowledge gap, I asked the following research questions:

1. *What are the attitudes towards interactive visualizations for improving access to information within discussion threads among members of an OHC?*
2. *How members of a community engage with different features for improving access to information?*
3. *What is the impact of the proposed features on the members' capacity to understand information within a discussion thread as measured by their ability to accurately answer questions and the time required to answer such questions?*

4.1.2 Methods

To answer the research questions from above I designed, develop and evaluated a sensemaking support tool called DisVis that strives to optimize access to information within a forum discussion for the OHCs members.

4.1.2.1 Design

The tool's intention was to serve as a prototype to test new interaction paradigms and already known sensemaking support features in an OHC setting. The design of the tool was primarily based on existing literature for discussion visualization outside of the healthcare domain. In addition, it also relied on some of the secondary findings from the Study A1.1 on collective sensemaking in OHC forums, mostly related to information access; notably my goal here was to explore the design space for supporting individual rather than collective sensemaking. A following Aim 3 more specifically focused on investigating opportunities for promoting collective sensemaking with novel design solutions. The goals of the tool were aligned to the needs and preferences of community members that make sense of forum discussions in the existing literature, predominantly outside of the OHC domain, and were therefore meant to

provide assistance to the users in three main directions: a) *forming an overview of the entire discussion thread*, b) *finding prevalent topics within a discussion*, and c) *summarizing different opinions in regards to the prevalent topics*. The intent of the design was to see how these needs and features that support them in order to make sense of a discussion translate to OHC forums.

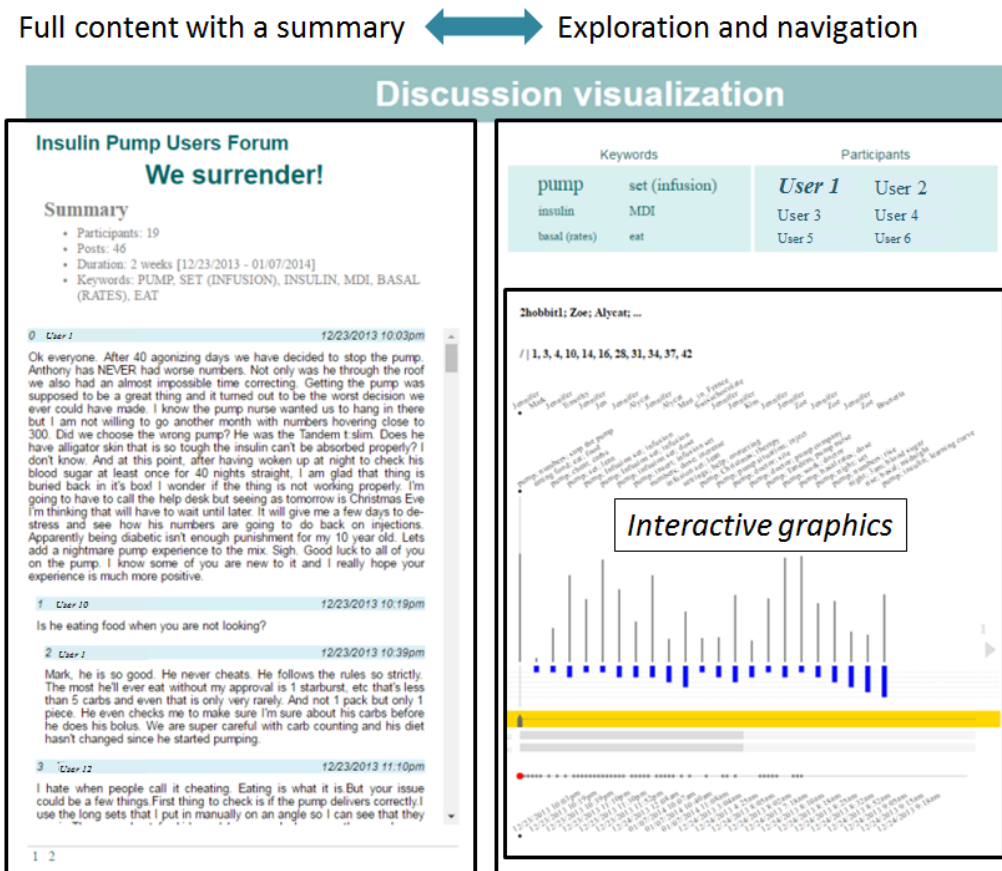


Figure 13. Logical and functional division of DisVis.

DisVis’s interface is logically and functionality divided into two main segments: *Exploration and navigation area* (Figure 13, right) and *Full content area with a summary* (Figure 13, left). These two segments were introduced to allow users to move seamlessly between exploring different aspects of the discussion and reading the text of interest in more detail, respectively.

Discussion overview

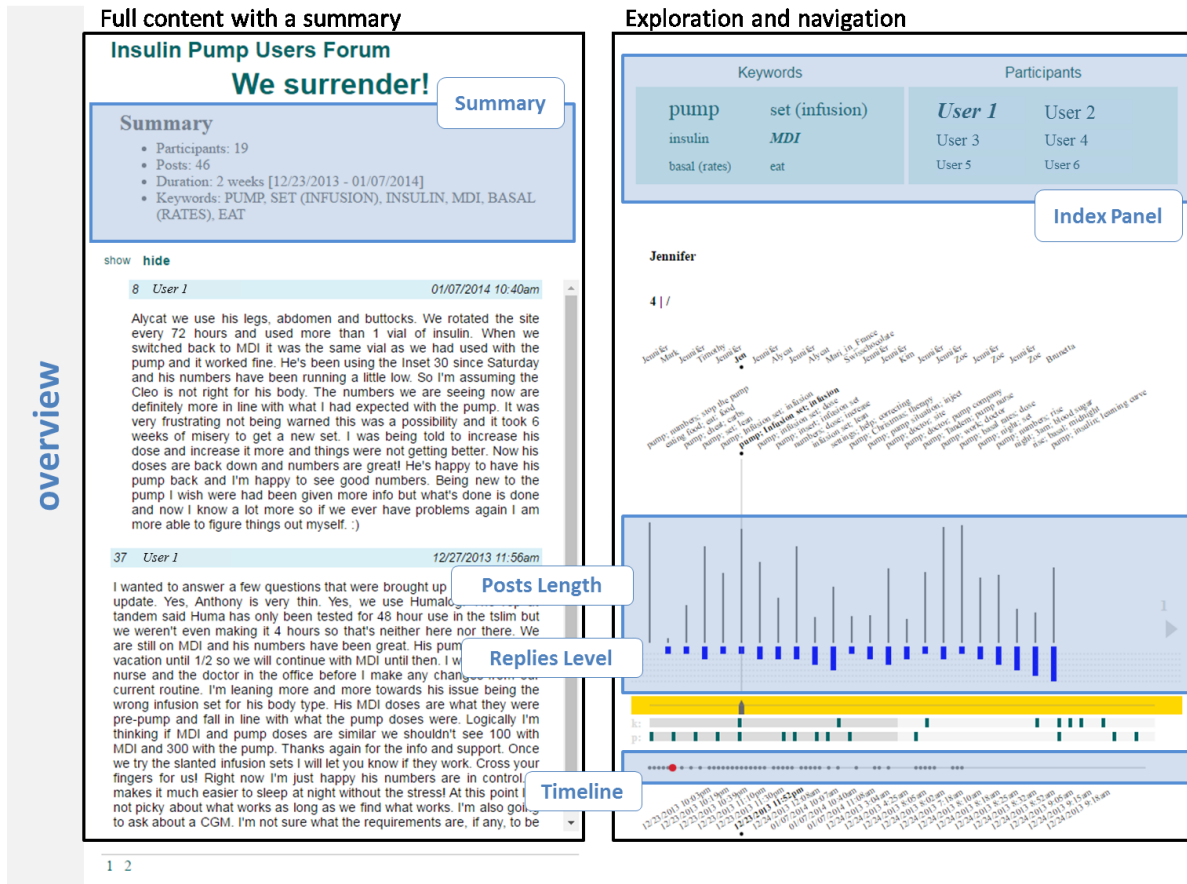


Figure 14. Features that support forming an overview of the entire discussion thread (blue).

The first set of features described here was included to help individuals form a quick impression of the entire discussion thread (Figure 14). The Summary section provides a brief summary of the discussion, including its key descriptors: number of posts, number of participants, duration, and keywords. The Index Panel lists the most prevalent keywords (identified using frequency of keywords within the discussion) and most active contributors (number of posts) in descending order from left to right. The Timeline gives the overview of when the posts were posted, thus helping to determine the distribution of activity in the discussion over time. The Posts Length section shows the amount of elaboration in terms of numbers of words in each of the posts, the

line length being proportional to it. The Replies Level section gives the overview of the users' depth of engagement – the length of the blue bar represents the depth of the reply.

Finding topics of interest

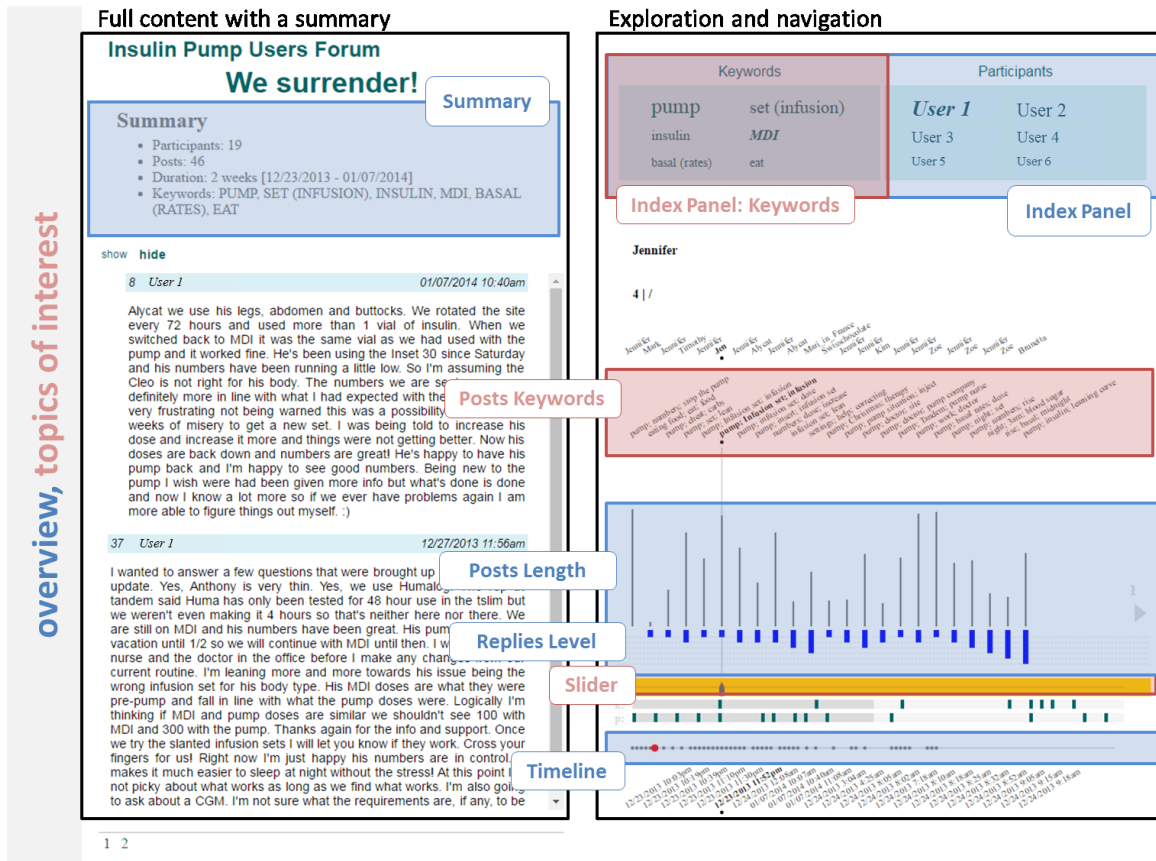


Figure 15. Features that support forming an overview of the entire discussion thread (blue) and finding prevalent topics within a discussion (red).

The key feature for enabling this capability is the Keywords in the Index Panel (Figure 15, red). By selecting a keyword from Keywords, only posts that contain that keyword are displayed in the Discussion section, keeping their sequential order. A second level of filtering topics of interest is introduced in the Posts Keywords (identified by tf-idf metric where a post is

considered to be the document and the discussion the corpus) section, where the user can see which are most important keywords for that particular post.

Summary of opinions

The key feature in this category is the Index Panel again (Figure 16, green). By selecting a keyword from Keywords and a discussion participant from Participants, the user can filter the posts that mention that keyword and come from that participant. The Content-contributor Overview Bar (Figure 16, green) provides the overview of where in the discussion a selected user talked about a particular keyword of interest. The “k” label provides insight in the distribution of the presence of a given keyword in the discussion, selected from the Keywords in the Index Panel. Analogously, the “u” label does the same for a given user, selected from the Users in the Index Panel.

In addition to these three main groups of features, the remaining features of DisVis allow for integration between the two main segments in the interface: presentation of full content and exploration and navigation. The most important of these is the Slider (Figure 16). Its cursor can be moved to point to a given post in its graphical presentation. Here, each post is represented by a vertical line segment, preserving the sequential order in the standard discussion representation; the different characteristics of these segments indicate their length, keywords, author, chronological position, time and date, and depth of engagement. To provide the social and informational context of the selected post, the Interaction feature shows the set of people the author of that post had interacted the most in the discussion and through Context it shows the posts that replied to it and the post it replied to (Figure 16).

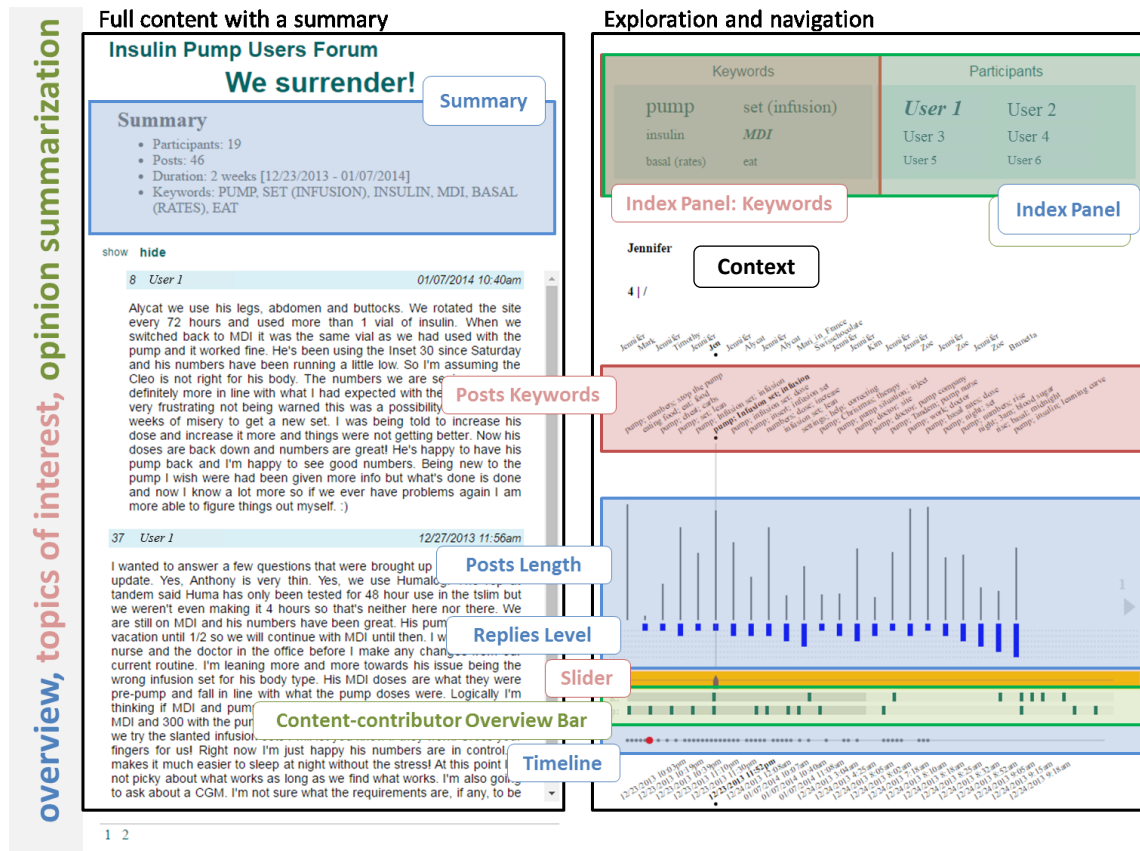


Figure 16. Features that support forming an overview of the entire discussion thread (blue), finding prevalent topics within a discussion (red) and summarizing different opinions in regards to the prevalent topics (green).

Usage scenario

Elizabeth was recently diagnosed with Type 1 diabetes and was recommended an insulin pump as a treatment. She has heard about TuDiabetes and decides to visit the forum to learn more about it. She finds a discussion thread (displayed in the traditional way) that appears to be focused on insulin pumps, but finds that it has 5 pages of posts (a minimum of 41 posts). Elizabeth is not sure whether this is the right thread to focus on and decides to use DisVis to learn more about who participated and what was discussed.

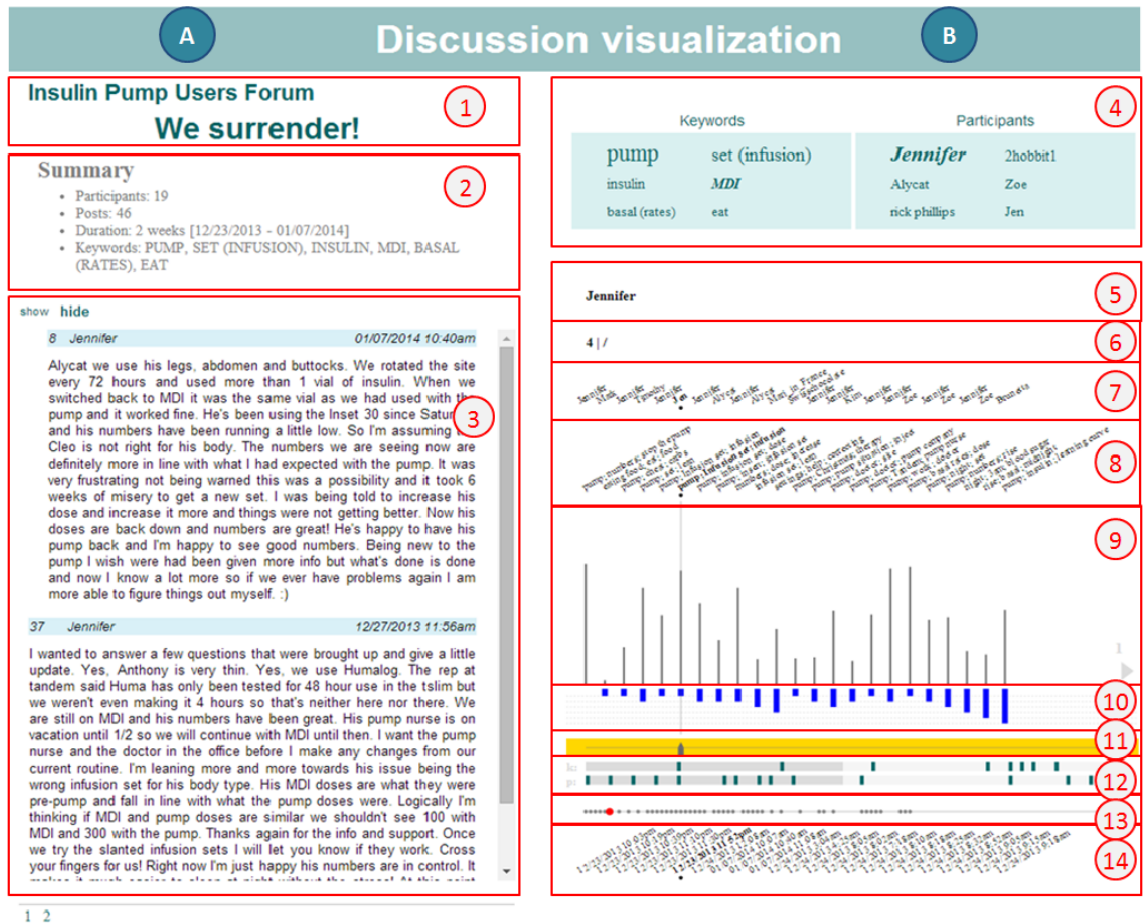


Figure 17. A snapshot of the DisVis user interface in use with functionality markers: (1) Category and Heading; (2) Summary; (3) Discussion; (4) Index Panel; (5) Interaction; (6) Context; (7) Authors; (8) Posts Keywords; (9) Posts Length; (10) Replies Level; (11) Slider (12) Content-contributor Overview Bar; (13) Timeline; (14) Time and Date

From the Summary section (Figure 17, 2), Elizabeth can immediately see that 19 members of TuDiabetes participated in the discussion contributing 46 posts over only 2 weeks, and that the main topics included insulin pump, infusion sets, insulin, MDI, basal rates and eating. She notices that one of the keywords included in the Index Panel (Figure 17, 4) refers to the topic she is interested in, “pumps”, and decides to investigate further. Elizabeth also notices that many of the posts have multiple replies by looking at the Replies Level section (Figure 17, 10), which

suggests to her that participants engaged in a discussion over the topics of mutual interest. This high-level overview gives Elizabeth a good sense of the complexity, richness and duration of the discussion, as well as participants' engagement. The initial post of the discussion is an appeal from Jennifer for troubleshooting unsuccessful insulin pump treatment and finding alternatives. After reading that, Elizabeth wants to explore Jennifer's opinions about pumps and whether they changed during the discussion. In the Index Panel (Figure 17, 4), she selects "Jennifer" as the user, and selects the keyword "pump" from the Index Panel (Figure 17, 4) as her topic of interest. In the Discussion section (Figure 17, 3), she sees filtered posts that contain "pump" as a keyword and Jennifer as the author. She then reads those posts and formulates the opinion that Jennifer had on pumps. She does that for 2hoobit1 and other participants. However, she also notices that participants are mentioning MDI as an alternative treatment. Elizabeth goes through an analogous process to find out what they think about MDIs. As a result of these explorations, Elizabeth forms a pretty good idea of the different perspectives on pumps that were expressed in this discussion, and how members' perspectives changed over time. She also identifies an alternative treatment – MDI, that she can read more about in the future. She makes a mental note of the names of active participants and decides to pay attention to their posts in the future. And she is able to accomplish all of that in a matter of minutes, without reading every single post in this discussion thread.

4.1.2.2 Development

The tool relied on a simple client-based architecture. It was developed using HTML and JavaScript. It involved only one discussion stored in an .html page, dynamically rendered depending on the user's interaction with the interface. There were no computational algorithms

for processing the discussion’s content – all “text mining” functionalities the tool will provide were hardwired based on human pre-processing of the text.

4.1.2.3 Evaluation study

The evaluation of the tool was done in a between-subjects study (Figure 18). In the first stage, I measured the tool’s performance on efficiently supporting discussion comprehension. In the second stage, I obtained feedback on users experience using the tool.

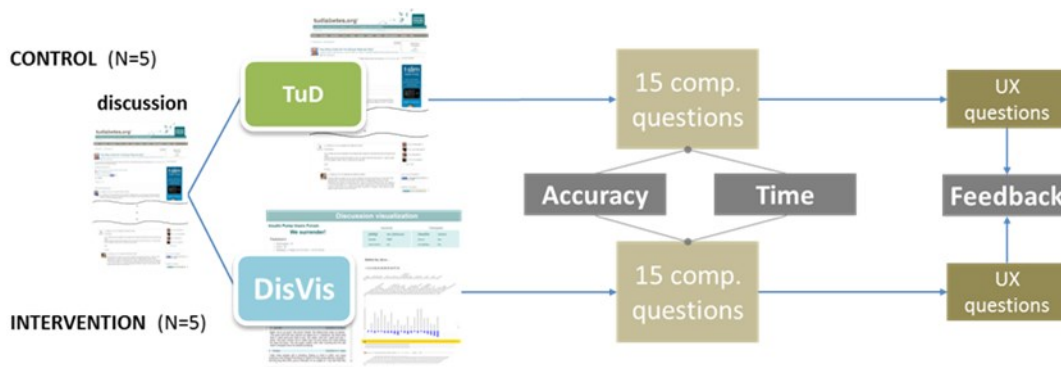


Figure 18. DisVis evaluation study design.

The participants of the study were recruited among members of the TuDiabetes OHC using announcements on its home page and with the help of the community leadership. Being a member of this OHC and not being familiar with the discussion used for the evaluation was the only eligibility criterion for the study. The study was conducted on-line, using the Join.me shared screen platform for interacting with a discussion using the tool or within its original environment in TuDiabetes.org. Upon enrollment, the participants were randomized into the experimental condition or the control condition (N=5 for each group, Figure 18), 6 male and 4 female. More than half of the participants were above 60 years of age; diabetes diagnoses included both Type 1 and Type 2 diabetes having experience living with the disease ranging from 3 to 45 years (half of

them for more than 20 years). The experience with the TuDiabetes.org ranged from only several months to being present in the community since its inception – almost 8 years. However, the vast majority of the participants were regular visitors of the forum, both for reading and contributing purposes; only one participant self-described as a sporadic user of TuDiabetes. The participants in the Control group were presented with a discussion thread within its original environment, TuDiabetes, and were asked a set of questions about the information contained in the discussion. After they answer all the questions, they were presented with DisVis, received a short tutorial, and asked for their initial feedback about the tool. The participants in the Intervention group were presented with the same discussion thread within the DisVis interface. After receiving the tutorial for the tool, they will be asked the same questions as the control group. Then, they were asked for their feedback on the design of the tool and their experience using it. All evaluation sessions were audio recorded and transcribed verbatim for analysis.

There were three types (subsets) of questions used to evaluate the tool: S1, S2 and S3, with a total of 15 questions (Table 3): a) *general overview of the discussion (S1)*, related to providing a summary of the discussion - finding the key concepts discussed and most active participants, activity of the discussion, etc. (e.g. What were some key concepts discussed here?); b) *finding topics of interest (S2)*, related to the ability to filter posts about a given topic (e.g. Who contributed the most posts that talked about infusion sets?); c) *opinion synthesis (S3)*, related to finding what different opinions are on a given topic (e.g. How would you summarize the general opinion about MDI, do you think most participants think it's a good idea, bad idea, or is there a split in opinions?). To assess participants' *accuracy*, I developed a *gold standard answers (GS)* for each of the 15 questions.

Table 3. Categories of questions asked to the participants for the evaluation of the tool on accuracy and time to answer.

Category	#	Question
<i>general overview of discussion</i>	1	Can you please summarize this discussion in a couple of sentences? What was it about?
	2	How many individuals participated in this discussion?
	3	Who were the main three contributors?
	4	How long did it last?
	5	What were some key concepts discussed here?
	6	Can you please locate the lengthiest post.
	7	What were the key concepts discussed in this post?
	8	Were there times when there was a break in the discussion, when nobody posted replies for some time?
	9	When did it happen, at the beginning of this thread or at later phases?
<i>topic specific</i>	10	One of the themes in this discussion is in regards to infusion sets; can you tell me who was the first to bring it up?
	11	Who contributed the most posts that talked about infusion sets?
<i>opinion synthesis</i>	12	Another concept that was discussed was MDI, do you know what it stands for? Can you find where it appears for the first time?
	13	Who was the first one to bring it up?
	14	How many other users discussed MDI in their posts?
	15	How would you summarize the general opinion about MDI, do you think most participants think it's a good idea, bad idea, or is there a split in opinions?

For purely objective questions (e.g.: How many individuals participated in the discussion?) the answers were generated by the members of the research team. For questions that required domain knowledge and synthesis of opinions (e.g.: What were the key concepts discussed in this post?), the gold standard answers were generated by a clinician (a doctoral student in nursing with experience in diabetes self-management). I took the following approach to measure the accuracy based on the developed gold standard. For answers that had a single discrete value, the score could be either 0 or 1 (accurate=1, inaccurate=0) and for those that had several discrete

values, I calculated the Jaccard similarity coefficient between the values provided in the answer and the gold standard answer. For those that were qualitative and more descriptive, I assessed the similarity by Jaccard to the gold standard based on the key points covered in the answer compared to the gold standard (each key point being a discrete value, hence the user's answer and the gold standard answer being two sets of discrete values). To assess participants' time to answer questions, the researchers reviewed audio records of the sessions and measured time (in seconds) from the end of the question to the end of the final answer provided by the participant. The participants were given a maximum of 5 min. to start answering a question. If in that time frame an answer was not provided, their accuracy score would get set to 0 and time to answer would get set to 300 sec (this never happened however).

To find out whether DisVis had an effect, I performed a two-tailed two sample t-test for each of the two outcomes: time and accuracy. Additionally, I wanted to see the tool's effect for each type of questions separately: S1, S2 and S3. Due to the small number of questions in each of the question categories, I used non-parametric Mann-Whitney U Test (Wilcoxon Rank Sum Test) to determine the statistical significance of my findings. For the ranking, I used the average performance of each participant for the given set of questions. For the qualitative data collected in the study (participants reflections on the tool and their experience with it) I used inductive thematic analysis. The recorded evaluation sessions were transcribed and open coding approach was taken to help me identify and categorize the prevalent themes from the user feedback. I coded all transcripts independently. The emerging categories were then discussed during meetings between me and my thesis advisor (Dr. Mamykina) and iteratively refined in a collaborative process.

4.1.3 Results

The purpose of Aim 2 was to develop new approaches to supporting sensemaking within OHCs through designing, developing and evaluating a prototype informatics solution for supporting individual sensemaking within online health forums through improved access to information.

The evaluation of the tool had two parts: one related to its performance (quantitative) and one related to perceptions of this new technology from the community members (qualitative).

Ten participants were recruited to participate in the study (N=5 in each group, labeled with P1-P10), 6 male and 4 female. More than half of the participants were above 60 years of age; diabetes diagnoses included both Type 1 and Type 2 diabetes having experience living with the disease ranging from 3 to 45 years (half of them for more than 20 years). The experience with the TuDiabetes.org ranged from only several months to being present in the community since its inception – almost 8 years. However, the vast majority of the participants were regular visitors of the forum, both for reading and contributing purposes; only one participant self-described as a sporadic user of TuDiabetes.

Performance

The tool was evaluated on its ability to improve discussion comprehension in the OHCs forum and it was shown that it *improved the accuracy of the answers* by 68% which was statistically significant. It also *reduced the time to answer questions* by 38%, which was not statistically significant (Table 4). Noticeable differences were observed in the advantage the tool brings over the control group. The tool was shown to highly improve the accuracy of and time to answering questions. Also, participants in the intervention group outperformed those in the control group for some, but not all of the question sets tested. From Table 4 we can see that the average time to

answer a question for the control group was 65.52 sec (sd=46.77 and median of 63.8 sec) as compared to 40.51 sec (sd=26.38 and median of 37.6 sec) for the intervention group. The average accuracy score for the control group was 0.38 (sd=0.28 with median of 0.35), and 0.64 for the intervention group (sd=0.31 with median of 0.8).

Table 4. Average time to answer and average score of answers for a set of questions and all questions overall. Significance tested with Mann-Whitney U Test.

category	measurement	group	mean	sd	significance test ($\alpha=0.05$)
S1	Time (sec)	Control	70.16	42.23	(U=4, p=0.095)
		Intervention	34.73	23.37	
	Accuracy	Control	0.34	0.06	(U=1, p=0.016)
		Intervention	0.59	0.14	
S2	Time (sec)	Control	94.3	41.72	(U=4, p=0.095)
		Intervention	47.9	43.30	
	Accuracy	Control	0.6	0.22	(U=12.5, p=1)
		Intervention	0.6	0.22	
S3	Time (sec)	Control	40.7	16.10	(U=12, p=1)
		Intervention	49.8	36.37	
	Accuracy	Control	0.37	0.19	(U=1, 0.016)
		Intervention	0.77	0.11	
All	Time (sec)	Control	65.52	46.77	(t=1.80, p=0.082)
		Intervention	40.51	26.38	
	Accuracy	Control	0.38	0.28	(t=2.41, p=0.023)
		Intervention	0.64	0.31	

The t-test showed that there is an effect for the accuracy of answering when using the tool: the accuracy when using the tool being 68% higher than without the tool (p-value = 0.023). However, the positive trends in reducing the time to answer questions by 38% was shown to be statistically insignificant (p-value = 0.082). The tool was shown to perform better than or at least as good as the control in all cases, except for time to answer questions from S3. However,

statistical significance was observed in only two of the cases in respect to question types: improving the accuracy of questions of type 1 (S1) and type 3 (S3), both with p-value = 0.016.

Perceptions and design feedback from community members

The focus of the qualitative interviews was on the participants' subjective impressions of the tool and their experience using it. The analysis of the transcripts suggested that the participants' experiences with the tool, and with the forum at large, differed depending on their overall goal. In some cases, the participants came to the forum without any specific questions, but rather to look around for what's new, which included browsing of recent additions to the discussion threads, and skimming of the new content. However, in other cases, the participants came to the forum with a particular question in mind and their interaction focused on identifying relevant information through reading relevant posts and threads, and comparing different opinions on the topic. Notably, these two scenarios were interchangeably utilized across most of the participants. Also, and not surprisingly, these two usage scenarios were associated with very different expectations for how to optimize individuals' experiences and the desired set of functions within the forum. Below, I describe the participants overall assessment of the DisVis tool in terms of usefulness and usability, as well as the more specific comments from the perspective of browsing and searching for specific information.

Overall assessment of the DisVis tool

Overall, the majority of participants agreed with the general premise of the tool, and found its goal of increasing readability of discussion threads and promoting individuals' ability to explore threads to be promising and potentially useful:

P1: *“Well, I think it’s a great idea because I’ve had some struggles reading discussions, to be honest...”*

P8: *“Well, for sure the tool is good to have since it gives you a clear idea about what's going on.”*

However, together with these positive general perceptions, the participants had many critical comments regarding the tools’ current design. Many thought it was too complicated and overthought and provided too much information, at times, without a clear purpose:

P5: *“And I back up a little bit more, from my way that I use the site, this stuff would be more noise than signal.”*

Notably, those who could not find personal use of the tool proposed that it might be most useful for those who started the thread, as well as for moderators, analysts, and researchers:

P9: *“I mean, if you are a scientist analyzing it [the discussion] and you are trying like to pinpoint things like you’ve been asking me, than I can understand it [the reason for using the tool], but just for an average reader – I don’ think I would use it.”*

Finally, the participants were split in their opinions about the tool’s intuitiveness. Most users were able to successfully navigate the tool after the brief tutorial. However, several noted that they would require more experience using the tool to become proficient, which indicated limitations in its intuitiveness:

P1: *“... there are also I think some struggles at the beginning, but now I think with a bit like getting used to it, it's not that difficult to use.”*

P2: *“Well, you know I understood the instructions when you gave them, but putting them into practice, I think after I practice with it a couple or three times, I would have a down path, but just based on one run through, I don’t -- I would need more time to learn it and practice with it.”*

To address this problem specifically, given the number of different features available to users, several participants suggested the use of tool tips to remind them of the purpose of different features.

Exploratory browsing

While talking about their experience using the tool, many participants contextualized them within their overall experiences with TuDiabetes and its particular platform. As I mentioned above, these experiences fell within two distinct categories: exploratory browsing and focused information search. I found that many of the specific comments in regards to DisVis’s usefulness were also made in reference to its ability to support either browsing, or focused search.

Most participants made positive comments in regards to the tool’s ability to support browsing. For example, the participants found the overview of the discussion, Summary statistics of the discussion and the Timeline, to be particularly helpful:

P2: *“I like the dates, I like the date of the -- I really like knowing the timeframe of the thread and the number of participants. All of that summary information is very good.”*

On the other hand, the Slider did not live up to the expectations. For example, the interactive graphical part of the visualization that involved the Slider, developed for navigational purposes for quick browsing, caused the most negative reactions. This was primarily due to the density of information, small font size used in that area and poor adjustability for different screen sizes, especially for small screens. The participants had split opinions about the list of participants and

their number. Some of the participants found those useful for formulating opinion summaries or knowing what positions to expect in the discussion; others found them somewhat irrelevant.

More generally, however, some participants questioned the tool's attention on a single discussion thread as the only focus in the visualization. When describing their browsing experiences, these participants often talked about the need to see a discussion within the context of the forum, rather than as an isolated instance:

P3: *"I'm more inclined to look at all the discussions, all the responses."*

These participants were likely to perceive individual threads as existing in a symbiotic relationship with other discussions that are on the same topic or have a certain amount of overlap in the topics they cover, alluding for a broader relevant context when reading a particular discussion. This colored their perceptions of the tool's focus on a single discussion thread:

P7: *"...so if you clicked on pump you would see a list here of all of the discussions' summaries of whatever, of, of whatever is related in, in another discussion, that, that would be good."*

These participants wished to see the overlap between different discussions on the same topic, and to compare the topics between discussion threads:

P10: *"Perhaps instead of, instead of this, maybe, on keywords, if you clicked on insulin or mdi or pump instead of showing where it shows up, here, what other discussions are mentioning pump, insulin and mdi..."*

Participants were also interested to see forum wide statistics, a more quantitative description of what was going on in the forum:

P3: *“I might want to compare this to discussions and see what the keywords are for both and see if I could cross reference some keywords. I might also want to know what the community’s trending keywords are.”*

Finally, the participants proposed the following new features for more efficient skimming of discussions: highlighting keywords of interest in the text, finding the latest posts in the discussion, and labeling the read posts.

Focused information search

According to the participants, the tool was helpful in finding specific information of interest. The most-liked feature for this task was the Index Panel with its Keywords section:

P2: *“I would love to sort of sort out especially with long threads the ones that really went back to the key points of the initial discussion, like in this case pump and insulin I would probably because I’m an insulin user. I would probably pick on insulin and pump. So it does help me ...”*

However, some participants thought they could not find much use of the Index Panel in real life, although it helped them answer the questions in the study. The participants also proposed specific enhancements to existing features. These included: more prominent highlighting of the selections in the Index Panel, and selection of multiple keywords for the purpose of building more complex Boolean queries.

Further, the participants made many comments regarding desired new features that could improve searching for specific information. These included features for identifying posts of relevance within a particular discussion (as was the case in DisVis) as well as for finding information of interest within the forum at large, or as some participants referred to it “starting from scratch”:

P10: *“So let’s say I go in, onto the home page, and I have a question about the pump... you know... how do I find it from scratch?! Instead of being right here on this open page that’s already started and everything, how would I get to that page from scratch?? – Do I see five different discussions going on, 20 different discussions and then, what would I do??”*

For the first case, the participants proposed keywords (terms) that distinguish a discussion from other similar discussions, as well as a keyword cloud:

P4: *”...I’m in the insulin pump users’ forum so I would already expect there to be discussions about the pump and oftentimes, a lot of the discussions are going to include comments about the infusion set, about the insulin, about the basal rates and multiple daily injections. So I guess the question for me is how could we better define keywords that actually provide more relevance... [...] Yeah, I think more about differentiating the discussions [in terms of keywords] because I think a lot of people will come out in these forums and will search for somebody having the same issue or same challenge that they have today.”*

For the second case, the participants strongly wished for a better search engine, claiming that the current one is simply not delivering the most relevant and recent discussions, and it seems to be more oriented towards individual posts within a discussion, rather than a discussion as a whole:

P1: *”If you search for a key word it doesn’t really show you what you are looking for, like searches for specific answers and I want the overall discussions , so that’s not much of help...”*

In addition, an ability to identify clusters of discussions was highly desired as a feature that can improve the searching process. Finally, the participants liked the idea of exploring different opinions about a topic of interest. However, there was no clear agreement regarding the best way to achieve this. Some wished for a condensed, potentially computer-generated summary; others

felt that only reading multiple posts from the same person on a topic of interest could help to synthesize their perspective, an ability which comes through long time presence in the community and reading of the forum.

In summary, the overall impression of the tool was that its goal of increasing readability of discussion threads and promoting individuals' ability to explore threads is promising and potentially useful, despite being deemed to be rather complicated as a current design solution. Features that summarized the discussion, helped in mapping posts to contributors and showed activity of the discussion over time had generally positive reactions from the participants. However, some suggestions across capabilities for *exploratory browsing* and *focused information search* surfaced. The suggestions for exploratory browsing were tied to the idea of integral view of the forum, where discussions are observed as dependent entities that are interrelated and have overlapping content. Being able to distinguish new information from duplicate information across discussions was valued as well as finding relatedness between discussions. The suggestions for focused information search were geared towards more powerful search engines for searching relevant posts within a discussion and assistance in finding multiple perspectives on a given topic of interest.

4.1.4 Implications of the results

Previously proposed tools for visualizing participant-generated content explored several different perspectives. Many tools focused on providing an overview of the entire volume of the content collected (e-mails or news group postings), rather than focusing on a specific conversation. These included visualizations of interpersonal interactions and topics covered in those interactions [153]; engagement of participants in discussions [151] and individuals' activity and

volume of contributions over time [151]. Other tools took an approach more consistent with the one explored in this work and focused on providing overviews of individual discussions as well as more detailed information about them. Some of these tools placed greater emphasis on finding relevant posts based on topics of interest and participants, while also incorporating information regarding the sentiment of the topic [76]. Others were concerned with providing visual, often scatterplot-based depictions of clustered discussion content. These tools distinguished discussions and threads of conversation within the discussion, highlighted different topics and participants, and importance of individual posts [47,114]. The evaluation studies of these tools focused on users' ability to find topics of interest, summarize, compare and contrast opinions, understand the sentiment about a topic, activity of the participants, their expertise and their interpersonal interactions and relationships. The authors' activity oriented studies showed that knowing authors behavioral patterns in terms of activity and types of contributions was highly valued for understanding their roles and domain knowledge in the community [151,153]. On the other hand, the discussion visualization studies found that users particularly liked the ability to find posts that match their topic of interest, which was found useful in answering questions related to summarizing opinions [76]. Here, however, the findings about the importance of authors' details were dependent on the task study participants were asked to complete [47,76].

Consistently with these previous studies, the participants in my study were positive about the general premise of an interactive tool for visualizing salient features of a discussion thread and exploring its different characteristics and attributes. I found that the participants viewed the tool in the context of two typical scenarios of use, corresponding to the two general types of engagement they experienced with the forum, a distinction not considered in the previous research. On one hand, they looked for features that could help to summarize the thread in a

bird's eye view, highlighting such characteristics as most prevalent keywords and most active participants. On the other hand, they particularly liked the possibility to find posts of interest using the Index Panel, which helped in finding specific pieces of information and formulating opinions about a topic. This is consistent with other studies which found that users particularly liked the ability to find posts that match their topic of interest [47,76]. In addition, the participants valued an ability to view a temporal visualization of the discussion in the interactive timeline, an ability that has not received much attention in prior research, but was considered particularly useful in my study. These positive impressions were also supported by the results of the quantitative assessment: participants in the intervention group who used DisVis interface were able to answer questions related to the discussion thread with higher accuracy and in less time (question types S1 and S3).

However, together with these positive impressions, the participants made a number of critical comments, particularly in regards to the tools' intuitiveness and clarity. Most importantly, they found the information display to be too dense and hard to read, and some of the interactive features, for example the Slider, too difficult to operate. This can be related to a finding from another study, where participants underperformed when exposed to both visualization of the discussion and text analytics compared to a standard discussion representation [47]. However, it contradicts our case in which, based on the quantitative findings, the complexity of the tool actually improved performance as compared to the baseline. From the perspective of general browsing, the participants questioned the tool's focus on a single discussion thread, and desired an overview of topics of interest throughout all discussion threads in the forum. In contrast to my work, this kind of an approach was predominant in VisOHC which focused on OHC moderators [93]. From the perspective of focused search for information, participants found one keyword

selection to be limiting and wished for an ability to construct more complex queries. In addition, they wished for an ability to see keywords selected within the Index Panel highlighted in the discussion's text.

The study helped me to formulate a number of design implications for the next generation of tools for visualizing discussions in OHCs. First of all, the study once again stressed the importance of designing tools that could be used by a variety of individuals regardless of their background, age, specifics of their disease, and computer literacy. Since these tools are likely to be used in an unsupervised fashion and without any possibility for training or instruction, they need to be intuitive and easy to learn. The study also generated a number of specific recommendations for features that could promote the two complementary ways of engaging with information. First, regarding the *browsing experience*, the desired features included: 1) *discussion summary*; 2) *larger context, including immediate access to relevant discussions*; 3) *capabilities to estimate and locate the overlap between the relevant discussions*; and 4) *keeping track of what was read and what is new*. Second, regarding the *focused information searching*, the desired features included: 1) *description of the discussion that distinguishes it from the others* 2) *building more complex queries to search a particular discussion* and 3) *computationally assisted ways to summarize different opinions within the discussion*.

This study had a number of limitations. First, because the study relied on a real discussion thread captured within TuDiabetes, and because I did not screen participants on their previous exposure to this particular thread, it is possible that some of them saw it before the study. In fact, one of the participants mentioned that the thread looked familiar, but could not recall any specific details. In addition, because the study used only a single discussion thread, it is possible that the findings of the study are specific to this thread and may not generalize to other threads within the

same forum or to other forums. In addition, the questions used for assessing the tool’s efficacy may not be relevant to all individuals who frequent OHCs. In fact, few of these questions were found less than relevant by some of the study participants. Additionally, sharing the screen occasionally caused some difficulties with interaction on the participants’ side for both study groups, which was more pronounced for those that needed to interact with the tool.

4.2 Summary of results for Aim 2

The completed work from this Aim 2 showed that the interactive discussion visualization approach for improving sensemaking in OHC forum discussions was positively perceived and had positive impact on members’ ability to comprehend discussions efficiently. However, room for improvement was also recognized primarily geared towards simplification of the interface for increased usability, detecting relatedness between information, finding relevant information based on expressive query formulation and summarizing it, and distinguishing between new information and duplication.

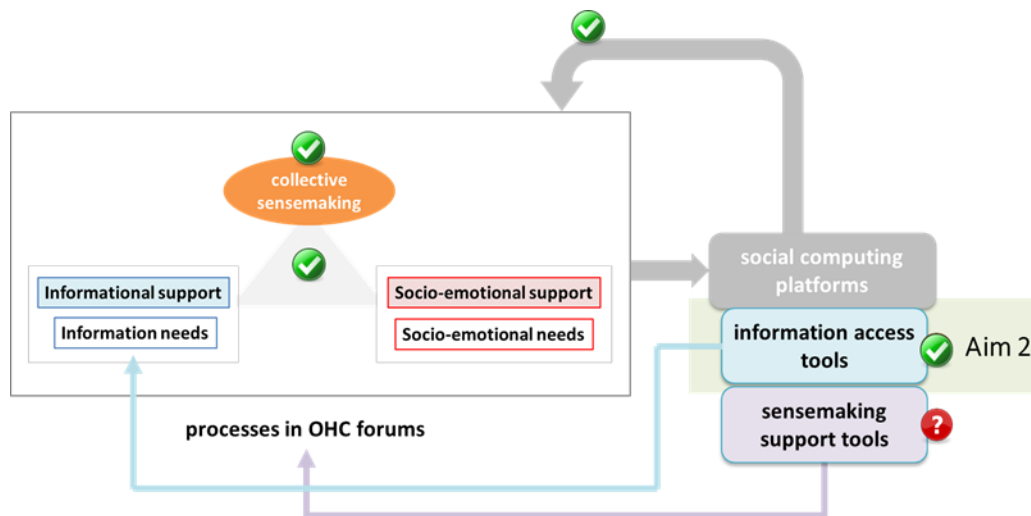


Figure 19. The knowledge gap addressed after the completion of Aim 2.

These findings call for sensemaking sensemaking support tools for OHC forum discussions that have: a) inclusive design for high variability of users, b) simple and intuitive interface for increased usability, and c) capability of finding relevant information with flexible definition of the information needs.

CHAPTER 5: AIM 3 – EXPLORING THE DESIGN SPACE FOR SENSEMAKING SUPPORT TOOLS THAT FOCUS ON INFORMATION ACCESS, WHILE PROMOTING COLLECTIVE SENSEMAKING AND SOCIAL AWARENESS AND CONNECTIONS

The purpose of Aim 3 was to synthesize the knowledge achieved during the studies conducted in Aim 1 and design exploration conducted in Aim 2, and to develop a set of novel mechanisms for supporting sensemaking within OHCs. To achieve this, I have designed and developed a novel informatics solution for supporting individual sensemaking through improving access to information in a way that is sensitive to OHC members' informational and socio-emotional needs and the need of the community to promote collective sensemaking. Further, while many previous studies examined the impact of tools for visualizing discussion threads on individuals' comprehension of information, there are few established methods for evaluating the impact of novel tools on individual and collective sensemaking and the social component of those processes. To address this gap, I have developed a method for conducting such an evaluation. Finally, I have conducted an initial evaluation of dSense with its target audience.

5.1 Designing and developing a holistic sensemaking support tool for OHCs forum discussions, dSense

The first part of Aim 3 covered the design and development of a sensemaking support tool that takes a holistic approach to the three main processes in the OHC and attempts to provide means to enhance them (Figure 20).

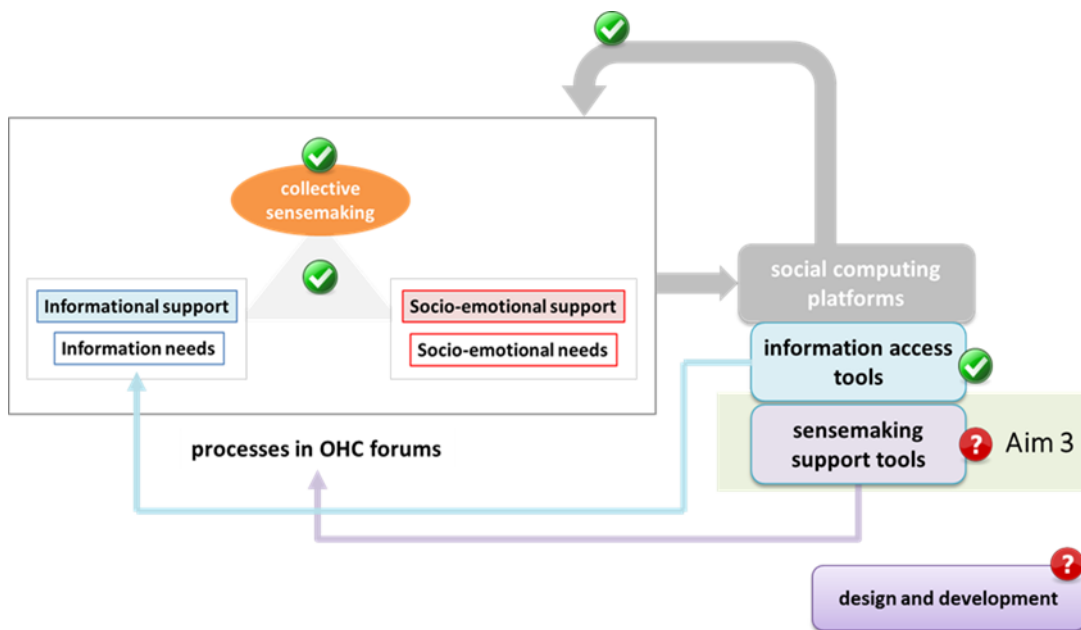


Figure 20. The knowledge gap addressed in the first part of Aim 3.

5.1.1 Related work and knowledge gaps

Previous research suggested many visual analytics solutions for improving access to information in forum discussions. These solutions focused on showing an overview of the topics covered in a discussion [47,76,93]; making connections between topics, sentiment and authors immediately apparent [76,93]; and filtering posts by topicality, similarity and levels of moderation [47,76,93,114]; all within a single view discussion representation that respects the length of the

individual posts and the sequence in which they were generated. Many of these tools provide both an overview of a discussion and means for dissecting its topical space for easier navigation and opinion synthesis, and also impose a structure through which this can be achieved. However, the applicability of these existing solutions to the OHC context is rather questionable because of some notable differences between the unique OHCs members' needs and knowledge production processes typical for those environments on one side and the feature sets available in the existing tools for sensemaking on the other. Consequently, current approaches have a number of limitations: *1) they allow for limited flexibility in the exploration of a discussion; 2) they generally model a given post as a monolithic structure, often ignoring the underlying mechanisms that contributed to its generation, such as individual and collective sensemaking; and 3) they don't account for the social component in the environment in which the discussions were created.* In regards to the limited flexibility in the exploration of a discussion (point #1 above), previous research showed that OHC members' information needs are complex and highly variable [78,104]. Consequently, it is important that users are able to apply their own viewing lenses, and formulate their information needs in a way that is both flexible and efficient. In regards to viewing posts as monolithic structures (point #2), in my previous work (Study A1.1) [101] and based on Rhetorical Structure Theory (RST) [103], I found that posts in fact are constructed from text segments that could have different degree of connection with each other and potentially span across multiple topics. Also, I found that there exist important rhetorical relationships between individual posts through which construction of new meaning is achieved as part of the process of collective sensemaking. This suggests that there is a mismatch between the conceptualization of the post and discussion structures in the current solutions and the reality of OHCs settings. This mismatch could potentially lead to limitations in these solutions' ability

to correctly recognize and match users' information needs. Additionally, it may have a detrimental impact on collective sensemaking within these communities. Finally, my previous studies (Study A1.2 and Study A1.3) highlighted the importance of the social context in which the discussions are created as well as social computing platform (SCP) features that are responsible for building that social fabric.

In the first part of this aim, I addressed these gaps in existing tools for supporting sensemaking by designing and developing a tool that allows for: *1) more flexible definition of users' information needs in the context of complex posts, 2) improved users' access to information of interest based on similar content that is sensitive to the overall flow of the discussion and collective sensemaking, and 3) integrating informational and social aspects of the posts of interest and maintaining social connections in the community while satisfying users' information needs.* This was executed in two steps: *a) a user-centered design of a sensemaking support tool dSense and b) development of dSense as a Chrome Extension for the Discourse forum platform.* I will focus on each of the steps individually in more detail in the remainder of this section.

5.1.2 Identifying user needs and formulating design goals

5.1.2.1 Identifying user-centered design requirements

In order to provide sensemaking support tools for OHC forums, it is important to articulate design requirements that rely on extensive and holistic understanding of user needs. Previous research offered insights about the needs of the OHC members [40,48,113,154,157,159,171]. However, with some exceptions [78,101,111], few previous studies translated into design of sensemaking support tools for OHC forum discussions. To overcome this limitation in approaching the design of such tools, I relied on published literature and my own explorations of

collective sensemaking within OHCs (Aim 1) [101,110,111] to outline a set of design requirements for sensemaking support tools within OHCs.

First, the OHC forum discussions serve as an important source of information regarding health and self-management for its members and must meet one of their primary purposes: *1) provide members with efficient access to information of personal interest* [154,160]. However, at the same time, it is important for OHCs to not only collect individual reflections of their members, but also to help them arrive at new knowledge and discoveries through collective sensemaking, thus suggesting the next requirement: *2) foster collective sensemaking and construction of new knowledge in the discussions* as was shown in the previous studies in Aim 1 [101]. Further, OHCs must strive to meet socio-emotional needs of their members and provide them with opportunities to socialize [111] thus presenting the next requirement: *3) build embracing, densely knit community and close social relationships* [110].

5.1.2.2 Balancing the competing forces generated by the needs of OHC members through design goals

Further, I found that these design requirements can at times be at odds with each other and can generate competing forces that need to be accounted for in designing solutions for supporting sensemaking. The design goals of dSense, that will be elaborated further, were geared towards balancing these forces. First, when looking for information of personal interest, individuals often consider many factors on what is relevant for them. However, capturing these factors when formulating and expressing individuals' information needs may be labor intensive and cognitively taxing. As a result, there may exist a tension between OHC members' *need to precisely formulate their information needs and the need to engage in light-weight fast*

interactions for information retrieval. In addition, special considerations should be given to the notion of relevance, and available computational methods for identifying text that can be deemed relevant. Second, providing efficient access to information may lead members to focus only on fragments of the discussion, rather than the interchange of opinions and slow accumulation of knowledge [101]. As a result, *efficient access to information of personal interest might threaten the collective sensemaking and construction of new knowledge that takes place in discussions.* Third, research has shown that the needs for *finding relevant content in fast and reliable fashion and building embracing densely knit community and close social relationships exhibit tensions and need to be supported in a balanced way* [111].

Precision in formulating information needs vs. the need for light-weight interactions

In order to promote individual sensemaking, it is important that individuals have an ability to formulate and express their information needs. A typical approach to achieving this is through a free-form search engine, in which a user specifies their information need through words or phrases used to query the available corpus. However, in the context of OHCs this approach may be challenging. When looking for information within OHC discussions, individuals' information needs may be impacted by many factors and their unique context, such as type of disease, medical history, previous and current treatment, strategies for self-management and health outcomes [72]. When considering traditional search engines as the main mechanism for retrieving information of interest, preserving or summarizing this type of context in a single user-typed query to find other similar or relevant examples can be challenging, especially for people with limited knowledge about and experience with the disease. This implies that text interpretation and paraphrasing, and potential condensing of the text in a query might hurt the process of finding relevant information or it might take longer time and overhead iteration cycles

before the appropriate query could be constructed. Additionally, in the context of multi-cycle sensemaking process, with very dynamic information needs, it could become very cognitively expensive.

An alternative approach to allowing users express their information need is by selecting a post that most closely resembles this need and using the text of the post as a search query. However, given that posts within discussions are typically complex and include several topics, predicting which part of this context is important to the current user need through hierarchical topic modeling [77] or text segmentation [84], and accurately extracting it automatically to avoid the difficulties with query formulation can be challenging. However, given that we can expect the full context is present within the margins of a post, we could allow the user to specify the portion of their interest in a very fast and cognitively cheap way. This leads to the next design goal:

Design Goal 1: Provide members with efficient access to information of personal interest - allow users to specify their information need in a fast and flexible way by leveraging text of posts pertinent to their information need and allowing them to inspect the relevant content in the rest of the discussion with respect to that information need.

Sub-goal 1.1: allow users to identify and highlight text within posts that most closely represents their current information need. This text can become the search query based on which relevant content will be retrieved.

Sub-goal 1.2: tools for sensemaking should include a visual representation of the overall flow of the discussion, in a way that allows for a quick examination of the relevant content with respect to the highlight.

Sub-goal 1.3: in addition, the tool should visually indicate posts that present potential match for a user's information needs according to some specified criteria (I further elaborate on different considerations regarding defining relevant posts in the next section).

Individual vs. collective sensemaking in a discussion

In the process of collective sensemaking, participants in OHC discussions “feed of each other” and contribute relevant posts, thus helping the discussion initiator satisfy their information needs and gaining new information in the process [101]. As the content builds over time, the discussion becomes a resource for addressing information needs not just for the initiator, but for other members as well [124]. In such scenario, in order to satisfy their own information needs, the participants might be compelled to selectively read the discussion, sample posts and assess their relevance [101].

In addition, diabetes self-management issues are complex, and involve drawing connections between many topics, some more related than others, in order to examine the questions in all their richness [78]. As a result, topics in discussion threads often diverge from their original starting point, but these divergences can be useful and different than those that push the discussion in a completely unrelated direction. This set-up makes the previously described activities that OHC members take to read the discussion more efficiently even more riskier and threatening to the individual sensemaking process. Due to this potential for unawareness of the content in the discussion and the broken picture about the topics of individual interests, the contributions of the participants might become damaging to the collective sensemaking process.

However, if a user has the access to the most relevant content for closing their knowledge gap that is put in the context of the entire discussion, they will have a better insight in what was

already said about it and what else to say that might help others; if they know where in the discussion there is an interest for such insight, they will be more motivated to share it; and if they put it in the right place in the discussion, they will drive it in the right direction that might help others who have tangible knowledge gaps. Therefore the second design goal is as follows:

Design Goal 2: Foster collective sensemaking and construction of new knowledge - help users to establish a holistic mental model of the discussion's content and potential collective sensemaking within the discussion, while at the same time helping them to satisfy their information needs.

This includes the following sub-goals:

Sub-goal 2.1: the sensemaking support tool should draw the user's attention to parts of the discussion thread that are indicative of collective sensemaking where the posts with similar content to the query are exchanged in a sequence.

Sub-goal 2.2: the tool should also draw the attention to parts of the discussion that are indicative of collective sensemaking where multiple participants are contributing relevant content with respect to the query.

Information access vs. social fabric in OHCs

Satisfying the previous design goals implies requirement for significantly improved access to relevant information. However, at the same time, it is important to allow for preservation of the social fabric in the community [110]. Examples of cues that might improve information access and gauge relevance of the information are badges for credibility and trust levels, or community approval of content such as a "like" button or up-voting and down-voting [91]. These

community produced meta-data about the content have been shown to have a positive effect on stimulating contributions and making sense of them in some fact oriented and problem solving communities [7,100]. However, in an OHC setting where giving everyone a fair chance to be heard and equality of members is highly valued, these forms of appraisal could be interpreted as promoting certain types of members over the others and creating an unnecessary competitive environment [110,111].

As a result, it is important to help users examine and develop awareness of connections between posts in a discussion thread and the social identity of authors of these posts. Maintaining such connections may help in mapping out the space of community members that have similar medical profiles, experiences and interests, more dependent on the quality of the content a member provides, rather than on how vocal they are or their status in the community. Further, it can make less established members' contributions visible, and stimulate their exposure and integration in the community. In addition, "stumbling" upon unfamiliar contributors, based on the relevance of the information they provide, may also grant establishing new bridges between cliques, which are typical for OHCs [111]. This "bridging" is essential for preventing fragmented social structure in the community, but also for more liberal flow of information necessary for obtaining multiple perspectives that add value to the sensemaking. Further, the users should be able to examine the profiles of individuals that contributed posts deemed as relevant. This ability can allow members to find details about the author's profile related to the disease and the contributions in the forum, and also their personal information available from their profile. This can not only enable members to assess the relevance of the information even more closely, but to also immediately learn more about the person behind the post on a higher personal level, which is important for building trust and closer social connections in the community [91,133].

To balance these competing forces I formulated the following design goal:

Design Goal 3: Contribute to stimulating awareness of community members and social interactions - information retrieval mechanisms used to satisfy individuals' information needs should maintain persistent and explicit connections between that relevant information and the authors who contributed it.

This includes the following sub-goals:

Sub-goal 3.1: make authors of posts visible and easy to inspect while viewing the discussion thread and its posts.

Sub-goal 3.2: provide users with the ability to view profiles of authors while inspecting posts identified as relevant.

As a consequence of the previous design goals, and taking into consideration long discussions with multiple relevant posts to the highlighted text that represents the search query and the iterative multicycle nature of the sensemaking process [127] the following design goal emerges:

Design Goal 4: Enable efficient exploration of the relevant content - provide mechanism for efficient and seamless exploration of the relevant posts identified by the system across the committed searches.

Sub-goal 4.1: once the user selects a post that was presented as matching their information needs, the tool should provide a user with a quick overview of the post before they commit to detailed reading.

Sub-goal 4.2: since the matching posts identified by the system can have segments more or less relevant to the highlight, there should be some form of assistance for reading them, which is especially pertinent to long posts.

Sub-goal 4.3: since sensemaking is highly cyclical process, the user must be able to refer to the history of their searches and interactions with the tool to provide refinement of their information needs.

Sub-goal 4.4: allow for a smooth transition between highlighting text to express information needs, reviewing results of matching and previewing potentially relevant posts, and reading the actual posts within the discussion thread.

Further in this dissertation I describe how these design goals and sub-goals drove the design choices for dSense.

5.1.3 Defining relevant content through similarity

5.1.3.1 Defining relevance in the context of OHCs forum discussions

Different types of relevance

In order to identify posts that match an individual's information needs, it is important to examine the concept of relevance and its application to OHCs. The notion of relevance has been actively investigated and debated within the research community, but with less emphasis on OHCs [106]. However, little agreement has been made over what it exactly entails. An overarching characteristic that unifies existent multiple perspectives is that it is *highly subjective to the information seeker, is domain specific, and goal driven* [11–13,70,81,106]. There have been

numerous attributes that researchers discussed that could be contributing to the information relevance assessment with respect to an information need generated by a person: tangibility, depth and scope, accuracy and validity, recency, consensus within the field, source reputation and visibility, relationship with the author, among others [12]. However, one actionable broad classification of relevance is the one related to: *objective relevance*, or system based relevance; and *subjective relevance*, or user-based relevance [11]. Objective relevance is usually referred to as *topical relevance*. In information retrieval terms, topical relevance, or topicality, tells us how well the topic of the information retrieved matches the topic of the request, without thinking about the person behind the request. On the other hand, subjective relevance takes the users into account and is related to concepts such as *pertinence*, *situational relevance*, *perceived utility*, *informativeness and beneficiality*, for example. While objective relevance can be considered static, subjective relevance is highly dynamic and is tied to the dynamicity of the information seeking process. This type of relevance is of particular interest for OHCs, since health related information searching is very subjective and very dependent on the current context of the searcher [38,171].

Assessing relevance in OHCs forum discussions context

It is worth mentioning that pertinent to the subject of sensemaking support in OHC forum discussions, information from the OHC forums can be used to infer some cues to support relevance assessment across the multiple dimensions listed previously. For example, timestamps of the posts can establish the *recency* of the information and NLP techniques could determine the *tangibility* between two different posts and a post's *depth* and *scope* for a given topic [44,84,163]. These techniques in tandem with social network analysis can have the potential to determine the *relationships between authors* [24,37,52], *credibility and authority of the authors*

[86,107,175], and *consensus about a topic in the community* [17,87]. Despite this potential, and to keep dSense design more focused, I only paid attention to topical relevance. This entails that aside from the text in the post, no other information was included to automatically determine the relevance of the posts to an information need i.e. search query. However, I reached some properties of subjective relevance by allowing users to investigate the detailed personal information about the authors of the relevant posts.

Assessing topical relevance in OHCs forum discussions context

Pertinent to this approach are the facts that the posts in OHC discussions exhibit dependencies between them: some more explicit, like a reply, citation, or tagging a user, and some less explicit, like expressing agreement or disagreement on a previous statement and expanding on it [101]. This means that a single post can be related to one or more posts, thus addressing one or more topics at the same time. Therefore, the question of what makes certain piece of text relevant to another piece of text is non-trivial and is heavily dependent on the discourse from which those texts are extracted.

Similarly to the information relevance at broad, a lot of work has been done in the domain of topical relevance. Previous research has attempted to provide formal discourse models for a single author and for a group conversation. The discourse model for a single author relies on the Rhetoric Structure Theory [103]. Based on this theory, a text is composed of *text spans* (or *rhetoric units*). There is a set of possible *relationships* that can hold two text spans together. The rhetoric unit to which another one is related is called a *nucleus*, and the rhetoric unit that is related in some form to the nucleus is called a *satellite*. The way through which the nucleus and the satellite are related is defined by the *rhetoric relationship* (or briefly - *relation*). The rhetoric

relationship of interest, when trying to find a satellite for a nucleus, makes certain satellites *relevant* to a nucleus and others not. However, the unit of analysis in this theory is a coherent single document generated by a single author and the relations between different units of the same document. Thus, the applicability of this theory to describing relations between different posts generated by multiple authors is unclear. Recognizing shortcomings of this theory for its applicability to group discourse, researchers proposed new models [63,129,130]. In one of these theories about discourse structure [63], the authors talk about three separate, but related components: the structure of the sequence of utterances organized in *discourse segments* (the linguistic structure), a *structure of the purpose* (the intentional structure), and the *state of focus of attention* (the attentional state). This theory assumes that each discourse utterance is linguistically and logically embedded in a discourse segment, and contributed based on the intention and the focus of attention. However, the development of this discourse model is based on verbal conversations that have been transcribed for the purposes of the analysis. There are important differences in this setting as compared to forum discussions. These differences are primarily related to the fact that in the forum setting, the contributions to the discussion i.e. posts happen asynchronously, and are stored and made available at any point of time to anyone who decides to participate in the discussion. In this setting, a contributor to the discussion has the opportunity to engage in reading a number of different discourse segments that span across extended period of time and “interrupt” other segments with contributing content based on the previous segments, but irrelevant to the one in which the new contribution is about to be placed. This is mainly due to the sequential presentation of the discussions in the forums. As a consequence, the attention of the contributor is hard to be defined since contributions related to different discourse segments maybe intermixed and scattered all around the sequence of posts.

The availability of the history of the forum discussion and the different dynamics of turn-taking compared to synchronous conversation allows the forum discussion participants to address different utterances from different discourse segments at the same time, thus giving posts more complex intra and inter dependent structures. In addition, the proposed models for discourse in a group are not developed through a lens of completing certain individual cognitive tasks, such as individual sensemaking, nor do they assume an underlying mechanism that generated that information, such as collective sensemaking. In Study A1.1 I addressed these shortcomings and came up with taxonomy of discourse moves that are used as building blocks to collectively construct meaning in the context of OHC discussions [101]. These are: 1) *agreement/disagreement with previously stated position*, 2) *presenting argument for/against previously stated position*, 3) *further developing previously stated position*, 4) *personal reconciliation*, and 5) *synthesis of previously stated perspectives*. However, these developed discourse models are still fairly removed from possible computational solutions that might use them for improving sensemaking in forum discussions in terms of precisely defining relevance and retrieving relevant information based on a specified information need.

To overcome this limitation and to operationalize the concept of relevance in our case, I decided to use the following definition: *a post is relevant to a portion of text from another post that represents the search query if it has at least one text segment that is similar to that query and is above a certain threshold of similarity (Figure 21, colored in shades of green). A post may have more than one relevant segment above the threshold, but we are only interested in the one with maximum value and that is the one that will define the relevance of the entire post (Figure 21, darkest green)*. This idea of relevance allows for finding the most similar content, but also leaves

room for finding related content that might broaden the sensemaker’s understanding of the topic of interest and could be valuable for the sensemaking process (Figure 21, far right).

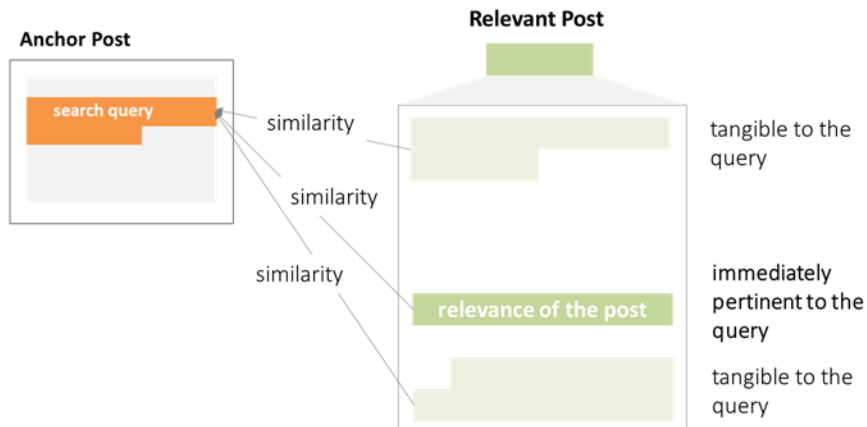


Figure 21. The Anchor Post contains the highlighted text segment to serve as a search query and the Relevant Post contains text segments that are similar to the highlighted text and are above a certain threshold.

5.1.3.2 Finding relevance between two texts based on similarity

Inspired by the work done in the domain of Q&A systems and news recommendation [21–23,28,80,131], in a previous preliminary study I took a relatively simple approach to defining information relevance in the context of OHC forum discussion sensemaking. This approach did not take into account any underlying mechanisms that are involved in generating the discussion. Similarly, it did not account for possible relationships between discussion posts, thus treating each discussion thread as a “bag-of-posts”. Moreover, this approach did not assume any internal structure of the discussion posts, thus treating them as monolithic structures. In addition to this, it assumed that the information of interest for a particular user is an entire post, that was called the *Anchor Post*, and that the relevant information to that post is represented with some of the remaining posts in the discussion, called *Candidate Posts*.

Evaluation of suite of algorithms for text similarity

By taking this high level model as a basis, I tested some of the existing algorithms for similarity between text documents as well as modifications and combination between them, to examine their suitability for this task (Table 5, leftmost column). I will only explain the algorithms that are pertinent for the remainder of the dissertation work in more detail.

TF-IDF is a well-known strong baseline in document modeling problems, and its approach is straightforward [85]. A post, represented as a bag of words, is converted into a vector of counts. Each dimension in this vector corresponds to a unique token in the corpus vocabulary. The result is a large but sparse vector of non-negative integers. These counts are then converted to a term-frequency (TF), by normalizing the vector by its sum – this accounts for variable length documents. Then each term in the TF is divided by the number of unique documents in the entire corpus that the term appeared in – this inverse-document-frequency (IDF) transformation shrinks the importance of terms that commonly occur in many documents, since they are less likely to be informative. The resulting transformation yields a post representation that promotes the words that are common to a particular post, but are not common in general. To compare the similarity of an Anchor Post to a candidate post, I simply took the cosine distance between their TF-IDF vectors. TF-IDF incorporates a strict definition of similarity in TF-IDF where the words in the documents have to match at symbolic level: entire words or roots after being stemmed, in order to contribute to the similarity metric. SF-IDF attempts to address TF-IDF's strict definition of relevance as lexical overlap [22]. SF-IDF has the serious limitation, however, that it is tied to a specific ontological resource (WordNet) that has been hand-curated and thus has quite low coverage of English, especially informal English on the Internet [184]. The Neural Continuous Bag of Words (NCBOW) addresses this issue in a completely unsupervised way by leveraging

token vectors that have been fit using the GloVe [126,185] algorithm on the entire Common Crawl of the Internet (42 billion tokens total). The resulting vectors encode “meaning” in a soft way, such that similar words will have similar vectors (at least in some dimensions). The resulting representation allows for a more graded notion of meaning as compared to TF-IDF and SF-IDF. These vectors represent only single tokens; to obtain a fixed-length representation for an entire document, I aggregated the vectors for the BOW of the post element-wise using three different approaches: sum, average, and TF-IDF weighted sum. To score a pair of posts, I took the dot product between the resulting low-dimensional, dense document vectors, out of which the SUM approach performed the best (Table 5, shaded). The main idea behind the algorithm was to be easily transferable and generalizable across many OHCs and not be reliant on any form of human supervision.

To train my unsupervised models, I scraped 20,404 discussions from Tudiabetes.org, an online health community for diabetes self-management. This resulted in 296,118 posts, averaging 14.5 posts per discussion. Additionally, I found that the posts were mostly short, with 52% of the posts having 25 tokens or less.

The performance of the algorithms was measured against a Gold Standard (GS) developed by 3 graduate students from the Department of Biomedical Informatics at the Columbia University Medical Center with experience in diabetes nutrition and self-management. Each student was assigned 1 discussion on a different topic from the TuDiabetes forum dataset (with no more than 50 posts in any of the discussions). For each of the discussions, the students were given a set of 3 posts (Anchor Posts) for which they assigned relevance scores to the remaining posts in the discussion. The scale was ranging from 0 to 3: *0 – not relevant; 1 - poor relevance; 2 – relevant; 3 – extremely relevant*. I used the nDCG metric for measuring the performance of the algorithms.

The nDCG is a standard metric in information retrieval that measures the quality of a ranking of documents relative to their ideal GS ranking, using only the top-k ranked documents (in my case $k=\{5, 10,15\}$) [186].

Results of the evaluation

Table 5. The performance of the individual algorithms for similarity between an Anchor and a Candidate Post as measured by nDCG@5, nDCG@10, nDCG@15.

MODEL	nDCG@5	nDCG@10	nDCG@15
Random Baseline <i>Term-Frequency, Inverse Document Frequency</i>	0.14	0.21	0.19
Neural Continuous Bag of Words (AVG) <i>Represent document by average of GloVe word vectors, trained on Common Crawl</i>	0.14	0.22	0.28
LSA Cosine (latent dim=10) <i>Latent Semantic Analysis</i>	0.31	0.33	0.40
LSA Cosine (latent dim=50) <i>Latent Semantic Analysis</i>	0.32	0.36	0.43
LSA Cosine (latent dim=100) <i>Latent Semantic Analysis</i>	0.32	0.38	0.43
TF-IDF Cosine with refitting <i>TF-IDF where IDF is recomputed for each discussion</i>	0.35	0.42	0.47
Neural Continuous Bag of Words (TF-IDF) <i>Represent document by TF-IDF weighted sum of Glove word vectors, trained on Common Crawl</i>	0.47	0.52	0.55
SF-IDF Cosine <i>Replace terms with their WordNet "synsets" for better approximation of word meaning</i>	0.48	0.53	0.56
Neural Continuous Bag of Words (SUM) <i>Represent document by sum of GloVe word vectors, trained on Common Crawl</i>	0.51	0.53	0.56
TF-IDF Cosine <i>Cosine without refitting (entire discussions corpus)</i>	0.49	0.59	0.62
TF-IDF and NCBOV (SUM) Ensemble <i>Committee of both classifiers. Most confident prediction is taken as decision.</i>	0.53	0.61	0.66

Of all the models evaluated, the most interesting result is that NCBO (SUM) performs best overall for nDCG@5, but then is outperformed by TF-IDF for nDCG@10 and 15. During error analysis, I found that there are at least two distinct “types” of relevant posts. The first type includes topically similar posts that discuss the same topic, but use different words. For example, in a pair of posts in the test set, the users discuss recipes for a diabetes-aware diet and exchange their preferred ingredients. This is precisely the situation NCBO (SUM) is designed for, since the tokens in these posts are distinct from each other, but have close word vectors. These types of posts are more likely to be given a gold relevance score of 3 (extremely relevant) by annotators and thus lie in the top 5 most relevant posts, giving NCBO (SUM) an advantage on this metric.

The second type includes posts that are topically tangential. These posts typically have a large topical overlap with the Anchor Post, but also then contribute information in at least one tangential topic and as such tend to have relevance scores of 2. In one example of this in the test data, the Anchor Post discusses a heart attack a user experienced and the Candidate Post briefly mentions the heart attack before discussing their lifestyle changes in response to their own personal heart attack experience. This type of post has multiple topics, which could potentially confuse NCBO (SUM) since multiple topics become averaged out in the overall representation. However, TF-IDF fares well in this scenario because disjoint topics typically have little lexical overlap and thus contribute little to the cosine similarity of the BOW vectors; TF-IDF is only concerned with aspects of the post with strong overlap, not the posts as a whole. Since these types of posts are slightly less relevant, but still typically high in the rankings (top 10 or 15), TF-IDF performs well on the nDCG@10 and 15 metrics.

It is this error analysis which motivated me to experiment with the TF-IDF and NCBO (SUM) panel of experts ensemble: a committee of both classifiers where the most confident prediction is taken as decision. It was shown that this is the best performing model (Table 5, shaded). The ensemble performs better than either of the individual models because these are distinct situations: some posts are on topic, but have variation in word use, while others discuss the same topic, but transition to other topics. This algorithm will be the one that I will base on the similarity calculations between a highlight and a post.

5.1.3.3 Calculating similarity between a highlighted continuous text segment and a post



Figure 22. The sliding window for calculating similar content.

Based on my preliminary work and modeling the posts as having complex inner structure, the similarity of the content is now determined by calculating similarity between a highlighted text in the Anchor Post i.e. the query and a sliding window in the Candidate Post. For this purpose, and based on previous literature [20,88] and the constraints for fast response of the information retrieval engine dedicated to dSense, I defined the two parameters for the window: the length of the window – 50 words, and the shift – one half of the window or 25 words (Figure 22, left). As the sliding window moves, at each step it generates text segments with different degrees of

similarity to the query (Figure 22, right). The window (W) with maximum similarity defines the similarity (S) of the entire Candidate Post (CP) to the highlighted text query (Q)(1).

$$S(Q, CP) = SIM_{max}(Q, CP) \quad (1)$$

$$SIM_{max}(Q, CP) = \max(TF_IDF(Q, W), NCBOW_{sum}(Q, W)) \quad (2)$$

Finally, the similarity between the query and the window (2) is calculated by an algorithm for similarity between two pieces of text based on an ensemble of the popular TF-IDF algorithm and NCBOW(SUM), which was previously explained in detail.

At this stage I had all the elements in place to start moving from design goals to the actual look of the interface.

5.1.4 Iterative design of dSense

Previous research showed that both information seeking and social practices within communities are closely tied to the affordances of their technical platforms [110]. As a result, it is important to ensure that new tools for promoting sensemaking within these communities are integrated with existing platforms, and operate within their technical ecology. To address this, and to leverage the existing technological and social capital of the communities, dSense was implemented as a Chrome Extension to a popular platform for online communities, Discourse. Following these technological constraints, the goal of the design process was to secure reliable and iterative mapping of the design goals to converging design solutions that will output a design of dSense ready for implementation and evaluation.

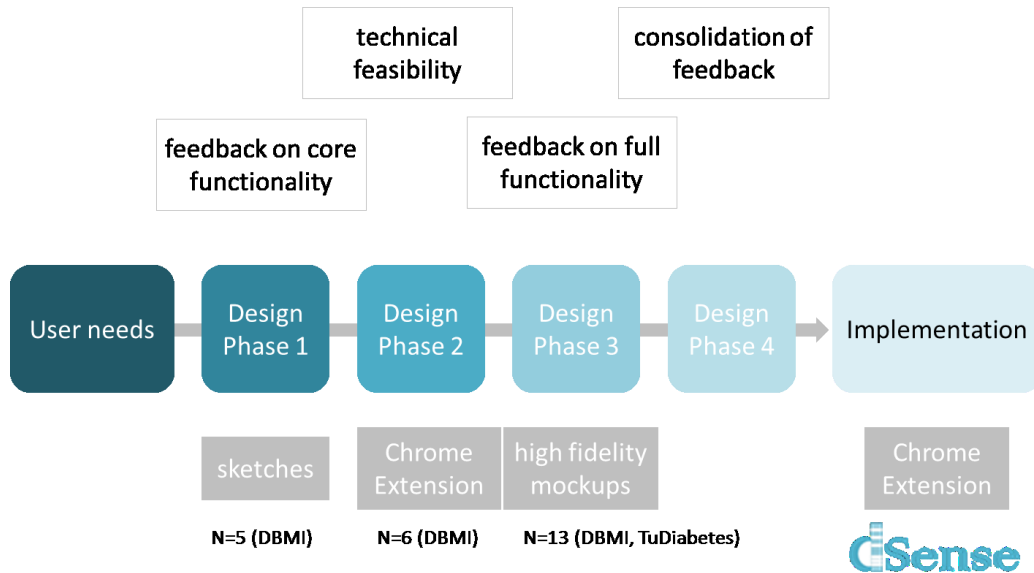


Figure 23. The steps involved in the iterative user-centered design of dSense.

The iterative user-centered design process involved 4 phases (Figure 23). In the first phase, Phase 1, I obtained a high level feedback on the idea behind the core functionality of dSense. In the next phase, Phase 2, I tested the technical feasibility of the design proposed in Phase 1 and updated based on the feedback. In Phase 3, I obtained feedback on the design for the full functionality of dSense that emerged from the output from the previous design phase. In the final phase of the design process, Phase 4, I consolidated the feedback from the previous design phases and came up with a final design for dSense that was used for implementation and evaluation.

5.1.4.1 Design phase 1: Operationalizing the design goals and developing initial design sketches

The main goal of this phase was to: *a) translate the previously identified design goals into concrete design solutions and b) on a high level, test the idea of the core functionality of the dSense tool (Figure 24).*

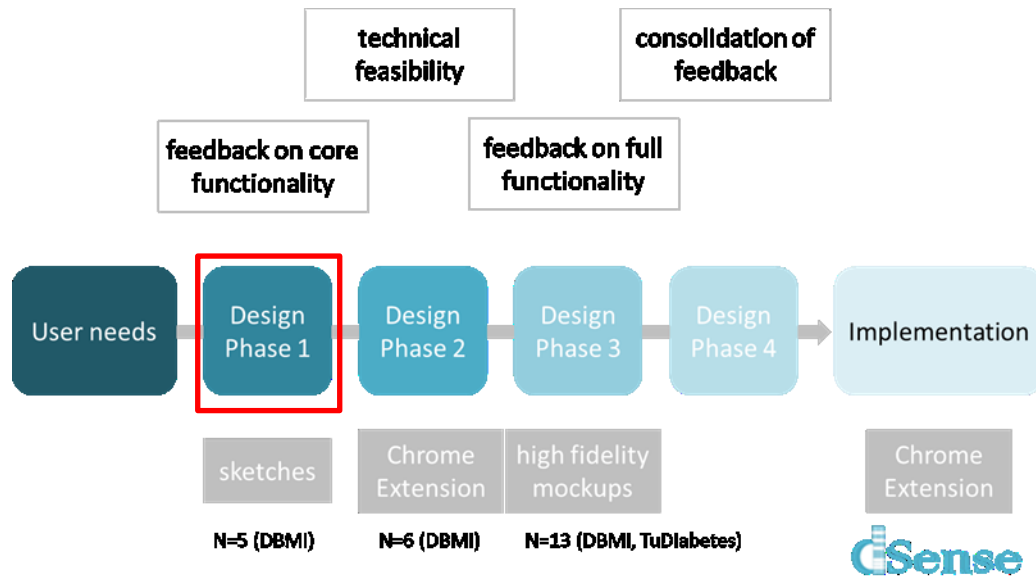


Figure 24. The first step in the design process (Phase 1) – getting feedback on the core functionality of dSense.

To accomplish this, first, I mapped the core design goals to design solutions, which heavily relied on visualization techniques (Table 6). After this step, I developed rough design sketches based on the high level conceptualizations of the interactions. Because this was the initial phase of the iterative design process, I focused only on the core design goals that are the backbone of the tool.

Table 6. Mapping the core design goals to solutions that rely on visual representations.

Design goals	Design solutions
PHASE 1: Design Sketches	
Design Goal 1: Provide members with efficient access to information of personal interest	<ul style="list-style-type: none"> highlight text from the post of interest discussion as sequence of post tiles, color coded for relevance
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> discussion as sequence of post tiles, color coded for relevance post tile with author
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	post tile with author with profile card on demand, color coded for relevance

Design Goal 1: Provide members with efficient access to information of personal interest

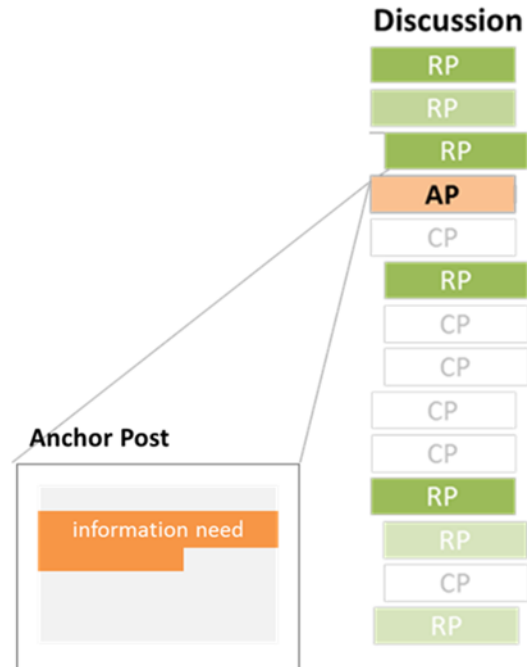


Figure 25. Left: Highlighted continuous text segment that represents a search query (orange) from the text of the Anchor Post of interest (gray), Right: the visual rendering of the relevant posts in the discussion color coded for relevance (the darker the green the more relevant).

I previously established that a user can be interested in only one part of the post (some text segment) instead of its entire content that reflects their information need. To help users define their information need in a flexible and easy-to-use way, I proposed a simple interactive solution, which allows the user to highlight a segment of a post that they identified as the best articulation of their information need. This highlighted segment will serve as the representation of the information need for which similar content will be looked for in the rest of the discussion. Therefore, the interaction modality for specifying an information need will be modeled as a fast

and simple text selection from the post of interest called the Anchor Post (design goal #1.1: Figure 25, left).

Based on the highlighted text that serves as a search query, dSense shows the distribution of the relevant content in the entire discussion in a single view (design goal #1.2, Figure 25, right). To accomplish that, dSense visualizes the entire discussion thread as a collection of Post Tiles that follows the sequence of posts in the original discussion representation in Discourse. dSense uses orange to mark the Anchor Post that holds the text of interest that represents a user's information need and relies on color-coding to signify posts deemed relevant with shades of green in a thumbnail representation of the entire discussion. The coloring reflects the level of similarity, the darker being the more relevant (design goal #1.3: Figure 25, right). However, unlike the representation in Discourse, the dSense has the replies to the posts expanded at all times represented by tiles that are indented towards the right to make the relevant information transparent at all times. This representation is chosen to show the relevant posts within the context in which they were created and help users focus on appropriate segments of the discussion while at the same time preserving relationships between posts. To drive the attention to the most relevant posts first, and then consider the length of the post, all of the tiles have equal height. In addition, due to the algorithm for identifying relevant content, longer post marked as relevant doesn't imply more relevant content, thus preserving the length of the posts in the tiles by making them taller like in other solutions [47] might give them more "green space" than they actually deserve, which can be misleading to the sensemaker of the discussion.

Design Goal 2: Foster collective sensemaking and construction of new knowledge

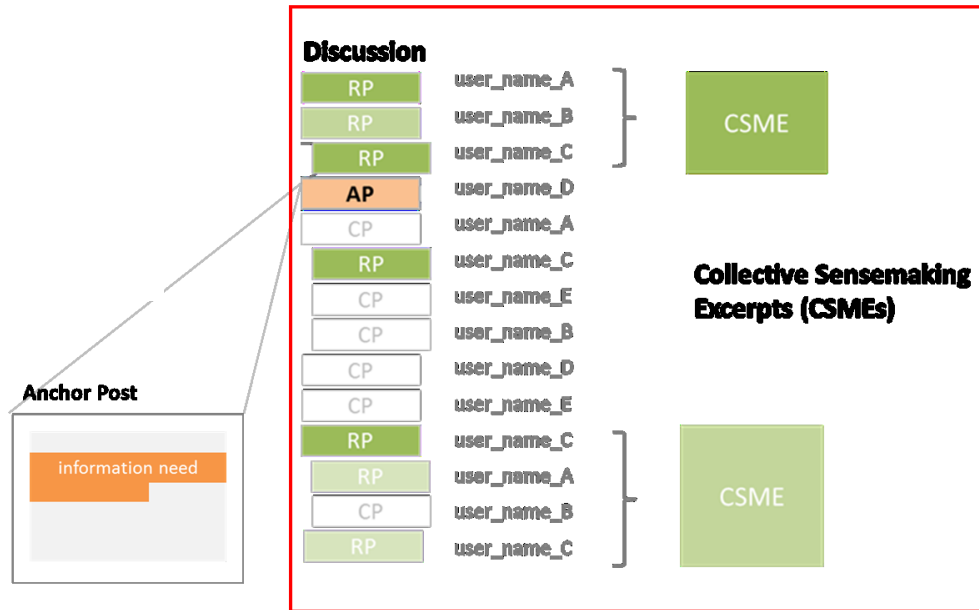


Figure 26. Holistic mental model of a discussion while at the same time supporting information needs.

By this visual representation of the Relevant Posts, I'm also adding another level of abstraction for relevant content i.e. Relevant Segment, which could be visually inferred by the user based on the Post Tiles discussion representation. A segment with posts in the discussion that has more (highly) Relevant Posts could be likely representing a collective sensemaking excerpt that is more relevant to the text highlight in the Anchor Post as compared to scattered (highly) Relevant Posts (design goal #2.1: Figure 26). To add another layer of cues for identifying segments of collective sensemaking in the discussion, different than other solutions [76], dSense makes the lateral engagement of the participants explicit by putting the names of the posts' authors next to the tiles (design goal #2.2: Figure 26). This was added to help users to prioritize the posts that match their information need by the context of participation too, inspecting posts from a posts

segment with Relevant Posts first thus supporting quick examination of the discussion (design goal #1.2: Figure 26).

Conceptualization of the design for stimulating social interactions

Design Goal 3: Contribute to stimulating awareness of community members and social interactions

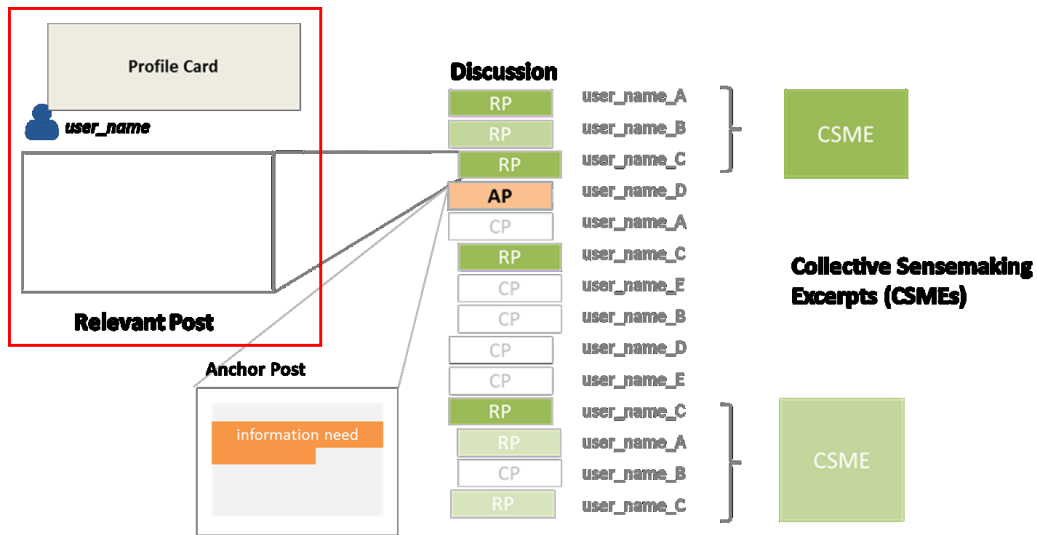


Figure 27. Providing personal information about the post author at the point of exploration and explicit links between posts’ relevance and authors’.

To help users maintain connection between relevant information and the authors persistent and explicit, dSense displays the author name next to each Post Tile (design goal #3.1: Figure 27, middle) and a Profile Card for an author of the post deemed relevant while they examine that post in more detail (design goal #3.2: Figure 27, middle). This was included to allow for establishing immediate links between a discussion participant and the relevant information they contributed (design goal #3.2: Figure 27, left), regardless of their status in the community.

User study

In order to collect initial user feedback on these design conceptualizations, I chose to develop dSense as a Chrome Extension for Discourse that can be activated on demand. In this implementation, dSense can be considered as an enhancement to the existing platform, preserving the well-established behavior for reading the full posts content in the Discourse environment. As a result, the design mockups were developed to fit existing design features of the Discourse platform to allow for easy integration during the implementation phase. In this early evaluation study I used paper prototypes.

Participants

The design sketches were tested for initial feedback about the fundamentals of the design with 5 members of the ARCH (Action Research for Connected Health) Lab in the Department of Biomedical Informatics at Columbia University Medical Center. None of these members was involved in the work on dSense or the ones that led to it; however a few of them had some familiarity with the previous stages of the project, primarily related to the earlier Aims from the thesis. The participants had different scientific backgrounds (psychology, nursing, applied mathematics) and their familiarity with OHC forums varied: none was a member of an OHC, but some visited them more frequently than others for health related issues. However, everyone was knowledgeable about online discussions and had experience participating in them. Since I was only obtaining a high level feedback of the backbone of the tool, this type of study participants for this stage of the design process was deemed appropriate.

Procedures

Each of the participants received a short explanation of what the tool tries to accomplish and was exposed to the sketches of the dSense features related to each of the major design goals. First, the participants were presented with the idea of defining a search query by highlighting a continuous segment from the text in the post of interest. To see if this is sufficient, I showed each of the 5 participants involved in the study the same print out of 3 posts extracted from a TuDiabetes.org forum discussion. For each of those, I asked them to highlight arbitrary number of continuous text segments that would represent their search query if there was a super capable engine to retrieve results for an information need that arose just from reading the post. The participants were asked to comment on the reasons for their highlighting and the experience with this interaction modality for defining a search query. Then, they were shown how it looks in the design sketch as a single continuous text segment (Figure 28A, left) and were asked to comment on that. After that, the participants were introduced to the feature that was supposed to allow the user to quickly assess the overall relevant content of the discussion and provide means to focus on a particular segment of the discussion where it seems like relevant content has been produced. The participants were shown the visual rendering of the discussion (Figure 28A, right) and asked to compare this form of displaying results to the more classical approach which involves typing a query and a list of ranked results. They were also asked about their impression to which extent this form of visual rendering is able to support the exploration.

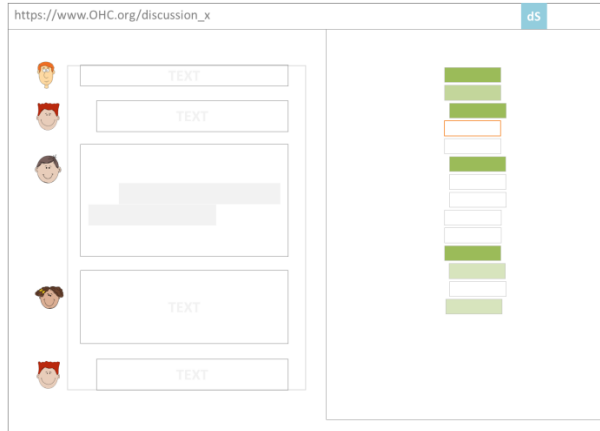
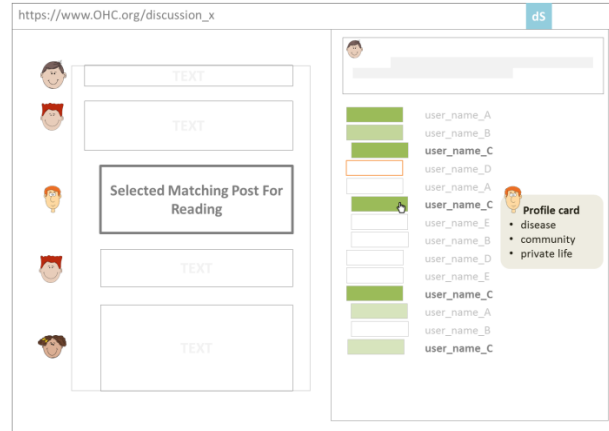
A**B**

Figure 28. dSense design sketches: A) On the left side, there are the posts of the discussion as represented in Discourse. The grayed area in one of the posts is the highlighted text segment that represents the search query. On the right side, there is the visual representation of the discussion as a result of executing the query. Each tile represents a single post. The indentation reflects a reply, and the whole structure reflects the way posts are ordered and displayed in Discourse when the replies are expanded. The three different shades of green represent the different levels of relevance of the posts - the darker the more relevant. B) Right above the visual representation of the discussion is the post with the highlight. Next to each tile is the author of the post it represents. When the user hovers on a tile, the authors name is bolded for each of the posts they contributed. By hovering over the author's name a profile card is displayed that contains some medical, community and personal information about the author.

Finally, the participants were introduced to the feature responsible for establishing explicit links between relevant posts and posts authors with their detailed profiles (Figure 28B). The participants were asked to comment on this idea of raising awareness of discussion participants

and their interests in order to stimulate further interactions in the community. The low fidelity mockup interviews took 30 min each.

Analysis

The interviews with the participants were audio recorded and analyzed using inductive thematic analysis. For each of the design goals from Table 6 with the appropriate stages the participants went through in the study, I assigned codes and identified prevalent themes.

Results

Participants found the idea of highlighting text to represent their search query appealing because of its simplicity. However, they also felt this feature should have the option to involve multiple continuous text segments and modifications of the highlight before it is executed as a query. One of the participants emphasized the need to accent certain parts of the highlight as more important than others for the search.

Overall the participants had a positive reaction to dSense's way of getting to the relevant content. The main argument was that the visualization helped them to obtain a general impression of the discussion, the distribution of the relevant content and the prioritization of which posts to read first based not only on relevance, but also the context in which they were created. However, strong suggestions were made to incorporate some intermediate level of detail about each post that will further inform its relevance and help in the decision whether to read it in detail or not. Some of the participants felt that it might be useful to provide some form of guidance with respect to the highlight when reading lengthy posts. In addition, one participant was very

concerned about the lack of ability to refer to previous search queries, since the sensemaking process is heavily cyclical in nature.

Participants found that the ability to assess similarity between themselves and authors of different posts was useful in assessing the reliability of the information it contains. Further, they wished for more efficient way to see if OHC members they know contributed relevant posts in the discussion. Although they were not members of any OHC, the participants recognized the potential to learn more about the community through the explicit links between the posts' relevance and their authors. They also reported that having the user names next to the posts tiles permanently clutters the view of the visually rendered discussion with relevant posts. However, some of the participants liked to see the patterns of engagement of users within the relevant segments of the discussion that was enabled with that layout.

Design implications

The features in the design were generally deemed as useful. However, few modifications were required:

- a) the highlighting should include multiple text segments and have the option to be modified before execution,*
- b) reduce the clutter of the discussion's visual rendering caused by the user names next to the post tiles,*
- c) include a brief summary of a relevant post before deciding to read it,*
- d) orient the user towards the relevant content during reading, and*
- e) provide access to past search queries.*

The last three features refer to the Design Goal 4, more particularly to the design sub-goals #4.1, #4.2 and #4.3 respectively, which served as a confirmation that the design thinking around dSense was moving in the right direction. However, as expected, the study participants identified a new design goal that I didn't anticipate and was related to an alternative entry point in the exploration:

- f) the user should be able to select the author first and then inspect the relevance of the posts they contributed (design sub-goal #4.5).*

This new design sub-goal #4.5 was a new addition to Design Goal 4 related to efficient exploration of the discussion and is reflected in Table 7 in the following design phase. This new design sub-goal is also expected to have a positive effect on the Design Goal 3 related to keeping links between authors and the relevant content they produced in the discussion.

The lessons learnt from this design phase were translated in the next one.

5.1.4.2 Phase 2: Technical feasibility and detailed design features

The main goal of this design phase was to ensure that: *a) the design from the sketches can be technically achieved, b) the algorithm for finding relevant information performs well and is useful, c) the interactions and rendering on the client side based on the returned results is fast enough to provide seamless user experience, and d) explore how the features of dSense will influence making sense of a discussion in a real life setting and what new features will be requested as a consequence of engaging with the dSense prototype (Figure 29).* To achieve the previously listed goals in this design phase, based on the feedback from the design sketches and my previous analysis of design goals, I updated the design and implemented the basic functionality of the dSense tool as a Chrome Extension (Table 7).

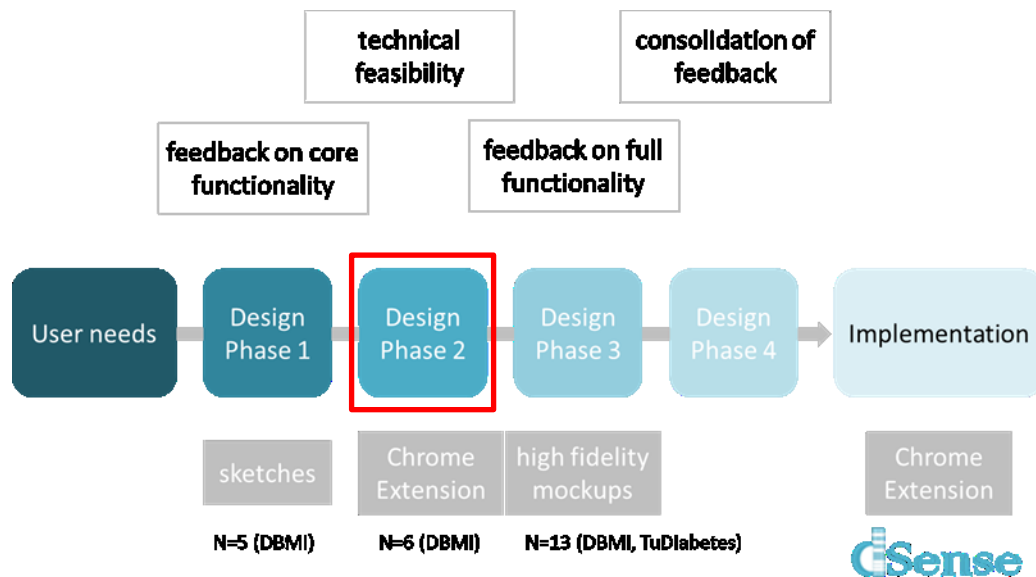


Figure 29. The second step in the design process (Phase 2) – testing the technical feasibility of the design for dSense.

Table 7. Mapping the design goals to solutions that rely on visual representations tested for technical feasibility. The design solutions that are bolded are the new additions to the previous design.

Design goals	Design solutions
PHASE 1: Design Sketches	
Design Goal 1: Provide members with efficient access to information of personal interest	<ul style="list-style-type: none"> • <i>highlight text from the post of interest</i> • <i>discussion as sequence of post tiles, color coded for relevance</i> •
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>post tile with author</i>
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i>
PHASE 2: Technical feasibility	
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>authors next to tiles only in immediate context of interest</i>

Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i> • <i>explore by author</i>
Design Goal 4: Enable efficient exploration of the relevant content	<ul style="list-style-type: none"> • <i>history of search query represented with tabs</i> • <i>marking posts for relevance in the Discourse discussion rendering</i> • <i>explore by author</i>

Updates in the design

To fit discussions with larger number of discussion posts, the height of the Post Tiles was reduced (Figure 30, A). This eliminated the presence of the authors next to the tiles. This elimination was actually desired in the previous design feedback, but for a different reason – the Post Tiles view being cluttered with the user names. However, this modification erased the persistency and transparency of the links between the authors and the posts, which was against the Design Goal 3. On the other hand, by implementing the capability for *discussion exploration starting from the author*, I preserved the transparency of the discussion participants at all times and the links to the posts upon selection of one of them (Figure 30, B). Consequently, to be able to preserve the links between the relevant posts and the participants without burdening the main focus of attention with too many elements, and also display the lateral engagement (the participants who contributed posts in the immediate context), *a fish eye effect was used (enrichment of the solution for Design Goal 2)*. This effect entails that a sequence of posts, which follow the one that is hovered on, becomes enlarged allowing the authors’ names and avatars to appear right next to the Post Tile (Figure 30, C). Here, there is also the possibility to see the *author’s profile* as well, with personal and medical information, as suggested in the previous design phase (Figure 30, D).

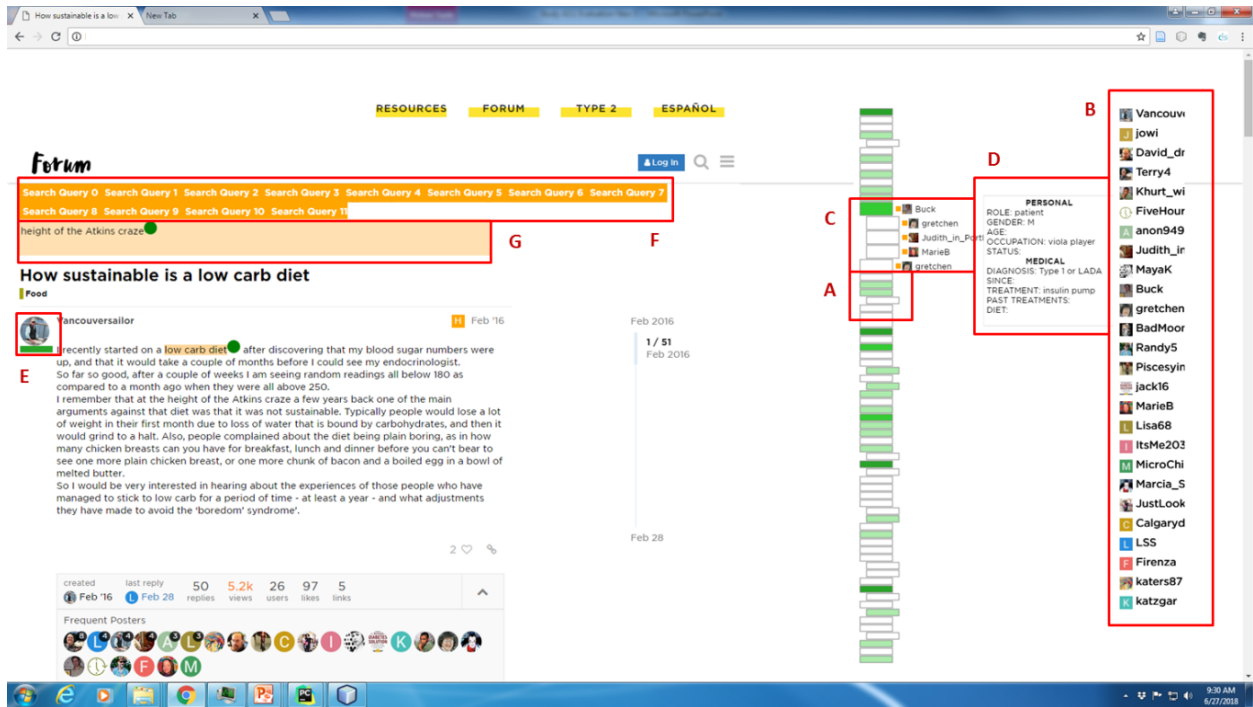


Figure 30. The implementation of the core features of dSense within the Discourse platform: A) Post Tiles color coded by relevance, with reduced height to fit a larger number. B) List of discussion participants to enable exploration by author and reduce the clutteredness in the Post Tiles view, ordered by the sequence in which they joined the discussion, C) Post Tiles with authors and their avatars in the immediate context of interest to display the lateral engagement valuable for signaling collective sensemaking, D) Profile Card for the author of the post, E) Relevance Bar that reflects the relevance of the post to preserve the relevance context for the reading mode during sensemaking, F) History Bar with tabs for all executed queries and G) Previews of the query with option to execute it again.

In addition, I preserved the relevance context from the visual rendering of dSense in the standard Discourse discussion representation by adding *post relevance labels below the avatars to enable staying in the reading mode without losing any context of the posts' relevance* (Figure 30, E: design goal #4.4). Finally, the *history of search queries was also implemented* (Figure 30, F:

design goal #4.3) that allowed users to go back and forth between the queries they executed during the sensemaking process. From the history of search queries, the user could *preview and execute a query* by selecting a search query tab (Figure 30, G).

However, the multi-text segment query formulation and editing before execution was not implemented and was not considered in the design, because of the possibility that it might stimulate time consuming and complicated queries, and a different way of how to think about relevance. On the other hand, the *post summary information* and the *reading support* were only postponed for after the informal pilot evaluation. This was mainly because these features have a broad design space and it would be useful to first observe the user behavior while using the tool to more closely inform the possible design solutions.

User study

A small scale pilot study was conducted to get high level insights about the technical feasibility of the design for dSense and how it actually fares for real sensemaking tasks and for a real discussion.

Participants

I tested the core implementation of dSense with 6 graduate students from the Department of Biomedical Informatics at Columbia University Medical Center.

Procedures

The participants were randomly assigned to a control and intervention groups, with 3 participants in each. This division was primarily made for the purpose of comparing and contrasting the sensemaking behaviors with and without dSense, rather than obtaining formal evaluation metrics

of the tool’s support of the process. However, it was beneficial to get some initial insights about the usability and the usefulness of the tool to complete sensemaking tasks from a real discussion.

Table 8. Sensemaking tasks.

SENSEMAKING TASKS	
1.	<i>To which extent do you think this discussion provides information that can be found relevant for learning about sustainability of low carb diet?</i>
2.	<i>Can you explain to me how you arrived at that conclusion?</i> <ul style="list-style-type: none"> • <i>Do you recall encountering any posts that seem to be providing a lot of relevant content?</i> • <i>Where in the discussion participants seem to be providing content most related to sustainability of low carb diet?</i>
3.	<i>Overall, what is the participants’ position on sustainability of low carb diet?</i>
4.	<i>What did participants report about the sustainability of low carb diet? Please include the opinions that participants expressed about it.</i>
5.	<i>Can you please explain me the process of how you formulated your overall impression? Were there some other answers for the overall impression you temporarily considered according to what was laid out in the discussion? Please explain the process for coming up with your final answer.</i>
6.	<i>Based on this discussion, what are the things diabetic patients should do in order to sustain low carb diet according to this discussion?</i> <ul style="list-style-type: none"> • <i>For each of these things, please provide a brief summary of their role in sustaining a low carb diet.</i> • <i>Which posts did you base your answer on? Please point to them.</i>
7.	<i>Based on this discussion, what kind of food should one subscribe to in order to sustain low carb diet?</i> <ul style="list-style-type: none"> • <i>Please list some examples of meals and snacks.</i> • <i>Which posts did you base your answer on? Please point to them.</i>

Both groups were exposed to the same discussion with 51 posts and asked to complete a set of sensemaking tasks related to it (Table 8). The discussion was about sustainability of low carb diet and came from the TuDiabetes.org forum. These tasks were related to assessing the potential of the discussion to satisfy a particular information need, answering a set of questions that will result in finding the answer that will satisfy that need and identifying posts that contributed to the formulation of that answer. The control was using just the Discourse platform and the intervention was using the dSense tool as an extension to that platform. Upon the completion of

the sensemaking tasks, the intervention group was asked for some feedback about their experience with using the tool.

Analysis

All study sessions were audio recorded and notes were taken about the behaviors participants exhibited for making sense of the discussion in this study. The outcomes of the sensemaking tasks and answers to the questions the participants provided were audio recorded and carefully reviewed for analysis to identify patterns that could inform the design further.

Results

From technical feasibility point of view, the tool exhibited satisfactory performance: the interactions with the interface were perceived as smooth and seamless, with responses from the server being within a tolerable timeframe. No complaints were received from the participants about the responsiveness and reliability of the system, except in a very small number of cases where the tool exhibited unpredictable behavior due to minor flaws in implementation. Overall the participants felt that they can rely on the relevance rendering of the discussion. In most of the cases the participants found the posts marked as relevant to be useful, and, expectedly, in few cases they were not as useful as one would expect them to be.

Similar to my previous findings, the participants in the control group engaged in sequential reading of the posts as they were presented with the different sensemaking tasks. During the sequential reading, they also practiced skimming of the posts, by reading the beginning of the posts or each of the paragraphs in it. If that sampling of the post's content sounded promising, they engaged in more detailed reading. However, even with this approach for more optimized

discussion exploration they were not able to quickly formulate an impression of the discussion with respect to the information need they were presented with. Additionally, they generally expressed low confidence in the answers they provided, and often felt that they did not have a chance to explore some parts of the discussion. Indeed, the participants in the control group never completed reading the discussion; generally, the last quarter of the discussion was never reached.

In contrast, the participants of the intervention group were able to formulate a quick impression of the relevant content in the discussion and to which extent it can satisfy their information need. Because they were able to locate the relevant segments of the discussion, dispersed through its body, the participants in the intervention group were generally able to examine the discussion in its entirety. This was particularly important because posts in the last quarter of the discussion contained valuable information needed to accomplish sensemaking tasks. These participants typically made decisions whether to read a post based on the color of the post tile and the color of the other post tiles in its proximity. However, they felt that this information was not sufficient to determine what proportion of the posts identified as relevant was actually similar to the highlighter text of interest. In addition, there was no support for reading longer posts, so the participant did not know which parts of a post are relevant to be prioritized for reading, and which parts should be paid attention to afterwards. Consequently, this led to inefficiencies in the exploration process. Despite these limitations, when asked about their overall impression with the dSense tool, the participants in the intervention group expressed satisfaction in how it enabled them to quickly formulate search queries and efficiently locate interesting parts of the discussion to read.

Design implications

These observations led to the following implications for the next design iteration:

- 1) The sensemaker needs a fast way to see a summary of the post—Post Card—before they decide to read it and learn how much relevant content is in the post and how that content is relevant to the search query (design goal #4.1).
- 2) Once a relevant post is selected for reading, relevance cues should be made consistently transparent to provide Reading Support (design goal #4.2).

These features can support the exploration in a more informed way than just sampling the beginning of each post or paragraphs within it. In addition, these findings align with findings from the first study with initial design sketches, and are consistent with the theoretical analysis that informed the design goals (Design Goal 4). These findings were reflected in the high-fidelity design mockups in the following phase of the design process, in a more robust design feedback study.

5.1.4.3 Phase 3: High fidelity mockups feedback for full functionality of dSense

Based on the previous rounds of feedback, I developed high-fidelity mockups that were subject to more robust examination in a user study and represented the last stage before the final design of dSense. After conducting this study, I produced the final design of the dSense tool, which was developed and evaluated in a separate study in the second part of this aim.

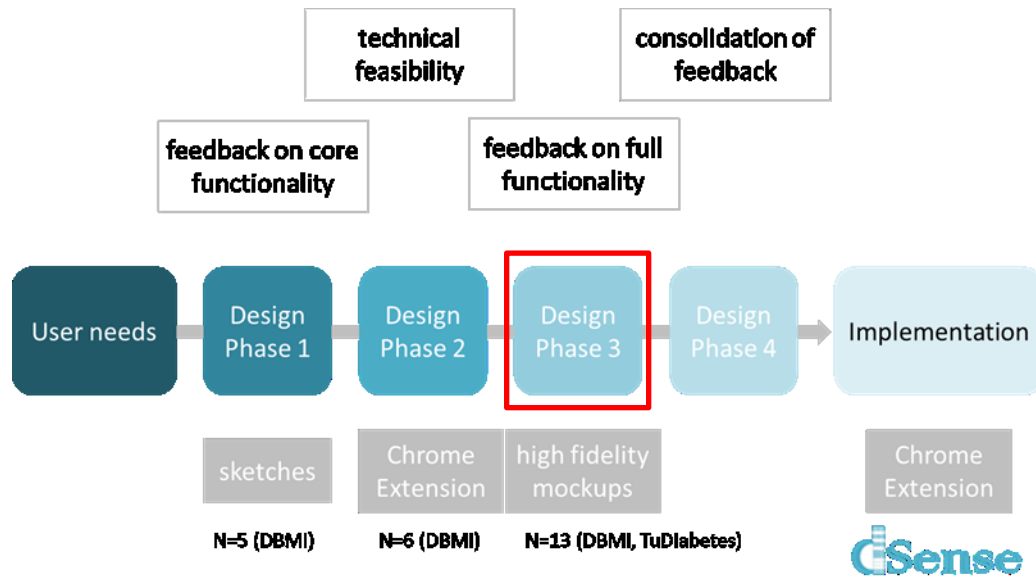


Figure 31. The third step in the design process (Phase 3) – obtaining feedback on the design with full functionality of dSense.

The main purpose of the high fidelity mockups was to: *a) obtain rich and in-depth feedback of the more complete set of dSense features across all design goals and sensemaking processes they support (Table 9) and b) engage the study subjects in participatory design exercises around features with large design space, such as the Post Card (design goal #4.1) and the Reading Support (design goals #4.2) (Figure 31).* To accomplish this, I incorporated the insights from the previous informal pilot evaluation into the design of high-fidelity mockups and expanded on the design from that phase.

Updates in the design

To provide mechanism for efficient and seamless exploration of the relevant posts and as described in the design implications from the previous design phase, in this version of the design I incorporated the Post Card that summarizes the post with respect to the highlight and the post’s inner structure, and the Reading Support that allows guidance for reading based on the highlight

and the post's inner structure (Table 9, Design Goal 4). To further reinforce the links between the discussion participants and the relevant content, I incorporated a history of search queries represented with tabs that feature their user names and their avatars (Table 9, Design Goal 3).

Table 9. Mapping the design goals to solutions that rely on visual representations present in the high-fidelity mockups. The design solutions that are bolded are the new additions to the previous design.

Design goals	Design solutions
PHASE 1: Design Sketches	
Design Goal 1: Provide members with efficient access to information of personal interest	<ul style="list-style-type: none"> • <i>highlight text from the post of interest</i> • <i>discussion as sequence of post tiles, color coded for relevance</i>
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>post tile with author</i>
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<i>post tile with author with profile card on demand, color coded for relevance</i>
PHASE 2: Technical feasibility	
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>authors next to tiles only in immediate context of interest</i>
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i> • <i>explore by author</i>
Design Goal 4: Enable efficient exploration of the relevant content	<ul style="list-style-type: none"> • <i>history of search query represented with tabs</i> • <i>marking posts for relevance in the Discourse discussion rendering</i> • <i>explore by author</i>
PHASE 3: High fidelity mockups	
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i> • <i>explore by author</i> • <i>history of search queries represented with tabs that feature the authors and their</i>

	<i>avatars</i>
Design Goal 4: Enable efficient exploration of the relevant content	<ul style="list-style-type: none"> • <i>history of search queries represented with tabs that feature the authors and their avatars</i> • <i>marking posts for relevance in the Discourse discussion rendering</i> • <i>explore by author</i> • <i>summary of the post with respect to the highlight and the post's inner structure</i> • <i>reading support with respect to the highlight and the post's inner structure</i>

Algorithmic support for the Post Card and the Reading Support

Two of the new features in the design were planned to involve algorithmic support in the implementation of dSense, so before I developed the mock-ups I also explored the feasibility of the algorithms that might be involved in the Post Card and the Reading Support. Since the purpose of dSense is to explore most of the features that could support the sensemaking process in OHC discussions, I have implemented simple and fast algorithms that would respond to the requirements from the design. This was done instead of conducting complex analysis and evaluation for the suitability of existing algorithms for query based summarization or snippets from the web [148,150] and relatedness between texts [98] to the high variability of the posts' length and language used in OHCs. The idea was that once a solid feedback for the features supported by these simple algorithms is obtained in the evaluation of the deployment of dSense, more systematic and resourceful approach will be taken to develop the most suitable algorithms, which is currently outside of the scope for this thesis.

Based on previous feedback, the information in the Post Card was selected to satisfy the following requirements: *a) help in identifying relevant text segments from a given post to the*

query (inherent to the relevance algorithm already in place), b) help in identifying salient terms in the highlighted query and the post or post segment, for finding overlaps and new information in the post with respect to the search query, and c) providing a simple summary of the post and the relevant text segments based on the salient terms.

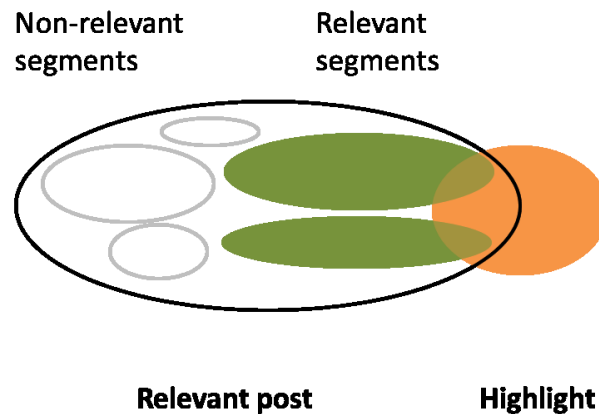


Figure 32. A Relevant Post with inner structure containing text segments relevant to the highlight and others that aren't.

The idea for identifying relevant text segments to the query is based on the notion that the post has inner structure and can cover multiple topics and ideas. Thus, it is expected, especially in longer posts, that some parts of it are more relevant to the query than others (Figure 32, Relevant Post). The idea for identifying overlap between the query and the post or post segments is based on my model of the dependency of discussion posts due to collective sensemaking, a process through which discussion participants build on each-others contributions. The idea of identifying what is important to the post, but is not overlapping with the highlight is still related to the idea of building on previous contributions, but mainly focuses on the new content that is added. By having this notion of what is similar and what is new between the highlighted text of interest and the post, dSense allows for enriching and expanding the initial information need with new related

content that might be worth exploring in more detail and is valuable for the sensemaking processes overall.

Identifying relevant text segments

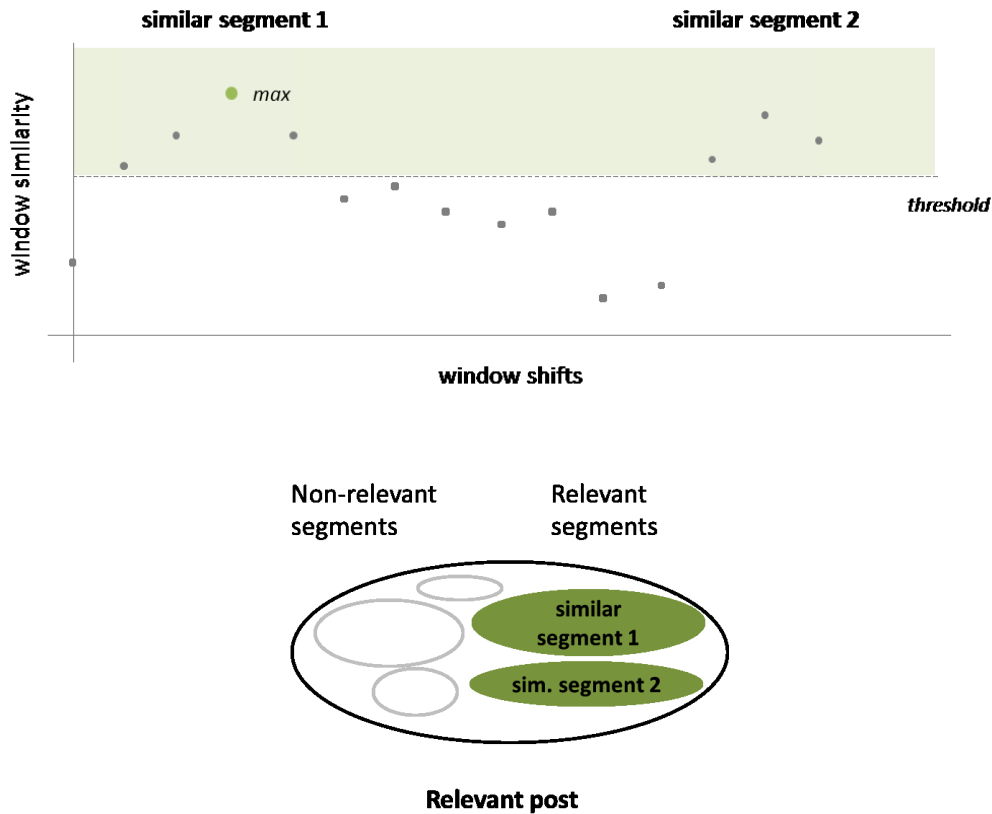


Figure 33. Identifying similar segments from the post to the query.

The algorithm that determines the relevance between the query and the post is based on a sliding window explained earlier. As the window slides through the text of a post, it produces similarity scores between the query and the window. The similarity scores are calculated based on the algorithm for similarity between two pieces of text, also explained earlier. We could identify a stream of those scores that are above a certain threshold to identify a longer text segment, within the post, that is relevant to the query (Figure 33) [88]. One post may have one or more of those segments. In Figure 33, we could see how the post has two segments that are similar to the

query: one is comprised of 4 sliding windows (with a length of 125 words) and the other one of 3 (with a length of 100 words).

Identifying text overlaps based on key phrases

Based on the previous feedback, to determine the quality of relevance more closely and enable exploration, there needed to be a way to identify: a) *how the highlighted text that represents the query “latches” to the post as a whole and its relevant segments (Figure 34, right) and b) what else is talked about in the post or the relevant segments that is important for those texts, but it’s not immediately relevant to the highlight (Figure 34, left).* To achieve this, I took a simple approach that relies on extracting key phrases from texts.

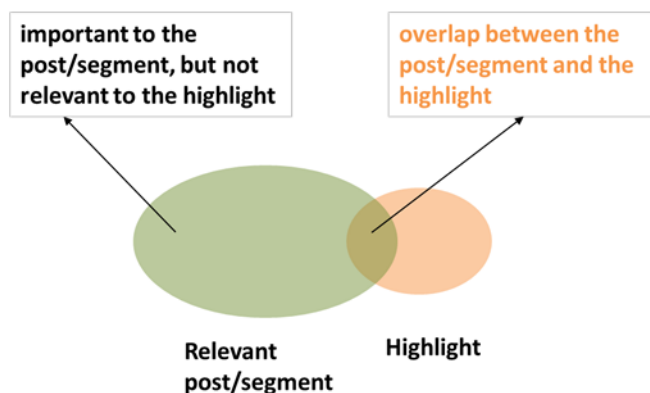


Figure 34. Explaining the quality of the relevance by identifying overlap between the post or the post segment and the highlight and the rest of the important content of the post not relevant to the highlight.

“Latching” between two text segments: the highlight and the post or the relevant post segments. Here, my goal was to determine the intersection of two pieces of texts: the highlighted query and the post or a relevant segment within it. A text segment can be represented by ordered pairs of its noun phrases and their normalized frequencies to address the variety in text lengths.

$$T = \{(\hat{f}_1, np_1), (\hat{f}_2, np_2), \dots (\hat{f}_k, np_k)\} \quad (3)$$

To find the phrases I used the nltk Python package and a filter that included noun-phrases which involve one or more adjectives and nouns. The idea of using noun-phrases instead of keywords was selected because phrases can capture some of the complex concepts related to diabetes self-management more closely. The adjectives part was intentionally included to capture the trends in diabetes self-management such as: **low** blood glucose, **high** morning spikes, **moderate** protein meal, **stable** readings, **long** acting insulin or **fast** acting insulin, for example. To find the frequencies of the phrases, I converted them in lower case and stemmed them, so that phrases as: *low blood sugar* can be considered same as *low Blood Sugars*.

In a simplistic way, we could assume that the more frequent a phrase is, the more important it is for the text. Therefore, what constitutes intersection between two texts represented as two sets of pairs of phrases and their frequencies (4) could involve a degree of similarity between the phrases and their importance for the text. The algorithm for finding the intersection is the following. First, I rank the noun phrases in each of the texts by frequencies.

$$T_1 = \{(\hat{f}_{1,1}, np_{1,1}), (\hat{f}_{1,2}, np_{1,2}), \dots (\hat{f}_{1,n}, np_{1,n})\}, \quad \hat{f}_{1,1} \geq \hat{f}_{1,2} \geq \dots \geq \hat{f}_{1,n} \quad (4)$$

$$T_2 = \{(\hat{f}_{2,1}, np_{2,1}), (\hat{f}_{2,2}, np_{2,2}), \dots (\hat{f}_{2,m}, np_{2,m})\}, \quad \hat{f}_{2,1} \geq \hat{f}_{2,2} \geq \dots \geq \hat{f}_{2,m}$$

The task is to find the three most important phrases from T_1 that are most similar to the most important phrases from T_2 . To do this, I calculated the similarity between all phrases from T_1 and T_2 and weighted those similarities by the product of the normalized frequencies of those phrases in each of the texts (5). The entry in that list was of the format:

$$(\hat{f}_{1,i} \cdot \hat{f}_{2,j} \cdot sim(np_{1,i}, np_{2,j})) \quad (5)$$

The similarity was calculated based on word-embedding based representation of the noun-phrases. I used the TuDiabetes.org corpus with more than 20, 000 discussions to train a Word2Vec model using the python package Gensim. Each of the words in the phrases was represented as a vector and the phrase was represented as a sum of those vectors. These summed word-embedding vectors were used to calculate the similarity between the phrases using cosine similarity. Once I had the complete list of the weighted similarity between phrases and sorted it in descending order, I picked the top three entries that gave me the “overlap” between the two texts (Figure 35, right).

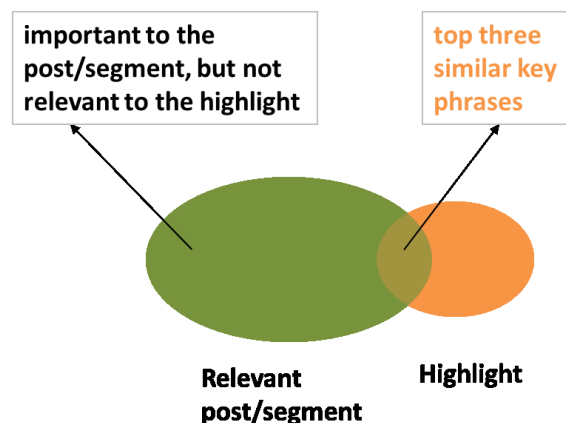


Figure 35. The intersection between the relevant post or a post segment and the highlight represented with top three similar key phrases.

“Non-latching” important content: new content in the post or a relevant post segment to the highlight. To see what other phrases are important for the post or a given relevant post segment, but were not included in the “latching” with the highlight, I referred to (4) and selected the 3 topmost phrases that were not included in that overlap (Figure 36, left).

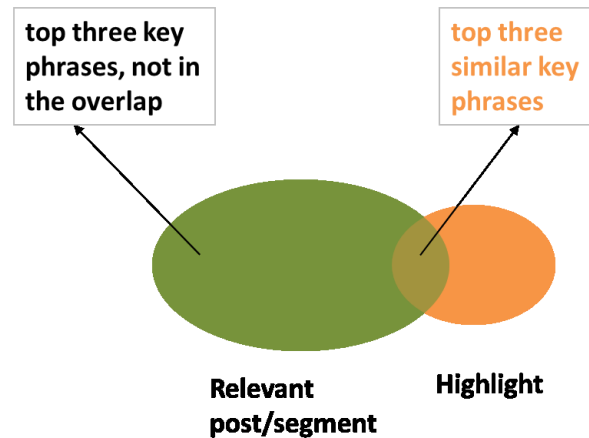


Figure 36. The part of relevant post or a post segment that is important, but not immediately relevant to the highlight, represented with top three key phrases.

Post summary based on key phrases

To keep the Post Card compact, I was relying on a text summary given a maximum of 6 most important noun phrases in it (Figure 37, 3 for the overlap with the highlight and 3 most important for the post or the relevant post segment that are not overlapping with the highlight). The given text, be it the whole post or a similar segment, was split into sentences. For each of the phrases a sentence contains, it would get a point. Based on these points, the sentences were ranked in descending order. The algorithm would first pick the topmost one and the following one would be the one that would add the most of the not covered phrases up to that point. This was repeated until all phrases were covered. Then, the selected sentences were ordered in the same way they would appear in the original text. However, in the summary, only three words that preceded and followed the phrase were included.

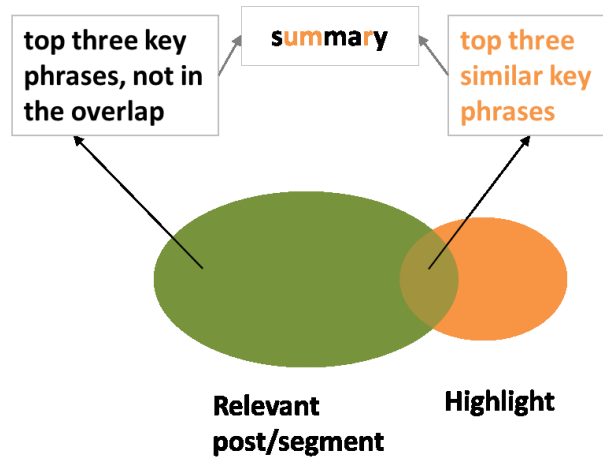


Figure 37. Conceptual representation of the summary of the post or the post segment based on the key phrases that represent the overlapping with the highlight and the other important information which that piece of text is covering.

User study

In this phase of the design process, my goal was to obtain a more rigorous and systematic feedback on the different features of dSense that could lead to the final design of the tool.

Participants

I recruited 7 graduate students from the Department of Biomedical Informatics at Columbia University Medical Center not involved in the design until this point and 6 members of TuDiabetes.org recruited among participants of our previous studies with this community through personal communication. My expectation was that the students will have attitudes similar to individuals with little experience with either diabetes or online health communities, who, perhaps, recently joined the community. In contrast, the participants from the community were experienced with the disease and have participated in diabetes related OHCs regularly.

Procedures

The high fidelity mockups were designed in InVision with the goal of partially simulating the full functionality of dSense. The mockups ensured that the participants were able to go through the most important states of the sensemaking process with dSense: *highlighting, exploration, reading and accessing the search history*. With the graduate students, the study was conducted locally in the Biomedical Informatics Department at Columbia University Medical Center and with the OHC members it was done remotely using the shared screen platform Cisco Webex. In both cases, the mockups were run on the investigators machine displaying them in the InVision platform and the participants were able to take over the control of the machine. They were able to get control of the mouse and interact with the mockups freely.

To assess the intuitiveness of the dSense design, the participants were explained the goal of the study and the general features of the tool, but were not provided with a detailed tutorial. Instead, they were encouraged to explore the different features and construct their own interpretation of what those features did.

The mockups included a TuDiabetes.org forum discussion about sustainability of low carb diet. Each participant was presented with a use case scenario in which they were asked to find examples of daily food intake for a low carb diet that involves 50g of carbs. This task involved a single cycle of the sensemaking process with multiple states: highlighting a text from a predefined post of interest, identifying a relevant post for inspection in more detail with the assistance of the Post Card and reading that post in detail with the assistance of the Reading Support. Depending on the state, each participant was asked a set of questions. The interview was designed (APPENDIX, Table 21) to allow participants to progress through the different

stages of the Foraging Loop responsible for collecting information for the Sensemaking Loop: highlighting (defining a query for the information need), exploration (finding potentially relevant posts), reading (extracting evidence) and accessing the search history (reflecting back on previous cycles) [127]. At the end of each stage, before transitioning to another one, questions that summarize the experience up to that point were asked.

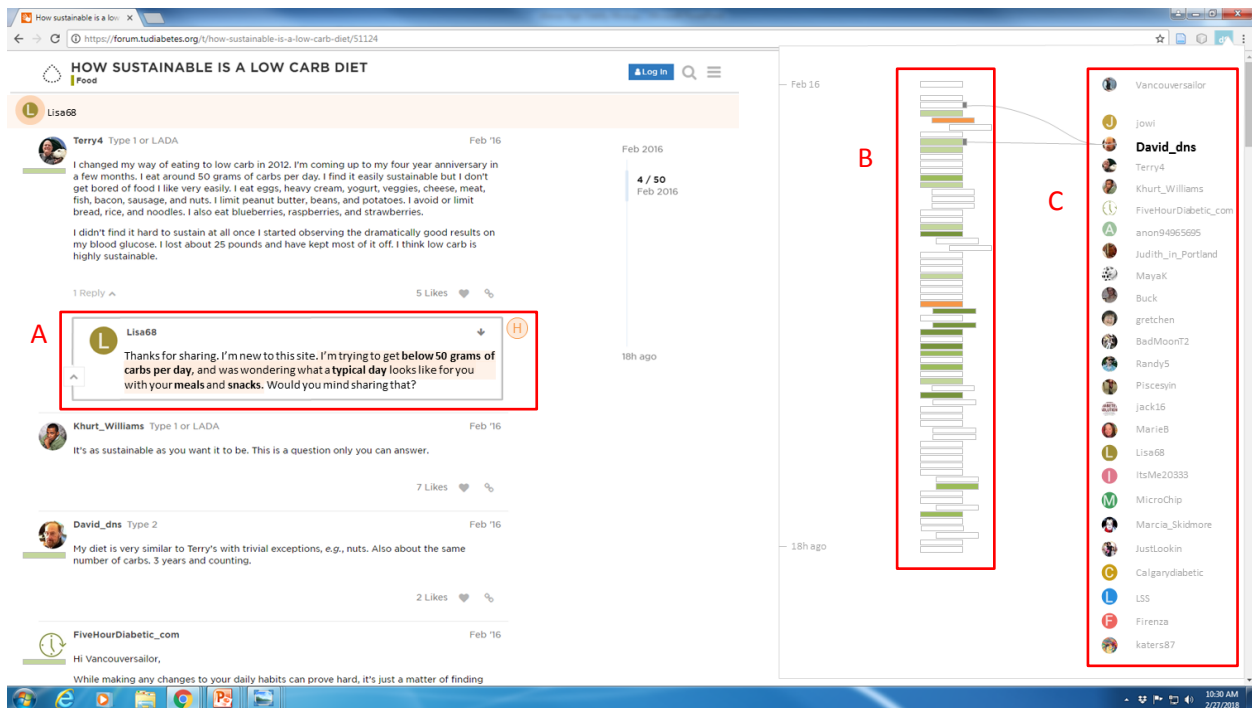


Figure 38. A) The highlighting stage, B) Exploration by relevance and C) Exploration by author.

In the Highlighting stage (Figure 38A), participants were asked to formulate an information need based on the text of a specific post and highlight text that best represents that information need and will serve as a query for which relevant posts will be identified. For this task, the participants were asked to read a designated post from TuDiabetes.org forum. Then, to ensure consistency across participants regardless of their personal experiences, they were given a scenario that specified their knowledge gap related to the designated post, and asked to formulate their

information need and specify a text query based on that need. After that, they were asked to specify which part of the post they wished to highlight to represent that query the best. Upon completion of these tasks, similarly to the feedback in the low fidelity mockup, they were asked to comment on the text highlighting as a device for query formulation. Once they were introduced to the implementation of this feature in dSense, they were asked to reflect on the highlighting experience and comment on their perceptions of how close it comes to an ideal scenario of query formulation.

After executing a search for the highlighted query, the participants entered the Exploration stage in which they were asked to explore the visual representation of the discussion thread with color coding signifying posts identified as relevant to their query (Figure 38B and 38C). Here, the participants were asked to comment on their perception of the discussion based on the visual rendering. They were also asked what questions related to the relevance of the content in the discussion and exploration prioritization this approach of displaying results they can answer using the visual representation of the discussion. Further, they were asked to compare this form of displaying retrieved results while preserving the flow of the discussion and the context of the relevant content with the more traditional approach which involves typing a query and receiving a list of ranked results. After this, the participants were offered a choice to start exploring the discussion from the relevance or author entry point and asked to comment on their decision to take either of the approaches.

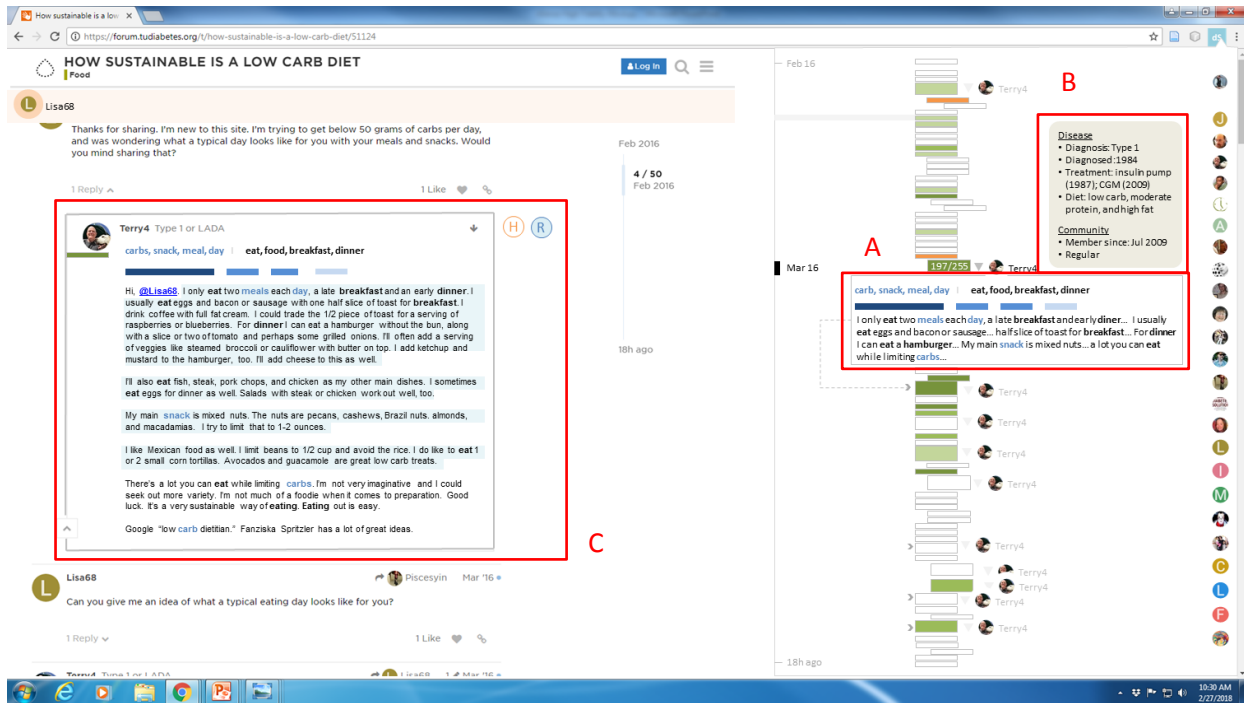


Figure 39. A) The Post Card for a post of interest, B) The Profile Card for the author and C) The Reading Support after inspecting the Post Card and deciding to read the full content.

One of the goals of the Exploration stage was to examine participants' attitudes toward the Profile Card (Figure 39B) and the Post Card (Figure 39A). While the Profile Card was present in previous designs, the Post Card was the new feature that was introduced to support detailed inspection of a post before committing to read its full content. Because its design can widely vary in terms of the richness of the summary information for the post, the participants were shown two different versions of the Post Card and asked to choose the version that best fitted their needs. One of these versions featured a Post Card with rich summary of information and high interactivity; the alternative version offered a simple summary of the post with no interactivity. The two designs were intentionally placed on the two ends of the spectrum to stimulate participants' brainstorming of ideas over the whole spectrum based on the two examples. The two participants were first exposed to the richer and more interactive design and

allowed to interact with it and comment on its capabilities to support the decision of whether to examine the identified posts in further detail or not or not. Once they have established a good understanding of the intermediate information the Post Card provides, they were exposed to the alternative design, which was explained to them. After this, participants were asked to compare and contrast the two solutions and come up with suggestions of a possibly more appropriate design.

After exploring the visual representation of the discussion thread with highlighted relevant posts, the participants examined the posts in details in the Reading stage (Figure 39C). Similar to the Post Card, the design of the Reading Support can span widely. Accordingly, the participants were offered two alternative sets of features providing readings assistance: a more comprehensive and complex one, and a simpler one. Participants went through the same procedure as for the Post Card in order to provide their preferences what should be included in the Reading Support feature.

Because dSense was developed as Chrome Extension to the Discourse platform and was meant to complement native Discourse features, it was important to ensure synchronization and seamless transition between the different stages of sensemaking described above. Participants were exposed to an example of transition from exploration to reading and from reading to exploration to allow them to comment on the synchronization.

Finally, the participants were presented with the search history in dSense. They had a chance to interact with a history of two searches, to experience this functionality and provide comments on their experience with it (Figure 40).

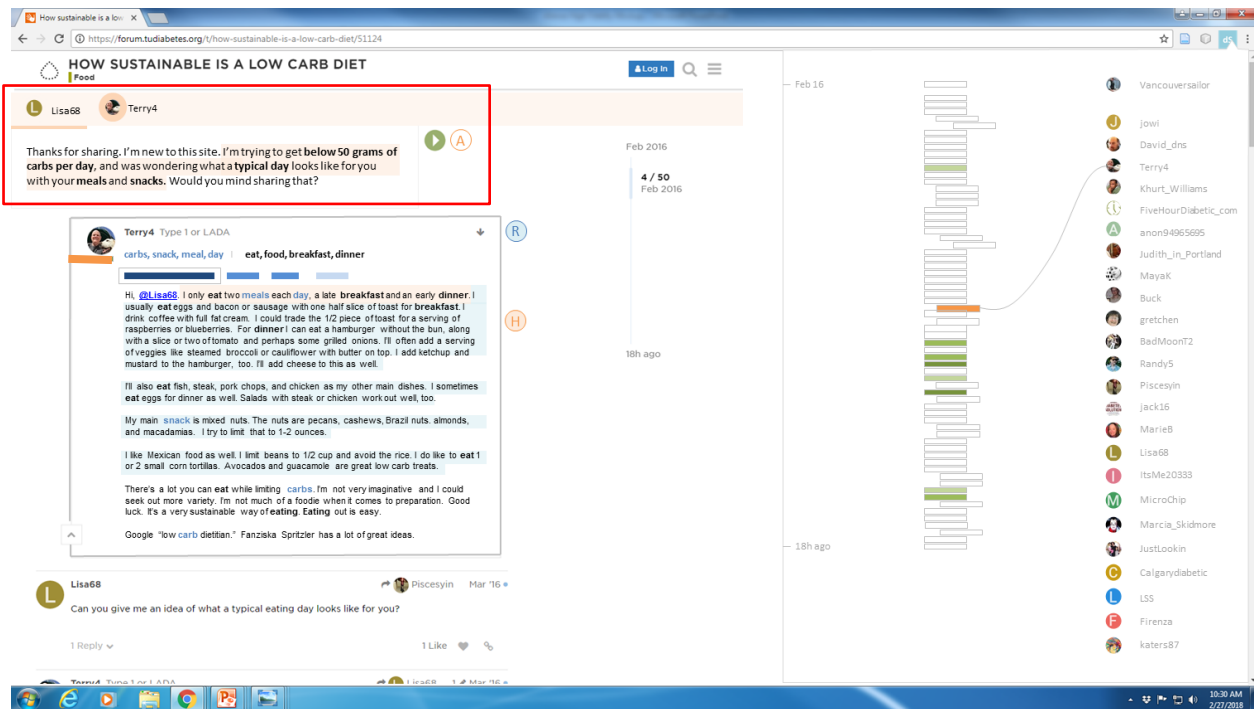


Figure 40. The search history bar with two tabs, one for each executed query in the context of the post it belongs to.

Analysis

The interviews with the participants were audio recorded and carefully reviewed for analysis. For each of the sensemaking stages that the mockups support and the participants went through in the study, I assigned codes and identified prevalent themes.

Results

Highlighting

Similar to the study with the design sketches, the participants in this study recognized text highlighting as an easy and fast way to formulate queries in a way that was perceived as reliable. However, some participants raised the issue of having “unnecessary” words in the query as a

consequence of that, which could potentially introduce noise and negatively affect the information retrieval process. Others felt that a single continuous segment might not be enough in all cases and specified that in some occasions they could benefit from multiple selections. Editing the highlight in terms of deleting some words, adding new ones and specifying their importance for the query was something that participants thought might be useful to adjust the highlighted text to a more desirable query. One participant said that putting some extra work in careful specification of the query based on the highlight would not pose a limitation, as long as that enables high reliability of the returned results. Another interesting comment came from a participant who said that while they believe highlighting can be a very useful way for defining information needs, it should not be the only one and saw the potential of it being paired with the traditional typed query approach. However, most of the participants expressed concerns about the capabilities of current discussion search engines in OHC platforms and mostly relied on simple key word search provided by the Internet Browser, and not the OHC platform. Due to these shortcomings of the current platforms, the highlighting suggested by the dSense design was received as a potentially useful feature in support for finding information of interest.

Exploration

This representation of the results was generally intuitive for the participants. Several of them found it difficult to immediately make sense of it, but after receiving additional explanation they were able to understand it and see its value. The participants could easily determine that the color-coding was associated with the relevance of the content in the posts. They perceived this way of representing results to be useful since it gave them a quick insight about the relevance of the discussion overall, but also provided an overview where in the discussion a potentially relevant and interesting content was generated. They reported that it allows them to more easily

identify a promising starting point when exploring a discussion. Based on the rendering, there were three different starting points of exploration that participants attempted during the study: a) the first darkest green post from the top of the discussion, b) the first darkest green post that is a reply to or follows the one that contains the highlight and c) the discussion segments that contain several densely colored dark green tiles, especially the ones that follow the post that contains the highlight. When compared to the classical list-based display of relevant results, the participants felt more familiar with that approach, but they immediately recognized the advantage of the visual rendering since it preserved connections among the individual posts and the context in which they were created.

Author entry point feedback. Participants recruited from TuDiabetes, particularly those with considerable experience with the community, expressed interest in seeing posts by members they know and follow, and those who have a reputation as knowledgeable about the topic of interest. They also immediately recognized the potential of this feature to expose new members to others in the community in an efficient fashion and make those who posted relevant information stand out. Participants also liked that these explicit links between the community members and the relevant information in the discussion could help them learn more about members with similar interests. Two interesting suggestions came related to this idea. One participant mentioned that it would be nice to give a cue right next to the participants to indicate the highest relevance of the post they contributed, so that one could get an immediate idea whether to dedicate more attention to that person upfront. Another participant said that direct messaging should be enabled right where the links between the relevant content and the authors are established to stimulate new social interactions.

Profile Card. The idea of having the user's Profile Card accessible right at the point where making sense of the discussion is taking place was perceived as particularly useful to additionally assess the reliability of the information in the post. On the other hand, it was recognized as a useful device for receiving a brief introduction to a person and more personal communication afterwards, as health was perceived as a deeply personal topic.

However, some participants expressed concerns that members of TuDiabetes do not usually reveal personal information in their Discourse profile page. Given that this profile page is used as the sources of information for the Profile Card, this may present a challenge to the applicability of this feature in real life. To overcome this issue, the participants suggested mining members' posts for extracting personal information and using that extracted information to populate the Profile Card, in addition to what is already available in the Discourse profile page. However, this approach immediately raised ethical issues and was perceived as highly controversial. Other participants said that they don't rely as much on what is provided in the profiles of the members, but rather learn about the person from reading their posts in the discussions and the topics they cover. For these reasons, they wish to see a summary of the content and the volume of members' contributions in the Profile Card, rather than their personal information. Some participants acknowledged that different members invest different amounts of time and energy in contributing to the community. At the same time, they acknowledged that contributions of less active members aren't always less relevant and reliable. Further, they highlighted that a level of activity does not always translate into expertise on a given topic. As a result, they suggested displaying a summary of member's contributions with respect to the highlight (the query), which would allow to dynamically assess their expertise on the topic of interest. In addition, some of the participants saw value in knowing how well a member's posts were received from the

community, while others didn't pay too much attention on that. Several participants didn't feel they can rely too much on the information in the Profile Card, since they couldn't know if it represented the most recent information about the member or felt that some concepts should be explained in more detail to eliminate ambiguity and misleading information. However, they did see how it can help them to do further research on the reliability of the content the member provided.

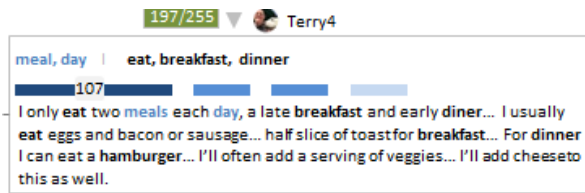
Relevance entry point feedback. The participants who were not familiar with the community (graduate students) generally preferred to start exploring the discussion from the relevance entry point and overtime try to establish awareness of the discussion participants and their contributions. They saw the possibility of transitioning from relevance to author entry point, once they became more familiar with the community. The participants who were familiar with the community (members of TuDiabetes) typically placed equal preference on relevance and author as a starting point for exploring discussions and mentioned that this choice would most likely depend on the context.

All participants said that the color-coding of the relevant posts quickly gave them an overview of the relevant content in the discussion and suggested where to primarily focus their attention. In addition, participants received the "fish eye" effect for the exploration very positively, saying that it allows them to get an idea of who is participating in that small section of the discussion. Some of the participants said that they would prefer a discussion that involves a variety of contributors over the one which looks like a back and forth between just a few of them. They also liked to see more engagement from the initiator of the discussion saying that that was an indicator that the discussion is staying on the topic of interest. Pertinent to these perceptions, they recognized the segment in the discussion that was used in the mockup to represent the "fish

eye” feature as a good example of a relevant segment because it was following the post that contained the highlight, had a lot of relevant posts contributed interchangeably by a set of different participants, and the author of the post that contains the highlight was involved. However, the participants said that the tiles could be taller so that the avatar images and the user names can become larger and easier to recognize and read, respectively.

Post Card. Most of the participants wished for some form of a post preview before deciding whether to read it in full content. They wanted to see a rich summary of the post; however some participants acknowledged the challenge of arriving at such a summary. Overall, many participants were satisfied with the keywords and some mentioned that the keywords gave them an idea how the post is related to the highlight and what new information it contains (Figure 19). In addition, they saw a lot of potential in the Post Card to make the browsing through the posts and the exploration of the discussion more efficient. However, both groups generally agreed that this process could be improved with some additional visual cues indicating the length of the post and the amount of relevant information; these cues could help to explain the numerical explanation in the post tile, which was sometimes perceived as a non-obvious way to convey that information. Overall, participants perceived the Post Card to be not immediately intuitive. However, once explained, it was found to be easy to understand and useful for assessing the likelihood of whether the particular post can satisfy the information need and informed the decision to read its integral content or not.

A



B

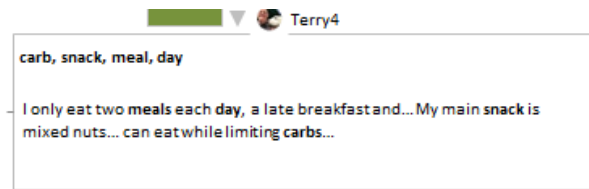


Figure 41. The design alternatives for the Post Card: A) The numbers in the Post Tile that was expanded represent the number of words in the relevant content over the total words in the post. Left of the vertical divider are the overlapping keywords between the query and the text in focus, and right to it - the most important keywords for the text in focus that are not overlapping with the query. The text in focus is initially the entire post, or can be any of text segments from the post with similar content to the query when a user hovers over one of the blue shaded bars. The length of the bar represents the length of the similar segment in number of words and the color shade - the similarity of the content (the darker the better). On the bottom, there is a very short summary of the text in focus based on the immediate surroundings of the keywords. B) The design alternative only has the overlapping keywords between the query and the relevant post and an analogous summary to A) based on those keywords.

At times, rather than exploring different design features, participants chose a feature that resonated with them and used it more than others. Some participants were impressed by the complex solution for the Post Card (Figure 41A) because it helped them to find structure in different posts. One participant pointed that this feature can be useful for very long posts and help to draw a user's attention to the most relevant content first. Other participants preferred to see each post as a coherent unit and liked a simpler approach that didn't rely on any inner structure of the post (Figure 41B). Some of these participants saw the Post Card as unnecessary

and saw color-coding of post tiles and the patterns they bring in the discussion's rendering as sufficient to decide whether to read the content of the post or not. One participant was concerned about the tool suggesting which parts of the post they should read and what parts they should skip. This participant stated that health information can be highly context dependent, and that a single word or a sentence can change the meaning of what was previously said. This person was strongly convinced that the meaning of the post can be understood only if one reads its full content from the beginning to the end.

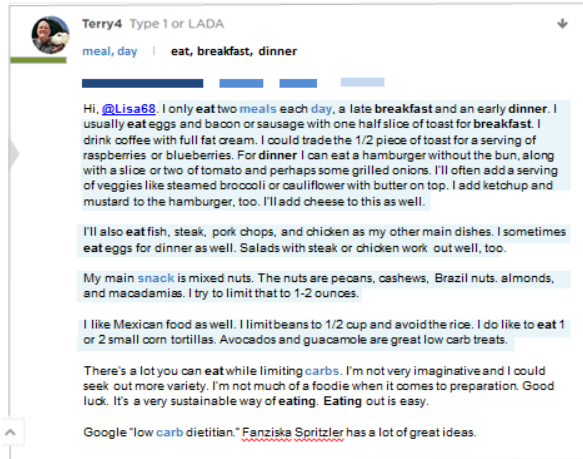
Reading

Similar to the Post Card, the participants required some help in order to understand how to use the reading support. However, due to the previous exposure to the Post Card with features analogous to those of the reading support design, the participants were able to more smoothly transition into using the Reading Support. Once the participants understood how the reading support works and how to activate and deactivate it on demand, they found it very useful. They felt they can "call" it for longer and more complicated posts, and deactivate it for shorter and simpler posts, thus reducing unnecessary clutter.

Expectedly, the participants' attitudes towards the Reading Support were comparable to their attitudes towards Post Card – those who liked the more detailed Post Card also preferred the more complex reading assistance, which heavily relied on inner post structure (Figure 42A). Those who preferred the less structured post summary wished for the simpler reading support (Figure 42B). However, overall, there was a preference for the simpler option for reading support mainly because it was easier for the participants to detect the relationship between the degree of

relevance and the text segment. Because of this, suggestions for improvement were made for the first design option in making the arrow for pointing to relevant segments more prominent.

A



B

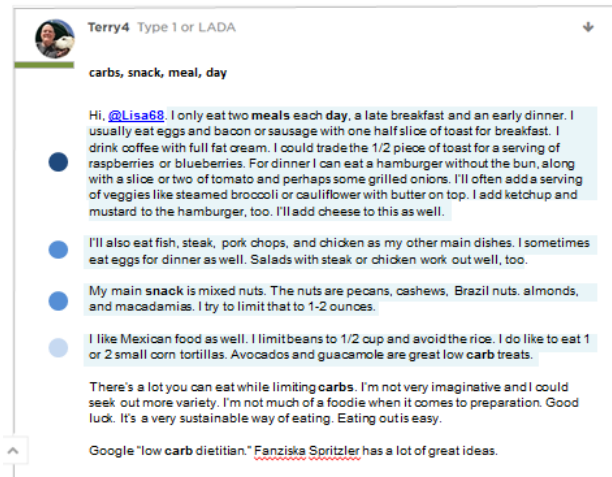


Figure 42. The design alternatives for the Reading Support: A) Initially, above the text of the post are the overlapping keywords between the query and the entire post (colored in blue). The most important keywords from the post that are not overlapping with the query (colored in black) are shown right next to them, following the vertical divider. When the user hovers over a blue shaded bar (the darker, the more similar) a marker will indicate where to focus the attention for reading. The keywords list will be updated accordingly based on the similar text segment that the bar represents, following the previously described principle in the Post Card. B) In the simpler reading support, there is a small circle colored with shades of blue (the darker, the more similar) next to each of the similar segments. When the user hovers on one of the circles only the overlapping keywords between the highlight and that segment will be shown.

Synchronization and search history

Participants were satisfied with the ability to easily “jump” from a post tile to the corresponding post text in the Discourse discussion by putting that post in focus for reading. In addition, they found useful the ability to see the relevance of the posts in the scrolling stream based on the Relevance Bar below the avatar. They found this feature to be intuitive because it reminded them of the typical Internet browser features and their organization of tabs, with each tab representing a separate web address (query to the web). They found it useful to go back and forth between the searches they performed and refer to the content that was retrieved as a consequence. One participant interpreted it as leaving bread crumbs in the search space that one can easily trace back in order to get to some of the more important or interesting queries.

Design Implications

Summary of the results

Overall, the participants had positive perceptions of dSense and its design features. They felt that dSense can help in navigating long discussion threads and assist OHC members to prioritize the reading of the discussions’ posts during their sensemaking process. Only one participant (out of 13) had overall negative comments and felt that such a tool can increase technological burden on OHC members who were already struggling to stay up to date with the technologically advanced Discourse platform.

Most of the participants found the core features of the tool to be intuitive; these included highlighting and color-coding to indicate relevance of the posts. However, the more complex features, such as the Post Card and the Reading Support required some explanation before they

could be understood. At the same time, the participants generally felt that after an explanation these features were easy to use and added value to the process of fast exploration of the discussions content and provided a form of guidance for reading long posts.

The participants liked the highlighting feature, which enabled them to quickly formulate a query, and the visual rendering, which allowed them more contextualization of the relevant posts they wished to read; these features were found to be superior to the current search capabilities of the OHC platform. Participants were impressed with the ease they could assess the overall relevance of the discussion to their query, but also with the possibility to identify positioning of the interesting discussion segments. Those participants who valued variability of contributors and wished to be aware of authors of different posts made positive comments about the Fish Eye effect, which made the degree of lateral engagement more transparent. Further, they found the search history to be helpful for tracing back their previous searches.

The participants perceived the transition between examining discussion visualization with dSense and reading the actual posts within Discourse to be seamless. The Relevance Bars that indicated relevance of posts identified with dSense within their original Discourse discussion further helped to maintain a connection between the two representations of a discussion.

The participants had different assessment of the usefulness of the Post Card and Reading Support. These were apparently due to difference in perception of whether posts in discussions can be broken into components or whether it was critical to read the entire post to understand it. Not surprisingly, those who allowed for a possibility of posts consisting of components to have a more favorable view of the Post Card and the Reading Support. On the other hand, those who perceived posts as generally unbreakable into units, did not see value in these features.

From the feedback of the participants, it appeared that the social component and willingness to connect with members who can potentially provide help is very prominent. Participants who already were members of OHCs immediately recognized the potential of exploring a discussion by author, and saw this feature as giving them an ability to quickly navigate to posts from members they have similarity with or already established trust for, and identify members that produced relevant content which can help them learn about their interests and expertise. However, the most challenging part was to consolidate the feedback about the Profile Card. Issues with sparsity of data available to populate it, the ethical concerns about mining the forum to overcome this limitation, the right level of detail for personal information sufficient for posts' relevance assessment, and the recency of that information were raised. However, participants felt that personal information, medical history, and community activity, especially in terms of volume of contributions on different topics, and community approval of that content can be helpful signals for assessing the relevance of the posts.

These results led to several updates in the design of dSense.

Updates to the design

Highlighting stage. Given the continuous positive feedback to highlighting as a way to express an information need, no changes were made to this feature.

Exploration stage. Based on the feedback obtained from the exploration stage, the design was changed in the following ways: a) enlarged the Post Tiles in the Fish Eye effect together with the avatars photos and the user names that appear next to them, b) added additional cues next to each discussion participant in the list to indicate the relevance of the most relevant post they contributed, c) added more information about the participants' activity in the community in the

Profile Card, d) allowed users to toggle between a summary of the post in the Post Card that assumes structure in it and one that doesn't and e) followed the previous principle for the Post Card for the Reading Support.

Reading stage. Given the preference for the ability to turn reading support on and off, this feature was carried into the final design. In addition, to address the differences in individual preferences for level of support, dSense will include a toggle between different versions of reading support.

Synchronization and search history. To address participants' comments, the final design enabled modularity of features and provided all users with the basic functionality, as well as enabled adding more complex features on demand.

5.1.4.4 Phase 4 - The final design of dSense

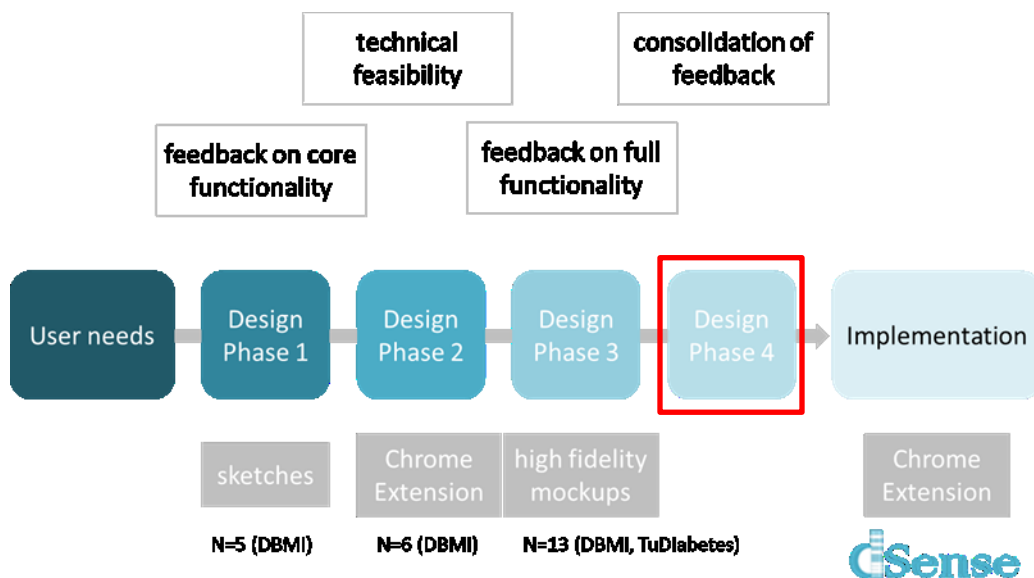


Figure 43. The final step in the design process (Phase 4) – consolidating the feedback from the previous design phases for dSense

In this final stage of the iterative design process (Figure 43), I consolidated all the observations and lessons learnt in the final design of dSense ready for development (Table 10).

Table 10. Mapping the design goals to solutions that rely on visual representations in the final design. The design solutions that are bolded are the new additions to the previous design.

Design goals	Design solutions
PHASE 1: Design Sketches	
Design Goal 1: Provide members with efficient access to information of personal interest	<ul style="list-style-type: none"> • <i>highlight text from the post of interest</i> • <i>discussion as sequence of post tiles, color coded for relevance</i>
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>post tile with author</i>
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<i>post tile with author with profile card on demand, color coded for relevance</i>
PHASE 2: Technical feasibility	
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>authors next to tiles only in immediate context of interest</i>
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i> • <i>explore by author</i>
PHASE 3: High fidelity mockups	
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i> • <i>explore by author</i> • <i>history of search queries represented with tab that feature the authors and their avatars</i>
Design Goal 4: Enable efficient exploration of the relevant content	<ul style="list-style-type: none"> • <i>history of search query represented with tabs</i> • <i>marking posts for relevance in the Discourse discussion rendering</i> • <i>explore by author</i> • <i>summary of the post with respect to the highlight and the post's inner structure</i> • <i>reading support with respect to the highlight</i>

	<i>and the post's inner structure</i>
PHASE 4: Final design	
Design Goal 1: Provide members with efficient access to information of personal interest	<ul style="list-style-type: none"> • <i>highlight text from the post of interest</i> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>discussion as a Heat Map of post cells</i> • <i>slider to focus on discussion segment of interest</i>
Design Goal 2: Foster collective sensemaking and construction of new knowledge	<ul style="list-style-type: none"> • <i>discussion as sequence of post tiles, color coded for relevance</i> • <i>authors next to tiles only in immediate context of interest</i> • <i>discussion as a Heat Map of post cells</i> • <i>slider to focus on discussion segment of interest</i>
Design Goal 3: Contribute to stimulating awareness of community members and social interactions	<ul style="list-style-type: none"> • <i>post tile with author with profile card on demand, color coded for relevance</i> • <i>history of search queries represented with tab that feature the authors and their avatars</i> • <i>marker next to author color coded as the most relevant post contributed</i>

Additional design changes

In addition to the design limitations identified by the participants of user studies, there were several other design challenges that needed to be addressed for the final implementation of dSense. First, the discussion used in user studies included only 51 posts; which could be easily presented in the tiled visualization. However, as the number of posts in discussion increases, such tiled visualization would become not scalable. The two simple approaches to this challenge include decreasing the height of the tiles and enabling scrolling. However, both of these solutions have their limitations. Small tiles would make the selection of a tile using a mouse more challenging, particularly for those with decreased manual dexterity, common for individuals with diabetes. The scrolling could jeopardize individuals' ability to form an overview of a discussion

and present new challenges for seamless transition between posts within Discourse and the dSense visualization.

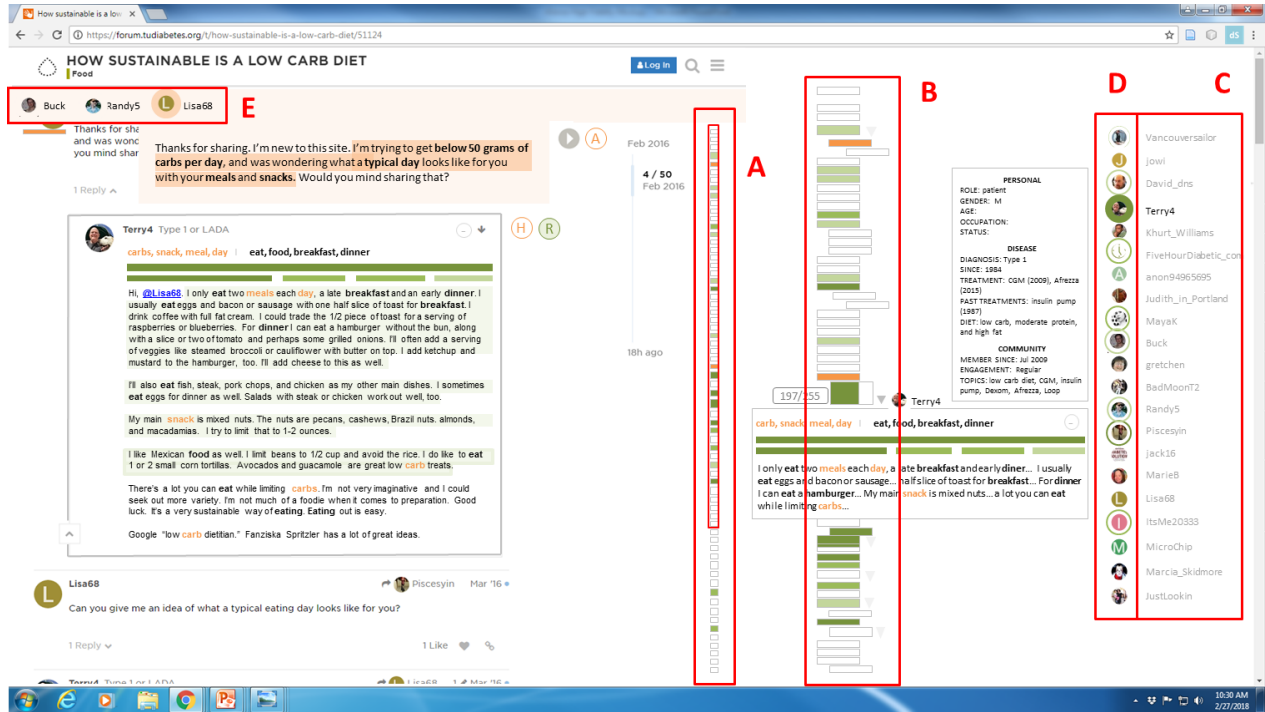


Figure 44. The final design of the dSense tool with the Heat Map with the Slider (A), the Post Tiles discussion segment (B) and the Participants Panel for that discussion segment (C), together with the author-relevant information reinforcements in the Participants Panel (D) and the Search History Bar (E).

Similarly, the design used in this phase was optimized for a limited number of participants, and would be challenging to scale. At the same time, obscuring participants or requiring scrolling through the list of participants would challenge the goal of persistent exposure of users to participants of the discussion.

To overcome these scalability problems with respect to discussion length and number of participants in it, present in my previous design and existing solutions [47,76,114], the new

design of dSense introduced a discussion *Heat Map* and a *Slider* (Figure 44A). The discussion Heat Map represents the entire discussion where each post is represented with a Post Cell. It follows the sequential ordering of posts and replies in a discussion and renders them in columns with each column having a 100 Post Cells (corresponding to a 100 Post Tiles in the previous nomenclature). The number of columns can vary, but the Heat Map can easily fit discussions with up to 1, 000 posts. The Slider is a window of 50 Post Cells that becomes the focus of the discussion and that discussion segment is rendered using the Post Tile based rendering, the same way as in the previous version of the design (Figure 44B). Only authors of posts in that segment are rendered in the Participants Panel to the right of the Post Tiles (Figure 44C). This solution enables representing discussions with a large number of users. In order to see all the participants in the discussion, the sensemaker can use the Slider to parse the entire discussion. During that process, they will be exposed to some of the participants in the discussion more than once and will have a chance to initially map out their participation throughout the discussion in their mental model of the discussion. When a particular participant is selected, their contributions are marked in the Heat Map. This emphasizes the idea of raising the awareness of the participants.

The size of the Slider was constrained by the Fish Eye effect and the height of the Post Card. This adjustment was made due to the comments that the avatars and names that appear in the Fish Eye effect are very small and need to be bigger and the observation that the Post Card shouldn't force the Post Tiles to overflow from the current view.

Reinforcing the author-relevant content links

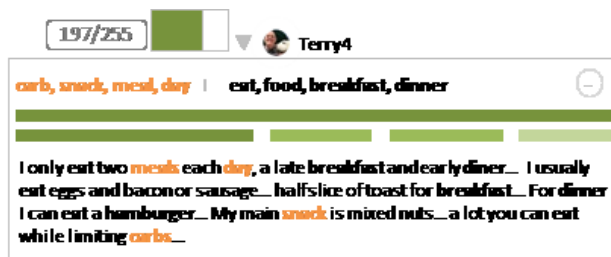
Another change in the design was introduced to visually highlight members who made relevant contributions by adding green circles with the color of the most relevant post they contributed

around their avatars in the Participants Panel (Figure 44D). This was added to further reiterate connections between relevant content and its authors and highlight authors that contributed relevant posts. Similar approach for reinforcing links between authors and aligned interests was taken when logging the search queries. In the Search History Bar, the entries have the avatars and the names of the participants whose posts contained the queries, with highlighting the most current one (Figure 44E). Finally, information about community activity for the participant was added to the Profile Card.

Meeting the needs for the Post Card

To address the recommendations generated during the user study, when a Post Tile is hovered on, its height changes to be proportional to the number of words in the post, the shading of the green indicates the proportion of relevant content in the post, and right next to the Post Tile that proportion is translated in the ratio between number of words of relevant content vs. words in the post (Figure 45A). To meet the different user needs that emerged from the study, the updated design offers a Post Card, which can be viewed from a “shorter or longer distance”. The short distance view represents the “zoomed-in” view of the post and follows an interactive and more structured, hierarchical look into the post summary (Figure 45A), whereas the long distance look represents the “zoomed-out” view of the post and follows non-interactive, flat and monolithic view of the post (Figure 45B). The user can toggle between both views using the “+/-” button in the top left corner of the Post Card.

A



B

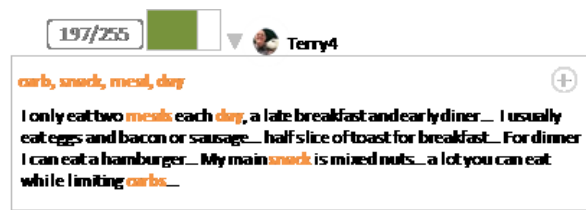


Figure 45. The Post Card in the final design: A) In bold orange are the overlapping keywords between the query and the text in focus, and in bold black - the most important keywords for the text in focus that are not overlapping with the query. The text in focus can be the post or any of the text segments from the post (4 in this case) with similar content to the query. The focus is determined by hovering over the green shaded bars (the darker the more similar), which are proportional to the number of words in the similar segment. On the bottom, there is a summary of the text in focus based on the immediate surroundings of the keywords. B) The other alternative only displays the overlapping keywords between the query and the relevant post, but the summary is still constructed in the same way as the previous example.

Meeting the needs for the Reading Support

Similarly, the new design offers two different Reading Supports analogous to the Post Card. The more complex, “zoomed-in” view, follows the structured post summary card (Figure 46A), and the more simple, “zoomed-out” view, the monolithic summary one (Figure 46B). Here too, the user can toggle between the two types of support using the “+/-” button in the top left corner of the post. However, the reading stage follows the preference in the Post Card’s “zoom” level when selected for reading. The reading support can be turned on and off as the user desires by toggling the “R” button.

A

Terry4 Type 1 or LADA

meal, day | eat, breakfast, dinner

Hi, @Lisa68. I only eat two meals each day, a late breakfast and an early dinner. I usually eat eggs and bacon or sausage with one half slice of toast for breakfast. I drink coffee with full fat cream. I could trade the 1/2 piece of toast for a serving of raspberries or blueberries. For dinner I can eat a hamburger without the bun, along with a slice or two of tomato and perhaps some grilled onions. I'll often add a serving of veggies like steamed broccoli or cauliflower with butter on top. I add ketchup and mustard to the hamburger, too. I'll add cheese to this as well.

I'll also eat fish, steak, pork chops, and chicken as my other main dishes. I sometimes eat eggs for dinner as well. Salads with steak or chicken work out well, too.

My main snack is mixed nuts. The nuts are pecans, cashews, Brazil nuts, almonds, and macadamias. I try to limit that to 1-2 ounces.

I like Mexican food as well. I limit beans to 1/2 cup and avoid the rice. I do like to eat 1 or 2 small corn tortillas. Avocados and guacamole are great low carb treats.

There's a lot you can eat while limiting carbs. I'm not very imaginative and I could seek out more variety. I'm not much of a foodie when it comes to preparation. Good luck. It's a very sustainable way of eating. Eating out is easy.

Google "low carb dietitian." Fanziska Spritzler has a lot of great ideas.

B

Terry4 Type 1 or LADA

carbs, snack, meal, day

Hi, @Lisa68. I only eat two meals each day, a late breakfast and an early dinner. I usually eat eggs and bacon or sausage with one half slice of toast for breakfast. I drink coffee with full fat cream. I could trade the 1/2 piece of toast for a serving of raspberries or blueberries. For dinner I can eat a hamburger without the bun, along with a slice or two of tomato and perhaps some grilled onions. I'll often add a serving of veggies like steamed broccoli or cauliflower with butter on top. I add ketchup and mustard to the hamburger, too. I'll add cheese to this as well.

I'll also eat fish, steak, pork chops, and chicken as my other main dishes. I sometimes eat eggs for dinner as well. Salads with steak or chicken work out well, too.

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There's a lot you can eat while limiting carbs. I'm not very imaginative and I could seek out more variety. I'm not much of a foodie when it comes to preparation. Good luck. It's a very sustainable way of eating. Eating out is easy.

Google "low carb dietitian." Fanziska Spritzler has a lot of great ideas.

Figure 46. The Reading Support in the final design: A) When the user hovers over a green shaded bar the appropriate text segment will get highlighted in a slightly darker color. The keywords list will be updated accordingly, following the previously described principle in the post card. B) The other alternative only displays the overlapping keywords, but still highlights the relevant segments if the posts length is above certain threshold for lengthy posts.

5.1.5 Implementation of dSense as a Chrome Extension to the Discourse platform

5.1.5.1 The architectural framework of the dSense system

The dSense tool was implemented as a Chrome Extension to the Discourse platform's particular instantiation for the TuDiabetes.org web site. The Chrome Extension has a client-server architecture (Figure 47). The client side is implemented as a thin client – responsible only for fast rendering of the interactive discussion visualization to secure seamless interaction. The interactive visualization of the discussion is presented in the extension (dSense) and synchronized with the traditional representation of the discussion in the TuDiabetes forum

(Discourse). Necessary modifications to the TuDiabetes.org discussion's page DOM were performed to simulate one integrated and holistic system between the two independent entities: the TuDiabetes.org web-site and the dSense Chrome Extension (Figure 47A). In contrast, the server side is responsible for the resourceful processing involved in calculating relevance of the posts and the information for the Post Card and the Reading Support (Figure 47B).

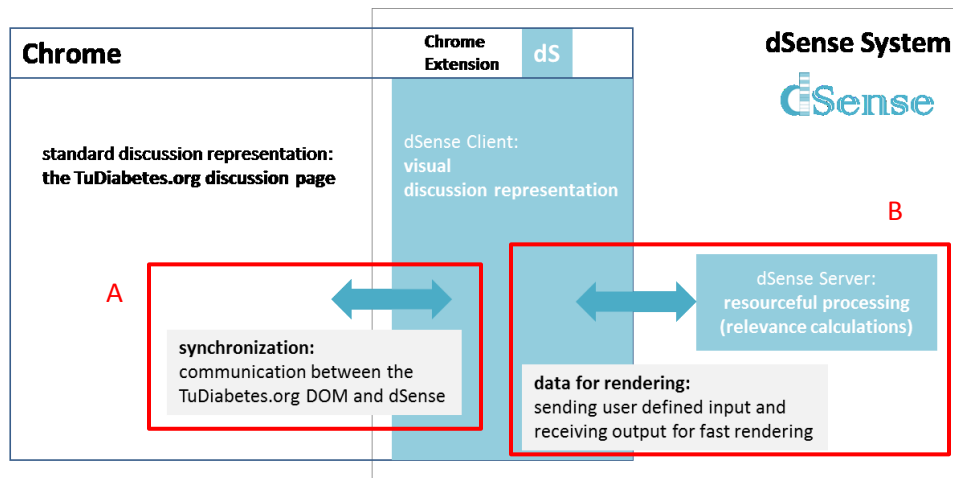


Figure 47. The dSense system architecture: Chrome Extension with a client for fast rendering and server side for resourceful processing

5.1.5.2 Communication for securing high responsiveness of the dSense system

The main challenge in the dSense architecture was to secure responsiveness from the system. The user interactions with the system were not supposed to suffer any delays that might interrupt their flow. For these reasons, tasks were distributed among the client and the server (Figure 48). The client side was implemented with jQuery, JavaScript and SVG Graphics, and the server was implemented as a Python Flask Server. Upon the first execution of the highlighted text i.e. the query, the server is called for returning the relevance scores of the posts in the discussion. That information is then stored in the Chrome Storage for later reference in case of page reload. It

however, constantly resides on the client side during the interaction as well. Similar approach is used for the Post Card information. That information is called from the server when a Post Tile is initially selected for more detailed inspection or when Reading Support is asked for. Once the Post Card information is retrieved, it is also stored in Chrome Storage for later reference in case of page reload. However, it constantly resides on the client side during the user interaction between two page reloads as well.

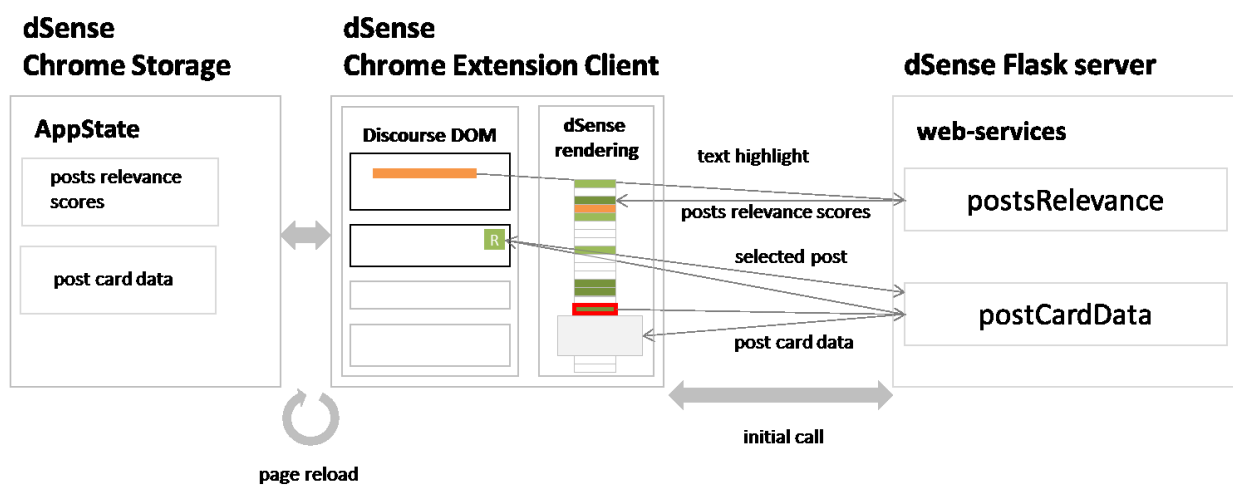


Figure 48. The detailed client-server architecture.

This architecture secured a very high responsiveness of the systems, and allowed for very short delays in the interaction only upon initial requests to the server, and seamless interaction as a consequence of storing that information locally for later immediate access.

5.1.5.3 Use case based on the implementation of dSense

In this section I will present the implemented version of dSense (Figure 49) through a use case scenario.

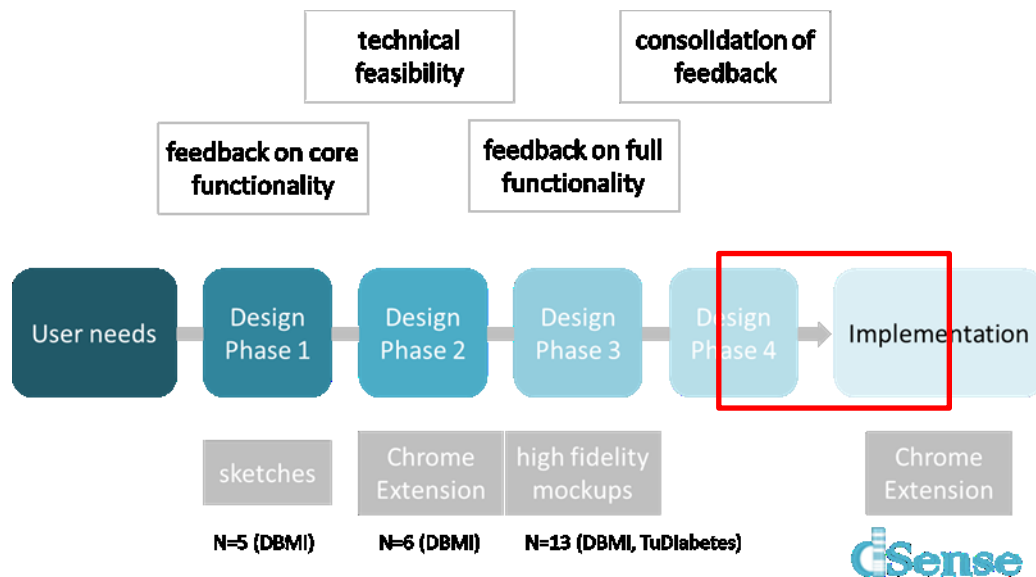


Figure 49. The implementation phase of dSense.

Meghan is a member of TuDiabetes.org and has been diagnosed with Type 1 diabetes for several years. She has been exploring new alternatives for her diabetes management recently. While exploring the TuDiabetes.org forum, she landed on a discussion that is titled “Exciting news since switching to Tresiba” (Figure 50). This is a rather long discussion with 116 posts and many participants, which poses challenges to making sense of it. Meghan has been using dSense for sensemaking of long discussion threads previously and decides to activate it for this particular one as well. Upon activation of dSense, on the left side in Figure 51 is the discussion presentation as it is in the Discourse platform and on the right side is the representation of the discussion in dSense.

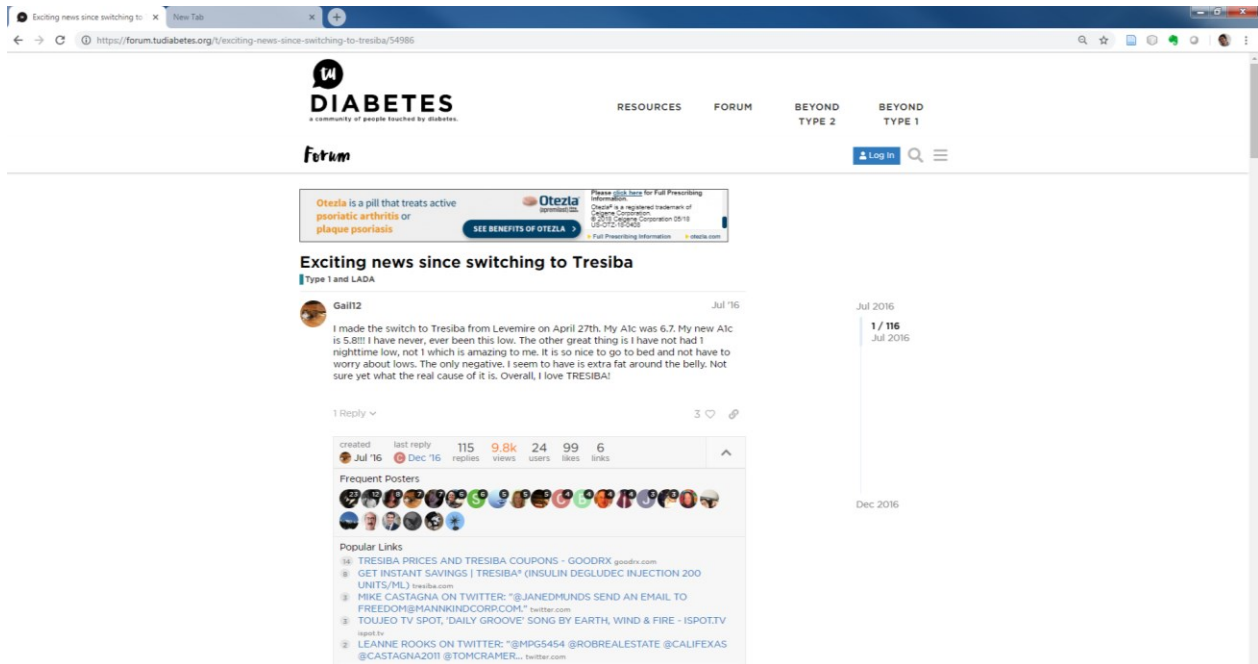


Figure 50. The Discourse discussion before the activation of dSense.

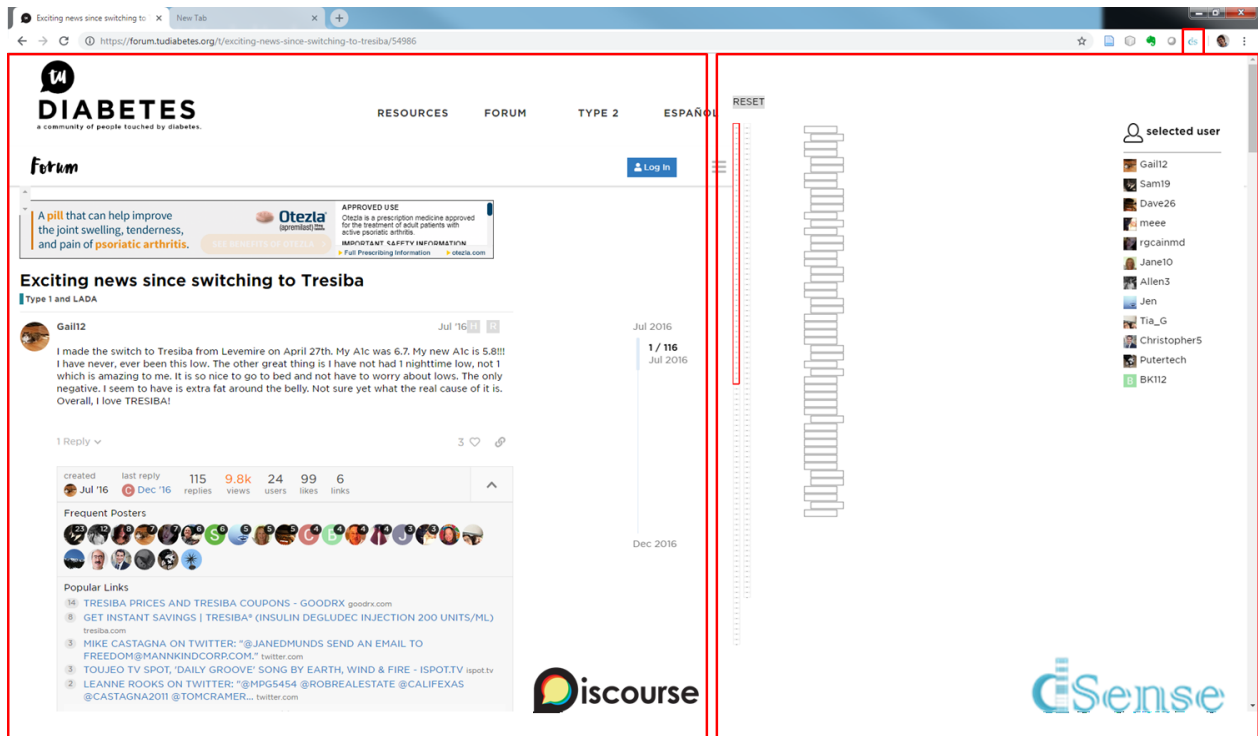


Figure 51. Initial state of the tool immediately after the sensemaker has landed on a discussion.

Meghan starts reading the initial post in the discussion and wants to see more examples of switching to Tresiba from some other insulin and reports on A1C values, so she highlights the first few sentences: “I made the switch to Tresiba from Levemire on April 27th. My A1c was 6.7. My new A1c is 5.8!!!” to represent her query (Figure 52, right). This query is sent to the server and the discussion is rendered accordingly based on the response it provided.

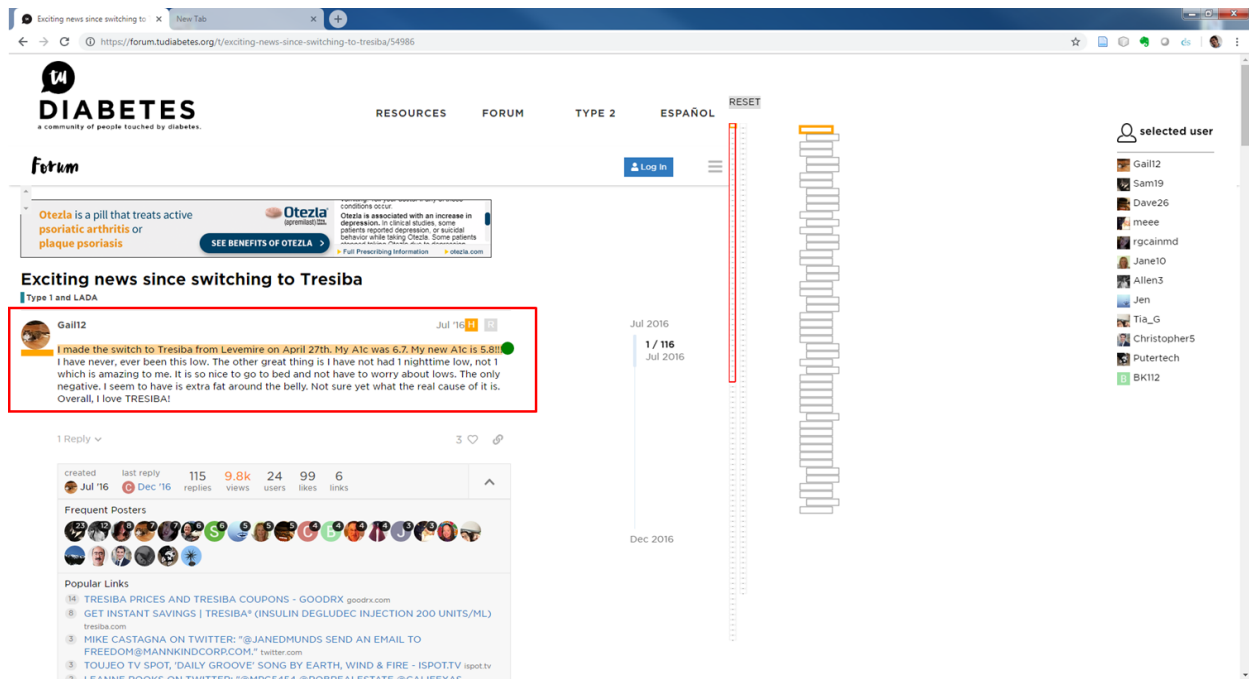


Figure 52. Highlighting a text to serve as a query.

Meghan now has the overview of the distribution of the relevant posts in the discussion and can decide where to start the discussion exploration from (Figure 53, middle). Using the discussion’s Heat Map, she immediately notices an area with a lot of highly relevant posts (colored with dark green) towards the end of the first column and the beginning of the second one and decides to focus her attention on that segment by moving the Slider to select that part of the discussion.

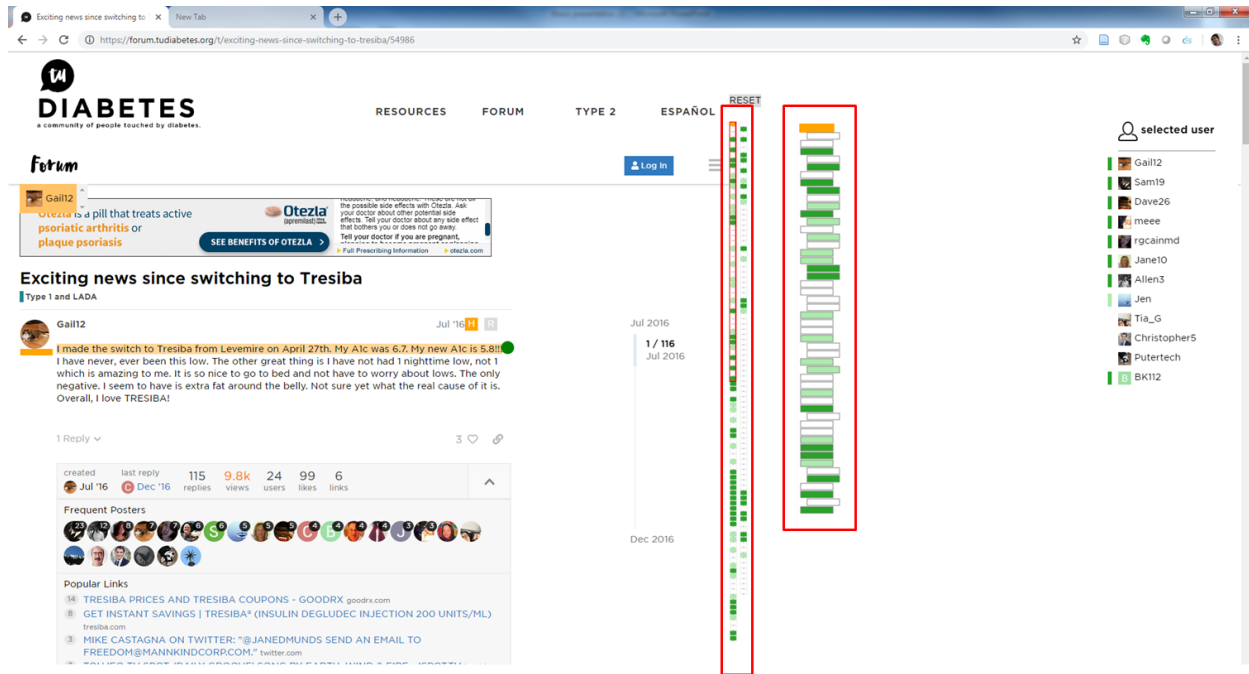


Figure 53. Rendering of the discussion based on the highlighted text to provide an overview of the distribution of the relevant content.

The selected segment of the discussion is now represented by the Post Tiles (Figure 53). Meghan notices that the top of that segment contains a sequence of highly relevant posts and decides to explore them. She hovers over the first post to see the participants that contributed in the immediate context of that post and looks if there are any additional collective sensemaking signals based on the lateral engagement element that would tell her that something interesting is going on there (Figure 54). Meghan decides that it is indeed an interesting sequence of relevant posts and wants to read the first one.

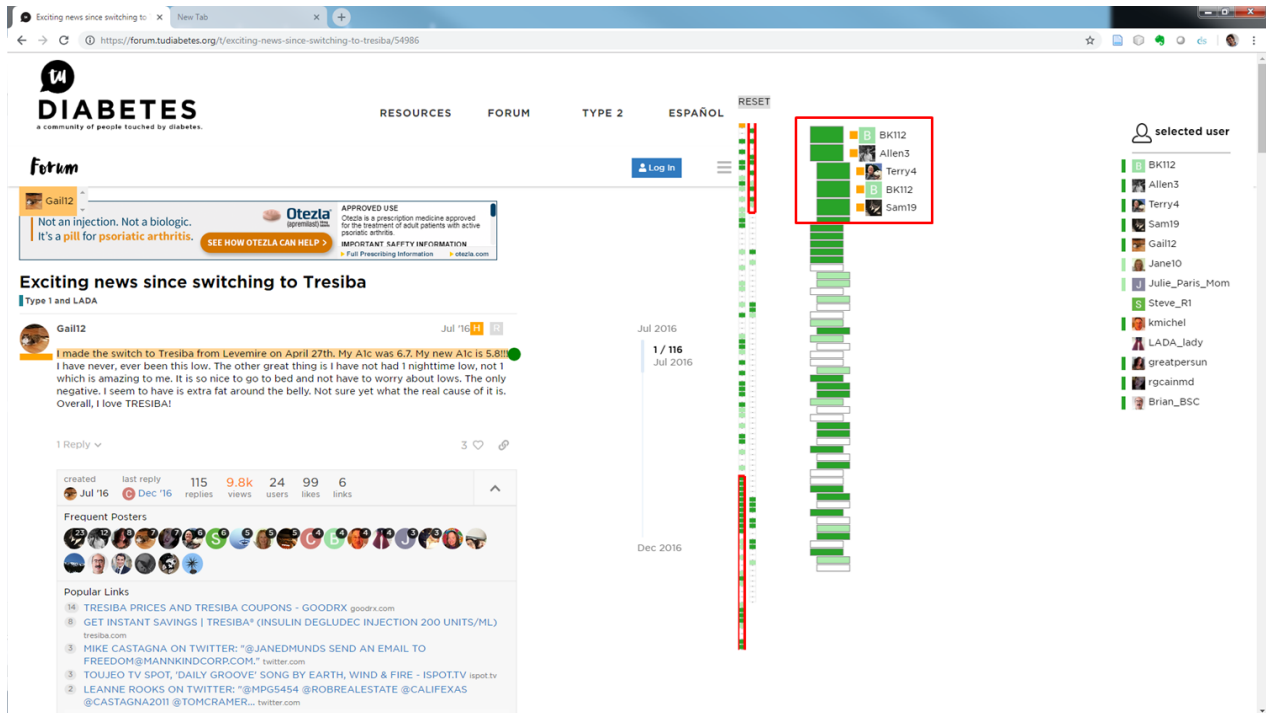


Figure 54. Using the Slider to focus on a particular segment of the discussion.

By clicking on the Post Tile (Figure 55, middle), the corresponding post is immediately put in focus for reading by automatically scrolling the discussion in the Discourse presentation on the left side of Figure 55. This post talks about the dosing of Tresiba during transition to it from another insulin, which Meghan thought is definitely a relevant post to her information needs.

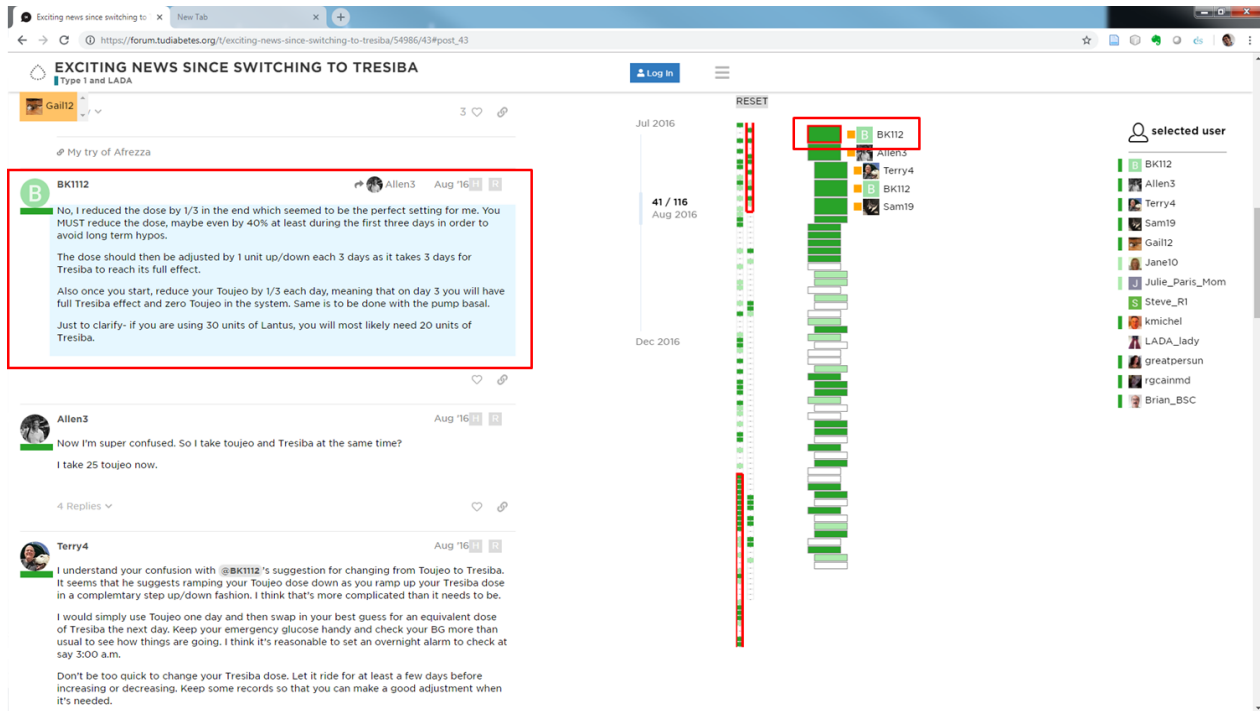


Figure 55. Jumping to a post of interest for reading its integral content.

Since she is in a reading mode, she refers to the Relevance Bars below the avatars of the authors of the subsequent posts (Figure 56, left) to decide what else to read in that immediate context without the need to go back to the visual rendering of the discussion segment she selected for more detailed inspection in the Post Tiles. Meghan reads the following couple of posts, but still thinks that what the participant BK112 posted is very useful. For these reasons, she decides to select them from the Participants Panel (Figure 57, right) to see where else in the discussion they contributed and what the relevance of those posts is. By observing the relevant contribution indicators to the left of each user, Meghan notices that there are others that contributed at least one highly relevant post, but still decides to focus on BK112 first (Figure 57, right). That participant is now the Selected User and markers are placed to indicate where else they contributed. Those markers are present both in the Post Tiles and the Heat Map as indicated in Figure 57 with red pointers.

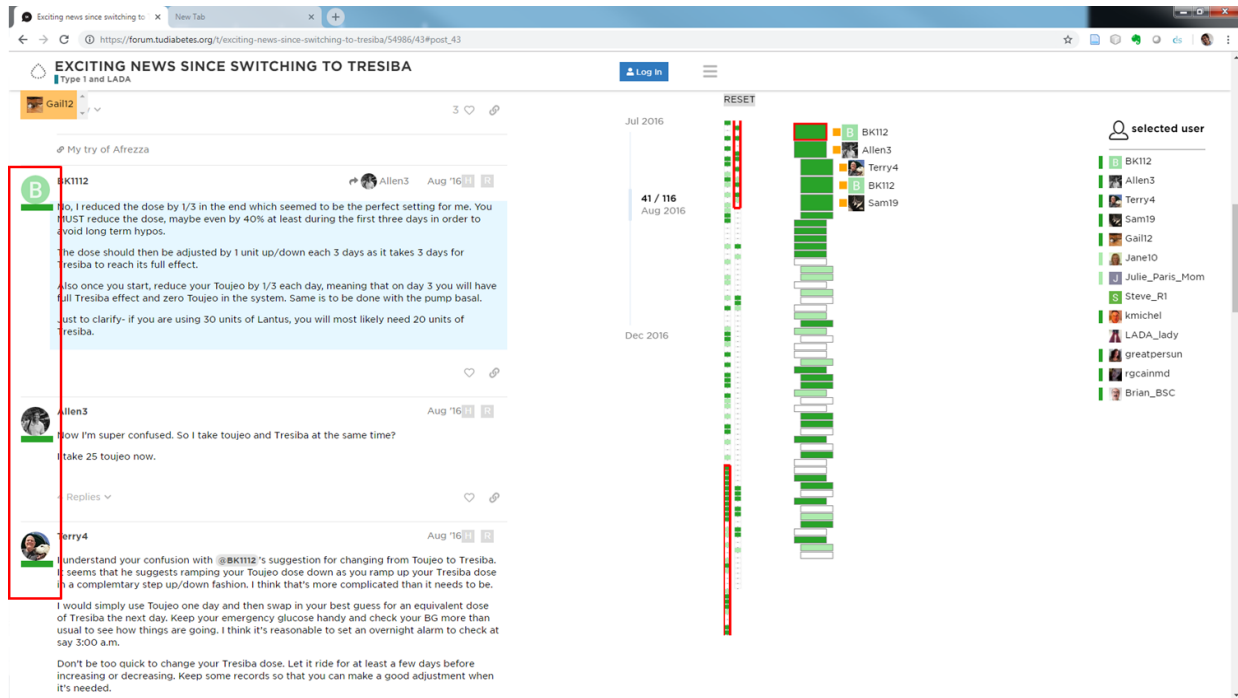


Figure 56. Following the relevance of the post in the reading mode.

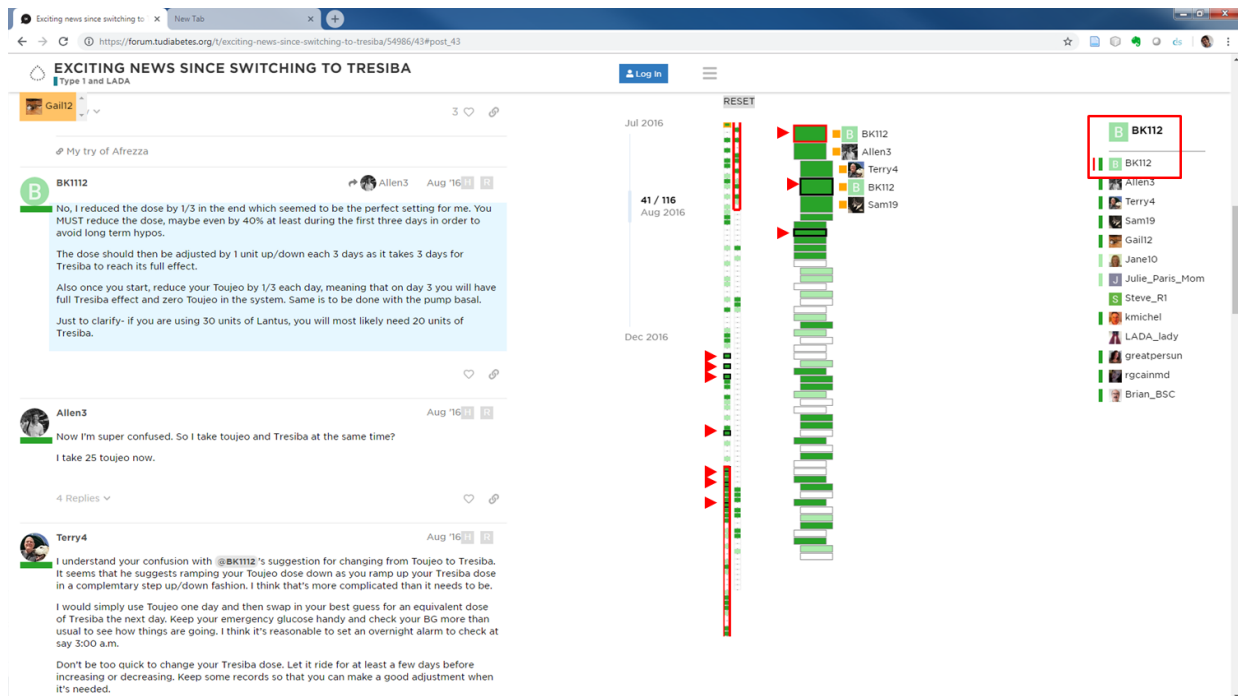


Figure 57. Selecting a user to see their posts.

Meghan now notices that BK112 has contributed posts outside of the selected discussion segment and wants to move the Slider to encompass all of them (Figure 58) to enable easier exploration using the Post Tiles.

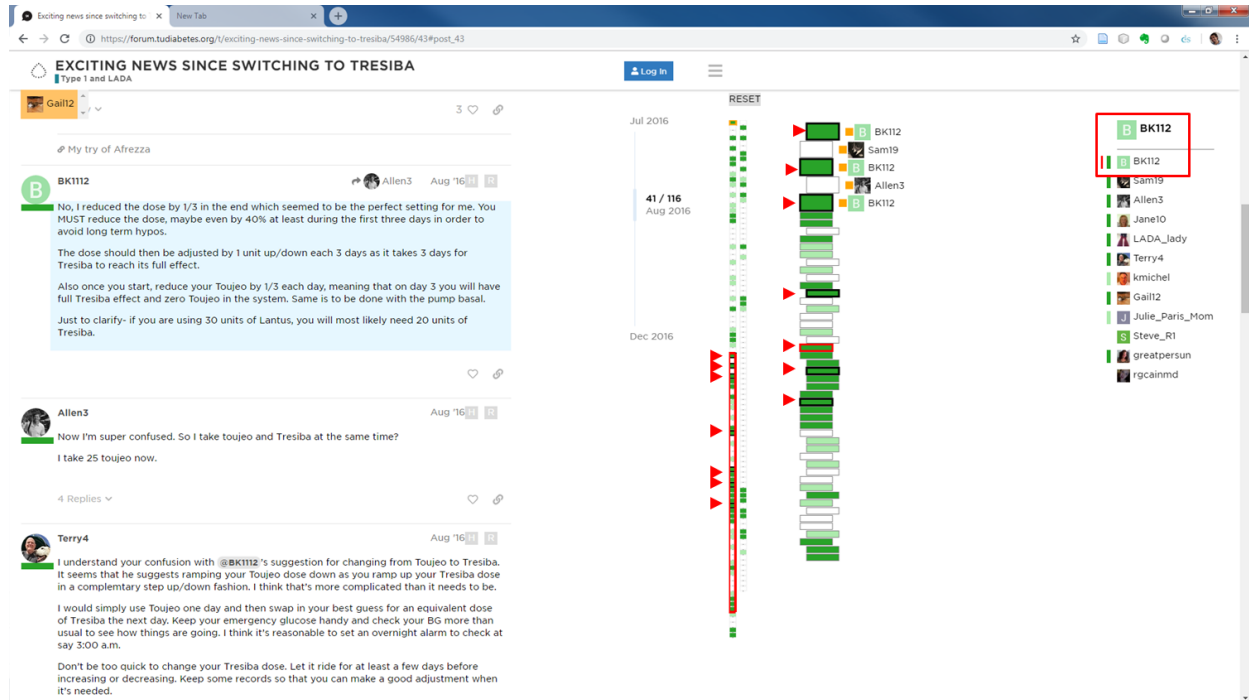


Figure 58. Moving the Slider to encompass the most of the contributions from a given user.

After exploring some of the more relevant posts, Meghan decides to check out some of the less relevant ones, to make sure she covered the topic of interest in enough breadth. She thinks that although the textual content was not deemed as relevant, it may come from a person that is similar to her, therefore increasing the reliability of what has been contributed. To do that, she hovers over the participant's user name and sees a Profile Card for that user (Figure 59). This Profile Card contains aggregated information that the members provide in their Profile when registering in the community and some information that the Discourse platform inferred, mostly related to the activity in the community. Meghan can now see some personal, medical and

community activity information about “rgcainmd”. She can see that “rgcainmd” is a parent of a Type 1 daughter, diagnosed in 2014, who usually talks about untethered approach to using Tresiba. This information increased the likelihood in Meghan’s eyes that some relevant content is actually provided in the post and decides to inspect it in more detail.

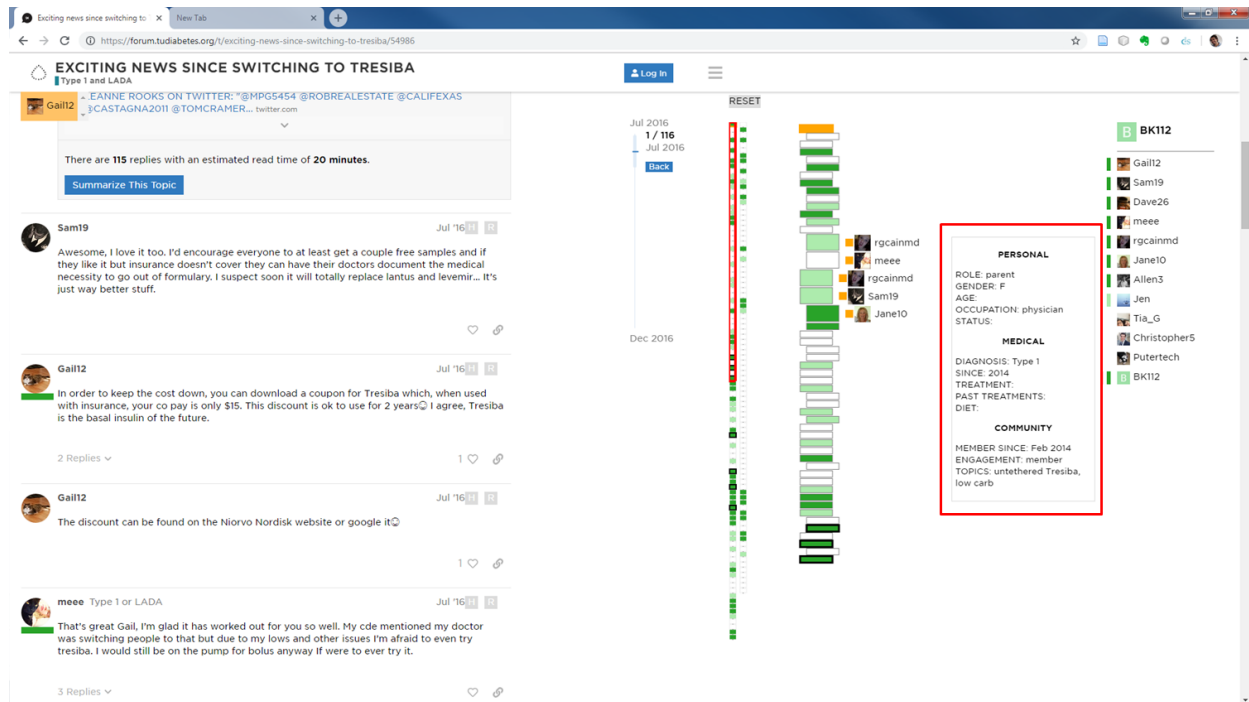


Figure 59. Personal information about a discussion participant contained in the Profile Card.

To do this, Meghan expands the Post Card to investigate the summary of the post before she commits to read it in more detail (Figure 60). She can immediately notice that it is a rather lengthy post with 466 words, but it also has a lot of relevant content based on how much the Post Tile has been covered with green and the corresponding number of words – 388. After taking a look at the key phrases and the summary and exploring the summaries of the two relevant segments in more detail by hovering over the bars that represent them, Meghan decides to read

the full text of this post. She clicks on the Post Tile and it is immediately put in focus for reading (Figure 61).

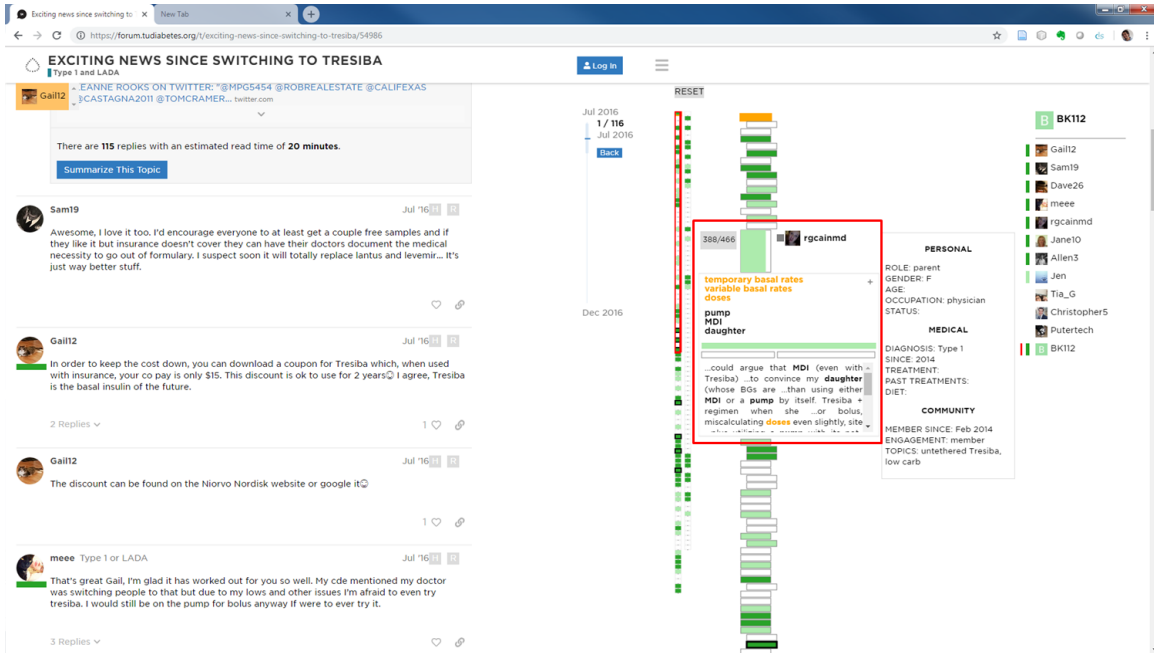


Figure 60. Expanding the Post Card to see a summary of the post of interest.

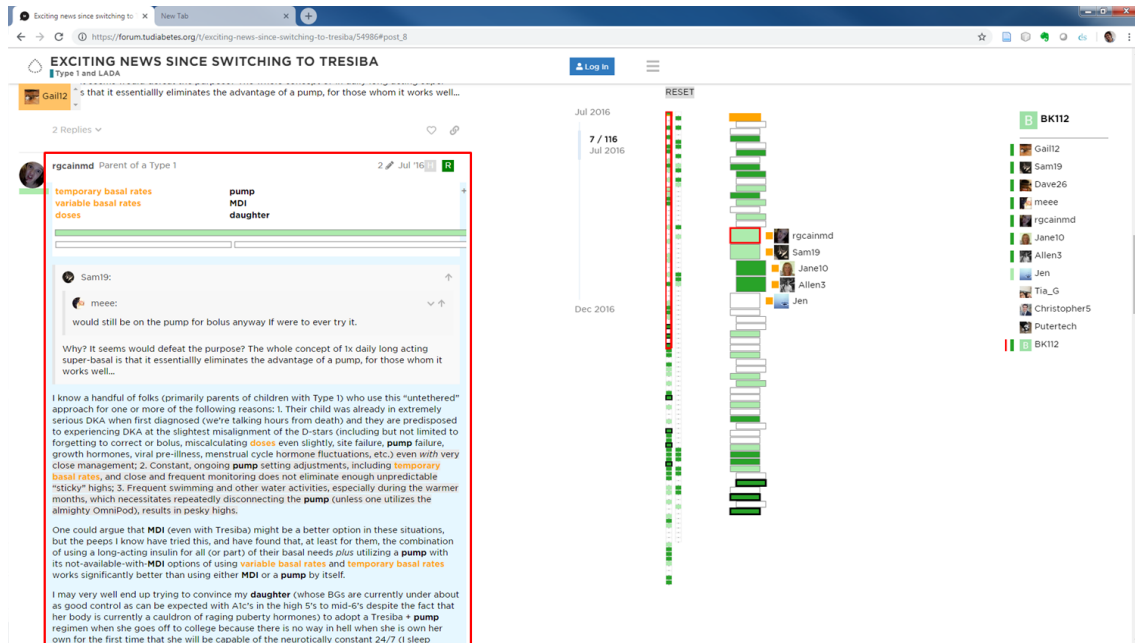


Figure 61. Reading Support provided for lengthy posts.

Here, Meghan activates the Reading Support that follows the information in the Post Card, to be able to see the distribution of the key phrases across the post as well as the relevant text segments.

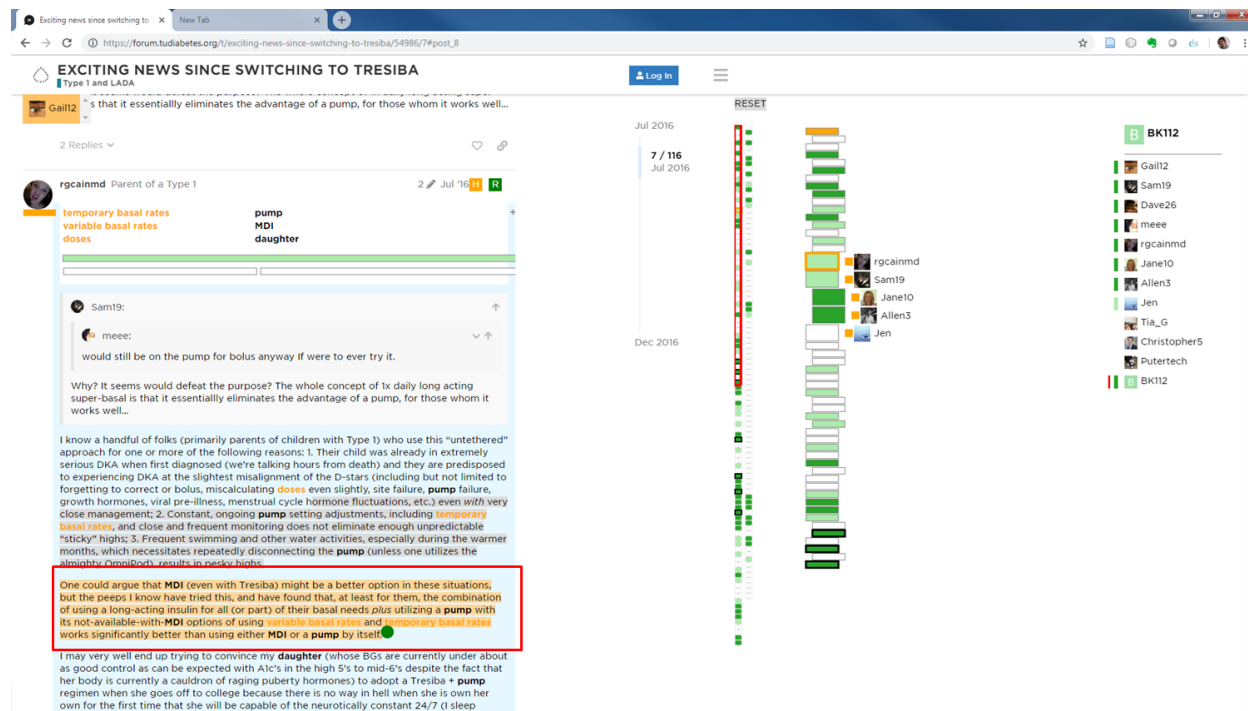


Figure 62. Selection of a new highlight within a Relevant Post.

After reading the post in detail, Meghan decides to issue another query. This time she selected a text that compares using MDI to the untethered approach, which combines Tresiba with a pump (Figure 62).

This new query is immediately stored in the Search History, right after the one she issued at the beginning (Figure 63). Meghan can browse the executed queries by clicking on the tabs for each of them (Figure 63).

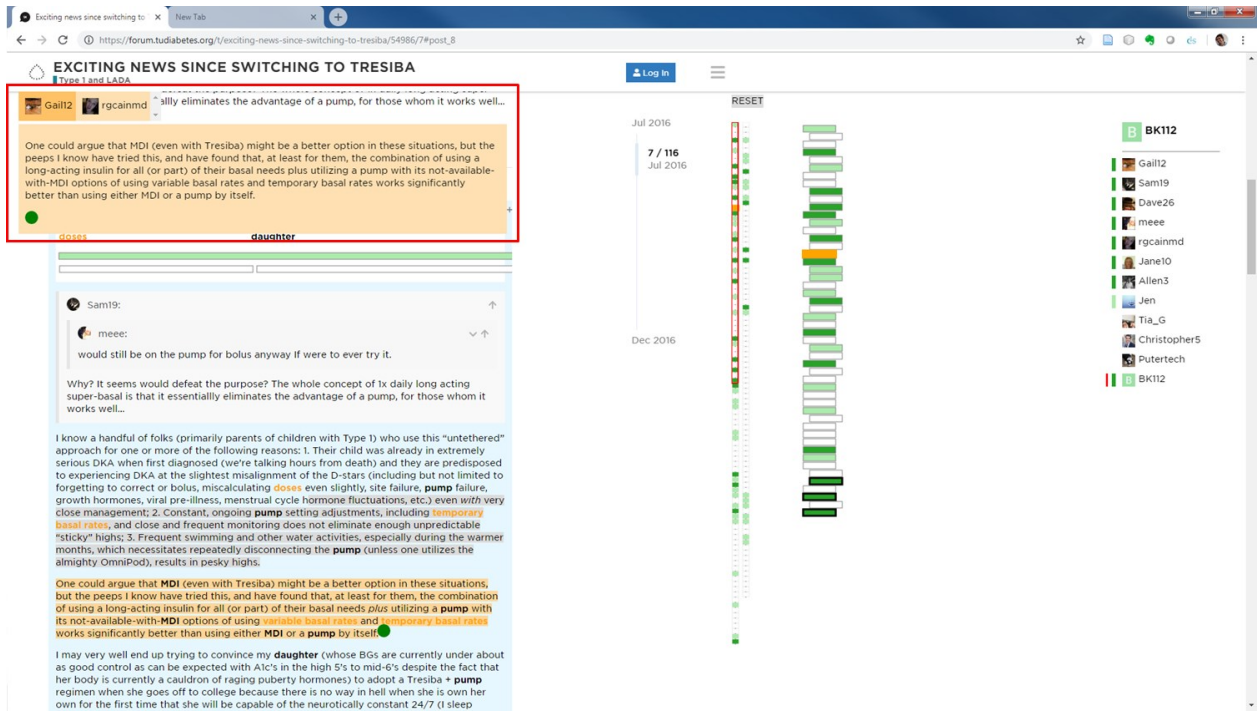


Figure 63. Queries are stored in the Search History.



Figure 64. Browsing of the queries is allowed by clicking on the tiles associated with them.

After some exploration of the discussions relevant content with respect to her last query, Meghan decides to come back to the first query and look for more information on how the transition to Tresiba from some other insulin affected the A1C values for other participants. To do that, she simply went to the Search History and selected the first tile. After the tile was expanded and the query became visible, Meghan executed it by clicking on the green button (in a very similar fashion as it is done when a query is issued upon actual highlighting) (Figure 64).

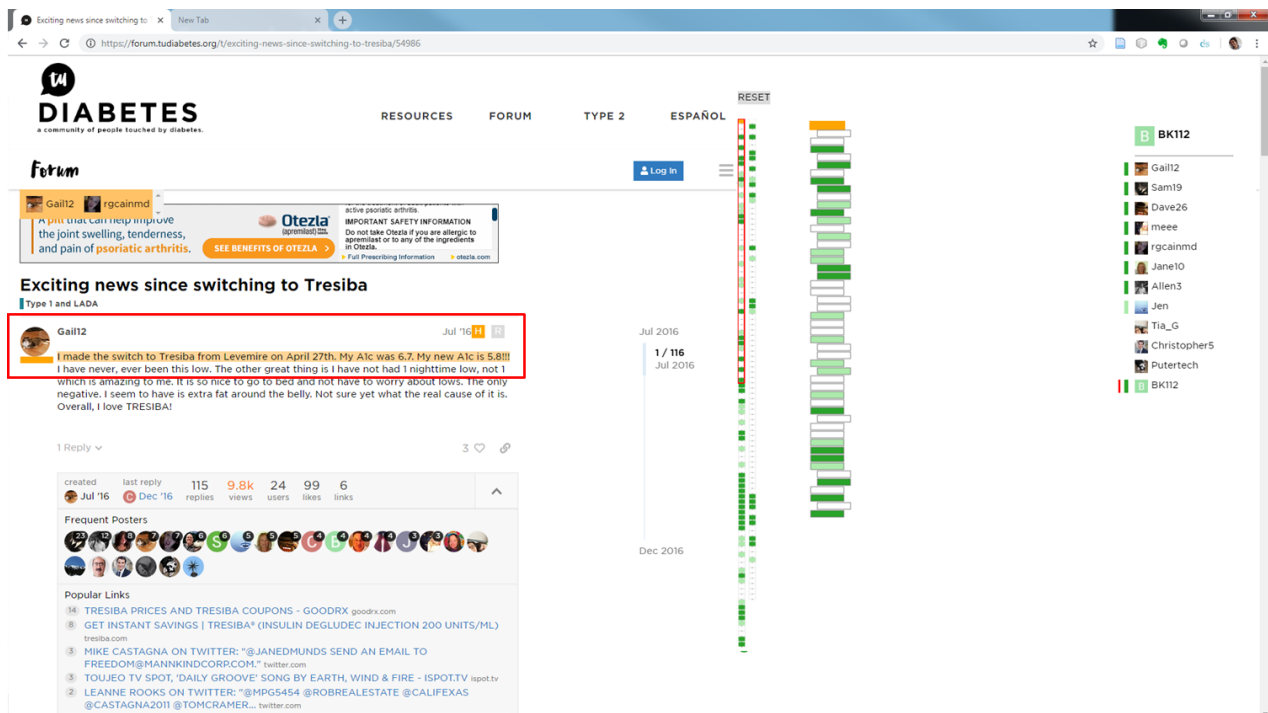


Figure 65. Executing a query from the Search History.

In this case the post that contained that query is placed in focus for reading and is actually ready for another highlighting in case Meghan feels she needs to update the query and issue a slightly different one by doing another text selection (Figure 65).

This closes the previous sensemaking cycle and starts a new one in which Meghan will go through a similar scenario that was described so far. This cyclical process will be repeated until

she closes her knowledge gap or decides to stop the process or leave the discussion for some other reason.

This concludes the presentation of the sensemaking tool dSense that gave a sense of how it could be used for sensemaking purposes and in the following part of Aim 3 I will perform an evaluation of the tool.

5.2 The evaluation study of dSense

In the second part of Aim 3 I focused on developing an evaluation framework for sensemaking support tools that take a holistic approach to the three main processes in the OHCs and attempt to provide means to enhance them (Figure 66). I then applied this framework to evaluate dSense.

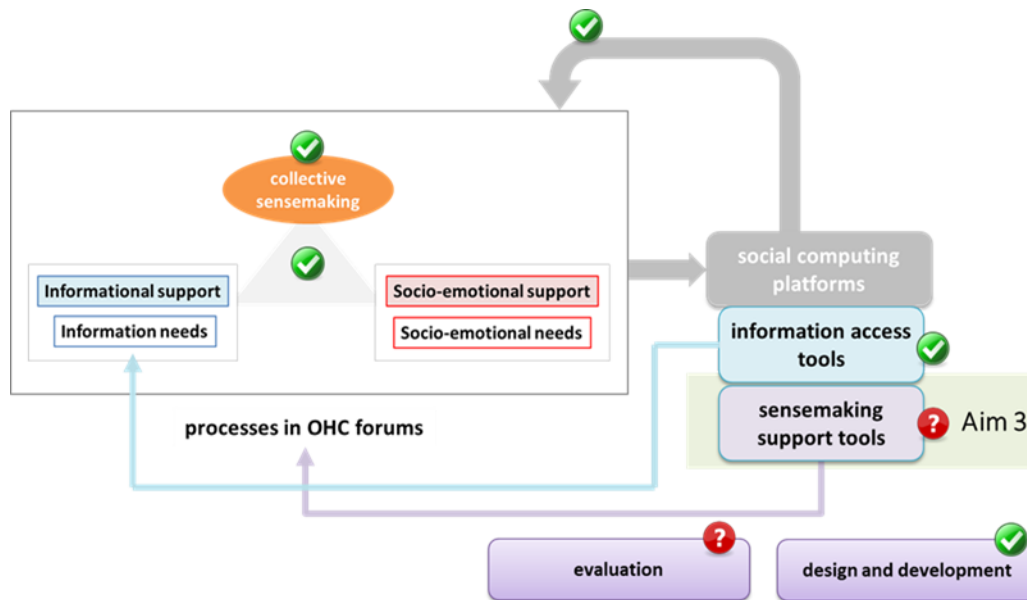


Figure 66. The knowledge gap addressed in the second part of Aim 3

dSense was designed to enable a synergistic approach to fostering individual sensemaking, collective sensemaking, and social connections within OHCs. Consequently, its evaluation study needed to focus on these three main constructs and the following research questions (Figure 67):

- *What is the impact on dSense on individual sensemaking?*
- *What is the impact of dSense on collective sensemaking, particularly, on the likelihood that the new posts added using dSense contribute to collective sensemaking?*
- *What is the impact of dSense on social connections among members, specifically on their awareness of forum discussion participants and their interest?*

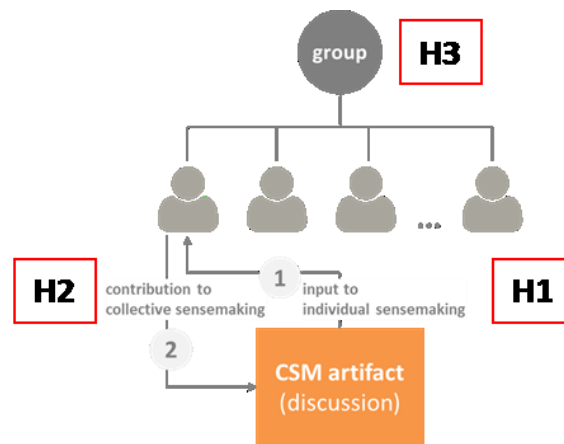


Figure 67. Assessing the impact of dSense at three key processes for OHCs forums: individual sensemaking, collective sensemaking and community building.

However, answering these questions presented a challenge in itself and required methodological innovation. Previous research on supporting sensemaking primarily focused on examining individual sensemaking, typically measured as an individual’s comprehension of information, rather than these broader set of phenomena. Thus, it was important to develop new approaches

for the evaluation study that focused on a broader set of constructs and impacts. Because of this, for the purposes of this dissertation, the study of dSense focused on assessing feasibility of the proposed evaluation method and feasibility of dSense as a tool for supporting sensemaking. In the future work I hope to conduct a larger-scale study evaluating the impact of dSense on the three outcomes of interest: individual sensemaking, collective sensemaking, and social awareness among community members.

5.2.1 Approach and assessment measures

5.2.1.1 Assessing impact on individual sensemaking

A cognitive model for discussion sensemaking in OHCs and points for tool support

To identify appropriate methods for evaluating the impact of dSense on individual sensemaking, I relied on the sensemaking framework proposed by Pirolli et. al [127]. The original framework was developed in the context of intelligence analysts examining collections of documents; I have adapted this framework to an individuals' sensemaking of information within a discussion thread (Figure 68). This model portrays sensemaking as a highly cyclical process that follows two main stages: the Foraging Loop and the Sensemaking Loop. Each of these loops is highly iterative and cyclical in itself. The Foraging Loop is the stage in which the sensemaker attempts to collect as much as possible evidence for closing a knowledge gap; the Sensemaking Loop is the stage in which the sensemaker organizes the collected information for inference, formulates and tests hypothesis and develops the final presentation of the answer that closes the knowledge gap the best. My specific focus was on the Foraging Loop in this model and on designing a tool that facilitates tasks within this loop that would have positive impact on the Sensemaking Loop.

The original model developed by Pirolli et al. describes the Foraging Loop and the Sensemaking Loop using a set of constructs that are specific to the context in which the model was created. In order to apply this model to sensemaking within OHCs, it was necessary to translate the model's constructs into terms more appropriate for the context of OHCs. To achieve that, I developed the following definitions adapted from the Pirolli's model:

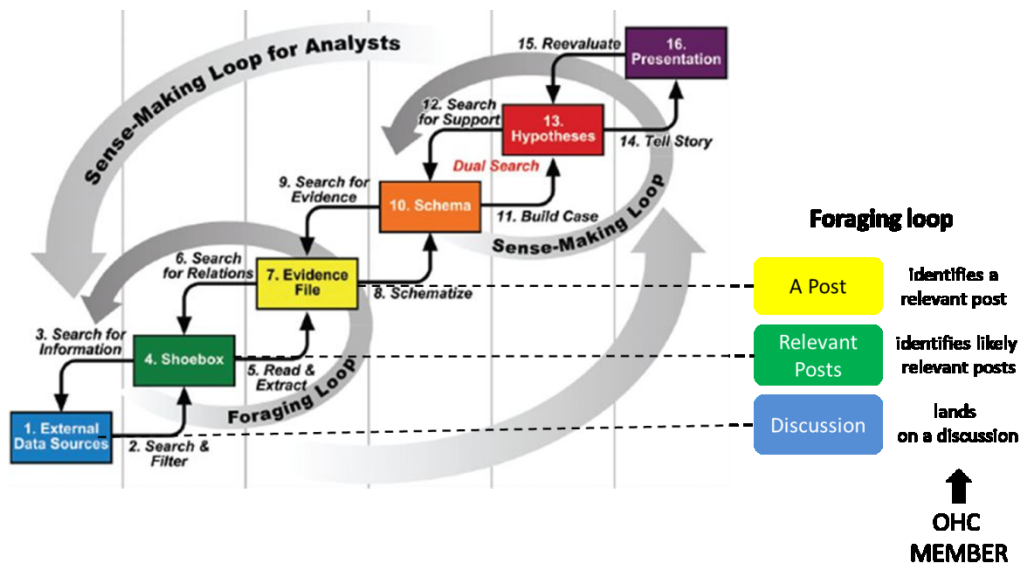


Figure 68. Sensemaking loop for intelligence analysts adopted for OHCs

- 1) *The External Data Source*, which includes a collection of Documents in the original model, is taken to represent any discussion thread, which includes a collection of posts.
- 2) *The Shoebox*, which in the original model includes a set of relevant documents that the sensemaker found through searching and filtering, is taken to represent a set of likely relevant posts to an information need in the context of OHCs.
- 3) *An Evidence File*, which in the original model represents a document that contains extracted useful information snippets from the relevant documents from the Shoebox is taken to

represent a collection of posts excerpts that were identified as useful in satisfying a certain information need.

Following this analogy, just like analysts begin their sensemaking process in the Foraging Loop, sensemaking for an OHC member starts with them identifying a discussion thread that has a potential to satisfy a certain information need. Based on that information need, the member may read through the discussion in order to identify relevant posts that could help them satisfy this information need, either through sequential reading of posts, skimming, or random sampling, and sometimes using the search tool for the discussion. Once a relevant post is identified, the sensemaker may read the post to extract useful information and, thus, may enter the Sensemaking Loop. While in the Sensemaking Loop, the sensemaker examines the new information, newly read discussion posts, and compares it with their existing mental models and with the knowledge gap they intend to close. If the sensemaker feels that more information is needed, they may re-enter the Foraging Loop and continue their search for relevant information.

An important caveat when drawing the analogy between the original sensemaking model for intelligence analysts and the OHCs forum context is that because posts are added in a sequence and in response to previous posts, they are likely to exhibit higher degree of dependency on each other and a different inner structure than the typical documents analysts rely on. In addition, OHC members might have different conceptualization of relevance due to the high specificity of the cases, context dependency of medical information, and the community environment in which the knowledge is produced. However, despite these differences, the main steps of the sensemaking framework are highly applicable to sensemaking within OHCs. Consequently, I believe the model can provide a firm theoretical foundation for identifying new solutions for supporting the sensemaking process and for evaluating the impact of such solutions.

Adapting the sensemaking framework for dSense evaluation

As mentioned previously, the goal of dSense was to support the sensemaking activities that occur in the Foraging Loop, and by doing this, lead to improvement in the activities within the Sensemaking Loop (Figure 69). Because the main research questions in this work were concerned with improvements in the Sensemaking Loop, I used constructs within this loop to formulate tasks for evaluation.

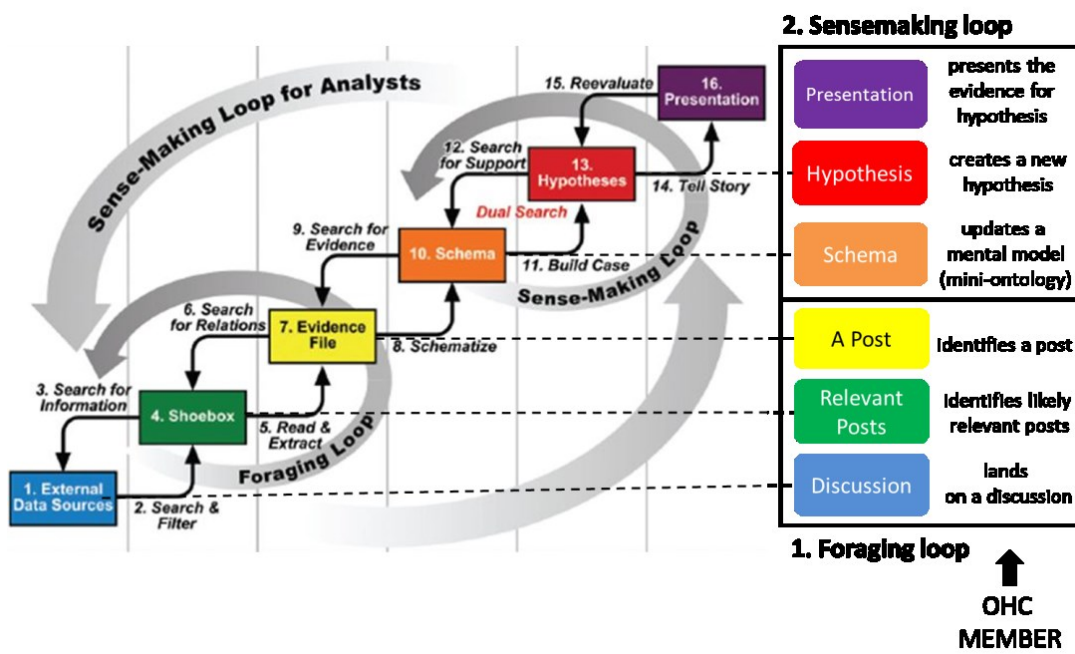


Figure 69. The sensemaking model for intelligence analysts adapted for the OHC forum discussion sensemaking.

As a result of their engagement in the Foraging Loop, sensemakers collect evidence that brings them closer to closing their knowledge gaps. The Sensemaking Loop starts when this collected evidence is organized into Schema in order to make inferences and create Hypothesis about the open question. In the Presentation, a story is laid out with arguments that support or reject the Hypothesis. This story is presented to an audience, which provides a feedback. After the

feedback, the sensemaker re-evaluates the Hypothesis, re-visits the Schema to attempt development of additional inferences and in order to gain additional support for the current Hypothesis or to generate a new one. In case there is not enough Evidence in the Schema, they go back to the Foraging Loop in search of new evidence, and the cycle repeats. I expected that dSense will have a positive impact on all three constructs within the Sensemaking Loop: it will *1) improve the sensemaker's ability to construct a richer Schema; 2) more thoroughly explore the space of possible Hypotheses; and 3) arrive at a final Presentation that more thoroughly closes their knowledge gap and leads to higher confidence in one's knowledge.*

To ensure a flow in cognitive tasks for the participants, it appeared appropriate to structure the evaluation in the reverse order, starting with an assessment of their ability to generate a comprehensive final Presentation, then assessing their ability to formulate and examine multiple Hypotheses and then assessing their ability to form mental Schemas (Figure 70).

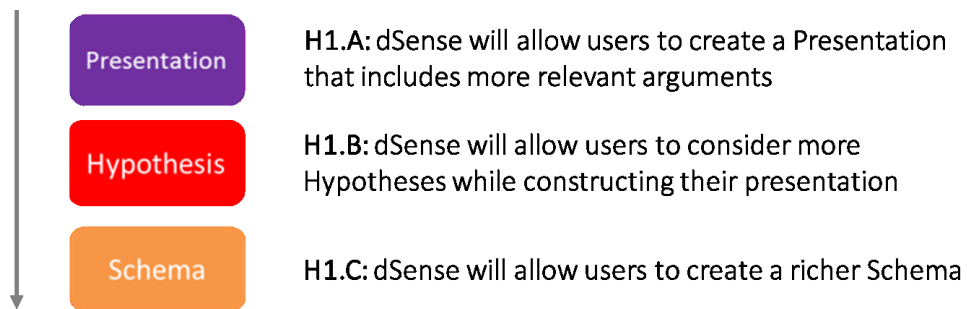


Figure 70. The flow of the evaluation and the hypotheses at each of the stages of the individual sensemaking process.

Finally, because this approach to assessing individual sensemaking relies on each individual's formulation of Presentation, Hypotheses, and Schema, it is possible that individuals' answers will be incongruent with each other and, consequently, not lend themselves to comparison across

individuals. To avoid this, it is important to provide sufficient scaffolding in the formulation of the questions that would establish directions for possible answers. Further, it was important to control for potential differences in individuals; prior knowledge of different topics related to diabetes self-management and their actual information needs. At the same time, it was important not to reveal too much of the anticipated answer with excessive scaffolding. To achieve this balance, I used several different mechanisms. First, to control for possible individual differences in knowledge, I created a persona of a friend with a particular information need (Figure 71); all tasks in the evaluation study evolve around closing the information gap for this friend and their specific information need. Further, for each task, I formulated questions in a way that was suggestive of the structure of the expected answer but without the actual content of the answer.

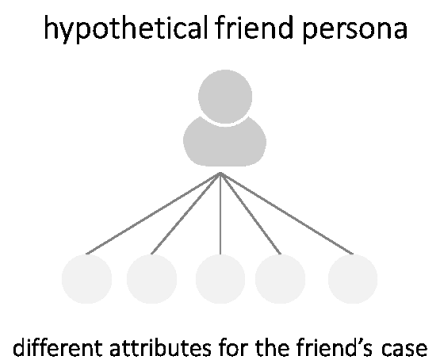


Figure 71. The hypothetical friend persona represented with the attributes of a specific case.

Specifically, I developed the following scenario that was presented to the participants:

“Imagine you have a diabetic Type 1 friend who is considering to include Tresiba as part of their diabetes management. They currently use only an insulin pump and have a very dynamic and active life, which causes them to sometimes eat larger meal portions, which requires insulin corrections. Also, your friend has been on low budget lately.”

During the exploration of the TuDiabetes forum, you found a discussion called “Exciting news since switching to Tresiba” and decided to explore it in more detail so that you can help your friend in their decision making.”

Below I describe the three constructs used for evaluation of individual sensemaking in greater detail and provide examples of questions used to assess these constructs.

1. Presentation

Arriving at the Presentation is the final step of the sensemaking cycle. As its name entails, this step involves presentation of arguments that support or reject the final hypothesis of the Sensemaking Loop. Based on the feedback from the audience, the sensemaker may revisit earlier stages of the Sensemaking Loop or even Foraging Loop and collect more evidence and generate and evaluate new hypotheses, until they are satisfied with the Presentation and its reception. At the end of the stream of sensemaking cycles, a final Presentation for the most reasonable hypothesis that could be supported by the best arguments is prepared (Figure 72). I take this final Presentation to be indicative of the quality of the sensemaking process and the impact of dSense on this process.

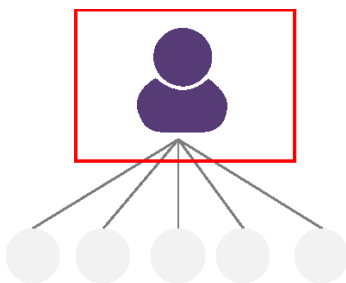


Figure 72. Providing a recommendation based on the specified knowledge gap, the given discussion and the friend’s case.

To assess the impact of dSense on an individual's ability to generate a comprehensive Presentation, I developed the following set of instructions:

“Please explore the discussion within the allotted time and come up with a recommendation to your friend about their idea of incorporating Tresiba in their diabetes management. In that recommendation, please remember about the special circumstances of your friend and their condition (currently using a pump, having dynamic and active lifestyle, occasional large meals that need correction and low budget). Please prepare a set of arguments regarding benefits and limitations of Tresiba for his particular condition that you can use to support your recommendation.

In your recommendation, be careful to rely only on the content in the discussion, without trying to add your personal opinion and knowledge, to the best extent you can.”

2. Hypothesis

Hypothesis is a step in the sensemaking cycle in which the sensemaker is trying to generate hypothesis based on some inferences from the Schema they have constructed up until that point. As the sensemaker explores the best possible answer for the open knowledge gap, they can visit this step multiple times to refine or create new Hypothesis that should be supported with arguments in the Presentation.

The purpose of this step is to measure how well the participants covered the space of possible answers to the question that was assigned in the presentation. Accordingly, the participants are asked to recall on any alternative answers they considered and the reasons why they discarded them in the following way:

“What other potential answers did you consider as you were exploring the discussion? Why did you discard those?”

3. Schema

Table 11. Probing questions to elicit individual’s Schema.

Probing questions
<i>1. What were the lifestyle and health benefits of switching to Tresiba that may be relevant to your friend?</i>
<i>2. Were there any side-effects or possible complications they mentioned pertinent to your friends case?</i>
<i>3. What were the non-health related barriers for switching to Tresiba that might affect your friend ?</i>
<i>4. How does Tresiba compare to other types of long lasting insulin (mention names of those types of insulin)?</i>
<i>5. How can be Tresiba used alone and what does the dosing look like?</i>
<i>6. How can it be used in combination with a pump or other fast acting insulin (inhaling insulin included) that may suit your friend?</i>

After the participants recall alternative hypotheses, it is appropriate to examine the quality of the Schema they were able to construct during their sensemaking. In this stage of the evaluation, it is important to provide the participants with additional scaffolding and with probing to examine the depth of their exploration of the information (Figure 73). Here, I have identified several probing questions that could help to elicit individuals’ Schemas (Table 11).

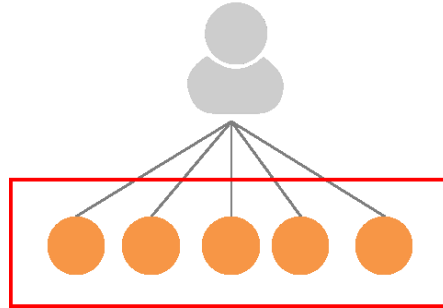


Figure 73. Delving into more specific question about each of the attributes for the friend’s case.

5.2.1.2 Assessing impact on collective sensemaking

While the framework described above addresses the cognitive aspects of individual sensemaking in detail, it is not extended to collective sensemaking. Further, while individual sensemaking can be assessed immediately after an individual examined available information, collective sensemaking is a longitudinal process that requires engagement of multiple individuals over potentially long periods of time; conducting such a longitudinal study is beyond the scope of this dissertation. To address these challenges, I developed the following approach. First, instead of attempting to assess the quality of collective sensemaking, I focused on assessing the likelihood of collective sensemaking based on underlying characteristics of individual contributions.

Specifically, in the study, after completing all the tasks related to individual sensemaking, the participants are asked to add a new post to the discussion thread that would make a valuable contribution to the discussion. These new posts are then assessed on their adherence to characteristics I associated with collective sensemaking in my previous studies (Study A1.1, Table 12). These characteristics include: *1) agreement/disagreement with previously stated position, 2) presenting argument for/against previously stated position, 3) further developing*

previously stated position, 4) personal reconciliation, and 5) synthesis of previously stated perspectives.

Table 12. Contributions to a discussion that serve as building blocks for collective sensemaking.

Sensemaking building block	Example
<i>1. Agreement/disagreement with previously stated position</i>	I agree with what everyone else has said, you need to be antibody tested to see if you are T1
<i>2. Presenting argument for/against previously stated position</i>	There was a study I saw a note about in a Diabetes Forecast "sidebar" that showed that T2 put straight onto insulin had better control or something to that effect
<i>3. Further developing previously stated position</i>	Humulin R may have a role as a supporting player or even as a primary insulin if cost is the issue but it is being prescribed for use before bed rather than before meals
<i>4. Personal reconciliation</i>	Dear, im sorry if i offended you
<i>5. Synthesis of previously stated perspectives</i>	You have gotten some excellent advice here at TuD, and I am glad you have an appointment with your endo. It is important to get testing to see if you have Type 1 diabetes, but the most important thing is getting excellent treatment and care.

I wanted to open the space of possible contributions without posing any constraints or providing instructions that might sound like asking for a particular type of contribution that fits certain template that is a collective sensemaking building block or combination of those. However, to inform the reasons behind the post more than just the text provided and obtain additional signal relevant to collective sensemaking, I asked a set of contextualizing questions for the contribution. Specifically, the participants are given the following instructions with the follow up questions from Table 13:

“Imagine that you are a member of this community and you really care about both the community and the conversations that happen in its forum. Think about what you could post in this discussion to help people like your friend learn about Tresiba and whether it is a good fit for their own management. In this case you don’t have to limit your contribution to the knowledge produced in the discussion, but you can combine it with your own knowledge as well.

Please, choose a location in the discussion where you would like to put your post and point to it.”

Table 13. Contextualizing questions for obtaining additional signal relevant to collective sensemaking.

Contextualizing questions
<i>1. For the post you just contributed in the discussion, please explain if there is a reason for placing it in that particular location?</i>
<i>2. For the post you just wrote, can you explain what motivated it and why you think it will be valuable to others who are similar to your friend?</i>
<i>3. For the post you just contributed, please indicate how much the content in the discussion influenced your contribution? Why was that?</i>

5.2.1.3 Assessing impact on social connections

Finally, my previous research suggested the importance of preserving close social connections within OHCs; consequently, it is important to evaluate the impact of dSense on social fabric of the community. Once again, the true impact needs to be assessed in longitudinal study beyond the scope of this dissertation. However, it is possible to assess to what degree dSense impacted individuals’ awareness of those who wrote the posts in the discussion, and their ability to develop an idea about the relevance of the content those authors contributed on different topics of interest in the sensemaking process.

In order to do that, I developed the following set of questions presented in Table 14.

Table 14. Question for social awareness after the sensemaking process.

Social awareness questions
Awareness of the participants
<p>1. <i>How can you describe your exposure to the participants in the discussion as you were trying to make sense of it?</i></p> <ul style="list-style-type: none"> • <i>Did you notice any change to what would be a typical participants awareness you are used to when reading discussions in the forum?</i> • <i>What do you think might have contributed to those changes?</i>
Learning about the person behind the post
<p>1. <i>During the first segment of the study, when you were asked to complete some tasks related to making sense of the discussion, how frequently did you check personal information about the participants?</i></p> <ul style="list-style-type: none"> • <i>How can you compare this to your normal habits?</i> • <i>What do you think are the reasons behind these changes?</i>
Establishing links between members and their interests
<p>1. <i>How can you describe your ability to establish links between the relevant information you found throughout the discussion sensemaking phase and the participants who contributed it?</i></p> <ul style="list-style-type: none"> • <i>What do you think contributed to that?</i> <p>2. <i>Suppose your friend was really interested in Tresiba and decided to join TuDiabetes.org in order to engage in the conversation about the topic and learn more about it. How would you feel about recommending some of the participants in this discussion to your friend to interact with and pay closer attention to in the future based on the information they contributed to the discussion? Who would that be? Why?</i></p>

5.2.2 Study materials

5.2.2.1 Selecting a discussion for the evaluation

According to my previous research in Study A1.1, once a discussion reaches over 30 posts, it typically starts to introduce challenges for sensemaking [101]. In the TuDiabetes.org forum, there are more than 300 discussions with 100 or more posts (close to 2%) and around 4000 discussions with 50 or more posts (close to 10%). Importantly, the discussions of these lengths are usually popular among members, attract attention of many users and have thousands of views. These discussions typically cover controversial or new topics, or topics that are constantly discussed and that can never reach consensus in the community. The selected discussion for evaluation reflects a typical example of an OHC discussion that poses problems for sensemaking and has 116 posts. It was titled: “Exciting News Since Switching To Tresiba”. In this particular discussion that was started in 2016 and lasted almost half year, there were 24 participants that covered multiple topics related to incorporating a new long lasting insulin called Tresiba as a part of one’s diabetes management.

5.2.2.2 Developing the gold standard for the evaluation

The Gold Standard was developed by two Registered Nurses (RNs), experts in diabetes self-management. Each RN was asked to work through the tasks from the individual sensemaking portion of the evaluation independently; unlike study participants, RNs were given unlimited time for answering questions from the tasks. They were also instructed to generate the most comprehensive answer they could and to include all the key points in the answers that are available in the discussion. Their individual written responses to sensemaking tasks were converted into statements that cover one or more key points.

Table 15. The overlap in key points between the gold standard developers about each of the questions from the individual sensemaking stage of the dSense evaluation.

Gold standard (GS) for individual sensemaking			
Question	Key points covered by GS developers		Overlap in key-points between GS developers
	A	B	
Presentation			
1. <i>What is your recommendation to your friend and arguments from the discussion that support it and address the key points of their case?</i>	17/21	19/21	0.71
Schema			
1. <i>What were the lifestyle and health benefits of switching to Tresiba that may be relevant to your friend?</i>	9/10	8/10	0.70
2. <i>Were there any side-effects or possible complications they mentioned pertinent to your friends case?</i>	1/1	1/1	1.00
3. <i>What were the non-health related barriers for switching to Tresiba that might affect your friend ?</i>	4/6	5/6	0.50
4. <i>How does Tresiba compare to other types of long lasting insulin (mention names of those types of insulin)?</i>	3/4	4/4	0.75
5. <i>How can be Tresiba used alone and what does the dosing look like?</i>	6/6	3/6	0.50
6. <i>How can it be used in combination with a pump or other fast acting insulin (inhaling insulin included) that may suit your friend?</i>	3/3	3/3	1.00
Average	0.87	0.86	0.74

Discrepancies in the individual answers were discussed in a personal meeting and reconciled, until agreement on all key points were reached, thus leading to the final gold standard for all the tasks in the study. To examine consistency between RNs in their coverage of relevant key points, I calculated the overlap between the key points they provided individually, presented in Table 15. I also present the coverage of key points for each of the gold standard developers individually.

Overall, the RNs achieved high consistency in their individual answers, averaging at more than 86%. They also exhibited a solid overlap between the key points they covered for each of the questions suggesting that the gold standard can be reliably used in the study.

5.2.3 Study design

5.2.3.1 Participants

The participants for the study were recruited among members of the TuDiabetes OHC using announcements in the forum and with the help of the community leadership. I also recruited participants from Craigslist and RecruitMe (a Columbia University Medical Center's service for study recruitment). The participants had to meet the following criteria to be included in the study: a) 18 years or older; b) fluent in English; c) have self-reported diagnosis of diabetes or provide care for someone with diabetes, d) have normal vision or well corrected vision with glasses or lenses, e) have some experience in participation in OHC forums; f) have not participated in the forum discussion used for evaluation of the tool "Exciting News Since Switching To Tresiba"; and g) are not familiar with the content of the this discussion. I recruited 12 participants in total (7 male and 5 female), with Type 1 and Type 2 diabetes that reported to be knowledgeable about the disease. The participants were very comfortable with technology

and were familiar with online forum discussions and the concept of online health communities, which they regularly visited and occasionally contributed to.

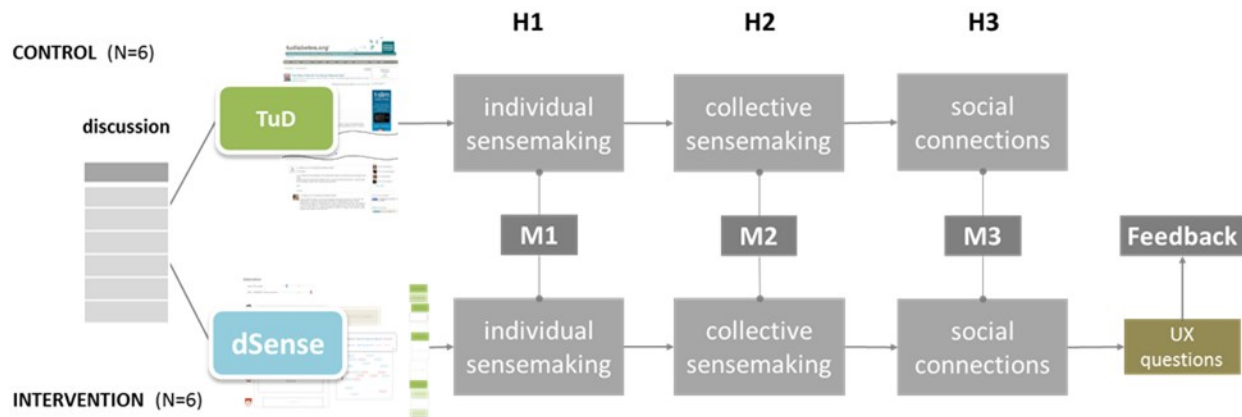


Figure 74. The evaluation study design.

5.2.3.2 Procedures

The study was conducted on-line, using the Cisco Webex shared screen platform that allowed the participants to control the investigator’s machine for the duration of the study. The intervention group (N=6) was asked to use the dSense Chrome Extension, and the control group (N=6) was instructed to use the regular features of Discourse. At the beginning of the session, the intervention group received a tutorial about the use of the dSense tool, and in case a participant in the control group had questions about the Discourse platform, they were explained before the evaluation started. Each group was asked to complete a set of tasks related to individual sensemaking and collective sensemaking, which were followed by a set of questions about the awareness of community members participating in the discussion (Figure 74). The participants provided verbal answers for the individual sensemaking and social awareness study segments, and a written answer for the collective sensemaking segment. The qualitative answers that required elaboration were broken into statements that cover key points that were used for further

analysis phases: M1 (individual sensemaking), M2 (collective sensemaking) and M3 (social awareness). In addition, video recordings from the interactions were collected to enable the analysis of the utilization of the tool's features for the completion of different sensemaking related tasks. After obtaining answers for each of these 3 segments, qualitative feedback about the dSense tool was obtained through semi-structured interviews with the participants from the intervention group.

5.2.4 Data analysis

Because of the small sample size in the study, I relied on the non-parametric Mann-Whitney U-test to test my hypothesis. This evaluation study is primarily designed for feasibility purposes and initial feedback for the directionality of the design. The results should serve as an indicator whether ideas behind dSense are moving in the right direction and whether the proposed evaluation could be used or extended for more robust evaluations.

5.2.4.1 Individual sensemaking

The dSense tool was expected to improve the individual sensemaking for forum discussions. This was operationalized more closely through three other smaller hypotheses:

- ***H1: dSense will improve individual sensemaking for forum discussions as compared to the original Discourse platform.***
 - *H1.A: Presentation: dSense will allow users to create a Presentation that includes more relevant arguments*
 - *H1.B: Hypothesis: dSense will allow users to consider more Hypotheses while constructing their presentation*

- *H1.C: Schema: dSense will allow users to create a richer Schema*

Presentation

The recommendations to the hypothetical friend from the scenario obtained from the participants in the control and in the intervention group were analyzed for identifying key points, in a way similar to the Gold Standard. To assess how close a given recommendation was to the Gold Standard recommendation, Jaccard similarity coefficient was calculated between the two. After this step, a non-parametric Mann–Whitney U test for small sample sizes was performed to test the hypothesis.

To assess the confidence in the answer for both groups, each of the possible answers was associated with a score: 0 – not confident at all, 1 – a little confident, 2 – confident, 3 – very confident, and 5 – extremely confident. After this step, a non-parametric Mann–Whitney U test for small sample sizes was performed to test the hypothesis.

Hypothesis

The answer to this question from the control and the intervention group was analyzed to identify how many different alternatives (Hypotheses) were considered during the process of sensemaking. This number was assigned to each answer and a non-parametric Mann–Whitney U test for small sample sizes was performed to test the hypothesis.

To assess the confidence in the answer for both groups, each of the possible answers was associated with a score: 0 – not confident at all, 1 – a little confident, 2 – confident, 3 – very confident, and 5 – extremely confident. After this step, a non-parametric Mann–Whitney U test for small sample sizes was performed to test the hypothesis.

Schema

Similar to the approach in the Presentation, each of the answers for the probing questions from Table 11 obtained from the participants in the control and in the intervention group were analyzed for identifying the key points covered in them. To assess how close a given answer was to the Gold Standard recommendation, Jaccard similarity coefficient was calculated between the two. The Jaccard scores obtained for the answers from a single participant were averaged to get the score for Schema richness that participant produced. After this step, a non-parametric Mann–Whitney U test for small sample sizes was performed to test the hypothesis.

5.2.4.2 Collective sensemaking

The dSense tool was expected to increase new posts' potential to contribute to collective sensemaking in forum discussions. This was operationalized more closely through four other smaller hypotheses:

- ***H2: dSense will increase new posts' potential to contribute to collective sensemaking in forum discussions.***
 - *H2.1: Structure: The newly contributed posts by the users of dSense will adhere more to a structure that promotes collective sensemaking in the discussion.*

Structure

Each of the newly contributed posts by the participants was analyzed for the presence of collective sensemaking building blocks according to Table 12. For each identified block identified in a post a point was assigned. The sum of the points determined the adherence of the post to the collective sensemaking process. The difference between the number of sensemaking

blocks between the experimental and control groups was assessed using a non-parametric Mann–Whitney U test for small sample sizes.

5.2.4.3 Social connections

The dSense tool was expected to stimulate the social awareness and connections in the OHC. This was operationalized more closely through three other smaller hypotheses:

- ***H3: dSense will increase awareness of forum discussion participants and their interest.***
 - *H3.1: Participants' awareness: dSense will raise users' awareness of the participants in the discussion, as indicated in their self-report.*
 - *H3.2: Person behind the post: dSense will enable users to inspect personal information of the participants in the discussion more frequently as indicated in self-report.*
 - *H3.3: Links between members and their interest: dSense will help users to establish links between participants and the relevant information they found in the discussion as indicated in self-report.*

For each of the hypotheses above, participants are presented with a multiple-choice questionnaire and asked to assess their perception on a Likert scale: 0 – much less than usual, 1 – less than usual, 2 – same as usual, 3 – more than usual, 4 – much more than usual. These scores between the control group and the experimental group are compared using Mann–Whitney U test for small sample sizes.

5.2.5 Results

5.2.5.1 Individual sensemaking

Table 16 includes descriptive statistics for measures of individual sensemaking for the intervention and control groups and results of comparison of these measures between the intervention and the control groups. The Mann-Whitney between group comparison test showed that individuals in the intervention group achieved statistically better performance for the Hypothesis measure ($U = 4.5$, $p = 0.038$), in that they considered significantly more alternative hypotheses before arriving at their final presentation. For the other two measures, Presentation and Schema, the results showed positive trends for the intervention group; however, there were no statistically detectable differences between the groups (Presentation: $U = 10$, $p = 0.230$; Schema: $U = 17.5$, $p = 1$).

Table 16. Individual sensemaking performance (Presentation: Jaccard similarity between the key points covered in the participant’s recommendation and the Gold Standard; Hypothesis: number of hypotheses considered for the final recommendation; Schema: average of the Jaccard similarities between the key points in the 6 answers for the Schema questions provided by a participant and the Gold Standard).

Control	Presentation	Hypothesis	Schema	Interv.	Presentation	Hypothesis	Schema
P1	0.24	1	0.21	P4	0.24	1	0.09
P2	0.22	0	0.11	P5	0.14	1	0.02
P3	0.24	0	0.26	P6	0.33	3	0.25
P7	0.14	1	0.09	P8	0.17	4	0.35
P9	0.16	0	0.08	P10	0.52	2	0.49
P11	0.17	1	0.11	P12	0.33	1	0.05
AVG	0.2	0.5	0.14	AVG	0.29	2	0.21

The analysis of differences in individuals' ability to construct richer Schema showed consistent trends towards improvement for the intervention group in all but one of the questions used to assess the overall Schema richness (Table 17). However, the differences between groups were not statistically significant (Schema: $U = 17.5$, $p = 1$).

Table 17. Individual sensemaking performance for the Schema sub-section (S1-S6: Jaccard similarity between the key points covered in the participant's answer and the Gold Standard; S-AVG – average of the scores for the answers S1 through S6).

Cont.	S1	S2	S3	S4	S5	S6	S-AVG
P1	0.1	1	0.17	0	0	0	0.21
P2	0.18	0	0.5	0	0	0	0.11
P3	0.18	0	0.67	0.25	0.11	0.33	0.26
P7	0.1	0	0.17	0.25	0	0	0.09
P9	0.2	0	0	0.25	0	0	0.08
P11	0	0	0	0.5	0.17	0	0.11
AVG	0.13	0.17	0.25	0.21	0.05	0.06	0.14

Int.	S1	S2	S3	S4	S5	S6	S-AVG
P4	0.1	0	0	0.25	0.17	0	0.09
P5	0.1	0	0	0	0	0	0.02
P6	0.4	0	0.17	0.25	0.33	0.33	0.25
P8	0.09	1	0.17	0.5	0	0.33	0.35
P10	0.2	1	0.5	0.75	0.17	0.33	0.49
P12	0.3	0	0	0	0	0	0.05
AVG	0.2	0.33	0.14	0.29	0.11	0.17	0.21

Confidence in the sensemaking process

The participants were asked to self-report on their confidence for two steps of the sensemaking process: the Presentation and the Hypothesis.

Confidence in the Presentation and Hypothesis

At baseline, there was no difference between participants in the intervention and control group in their self-reported diabetes knowledge based on a 5 point Likert scale (intervention: mean=3.67 St.Div.=0.60, control: mean=4.33, St.Div.=0.52, U=8, p=0.129). The results of the participants' self-assessment of their confidence in the quality of their presentations and their hypothesis are presented in Table 18 (purple for presentation, red for hypothesis). While there are trends towards higher confidence for the control group, the difference between the groups for both of these measures is not statistically significant.

Table 18. Confidence in the Presentation and Hypothesis (Purple: the performance for the Presentation in individual sensemaking evaluation (from Table 16) and the confidence in the answer; Red: the performance for Hypothesis in individual sensemaking evaluation (from Table 16) and the confidence in the answer).

Control	Pres.	Conf.	Hyp.	Conf.
P1	0.24	2	1	3
P2	0.22	3	0	2
P3	0.24	3	0	3
P7	0.14	3	1	3
P9	0.16	4	0	3
P11	0.17	4	1	5
AVG	0.2	3.17	0.5	3.2

Interv.	Pres.	Conf.	Hyp.	Conf.
P4	0.24	2	1	2
P5	0.14	2	1	1
P6	0.33	3	3	2
P8	0.17	3	4	3
P10	0.52	4	2	4
P12	0.33	3	1	3
AVG	0.29	2.83	2	2.5

5.2.5.2 Collective sensemaking

The measures of collective sensemaking for the intervention and control groups are presented in Table 19; it includes the overall number of building blocks associated with collective sensemaking in the newly contributed posts (Blocks), the number of words in the posts (Words), and a self-report on a Likert scale about the source they relied on for contributing the new post –

ratio between the content provided in the discussion and their personal knowledge. The new posts that did not include any building blocks of collective sensemaking were not included in the calculations for the Word and Source averages. Overall, there were no statistically significant differences in the measures of collective sensemaking between the experimental and the control groups.

Table 19. Collective sensemaking performance. Location: place in the discussion where the new post was supposed to be located: bottom/end of the discussion (B); Blocks: number of collective sensemaking building blocks; Words: number of words in the newly contributed post; Source: Likert Scale ratio between the content provided in the discussion and participant’s personal knowledge as a source they relied on to construct the new post.

Cont.	Location	Blocks	Words	Source
P1	B	5	96	1
P2	B	4	104	1
P3	B	4	135	3
P7	M	0	156	2
P9	M	1	75	2
P11	T	1	54	1
AVG		2.5	92.8	1.6

Inter.	Location	Blocks	Words	Source
P4	B	6	184	2
P5	B	0	83	2
P6	M	2	87	2
P8	M	1	105	3
P10	B	6	90	1
P12	T	2	61	1
AVG		2.83	105.4	1.8

Further analysis showed that the most prevalent building blocks of collective sensemaking included in participants’ posts were summarization and developing an idea further.

Finally, participants whose posts included a higher number of collective sensemaking blocks were somewhat more likely to add their posts to the end of the discussion; conversely participants whose posts had fewer collective sensemaking blocks were somewhat more likely to add their posts as responses to other posts in the discussion.

5.2.5.3 Social awareness and connections

The analysis of the measures for social awareness and connection are presented in Table 20. Mann Whitney U - Tests showed significant differences between the intervention and the control group in favor of the intervention group for their ability to establish links between the discussion participants and the relevant information they contributed pertinent to answering the questions from the individual sensemaking evaluation (Links: $U = 1.5$, $p = 0.010$). Their ability to establish awareness of authors participating in a discussion showed a trend towards better performance for the intervention group (Awareness: $U = 6$, $p = 0.066$). Finally, there was no difference in frequency with which participants checked personal information of these authors (Personal: $U = 9.5$, $p = 0.201$).

Table 20. Social awareness and connections (Awareness and Personal: answers on a 5 point Likert scale, and Links: normalized average between a 5 point Likert scale and number of participants considered for further interactions on the sensemaking topic).

Cont.	Awareness	Personal	Links	Social-AVG	Int.	Awareness	Personal	Links	Social-AVG
P1	3	3	2.5	2.83	P4	4	3	2.5	3.17
P2	3	5	1	3	P5	4	4	3	3.67
P3	3	1	1.5	1.83	P6	3	5	3.5	3.83
P7	3	3	1.5	2.5	P8	3	3	4	3.33
P9	3	3	1	2.33	P10	4	4	4.5	4.17
P11	3	3	1.5	2.5	P12	4	4	2	3.33
AVG	3	3	1.5	2.17	AVG	3.67	3.83	3.25	3.58

However, the combined average scores for the measurements for the previously described proxies for social awareness and interactions (Social-AVG) that represent the dSense's support of the social processes in the community showed strong advantage for the intervention group and were statistically significant ($U = 0$, $p = 0.005$).

5.2.5.4 Sensemaking behaviors using dSense

Defining information needs

Qualitative interviews with participants in the intervention group revealed that most of them felt comfortable using highlighting. However, they felt that it only partially met their needs and wished for more flexibility in defining their questions. The more common suggestions for improvement included: 1) a way to edit the highlight more directly by removing or adding words or specifying the more important ones, and 2) defining their search query through free text entry.

My observations of participants' interactions with dSense suggest that some participants adjusted to the constraints of the highlighting feature and found ways to use it to generate useful search queries. Others, however, appeared to try to use highlighting to simulate free-text search, which often led to frustration. In addition, some participants found using highlighting in dSense to be inconsistent with their previous use of highlighting to indicate text of particular significance. This created dissonance and required participants to re-learn this new use of highlighting to indicate information needs.

Highlight as a socializing tool

Because highlighting text in a post typically indicated relevance of the post to the information need, the post's author became noted as person contributing relevant information. Further, because Search History included reference to the authors of the posts, their identities became stored within the Search History together with the highlighted text. This led some participants to comment on their use of the highlight tool and Search History not only as a historical evolution of their informational queries but also as a reference to individuals who contributed relevant posts.

Discussion exploration behaviors

The analysis of participants' engagement with dSense to explore the discussion thread suggested that participants generally used one of the two broad strategies. Some began by highlighting text in a post that was found consistent with their specified information need, exploring the resulting visualization and relevant posts within it. After some exploration, they would record the results, and repeat the exploration cycle by highlighting new text. This strategy can be considered a "depth first" approach. Other participants, however, began by highlighting several queries one after another without engaging in deep exploration of their results, saving these queries, and then examining their results in more details later. This strategy can be considered a "breadth first" approach. For these participants, the Search History played an important role in enabling them to refer back to the saved queries.

In both of these approaches, some participants relied extensively on the Post Card, while others did not use it at all. Although the Post Card was designed to be a feature that will allow the sensemaker to examine a preview of the post before deciding whether to read its full content, several participants used it as a reminder as to which posts they have previously read and the content of those posts. The second use of the Post Card was attributed to the need to keep track of the visited relevant posts and the role they played in the sensemaking process. In some occasions participants engaged in exploration by selecting a discussion participant that was recognized as an important contributor and exploring their posts, rather than using highlighting.

5.2.6 Discussion

The evaluation study in this dissertation served two different yet complimentary purposes. First, it was meant to assess the feasibility of the evaluation methods themselves. Evaluation of individual and collective sensemaking remains challenging with limited methods and measures

for evaluation proposed in previous research. At the same time, it was designed to provide initial evidence as to the impact of dSense on the proposed measures of individual and collective sensemaking and social awareness. However, given the small sample size in this study, this evaluation should be considered as a preliminary feasibility study and further explored in future studies with sufficient power to evaluate the proposed hypotheses.

5.2.6.1 Assessing the impact of dSense

Overall, in regards to the measures examined in this study, dSense had the most pronounced impact on measures of social awareness: for most of these measures, the study showed statistically better performance for the intervention group. However, only one of the measures of sensemaking (Individual Sensemaking—Hypotheses) showed statistically significant difference between the intervention and the control groups, possibly due to the small sample size and large individual differences between participants. Overall, this suggests that the tool exhibited positive trends for improvement that deserve further investigation.

In the remainder of this section I will discuss on each of the results separately.

Individual sensemaking

The participants in the intervention group, on average, considered more alternatives before arriving at the final answer in their Presentation than those in the control group (Table 16, red). One explanation for this difference is that participants in the intervention group were exposed to a greater variety of opinions expressed throughout the discussion. As a result, they were able to consider multiple alternatives and refine their choice of the final presentation as they explored the discussion thread. In contrast, the participants in the control group limited their exploration to few initial posts at the beginning of the thread, that expressed consistent complimentary

perspectives regarding Tresiba, and missed some of the more critical perspectives expressed later in the thread.

In regards to the measures for Schema, the results showed that participants in the control group performed somewhat better on questions that referred to information included at the beginning of the thread; however, their performance was lower for questions that required exploring the entire thread. One explanation to this finding is in the different ways the participants explored discussion threads using Discourse and dSense. With Discourse, all participants without exception began by reading posts in their sequential order leaving only a few minutes to explore the rest of the thread. It is possible that, as a result of this style of exploration, they became familiar with opinions expressed in the first few posts within the thread; however, their ability to notice new perspectives expressed later in the discussion was limited. The participants in the intervention group began their exploration by reading initial posts in the discussion as well; however, they relatively quickly transitioned to using highlighting. This pattern of engagement could lead to both lower awareness of posts at the beginning of the thread, and higher awareness of posts later in the thread. Perhaps as a result, these participants' ability to answer questions concerning information that was discussed towards the end of the thread was somewhat higher (however, this was a non-significant trend).

Collective sensemaking

In regards to measures of collective sensemaking, the study showed trends favoring the intervention group; however, none of the measures showed statistically significant differences between the groups.

Notably, there was an apparent difference in ways the participants chose appropriate placement for their contributions that may deserve further investigation. Specifically, for both groups, posts that included more collective sensemaking blocks had a tendency to be added to the end of the discussion. This could have been due to the fact that these posts were included to respond to the discussion generated thus far in the thread, rather than to respond to an individual post in this discussion.

Finally, the results suggest that there may be an association between individual and collective sensemaking: on average, those participants who overall scored higher on measures of individual sensemaking also received higher scores on measures of collective sensemaking. However, these trends need to be evaluated in future studies.

Social awareness and connections

The results showed that dSense led to higher social awareness and social connections. The participants reported that they felt more aware of the members who participated in the discussion thread. This was potentially due to persistent placement of these members' photographs and names next to the Post Tiles, and in the Participants Panel. This continued exposure to members' identities may have contributed to the greater sense of awareness. Further, given that participants in the intervention group explored different parts of the discussion thread than those in the control group, who tended to focus only on the initial few posts in the thread, they were exposed to a more diverse set of members contributing to the discussion in the thread. The participants reported that they more frequently checked personal information or that they had plans to do it much more frequently, in a less time constrained situation. This could be attributed to the convenient placement of the Profile Card at the point of exploration by relevance. Finally, they were able to establish the links between the relevant content and the discussion participants that

provided it. This could be explained by the availability of such mappings throughout the interface: the Fish Eye effect for discussion exploration by relevance, the Relevance Bars below the avatars, the relevance contribution markers next to the user name and avatar in the Participants Panel and the Search History. These mappings could be explored further in the future evaluations.

Overall, the results showed that dSense at least partially met its design goals and showed trends towards improvement in several outcomes of interest. These results suggest feasibility and plausibility of the design concepts introduced in the tool. However, these findings need to be further examined and confirmed in future evaluation studies with larger sample sizes and greater statistical power to detect differences.

5.2.6.2 Reasoning about the sensemaking behaviors using dSense

Defining information needs

Participants generally accepted the highlighting feature, but they also wished to type their own search query. This finding was most likely due to both limitations in the design of the tool but also to the specific instructions given to the study participants: to ensure consistency in the goals for discussion exploration across participants that would enable comparison between groups, it was necessary to give them a specified task for exploration. In this context, the participants felt that typing a direct query could have helped them specify their information need consistently with the given task, and highlighting would have been a useful way to continue explorations of the discussion thread once this initial direction was set.

This suggests that highlighting as a way of specifying information needs may be best suited for serendipitous search, in which a user browses through posts in a discussion, encounters posts of

interests and wishes to find more posts on the same topic further in the thread. Further, highlighting may have advantages in cases when the user is unfamiliar with the topic they wish to explore and may find formulating a precise search query challenging and time consuming. Finally, this approach may be beneficial in cases when the information need is complex and includes rich context, which may be challenging to formulate in a precise search query. However, when user information needs are clear and well-defined, free-text search query could be a useful starting point and a complement to the features available in dSense.

Discussion exploration behaviors

The high variability in ways participants engage in discussion exploration further reinforces great individual differences in approaches to sensemaking. Consistently with my own previous research and with existing literature examining sensemaking processes, this study showed that while there are conceptual commonalities in sensemaking processes, their realization in sensemaking behaviors is highly individualized [95,127,139]. This suggests that tools for supporting sensemaking need to have sufficient flexibility to enable each user to approach sensemaking in their own way, consistently with their preference, or with demands of the task at hand. One way to enable such flexibility is to introduce a modular approach to design that includes both a core set of features for supporting the more common sensemaking tasks and abilities, and a rich set of peripheral features that could be called on demand to suit the more specific sensemaking needs of the users. These features, however, should not interfere with the overall usability of the tool and should not needlessly increase its complexity.

5.2.6.3 Sensemaking support tools design implications

Similar to the previous design studies, the participants in the intervention group expressed satisfaction with their ability to explore relevant content in the discussion based on the color-

coded visual rendering of the discussion. However, they wished for even more freedom in specifying their information needs using the classical typed search approach. Also, they wished for better ways to keep track of their sensemaking activity. They wanted to be able to easily identify which posts they visited and what impact that visit had on the sensemaking process they were undertaking.

The results from this study pointed to several design implications.

Integrating typed search and highlighting

The findings of this study suggest that future tools for promoting sensemaking should incorporate both the ability to express information need through free text search as well as the ability to serendipitously flag content of interest, for example through highlighting, and use this content as a basis for future search. This could enable the sensemaker to engage in either a focused search based on pre-existing information need, or in serendipitous exploration of the discussions based on information needs that emerge as a consequence of exploration.

In addition, to further enhance social use of the highlighting feature, future tools can introduce a more explicit connection between the authors of the posts and their search queries, even those expressed as free text. For example, a search prompt could be placed to each post within a discussion, rather than only at the top of the page, thus reinforcing association between that post that may have inspired the query and its author with the query itself. These can be stored in the Search History in the same fashion as the highlight and be available for future access.

In regards to the need to increase flexibility of defining search query when using highlighting, one approach to addressing this in future designs could be to enable editing of the highlighted text before executing the search. In this way, users can use the original text from the post as a

starting point for the query, but then edit it in order to more closely align with their actual information need

Tracing the sensemaking process

Another opportunity to improve future design approaches is by introducing new ways for a user to indicate which posts played a role in their sensemaking process and the specific role those posts played. For example, future tools could allow users to mark posts they found to contain relevant, useful, and actionable information as *evidence* (following the vocabulary from the sensemaking framework I relied on). Further, future tools could introduce richer taxonomies for different types of evidence, for example distinguishing posts that agree with a certain perspective from those that dispute it. Future research could investigate opportunities of developing a sensemaking taxonomy for specific diseases that could allow sensemakers to achieve faster and easier annotation. In addition, and following the approach to viewing discussion posts as including an inner structure and cover multiple topics, advocated in this dissertation, future tools for highlighting could allow sensemakers to highlight segments of posts that serve as evidence for the sensemaking process, and apply previously described annotations to those instead of the entire post.

5.2.6.4 Evaluating sensemaking support tools

Suitability of the current evaluation

In regards to the proposed evaluation methods, overall, the evaluation framework presented in this dissertation appeared suitable to studies of sensemaking in controlled settings. It allowed for clear definition of outcome measures and strategies for ensuring consistency between the study

groups that could allow for comparison of outcomes between them. However, there are several opportunities to refine this framework for future studies.

In regards to the individual sensemaking, the root driver of the sensemaking process is specifying the information need. In the case of dSense, the assumption was that the sensemaker wants to explore the discussion in a more serendipitous way: the user would start by reading posts in a thread, and when they encounter a segment of a post that triggers a new information need and requires sensemaking, the users could highlight it to serve as a query to find relevant content.

However, evaluating the impact of sensemaking tools on serendipitous exploration for sensemaking purposes is challenging, due to the highly individual nature of this process: different participants might have different interests tied to their different and specific backgrounds. Therefore, it was necessary to construct standardized sensemaking tasks in the evaluation and introduce a certain level of scaffolding that could ensure comparable answers. This, however, presented a discord between the focus of the tool on supporting serendipitous sensemaking where information needs emerge as part of users' exploration of discussion thread, and the sensemaking tasks in the study that introduce a relatively well-defined information need. Future studies may explore other ways to structure study tasks that avoid this discord and engage participants in sensemaking that more closely resembles serendipitous sensemaking that the tool is designed to support.

Further, imposing temporal constraints on participants was necessary to ensure they complete the study on time. However, in the real world, individuals' read with different speeds and different levels of attention. All participants of this study reported that they had to adjust and optimize

their sensemaking behaviors to maximize their performance in the given time frame. Therefore, the way they utilized the tool's features and the quality of their answers in the study may not reflect how they would use the tool in real life setting and how the answers would have looked like had they been given more time.

In regards to collective sensemaking, in order to assess the quality of sensemaking, I measured the number of collective sensemaking blocks included in newly contributed individual posts. This was taken as a proxy to indicate the potential of new posts to further promote collective sensemaking in the thread. However, the collective sensemaking is a group effort and the quality of individual posts in isolation could not reflect the quality of the process as good as if a group of people were engaged in collective sensemaking.

Similarly, establishing awareness of the participants in the community and social connections between members are processes that evolve over time. A single session and a controlled setting could only allow measuring proxies that might reflect the likelihood for these processes to occur.

All these observations suggest the need to complement controlled studies, such as the one conducted in this dissertation, with real world deployment studies, in which users have a chance to adapt their way of engaging with the tool to their real information needs and their real sensemaking practices and behaviors.

5.2.6.5 Limitations

This study has several limitations. The discussion used for this study was carefully selected to achieve the study objectives. However, the specific structure and content of this discussion may not be representative of all discussions in discussion forums and may have affected the sensemaking process. Also, some of the topics covered in the discussion have been more familiar

to some participants and less to others; therefore the efficiency of the sensemaking process may have varied between them. Further, imposing time constraints on the participants of the study may have had an impact on the results. In addition, the short time given to the participants in the intervention group to learn about the tool may not have been sufficient to fully understand its features and utilize them to their full extent. Finally, the study included a convenience sample of participants who may not be representative of its target population thus limiting generalizability of the results.

5.3 Summary of Aim 3

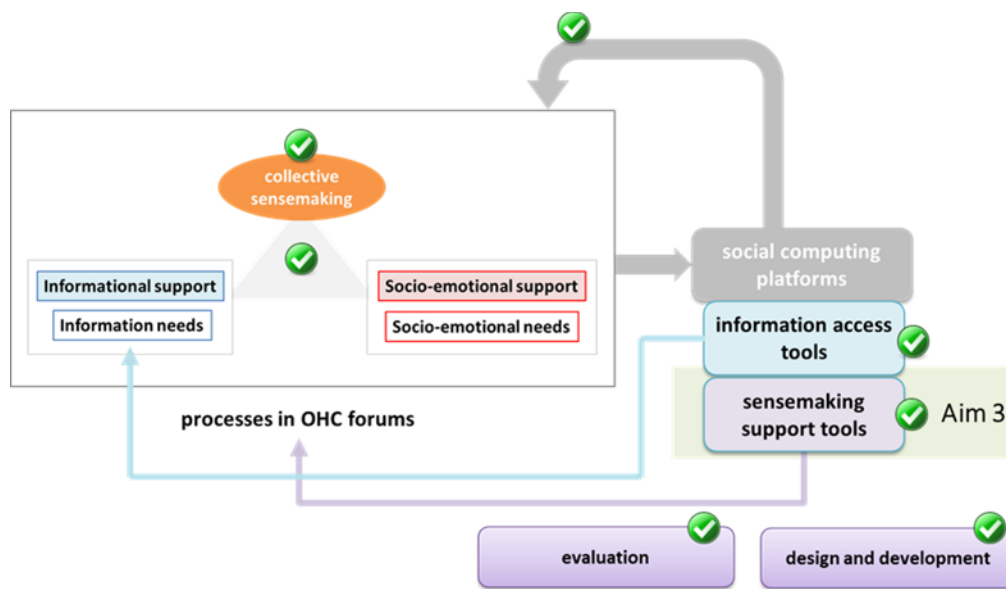


Figure 75. The knowledge gap addressed after the completion of Aim 3.

Aim 3 laid out a design process for sensemaking support tools that strive to facilitate the three key processes in OHCs: satisfying informational and socio-emotional needs and construction of new knowledge through collective sensemaking (Figure 75, design and development). This design process produced rich exploration of the design space for such tools and generated a generalizable and scalable visualization-based solution for supporting individual and collective

sensemaking in the forum discussions. At the same time, the solution incorporated features for promoting social awareness among community members, and, thus, stimulating social interactions.

The evaluation of the solution developed in this Aim, dSense, was conducted using an innovative evaluation framework, which presents an additional contribution of this Aim (Figure 75, evaluation). Overall, using dSense appeared to result in significantly better results in regards to measures of social awareness and social connections. In regards to individual and collective sensemaking, the tool showed positive trends for both of these processes, but few statistically significant differences between the intervention and the control groups, potentially due to the small sample size used in the study, and high individual differences between participants. These findings suggest feasibility of using interactive visualizations, such as dSense, to promote individual and collective sensemaking and social awareness within online health communities. Further, the study suggested several new opportunities for improving both the design of such innovative tools as well as methods necessary to evaluate their impact on these complex processes.

CHAPTER 6: CONCLUSIONS

6.1 Summary of work

The work in this dissertation was executed in three Aims.

In Aim 1 I conducted several studies that examined different properties of collective sensemaking within OHCs and described how it occurs and develops, what are its triggers, elements and building blocks. I also explored how informational and socio-emotional needs coexist in OHCs and described how this coexistence shapes and influences the collective sensemaking process. Further, I examined features of social computing platforms that host OHCs and these features impact on their ability to support sensemaking and socio-emotional needs in a balanced way.

In Aim 2, I designed, developed and evaluated a prototype of a novel interactive tool, DisVis, for visualizing discussion threads within OHCs that focused on enhancing individual sensemaking through improved access to information. Using this tool I examined new design features for promoting individual sensemaking within OHCs using interactive visualizations of discussion threads, as well the acceptance of specific design features by members of OHCs and their preference for different features. I also evaluated the impact of the proposed features on the members' capacity to understand information within a discussion thread as measured by their ability to accurately answer questions and the time required to answer such questions.

In the final Aim 3, I used the knowledge collected within previous aims to further extend the design space for supporting sensemaking within OHCs. I achieved this through designing,

developing and evaluating a novel informatics solution that supports individual sensemaking through improving access to information in a way that is sensitive to members' informational and socio-emotional needs and the need of the community to promote collective sensemaking. For evaluating such novel concept of supporting sensemaking in OHCs, I proposed a new framework for evaluating sensemaking support tools for these environments.

This body of work resulted in the contributions listed in the following section.

6.2 Contributions

The contributions in this dissertation are centered around providing: *a) a rich account of collective sensemaking in OHCs; b) an analysis of desired features and design principles for OHC forums sensemaking support tools, c) design of new informatics solutions for promoting sensemaking within OHCs that provides a more flexible and focused way of specifying users' information needs in order to improve precision in identifying matching posts with similar textual content; and d) evaluation framework for sensemaking support tools for OHCs.*

Rich account of collective sensemaking in OHCs. *I provided a rich description of collective sensemaking within OHCs, and its connection to informational and socio-emotional needs of community members, and to knowledge production. Developing deep understanding of this phenomenon can help to guide the design of new tools for supporting it.*

Analysis of desired features and design principles for OHC forums sensemaking support tools.

Based on a set of observational studies of collective sensemaking and the interplay of informational and socio-emotional needs, I *generated guidelines for the design of interactive*

visualizations for improving access to information that are sensitive to members' socio-emotional needs and their needs for collective sensemaking.

Design of novel interventions. The dSense tool advanced the previously proposed solutions in several ways. First, it provided for a faster and more flexible way of specifying users' information needs through highlighting a post or a segment of a post of particular interest to serve as a query. Second, it used text similarity as a metric to *identify posts that present the best match for the user's information need* (represented in a highlighted text). The similarity was based on a sliding window that selected text segments from a post and picked the one with highest similarity to determine the similarity of the entire post to the highlighted text. Moreover, dSense not only promoted more efficient information retrieval, but did it in a way that is *sensitive to collective sensemaking and to the social dynamics within the community*. I believe lessons learned from the design and deployment of dSense will help to reduce the tensions between informational and socio-emotional needs of community members and may facilitate knowledge production within OHCs.

Evaluation framework for sensemaking support tools for OHCs. Based on a well-established and widely accepted sensemaking model for intelligence analysts, I developed a framework for evaluating sensemaking support tools for OHC discussion forums that try to improve individual sensemaking through optimized information access and are respective of the collective sensemaking processes and the social fabric in the community.

6.3 Limitations

This dissertation has a number of limitations. First, several studies described here were conducted with members of an OHC for diabetes self-management called TuDiabetes. The forum discussions dataset, which was used for the development of some of the NLP algorithms, is also from this community. As a result, its generalizability to other communities that focus on different health conditions or have different social dynamics and culture may be limited. Moreover, although TuDiabetes is a diverse community that includes a wide spectrum of members differing by the type of, experience with, and knowledge about diabetes and diabetes self-management, and seniority and type of engagement in the community, obtaining an unbiased representative sample for qualitative studies was challenging. Despite my efforts to take multiple steps towards creating a balanced sample and working with the community leadership towards this goal, the recruited samples for most of the studies were skewed towards the more senior and regular members. However, to mitigate the consequences of this bias I performed member checks with community moderators who have a holistic view of the members in the community and their needs.

In addition, in the implementation of the sensemaking support tool dSense, I tackled only similarity of textual content between posts as a device for identifying information of interest. There could be other ways to define and identify such information, for example, based on a more complex and nuanced definition of relevance between two posts, which I will leave for future version of dSense. In addition, dSense is implemented as a Chrome Extension, but will only work with OHC forums that rely on a popular platform for online forums, Discourse.

Finally, each evaluation described in this dissertation was conducted on a single discussion that covered multiple topics. This might have imposed some bias since there could have been study participants that are more familiar with these topics than the others, or have more knowledge about and experience with the disease. In addition, familiarity with and willingness to adopt technology can vary among participants affecting the learning curve for using the tool and confounding its performance. Another limitation is that the evaluation studies were conducted in a controlled environment and simulated context with specific user tasks that focus on comprehension and collective sensemaking, thus limiting their ecological validity and generalizability to other types of interactions within OHCs.

6.4 Future work

This dissertation opens many possibilities for future work in several directions.

6.4.1 Relevance in OHC forum discussions

The evaluation of dSense and the obtained feedback point out that there needs to be a deeper investigation of the notion of relevance in OHC discussion forums. First, future research should explore other approaches that could help individuals define their information needs with high precision and low burden. Based on the participants' feedback, there appears to be several open questions as to the best use of highlighting as a tool for defining information need. Specifically, future research could explore the possibility for allowing users to highlight multiple text segments selections, allowing users to modify their highlighted segment(s), and solicit more information from the users in order to understand their context and intentions behind the query formulation.

Further, there is a need for a richer articulation of relevance as it applies to sensemaking within OHCs. This dissertation defined relevance as similarity with their formulated text query; however, this is a limited definition that only addresses one dimension of relevance that is most consistent with existing computational methods. Future research could further examine different dimensions of relevance, and identify new ways to help individuals articulate their own view of relevance, and new computational methods for selecting content that meets each individual's perception of what is relevant.

6.4.2 Discussion exploration

The evaluation of dSense showed the importance of enabling efficient exploration of lengthy discussions. One step in this exploration is the ability to quickly assess the content of a given post and its fit with the user's information needs. dSense used the Post Card feature to provide users with a brief summarization of the post. Future research could explore other solutions to addressing this challenge, and identify new ways to summarize content of posts appropriate for different stages of the sensemaking process, for posts with different lengths, and the importance of considering the inner structure of the post in summarization.

6.4.3 Going beyond a single discussion

During a sensemaking process for closing a knowledge gap, OHC members consult more than one discussion. These discussions are not completely independent and have overlapping points. Future research could explore ways to extend tools such as dSense to account for multiple discussions in a forum, with potential dependencies between them.

6.4.4 Evaluation of sensemaking support tools for OHCs

Finally, the work in this dissertation highlighted multiple challenges related to robust evaluation of tools for supporting sensemaking, particularly tools that target not only individual sensemaking, but also strive to promote collective sensemaking and stimulate social interactions in the community. While the evaluation of individual sensemaking could be performed in a controlled setting, the same doesn't apply to collective sensemaking and stimulating social interactions. These two properties naturally occur over time and require deployment of robust research prototypes for real use by OHCs, a task that may present formidable barriers to the research community. The question remains as how to build bridges between the research community and the leadership of OHCs such that both groups are motivated and have benefit from the work.

The questions raised here are directed towards building tools that can have greater impact and provide the most valuable lessons for the research community at each step of their design evolution.

6.5 Conclusions

This dissertation produced firm foundation for the design and development of future generations of OHC discussion forum platforms that incorporate sensemaking support tools. It contributed theoretical knowledge about the collective sensemaking process that takes place in these forums under the existing platforms' affordances, as well as the coexistence of informational and socio-emotional needs and support as influencers to this process, also dictated by the affordances of current platforms. Based on this knowledge, this dissertation thoroughly explored the design

space for tools that support the three key processes in OHCs: satisfying informational and socio-emotional needs and construction of new knowledge through collective sensemaking. As a result it produced design guidelines and design solutions, which are moving in the right direction and can be borrowed and reused further by other designers from the OHC domain, but also outside of it. Finally, it articulated a novel evaluation framework for sensemaking support tools; this framework can pave the way for more reliable and robust evaluation frameworks in the future.

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APPENDIX

Table 21. The questions at each of the stages of the sensemaking process.

HIGHLIGHTING	
1.	<i>How would you tell the system what to search for based on the post of interest? Please explain why?</i>
2.	<i>Can you please formulate a particular search query based on the content of this post that will help you learn more about low carb diet?</i>
3.	<i>How do you feel about highlighting as a way for defining what to search for?</i>
4.	<i>Based on the query you previously formulated, what would be the text that you would highlight here to represent your query? Please read it and explain the reasons behind the selection of that particular text.</i>
5.	<i>How close do you feel the highlight represented your query? Please explain why?</i>
6.	<i>How do you feel about the idea of highlighting text to represent your query for which posts with matching content will be found in the discussion?</i>
7.	<i>How complicated it was to go through the highlighting?</i>
8.	<i>Do you have any suggestions for improvement?</i>
EXPLORING	
1.	<i>How would you interpret what dSense displayed on the screen now?</i> <ul style="list-style-type: none"> • <i>What do the green shaded tiles mean? What does the orange tile mean?</i> • <i>What are the small horizontal bars under the member's profile pictures on the left?</i>
2.	<i>What do you think about this way of displaying the discussion?</i> <ul style="list-style-type: none"> • <i>What is this way of displaying telling you about the discussion?</i> • <i>How can this way of displaying help you find posts of interest based on the highlight?</i>
3.	<i>How can you compare this form of finding relevant content in a discussion to the more classical Google-like search engine approach? The more classical approach would involve typing a query for the discussion and receiving an ordered list of relevant posts.</i> <ul style="list-style-type: none"> • <i>What would be the advantages/disadvantages of the highlighting approach?</i>
4.	<i>How helpful was this form of displaying discussion to find out:</i> <ul style="list-style-type: none"> • <i>whether it contains enough relevant content based on your highlight?</i> • <i>where is the relevant information in the discussion?</i> • <i>what part of the discussion should you focus on first?</i> • <i>what post should you read first?</i>
5.	<i>Do you feel there is a need of visual encoding of some other discussion related information or maybe even alternative way to render it?</i>
Exploration by author	

1. <i>What impression did you formulate about this particular member in this particular discussion?</i>
2. <i>How much more would you like to know about the member at the moment of reading the post?</i>
3. <i>What information would you like to have about this member that will help you decide whether to pay more attention to the post or even read its full content?</i>
4. <i>To which extent can you rely on the information in the Profile Card for additional assessment of the post's relevance? Please explain why?</i>
5. <i>To which extent can you rely on this information to learn more about the person behind the post? Please explain why?</i>
6. <i>What information will help you in additional assessment of the post's relevance?</i>
7. <i>What information will help you in learning more about the person behind the post?</i>
Exploration by relevance
1. <i>What information would you like to have here before you decide whether to read the post's full content?</i>
2. <i>What can you tell about this post based on the additional information provided in the Post Card?</i>
3. <i>Please start interacting with the Post Card to see if you can learn something more about it?</i> <ul style="list-style-type: none"> • <i>What can you say about the post at this point?</i>
4. <i>How do you feel about the Post Card's capability to provide a more detailed overview of the post?</i>
5. <i>How helpful was the Post Card for you to decide whether to read the post in full detail?</i> <ul style="list-style-type: none"> • <i>What was helpful and what was confusing?</i>
6. <i>Can you suggest any other ideas of what should be included as intermediate information about the post before you decide to read its full content?</i>
7. <i>Can you please compare the two design alternatives? Which one does a better job for what and why?</i>
8. <i>What would be the ideal design for the post's card?</i>
9. <i>How comfortable did you feel with the matching posts exploration process imposed by the design of dSense?</i>
10. <i>How successful do you think dSense could be in helping you find the most important matching posts to read?</i>
11. <i>How useful did you find this idea of identifying matching content?</i>
12. <i>What would be possible improvements?</i>
READING SUPPORT
1. <i>What can you comment about the post that is ready for reading?</i>
2. <i>How helpful is this reading support feature in guiding you where to focus your attention when reading the post?</i>
3. <i>How do you feel about the usefulness of this reading support feature?</i>

<ul style="list-style-type: none"> • <i>What reading tasks it was helping you to accomplish and what not?</i> • <i>In which cases you would need the reading support? In which not?</i>
4. <i>Can you please compare the two design alternatives? Which one does a better job for what and why?</i>
5. <i>How do you feel the reading support helps in prioritizing reading of a set of relevant posts?</i>
6. <i>What would be the ideal design for the post's card?</i>
Synchronization
1. <i>How useful do you find this type of synchronization?</i> <ul style="list-style-type: none"> • <i>What could this type of synchronization help you with?</i>
2. <i>Should the synchronization be modeled in some other form so that it enables smoother transition from exploration to reading mode and vice versa?</i>
SEARCH HISTORY
1. <i>How important is the capability to go back and forth between different highlights?</i> <ul style="list-style-type: none"> • <i>How do imagine going back to one of the previous highlights should look like?</i>
2. <i>How do you feel about the transition between highlights dSense supports?</i>
SOCIAL INTERACTIONS
1. <i>How do you think a tool like this that tries to optimize access to the right information can stimulate social interactions?</i>
2. <i>Can you see if dSense is doing that? How is it doing that? Please explain.</i>
3. <i>Can you think of some ways in which this idea of stimulating social interactions can be improved?</i>
OVERALL IMPRESSION
1. <i>What is your overall impression of the tool?</i>