



COINs2010

## Towards Growing a COIN in a Medical Research Community

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### Abstract

In this paper we describe a longitudinal analysis of the evolution of a team of medical researchers who are trying to establish a COIN consisting of patients of a chronic disease, family members of patients, doctors, and researchers. The data analysis is based on an e-mail archive consisting of the full mailboxes of the six project leaders covering the whole period of COIN formation. We conducted a dynamic analysis of the e-mail network looking at social network analysis metrics such as betweenness centrality and density over time, as well as contribution index and core/periphery structure. We also did a semantic analysis of the e-mail subject headings. A netnographic analysis of patients was done through analyzing their Facebook friendship and discussion networks. External perception of team effectiveness was done through a Web buzz analysis.

Preliminary results indicate that after the first physical meeting of the full team the betweenness centrality of the official leaders went down noticeably, as tasks were delegated to other team members, whose centrality increased as the leaders' centrality fell.

The patients, who are the main constituency of this project and could contribute invaluable advise, are still surprisingly peripheral in the entire project team and have a low contribution index. We also found that a peripheral position was held by some very senior team members who seem focused almost exclusively on external projects, and are (not yet) well connected to the core of the project team. The team seems to be inwardly focused, engaged in internal coordination activities and scarcely involved in managing across boundaries. To increase the success of COIN formation, the team might need to extend their ties to the peripheral patients and senior members, whose specialized expertise is essential to disseminate knowledge outside of the team boundaries.

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Keywords: Collaborative Innovaton Network;COIN; medical community, C3N, social network analysis, Web monitoring

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## 1. Introduction

This paper describes a project at a major hospital, whose goal it is to create and foster communities among patients of a chronic disease, their family members, physicians, and researchers working on coming up with a cure for the disease. In particular, the goal of the project is to develop a pilot “collaborative clinical care network” (C3N) trying to harness the collective intelligence of nurses, doctors, and patients to improve care and outcomes on Crohn’s disease and ulcerative colitis, which affects about 100,000 young people in the United States. The aim is to structure collaboration along the COIN (Collaborative Innovation Network) model – cyberteams of self-motivated individuals with a collective vision, enabled by the Web to achieve a common goal by sharing ideas, information, and work (Gloor 2006).

The C3N project started in fall 2009 with the two principal investigators identifying and reaching out to a diverse group of recognized researchers in social network analysis, open source principles, community-based medicine, and participatory design. As the goal of the project is to create a COIN, it was decided to also try to structure the research team as a COIN. This paper documents the first nine months of this formation process. The methodology employed consists of three parts:

(1) We analyze the social network of project members through the mailboxes of the two principal investigators, plus the mailboxes of the initial co-founder of the predecessor network of C3N, called ImproveCareNow, and the project manager, project analyst, and project coordinator who have been brought in to run the daily operations of the project. This permits us to track the evolution of the social network, because a large part of the collaboration is over long distance. While the two Co-PIs are in the same office together with the three project administrators, most other team members collaborate remotely from locations all over the US.

(2) Additionally, Crohn’s patient networks in Facebook are tracked through the friendship networks and discussion content on their fan pages. This permits to identify latest discussion topics and key influencers among Crohn’s patients and their caregivers and supporters.

(3) As one of the goals of the project is to raise external awareness of the disease and attract Crohn’s patients and family members to its community, the external perception of the project is tracked through a Web buzz analysis using the Coolhunting approach (Gloor et. al. 2009).

## 2. Analyzing the COIN of Researchers

To understand the COIN formation process of the research team, a social network analysis of the key members of the project through the combined mailboxes of the six core members of the project was conducted: the two PIs, the co-founder the predecessor of C3N, plus the project manager, the project analyst, and the administrative supporter. Using the dynamic social network tool Condor (Gloor & Zhao 2004), we carried out a social network analysis of the entire team by analyzing their social ties through the e-mails captured by the six key members. In earlier work we have shown that this approach is representative of the group network (Zilli et. al 2006).

Figure 1. illustrates the evolution of the project according to the four phases of group development of (Tuckman 1965). A pre-phase (forming) started in late 2009, with individual meetings and project setup. End of January the first Design meeting brought most project members to an on-site two-day workshop in Cincinnati (storming). Afterwards, team members started collaboration locally and virtually, developing norms of collaboration (norming). A second design meeting in Cincinnati in July concluded the norming phase. During the storming/norming phase a first deliverable, the “ecology model” was developed, as a foundation for a Web site hosted by Lybba whose goal it is to become the connecting online community of all stakeholders in Crohn’s.

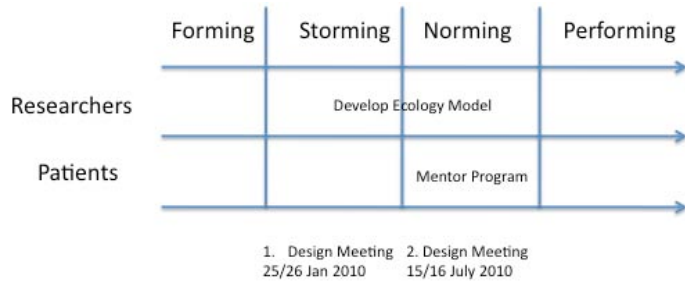


Figure 1. Phases of C3N Team Development (according to Tuckman 1965)

Figure 2 illustrates betweenness centrality and total amount of messages sent and received from January to June 2010. It illustrates the buildup of project specific message traffic as the new project members are brought in. In the beginning only the two PIs and the Co-founder of the C3N predecessor network improve care now are active. In the later months the mailboxes of the three newer project members start to add traffic and network ties.

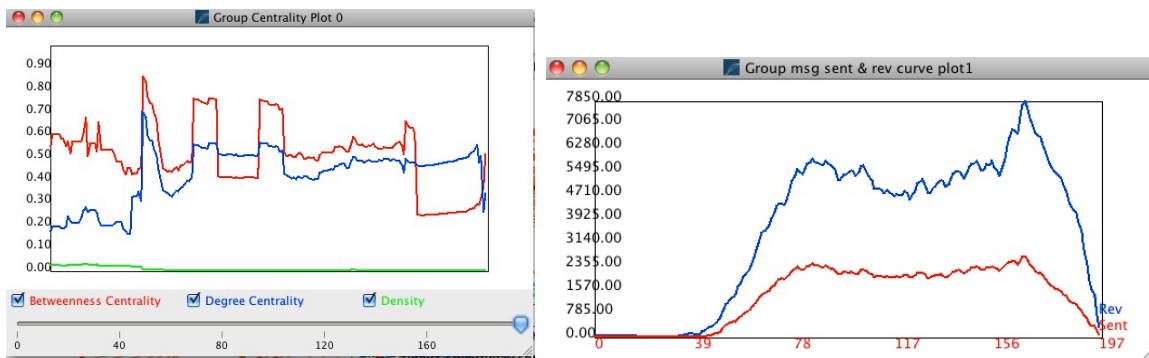


Figure 2. Phases in the C3N e-Mail network from January to June 2010, betweenness centrality (left) and amount of messages sent and received (right)

The left chart in figure 2 illustrates spikes in betweenness centrality. Each spike means that the discussion moves from one with many centralized participants to one that is dominated by a few players. Further analysis reveals that the spikes coincide with the organization of the design meetings, and with setting up and running some Webcasts using a Web conferencing tools. In earlier work we found that this pattern of oscillating betweenness centrality is predictive of creative activity (Kidane & Gloor 2007).

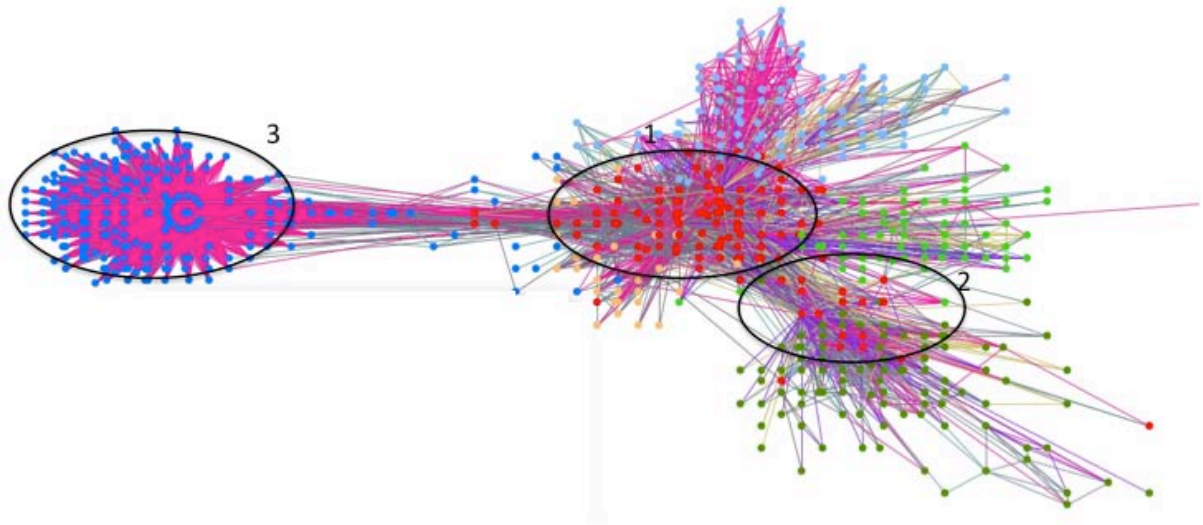


Figure 3 illustrates the full network of the entire project, based on the combined 6 mailboxes of the 6 most active project members

Figure 3 illustrates the full network. Out of 5247 people in the network, it shows the 633 actors who each exchanged at least 20 e-mail messages. The red dots in circle 1 in figure 3 illustrate the key C3N group, each red dot denotes a person who is in at least two e-mailboxes. Circle 2 shows the project members with strong ties to the ImproveCareNow project (the predecessor project of C3N), one of the PIs and the network director of ImproveCareNow are in this cluster. The dark green dots at the bottom right are members of the ImproveCareNow network only, captured through the mailbox of the ImproveCareNow network director. Circle 3 illustrates the bridge role of the C3N project coordinator who is also taking care of another project, whose members do not officially collaborate with the C3N project, but share numerous communication links, suggesting that they might profit from more mutual interaction.

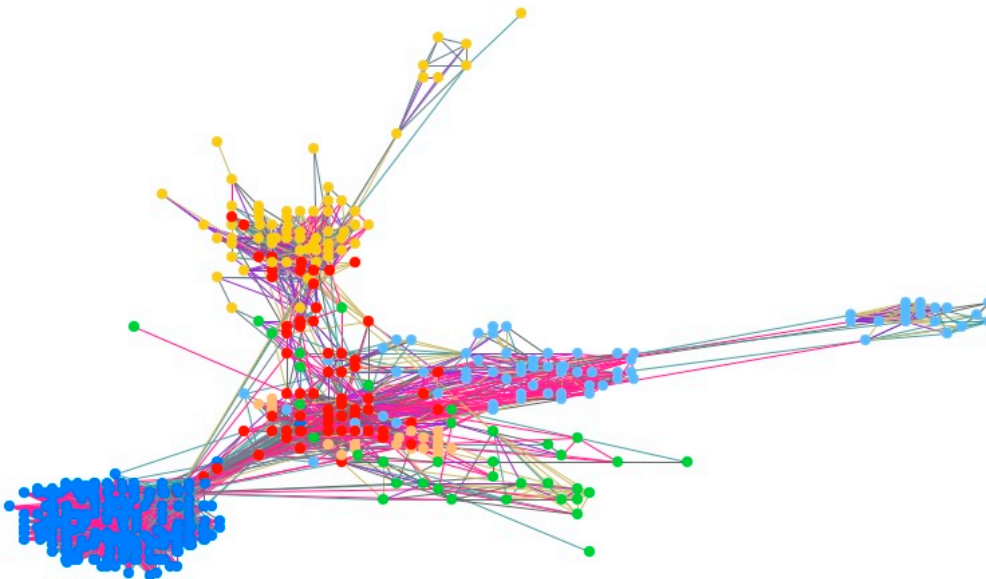


Figure 4 illustrates the full network of the entire project (just as figure 3), with the 6 mailbox owners removed

Figure 4 shows the full group network, with the 6 mailbox owners removed. As can be seen, the basic network structure remains very much the same. The graph again contains everybody in the network who exchanged at least 20 messages from January to mid-July 2010. The number of actors is going down from 633 to 481, because all the people who exclusively communicate with one of the mailbox owners are now removed. The blue cluster at right is again the second project administrated by the C3N project coordinator. It is still connected, which means there must be other links between the C3N project and this project, it therefore makes sense to include it into this analysis. The red cluster in the center – representing the C3N core team – also maintains the same structure, even with the most senior leaders removed. The yellow cluster at the top is the ImproveCareNow network, which also keeps strong connectivity to the C3N project, even without the direct ties of its two founders.

That the structure in figure 4 is so similar to figure 3 is a sign of good organizational health, because it means that the network is resilient if a key member would leave the project.

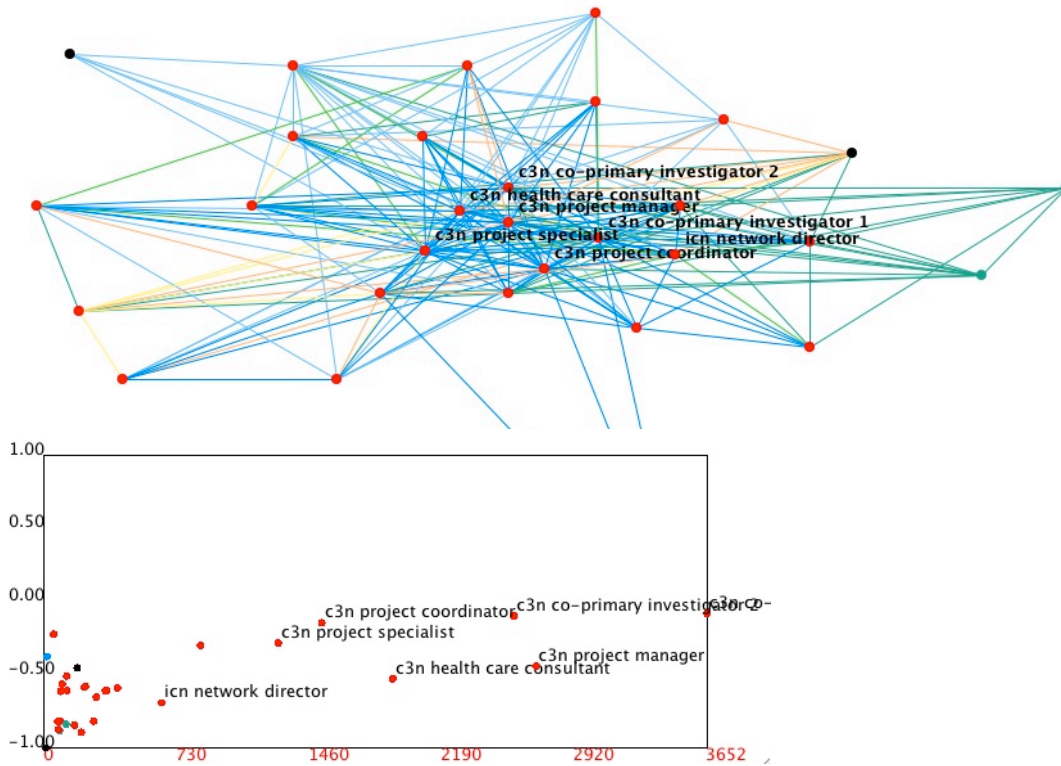


Figure 5. E-mail ties between 34 key project members (top) and contribution index (bottom)

Figure 5 is based on the same 6 mailboxes, but now all actors other than the 34 key project members have been removed. The network is constructed exclusively through the e-mails exchanged between the 34 members. There is a core cluster, with the two PIs and the administrative assistant at the center. The two black dots represent the two patient representatives in the project team. Unfortunately, they are (still) quite peripheral. The contribution index in figure 5 reveals that the two C3N co-principal investigators are the most active senders in the e-mail network, together with the C3N project manager.

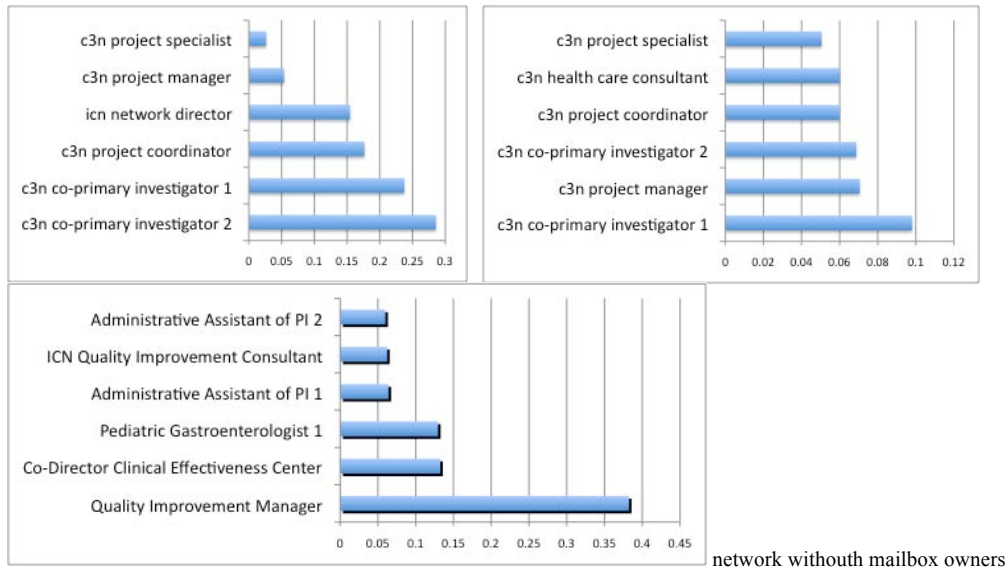


Figure 6. People with highest betweenness centrality: full network of figure 3 (top left), project network of figure 5 (top right) and the full network without the six mailbox owners (bottom)

Figure 6 reveals the most central project members in the three views of the network described above: the full network view, where all communication with the outside world is included (top left chart in figure 6), the team-only network (top right chart in figure 6), and full network, with six mailbox owners removed (bottom chart in figure 6). The top three positions in the first two networks are taken by the two principal investigators plus either the project coordinator (full view) or the project manager (project view). The network director of ImproveCareNow has surprisingly high centrality in the external full network. Based on prior work, this indicates a solid team structure, as the project leaders are both in charge of running the daily project activities, as well as connecting with outside partners. There is also an “ambassador” (the improvecarenow network director), with high centrality in the external network, and not so high centrality in the group only project network, who focuses on carrying ideas to the outside world. It is interesting to note that the C3N project manager has the second highest centrality in the group-internal network. This suggests that internal coordination tasks are well managed.

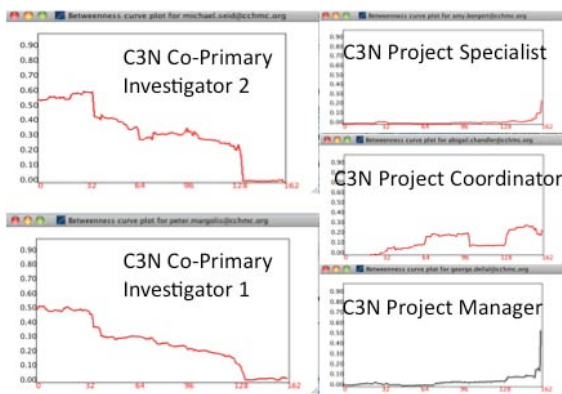


Figure 7. Changes in betweenness of key project members (full network), y-axis is betweenness , x-axis is time in days

Figure 7 displays the different leadership styles of established and emergent leaders in the nascent COIN. It illustrates, through the changes in betweenness centrality, the increasing activity of the new team members as

project leaders. The betweenness centrality of the two PIs goes down over time, which means that they are delegating communication tasks to the new members (C3N project specialist, C3N project coordinator, C3N project manager), whose betweenness centrality is going up in parallel to the decrease in betweenness centrality of the two PIs. This is again a sign of positive group health and an indicator of the established leaders focusing on reaching out to external people, while transferring the responsibilities of day-to-day management to new leaders.

### 2.1. Analyzing Emergent Topics Through Content Analysis of E-Mail Headings

In addition to the social network analysis, we also used the content of the e-mail subject line to track new and emergent topics in the project. Because of privacy reasons, we did not collect the e-mail text body, but because most people are good in resuming the gist of the message in the subject line, analyzing the subject line provides a good indicator of what the project team is working on at any given time. Figure 8 illustrates the changing importance of the key terms automatically extracted from the e-mails by measuring their changes of betweenness centrality over time (Gloor & Zhao 2006).

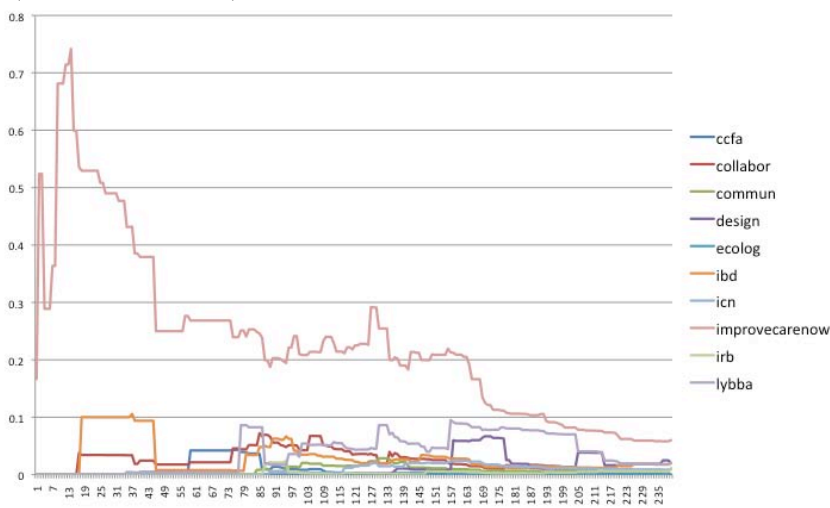


Figure 8. Evolution of a project-specific vocabulary, y-axis is betweenness, x-axis is time in days

The term “improvecarenow”, the name of the predecessor project to C3N, comes up most prominently, although going down in importance as time progresses (light brown line in figure 8). Figure 8 also illustrates how and when new concepts, such as the “ecology model”, or “lybba” grow in significance over time. Process concepts, such as “collaboration” and “design” are also important over the entire time period, with spikes at the time when, for example, the design meeting was organized. The term “irb” (Institutional Review Board) also becomes somewhat significant for a short period while the project proposal is reviewed and approved by the IRB.

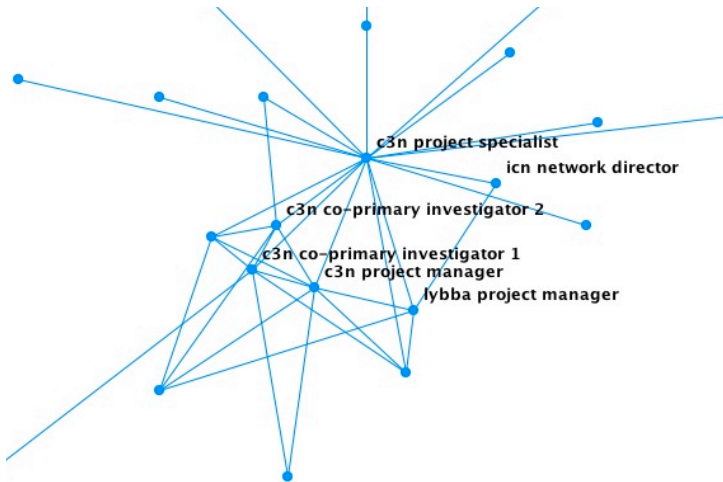


Figure 9. Social Network on Discussion Topic “Ecology”

Figure 9 illustrates the social network of people working on new concepts. The network in figure 9 was generated by filtering all messages containing the term “ecology” in the subject line in the six mailboxes. It illustrates that the C3N Project Specialist is the most central person coordinating work on the ecology model. It also shows that out of the 5247 people in the full network, a very small group, with a core of 10 people, and another 14 in the periphery, is involved in this subproject. This finding would recommend increased communication about this project, which indeed happened after this analysis was done.

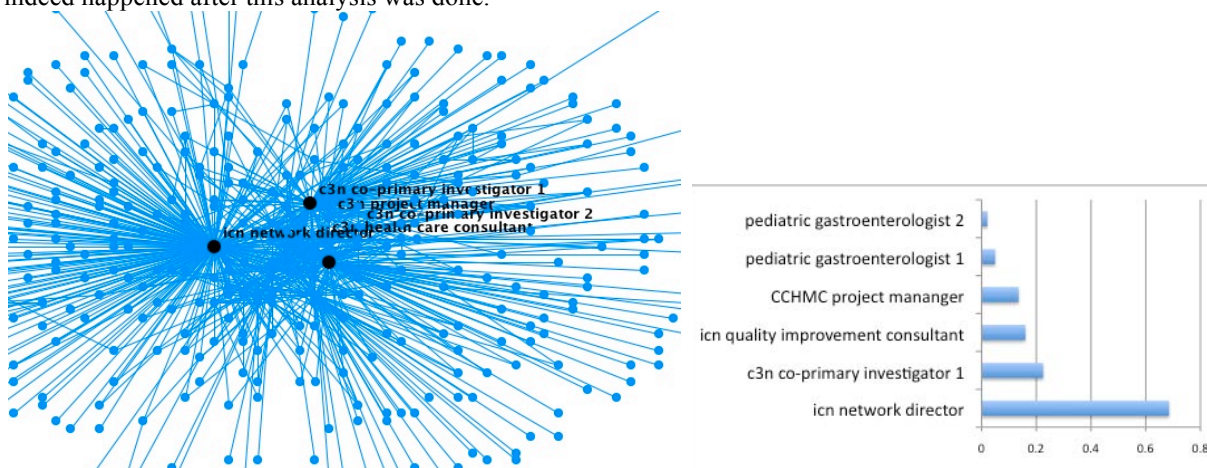


Figure 10. Social Network on “ImproveCareNow” and most important actors by betweenness centrality (Jan to June 2010)

The project network in figure 10 has been produced the same way, by filtering all messages for the word ‘improvecarenow’. As this is a much more mature project with a 10 year history, we get a much larger project network with 382 actors. The most central actors are the two founders of improvecarenow, followed by the ICN quality improvement consultant, illustrating the importance of long-term commitment of leaders for the success of such a venture.

After this project-internal COIN communication analysis, the next two sections focus on external activity of patients of Crohn’s (the Collaborative Learning Network (CLN) view) and perception of the C3N project activity on the Web (the Collaborative Interest Network (CIN) view) (Gloor 2006).

### 3. The CLN View: Measuring External Activities of Crohn’s Patients on Facebook

To complement the understanding of the needs of Crohn’s patients, we also conducted a netnographic analysis on Facebook (Kozinets 2002). We identified seven large Facebook groups whose goal is to improve the lives of Crohn’s patients, or even to find a cure. The groups range in size from 1117 to 10,037 people as of June 15, 2010 (table 1). This analysis helps us to better understand the networking behavior and the needs and wants of Crohn’s patients and their families and friends. This information provides valuable input to the creation process of the COIN of Crohn’s patients.

|   | Friendship Network | Discussion Network |
|---|--------------------|--------------------|
| <b>Crohn’s Disease and IBD</b>                                    | 9245               | 1119               |
| <b>Fight Against Crohn’s Disease</b>                              | 10037              | 171                |
| <b>Crohn’s Disease</b>  | 1251               | 237                |
| <b>Crohn’s Disease, Ulcerative Colitis and IBD – UK Group</b>     | (2728)             | 396                |
| <b>People with or know someone suffering with Crohn’s disease</b> | (1117)             | 31                 |
| <b>Crohn’s and Colitis Foundation of Canada (CCFC)</b>            | (3132)             | 370                |
| <b>People who live or support people with ulcerative colitis</b>  | (1565)             | 225                |

Table 1. Seven Facebook Groups about Crohn’s

Table 1 lists the data we collected. Because of time constraints, we only collected the friendship networks of the top three groups. We collected the discussion networks of all seven groups, however.



Figure 11. The discussion networks of the 7 groups form distinct clusters and are mostly unconnected

Figure 11 displays the combined discussion network of all seven groups. A link is made if one person responds to a post of somebody else on the group’s discussion page. A red dot identifies a person who is active in more than one group, and acts as a gatekeeper connecting different groups. The large red cluster in the upper center of figure 10 therefore is the group of most active Facebook users who are active in more than one group. Figure 11 nicely illustrates the fragmentation of the community, in that most members of the groups seem to keep their discussion to one group. This further motivates the goal of our project, trying to create a global network of people afflicted with Crohn’s disease.

Figure 12 illustrates the friendship network of one group. This network has been constructed by parsing the 9245 “friends” of the group “Crohn’s disease and IBD”, and collecting their publicly accessible friends through Google. This means that depending on the privacy settings on Facebook of each user, we miss about 50% of the links.

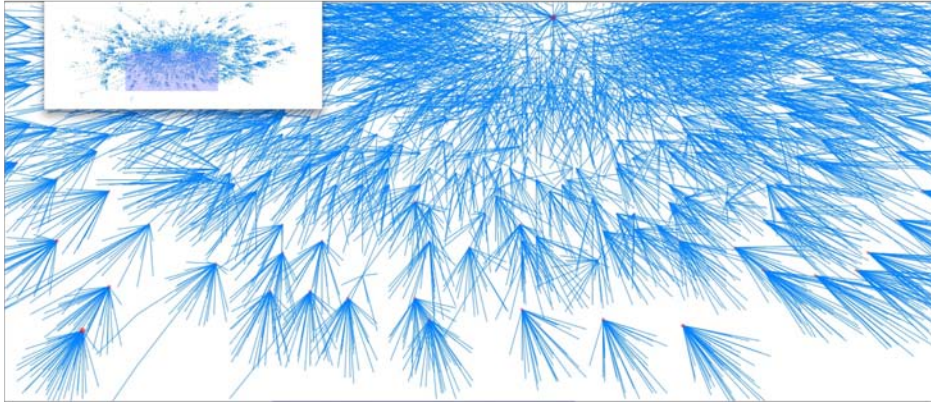


Figure 12. Extract of Friendship Network of “Crohn’s Disease and IBD”

The friendship network of the Facebook group (figure 12) is surprisingly unconnected, even considering that we are only able to collect the links of people who have made their friends public. There are only little star networks with very short average path length of three to four. When we manually checked a few of them, the person in the center was usually somebody affected with Crohn’s disease, and the people in the periphery where their friends. This does not mean that the people in the center don’t have bridge links through friend-of-friend connections. Rather, this means that the fans of the Crohn’s support pages don’t know each other. We also compared this network with other fan friendship networks of brands and celebrities, where connectivity was larger.

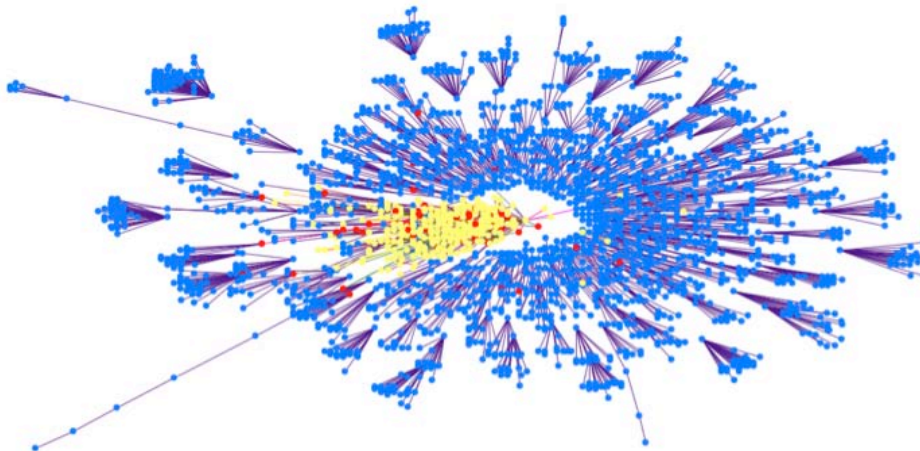


Figure 13. Combined Friendship and Discussion Network of Facebook Fan Page “Crohn’s Disease and IBD”, top 5000 people by degree centrality

Figure 13 combines the friendship and the discussion network of the Facebook fan page “Crohn’s disease and IBD”. The yellow cluster in the core is the discussion network, which is much better connected – meaning that people talk to each other – than the friendship network – meaning that Crohn’s patients are not very well connected outside their immediate friends and family network. The few red dots represent people who are both fans of the group, and also participate in the discussion. This shows that most fans have nothing to say, while the people who speak out on the discussion page have not chosen to be fans of the group. This again motivates the need to broker more connectivity among the disparate members of the Crohn’s stakeholder group.

Analyzing social network metrics allows us to identify the most connected, and thus most influential members of the friendship and discussion network. By social contagion theory, the most between members in the friendship network are in a position to influence their friends: if they post an update on their Facebook wall, it will be read by their friends. It has been shown that this is by far the most effective viral marketing method, superior to directly mailing others, or inviting them to other Web sites (Aral & Walker 2010).



Figure 14. Tag cloud of Facebook wall of girl afflicted with IBD (left), and a parent of a patient who is very active in the community (right)

Figure 14 displays two tag clouds generated by scraping the Facebook walls of two central members of the friendship network displayed in figure 12. The Facebook wall contains posts by the owners of the page, and their friends, so it gives a good overview of their interests. The left side of figure 14 displays the tag cloud of a teen with Crohn’s, the right side of a parent of a child with Crohn’s. As the teenager’s wall shows, the disease is mentioned only rarely and does not make it into the most significant word list. The teen just wants to go on with her life, and be as normal as her friends. This is very different for the mother’s wall, where Crohn’s is the largest topic, reaching in all aspects of her life.

Figure 15 displays a content map of the discussion page of the same Facebook fan page. The discussion page content is different from the wall, as latest concerns, new cures for Crohn’s, and strategies for coping with the disease are discussed.

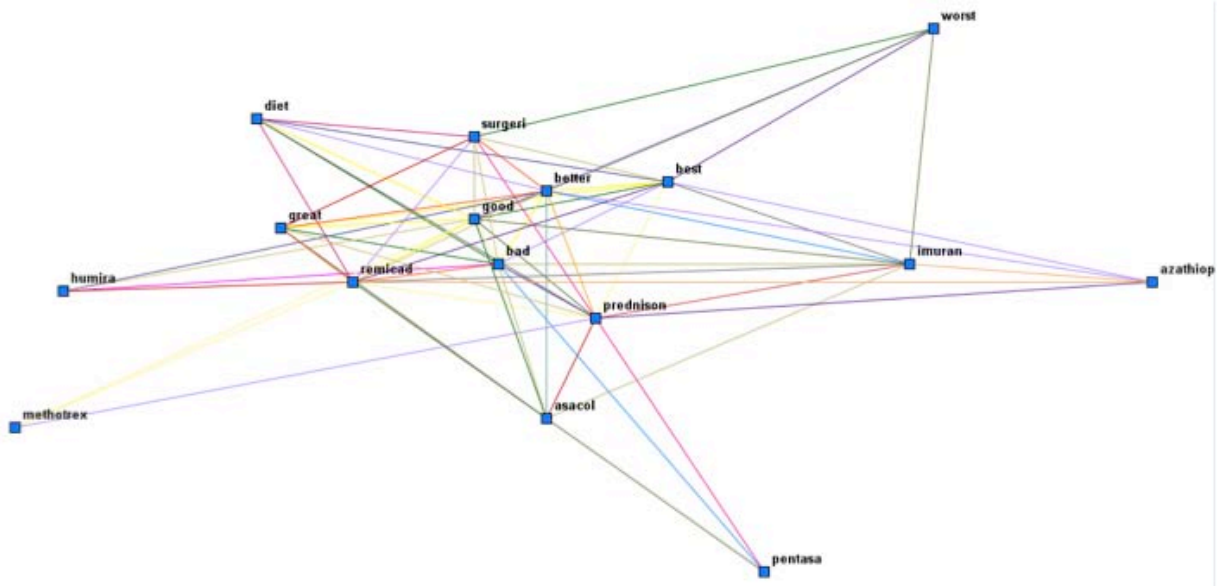


Figure 15. Key terms of the 7 discussion groups – Remicade is most important drug

A first insight from the analysis of the discussion threads on the Facebook page is the focus on the various drugs. Crohnies talk about drugs that reduce inflammation such as Sulfasalazine (Azulfidine), Mesalamine (Asacol, Lialda, Pentasa), Olsalazine (Dipentum), Balsalazide (Colazide, Colazal). There is in-depth discussion about a specific drug reducing inflammation, that some find highly effective but with heavy side effects (Prednisone). They also mention drugs that stop the immune system from causing inflammation, so called immunomodulators, immunosuppressants, or immunostimulators, such as Azathioprine (Imuran, Azasan), 6-mercaptopurine (6MP, Purinethol), Tacrolimus (Prograf), Methotrexate (MTX, Rheumatrex, Mexate). The biggest hopes seem to be placed on new bio drugs that attach to the inflammation-promoting protein, by far the most popular being Infliximab (Remicade), also mentioned are Adalimumab (Humira) and Certolizumab (Cimzia). The discussion board also hosts a discussion on the science behind whether mucosal healing might offer a cure. Some discussion board members also mention that surgery is not a definite cure since recurrence is likely, alternate therapies are recommended such as dietetic treatment, and psychotherapy (e.g. the Feldenkrais-method, and autogenic training).

This netnographic analysis gives a first overview of the characteristics and the hot topics of Crohn's patients and their family members. We are currently repeating this analysis with a larger sample of 15 Facebook groups.

#### 4. The CIN View: Measuring the External Impact of the Project Through Web Buzz Analysis

The third analysis measures the perception of the C3N project in the external world, tracking if the work of the project team changes perception of Crohn's disease on the Web and in Blogs. Towards that goal, we are using the Web Coolhunting methodology (Gloor et. al. 2009) by identifying the most important Web sites and blogs mentioning the terms we want to track, and then constructing their link network, and measuring the changes in betweenness of the terms. Figure 16 displays the Web and Blog site network of the search terms "lybba", "improvecarenow", "cefa" (Crohn's and Colitis Foundation of America), "crohn's disease", "inflammatory bowel disease" and "chronic disease" collected in the period July 12, 2010 to August 24, 2010. The snapshot shows the term-Web site network for the search terms on Aug. 24. The brightly colored dots are web sites containing the term, or linked to sites containing the search term and appearing new on that particular day. For example, the purple dots are sites linking to the search term "lybba", which illustrates that many new sites were talking about "lybba" for the first time on Aug 24.

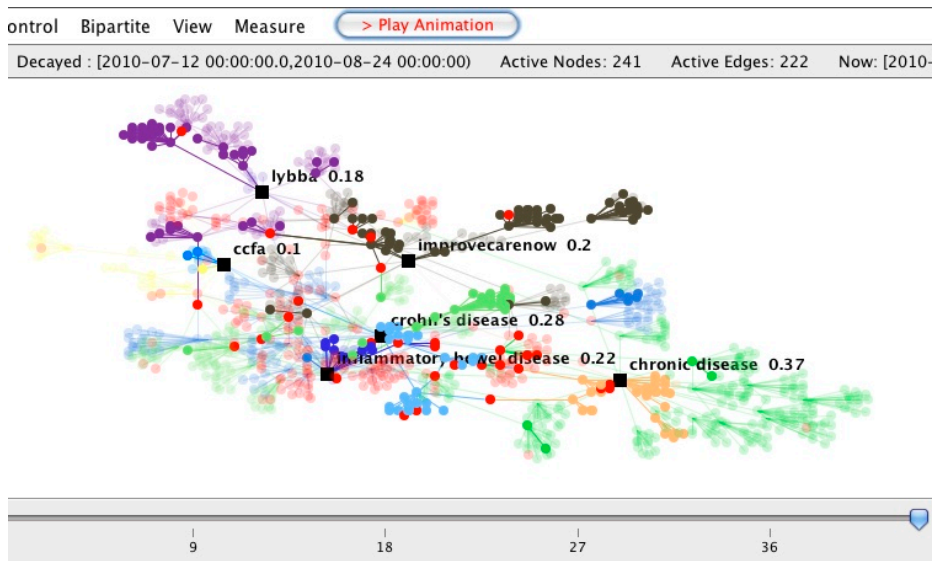


Figure 16. Web and Blog Betweenness of search terms lybba, improvecarenow, ccfa, crohn's disease, inflammatory bowel disease, chronic disease from July 12 to Aug 24, 2010

The dots in dimmed color are the sites that came up listed in the top 20 Google search hits on earlier days in the period July 12 to Aug 23. Figure 17 shows the betweenness curves of the search terms as well as the most central Web sites relative to each other over the 6-week period. Not surprisingly, “chronic disease” is the most important term, as it is spoken about on the most, and on the most important sites.

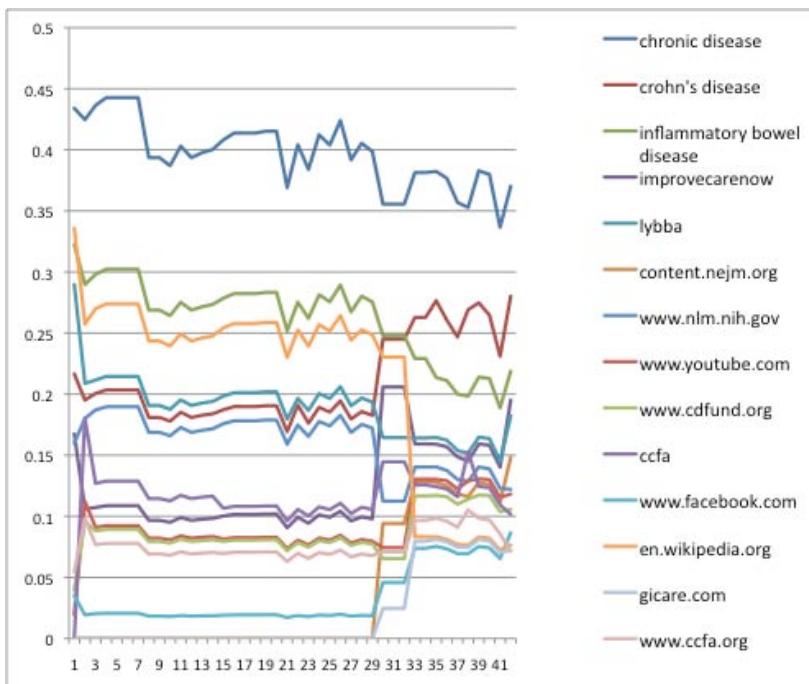


Figure 17. Betweenness curves of search terms and key Web sites over 41 days from July 12 to Aug 23. Y-axis is betweenness, x-axis is time in days

As a baseline, the betweenness curve of the generic term “chronic disease” is added. The change in combined Web and blog betweenness of search terms over 41 days in figure 17 illustrates that “inflammatory bowel disease” is the most important term until a scientific article about “crohn’s disease” in the New England Journal of Medicine ([www.nejm.org](http://www.nejm.org)) appears on day 29. The other Web site suddenly popping up on day 30 is [gicare.com](http://gicare.com), a gastroenterology practice that mostly likely relaunched its Web site on that day. The [ccfa.org](http://ccfa.org) Web site, on the other hand, is consistently popular.

As the trend curves show, continued presence on the three Web sites Facebook, Youtube, and Wikipedia is essential for marketing new concepts, they therefore are key to boosting the importance of new ideas.

## 5. Conclusions

This paper introduces a preliminary analysis of the first three stages of group development of Tuckman in the lifetime of a COIN. The distinguishing feature of the project team analyzed in this paper is that not only is the team striving to operate as a COIN, but it also has the task to create a COIN. First results indicate that after initial difficulties the team members succeed in structuring their interaction in COIN-like fashion, by nurturing new and unofficial leaders. Much further work needs to be done, however, for the leaders of the COIN to successfully create a COIN of Crohn’s patients and their caregivers.

In further work we hope to identify key characteristics of COINs in the performing stage of group development, e.g. oscillating leadership, and emergence of new sub-COINs.

## 6. Acknowledgements

We thank Cole Jackson and Jill Plevinsky for being great leaders and role models of the Crohn’s patient community. We thank Stefan Nann for parsing the Facebook data, Hauke Fuehres for integrating the e-mail data, and Abbie Chandler for continuous support. This work was funded by the National Institutes of Health through the NIH Roadmap for Medical Research, Grant 1 R01 DK085713-01. Information on this Roadmap Transformative R01 Program can be found at <http://grants.nih.gov/grants/guide/rfa-files/RFA-RM-08-029.html>.

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