

**Engagement in a newly launched online support community for Complex Regional Pain Syndrome: membership growth, header analysis and introductory messages.**

Richard M. Smedley <sup>a</sup>, Neil S. Coulson <sup>a</sup>, Jeff Gavin <sup>b</sup>, Karen Rodham <sup>c</sup>, Leon Watts <sup>d</sup>

<sup>a</sup> Division of Rehabilitation and Ageing, Queen's Medical Centre, Nottingham, NG7 2UH

<sup>b</sup> Department of Psychology, University of Bath, Bath, BA2 7AY

<sup>c</sup> School of Psychology, Sport and Exercise, Staffordshire University, Stoke-on-Trent, ST4 2DF

<sup>d</sup> Department of Computer Science, University of Bath, Bath, BA2 7AY

**Address for correspondence:**

Dr Neil S. Coulson  
Division of Rehabilitation & Ageing, School of Medicine  
Room B113 Medical School  
Queen's Medical Centre  
Nottingham  
NG7 2UH  
UK

+44 115 846 6642

## Abstract

Several studies have investigated forum engagement, with a small but growing body of research focussing on the number of people using a forum (membership growth), how they use it (header analysis) and how they introduce themselves (introductory messages). Most studies use established forums and little is known about newly launched forums. This study examines engagement in a newly launched forum for Complex Regional Pain Syndrome. Results showed that membership growth occurred in bursts that were closely linked to promotional strategies. Header analysis showed the forum was used throughout the day, evening and night, with a focus on providing support as well as receiving it. Introductory messages took the form of disease stories with six themes: personal details, precipitating event, symptoms, treatment, living with CRPS, and reasons for joining. Implications and areas for future research are discussed.

**Keywords:** Complex Regional Pain Syndrome; Online support groups; Patient interaction; Membership growth; Header analysis; Introductory messages; Thematic analysis

## 1. Introduction

Complex Regional Pain Syndrome (CRPS) is a chronic illness associated with a range of debilitating symptoms including unexplained pain, increased sensitivity to touch, motor dysfunction, and changes in skin colour and temperature (Turner-Stokes & Goebel, 2011), with an estimated incidence rate of 5.46-26.2 new cases per 100,000 annually (de Mos et al., 2007; Sandroni, Benrud-Larson, McClelland, & Low, 2003). Individuals with CRPS may find it difficult to participate in social and recreational activities (Galer, Henderson, Perander, & Jensen, 2000), leaving them with a greatly reduced network through which they can obtain support (Rodham, McCabe, & Blake, 2009). Consequently, individuals with this illness may benefit from social support received over the Internet.

The Internet and social media provide new opportunities for people to interact with like-minded individuals (Ridings & Gefen, 2004), and can be used to obtain health-related information and advice (Leung, 2008; Powell, Darvell, & Gray, 2003). Online support communities allow individuals to discuss health-related topics with others who have been through similar experiences, to support one another and talk about the unique difficulties associated with illnesses like CRPS (Attard & Coulson, 2012; Coulson, 2005; Rodham et al., 2009). These communities use several technologies including Web forums and e-mail Listservs, with forums being the most popular (Barak, Boniel-Nissim, & Suler, 2008).

Forums provide flexible access to support at any time of the day or night (Malik & Coulson, 2008), making it easy to fit support needs around work, family, study or other commitments (Coulson, 2013;

Coulson & Knibb, 2007). However, the lack of physical proximity can make it difficult to develop meaningful relationships and offer physical comfort, which may leave members feeling isolated in real life (Coulson, 2013).

### **1.1. Engagement with online support communities**

Engagement has typically been considered in a narrow context. For example, some researchers examine how often an individual accesses a community or the time spent online in the average session (Boberg et al., 1995; Zrebiec & Jacobson, 2001), while others describe engagement in terms of ‘posters’ (individuals who post messages) and ‘lurkers’ (individuals who only read messages) (Malinen, 2015; Mo & Coulson, 2010; Nonnecke & Preece, 2000). Although these are legitimate components of engagement, we argue that engagement is a broader concept requiring further elaboration. A small but growing body of research has considered engagement from alternative perspectives such as membership growth (Iriberry & Leroy, 2009), header analysis (Galegher, Sproull, & Kiesler, 1998; Winzelberg, 1997) and introductory messages (Barak et al., 2008; Galegher et al., 1998).

Additionally, most research has focussed on engagement within established forums that produce large volumes of messages and reward members for their contributions through feedback and social recognition (see Iriberry & Leroy, 2009). Less is known about engagement with new forums, and few studies have examined CRPS forums (for exceptions, see Gavin, Rodham, Coulson, & Watts, 2014; Rodham et al., 2009). Therefore the present study attempts to address some of these issues by investigating engagement within a newly launched CRPS forum. It considers engagement in terms of membership growth, header analysis, and introductory messages.

### **1.2. Membership growth**

According to Iriberry and Leroy (2009), online communities evolve through five stages. The first stage, *inception*, involves developing an idea for a new community, and the second stage, *creation*, entails building the technological components needed to launch it. The third stage, *growth*, is where new members join and post messages to request information, provide support, and enforce community etiquette. During the fourth stage, *maturity*, trust develops among members and they develop lasting relationships. Additional members continue to join and provide fresh topics for discussion, while existing members either continue using the community or lose interest and leave. The final stage, *death*, occurs if there is no longer enough content to sustain discussions.

Consequently, the growth of a new forum plays an important role in its success or failure. Forums need to achieve a ‘critical mass’ of members who are interested in interacting with each other and can

produce a sufficiently diverse range of messages for discussions to become self-sustaining (Jones, Ravid, & Rafaeli, 2004; McCarty, 1992).

Membership growth could take a number of different forms: a forum might have linear growth where a consistent number of new members join each month, exponential growth where a snowball effect causes an ever-increasing number of members to join, or burst growth where some months have a large increase in members while other months have little or no increase. Few studies have examined growth patterns, so little is known about forum growth and the number of people who engage with forums after they have been launched.

### **1.3. Header analysis**

Header analysis reveals how members use forums. Forum messages consist of both header information and the message body (Petrovčič, Vehovar, & Žiberna, 2012), and have a number of useful features. For example, headers contain the username of the individual who created that message, their avatar, the date and time when the message was posted, and possibly other details such as the date they joined the forum, the number of threads they have created, and the total number of messages they have posted (Holtz, Kronberger, & Wagner, 2012; Petrovčič et al., 2012). The message body contains the textual part of the message.

A range of statistical data has been examined including the number of messages posted each day, the number of replies received, how long it takes to receive a reply, and the time of day when messages are posted (Boberg et al., 1995; Galegher et al., 1998; Winzelberg, 1997). To date, no studies have analysed header information in CRPS forums. Consequently, little is known about how individuals with CRPS use forums, when they post messages, how many messages they write, how many replies they receive, or how long it takes to receive the first reply.

### **1.4. Introductory messages**

When an individual posts their first message, existing members may respond by being supportive and welcoming, critical and off-putting, or by ignoring it completely, all of which can influence the likelihood of the new member continuing to engage with the forum (Barak et al., 2008). Individuals may use their first post to talk about their medical history (Armstrong, Koteyko, & Powell, 2012), in effect telling their 'disease story'. This helps the individual to establish legitimacy (why they have joined) and authority (why others should listen and reply) within the group (Galegher et al., 1998).

In a recent study, Rodham, Gavin, Coulson, Watts, and Heath (2013) looked at the role of introductory messages in establishing a new forum, using the same dataset as the present study but focussing on how identities are formed when a forum is launched. In particular, Rodham et al. found that the earlier introductory messages 'set the tone' for how later members subsequently introduced

themselves. The present study<sup>1</sup> extends their findings by looking at the entire lifespan of the forum, and the wider role that introductory messages play in engagement.

### **1.5. Rationale for the study**

Most studies investigating engagement have focussed on existing forums, and little is known about how members engage with new forums. Additionally, despite the potential benefits of online social support for CRPS, few studies have investigated how individuals with CRPS engage with forums. This study investigates engagement in a newly launched CRPS forum, with three aims: First, to investigate the number of people who join by looking at membership growth. Second, using header analysis to investigate how members use the forum. Third, to investigate how members introduce themselves, the structure of these introductions, and what information they disclose.

## **2. Methods**

### **2.1. Data collection**

The data for this study was collected as part of a wider project investigating how the Internet can be used to support the needs of individuals living with CRPS (see Gavin et al., 2014). This was an exploratory project to examine how support processes evolve and develop, and was not intended as a feasibility study. Part of the project involved creating a closed, password-protected forum that individuals could use in any way that they found helpful. On completion of the project, the intention was to offer the running and upkeep of the forum to participants, with no further involvement of the research team.

Research into the sociability of online communities indicates that their success partly depends upon three factors: purpose, people and policies (Preece, 2001). The purpose of the forum was to investigate what happens when a new online support community is launched, so it was inherently a scientific project rather than a self-help group created by individuals with CRPS. The people who interacted using this forum are described in section 2.2. The policies comprised site rules designed to create a supportive environment where members respected each other's opinions and experiences, and they were not allowed to post abusive or offensive messages.

Unfortunately the forum was hacked seven months into the study, which severely disrupted communication within the forum. The forum did not recover from this hacking incident and all subsequent data had to be discarded, leaving seven months of usable data for analysis. This is

---

<sup>1</sup> This paper is a revised and expanded version of a paper entitled "Let me introduce myself: The role of first posts in establishing a common-identity community in an online support forum" presented at the Conference on Psychology and Social Harmony, Beijing, 24th May 2013.

equivalent to allowing one month for new participants to register followed by six months to use the forum.

Four boards were created on the forum, two were researcher-led for administrative purposes and two were member-led. The data for this study was taken from the member-led boards, where discussions reflected the feelings and experiences of individuals living with CRPS. All messages were included in the analysis, comprising 76 messages (2 threads) from the 'Welcome' board and 145 messages (17 threads) from the 'Your Thoughts and Experiences' board.

## **2.2. Participants**

An announcement about the project was sent to organisations and charities in the UK that represent individuals with CRPS, inviting their members to take part (for more information, see Gavin et al., 2014). Of the 60 who joined the forum, 23 participants (38.3%) posted messages, 2 were administrators (3.3%) involved in running the project, and 35 were 'lurkers' (58.3%). The sample consisted of the 23 participants who posted messages.

Demographic information was limited to information obtained from the content of messages. Gender was available for all participants, with 5 males (21.7%) and 18 females (78.3%). Age was available for 9 participants, ranging from 20 to 54 years with a mean age of 35.6 (13.0) years. Number of years since diagnosis was available for 14 participants, ranging from 5 months to 10 years with a mean duration of 3.9 (3.5) years.

## **2.3. Analysis**

**Membership growth:** The date of each participant's first message was used to calculate how many new members joined the forum each month.

**Header analysis:** The number of messages per day, number of messages per participant, number of threads per participant, and time of day when each message was written were calculated using combined data from both boards. The number of replies received and duration of time to receive the first reply could only be calculated for the 'Your Thoughts and Experiences' board because the 'Welcome' board only had two threads and the first message was posted three months before the forum was publically launched, creating an outlier that would have skewed the dataset.

**Introductory messages:** Inductive thematic analysis (Braun & Clarke, 2006) was used to identify recurring patterns in the first message posted by each participant. Previous research indicates that individuals may use their first message to talk about their medical history and why they joined the forum (Armstrong et al., 2012), so the analysis focussed on identifying the structure and key features

of these disease stories. Content analysis (Pfeil & Zaphiris, 2010) was used to count the number of occurrences within each theme.

## **2.4. Ethical considerations**

The Universities of Nottingham and Bath both granted ethical permission for this study, which was conducted in accordance with the British Psychological Society's ethical guidelines for online research (British Psychological Society, 2013).

When registering, all participants were notified that the forum was part of a 12 month research project and consented to their postings being used for research purposes. Participants' anonymity and privacy were protected by removing any potentially identifying information from the quoted extracts of postings. The use of a closed, password-protected forum makes it impossible to trace quotes back to their original source.

## **3. Results**

### **3.1. Membership growth**

Table 1 shows the number of new participants who joined the forum each month.

<< **TABLE 1 ABOUT HERE** >>

Forum membership grew in bursts. The first burst occurred in June when an initial group of 7 participants joined the forum. This was followed by a second burst in September and October when an additional 11 participants joined. The other months of the study experienced a consistent but much lower background growth, where only one or two new members joined each month.

### **3.2. Header analysis**

*Messages per day:* The number of messages posted per day ranged from 0-13, with a mean of 1.0 (2.1). The modal number of messages per day was 0, with 138 out of 213 days (64.8%) where no messages were posted.

*Messages per participant:* The number of messages posted by each participant ranged from 1 to 51, with a mean of 9.5 (12.9). The modal number of messages was 1, with 7 out of 23 participants (30.4%) only posting a single message. 17 participants (73.9%) were low frequency posters who each posted less than 9.5 messages, and collectively wrote 55 out of 221 messages (24.9%). The remaining 6 participants (26.1%) were high frequency posters who each posted more than 9.5 messages, and wrote 166 out of 221 messages (75.1%).

*Threads per participant:* The number of threads created by each participant ranged from 0 to 4, with a mean of 0.7 (1.1). The modal number of threads was 0, with 13 out of 23 participants (56.5%) not creating any threads and only replying to existing postings. 11 out of 19 threads (57.9%) were created by the 6 high frequency posters.

*Replies received:* The number of replies per thread ranged from 0 to 32, with a mean of 7.5 (10.4). The modal number of replies was 1, with 5 out of 17 threads (29.4%) only receiving one reply. 3 out of 17 threads (17.6%) did not receive any replies. When a new thread was created, the duration of time before receiving the first reply ranged from 2.2 hours to 11.8 days with a mean of 2.5 (3.3) days.

In longer threads where discussions continued for weeks or months, messages were not evenly distributed over time. Typically several messages would be written within a relatively short period, followed by a pause of inactivity lasting for days or weeks, and then another burst of messages would be written. This pattern was repeated with further pauses and bursts of messages until the discussion was concluded.

*Time of day:* 116 messages (52.5%) were posted during the daytime (7:00am to 5:59pm), 57 messages (25.8%) in the evening (6:00pm to 10:59pm) and 48 messages (21.7%) at night (11:00pm to 6:59am). The time of day when participants created new threads also showed a similar pattern, with 10 threads (52.6%) created in the daytime, 5 threads (26.3%) in the evening, and 4 threads (21.1%) at night.

### **3.3. Introductory messages**

21 participants (91.3%) used their first message to introduce themselves and tell their disease story. Two participants did not introduce themselves, with one using her first message to ask for advice about disability benefits, and the other campaigning to increase public awareness of CRPS.

Introductory messages were focussed around six themes: Personal details, precipitating event, symptoms, treatment, living with CRPS, and reasons for joining. All quoted extracts are presented verbatim with the original grammar, spelling and language used by participants.

#### **3.3.1. Theme 1: Personal details**

17 participants (73.9%) provided some personal and demographic information about themselves, disclosing their name, age, geographical location, occupation, marital status and/or how many children they have. Messages typically began with “Hi” or “Hello” followed by a brief introduction, similar to what might happen in a face-to-face interaction:

“Hi I’m [name], I’m [age] years old married with [number of] kids.” (Participant 8)

“Hi all! I’m a [age] year old pharmaceutical science student in [city].” (Participant 12)



### **3.3.2. Theme 2: Precipitating event**

13 participants (56.5%) talked about the precipitating event that triggered their illness, illustrating the diverse range of incidents that can lead to the onset of CRPS. Three participants developed CRPS following surgery, three were in a road traffic accident, three suffered a fractured or broken bone, two had either a sporting injury or impact to the affected limb, one experienced numerous medical complications making it difficult to establish what caused her illness, and one participant developed CRPS spontaneously.

Some descriptions went into considerable detail about how they were diagnosed, providing a powerful and vivid account of the difficulties they had gone through. In the following quote, RSD (Reflex Sympathetic Dystrophy) is the term typically used in the USA for CRPS:

“I had a car accident 20 years ago [...] I originally hurt my left knee it smashed off the dashboard [...] 8 years ago they found I have Rsd in both my knees and each operation made my pain much much worse to a point that it isn't really controlled. I had an op on my right shoulder which has left it with Rsd and across my neck and down the other arm is playing up same symptoms as Rsd.” (Participant 7)

Others gave shorter descriptions, typically providing the minimum detail needed to convey their experiences:

“I came off a motorbike in [year]. I developed CRPS very quickly afterwards and was diagnosed about 6 or 7 months later.” (Participant 19)

### **3.3.3. Theme 3: Symptoms**

19 participants (82.6%) described the body area affected by CRPS and what symptoms they experience.

Nine participants had CRPS in their lower limbs, five in their upper limbs, and four in both upper & lower limbs. Six participants said their CRPS had spread, either because the affected area had expanded or they had developed CRPS in multiple regions:

“The initial site being my right hand/arm [...]. This gradually spread to my left side although not quite as bad there. Then after 5yrs I had a fall and after a month in hospital suffered a bad spread to my right leg.” (Participant 22)

Symptoms included severe pain, burning sensations, heightened sensitivity and/or disproportionate pain when touched, swelling, changes in skin colour or temperature, and motor restrictions:

“I have the CRPS now in both feet and legs, both hands and arms, with the mottling across my back and down my left arm and the bone changes and hand changes, swollen feet and legs, dry sore blurry eyes, and spinal pain, tinnitus, dizziness, vertigo etc. [...] It was in [year] the CRPS symptoms of dystonia, memory problems, muscle spasms, oedema night sweats, and blinding head pains began.” (Participant 6)

#### **3.3.4. Theme 4: Treatment**

13 participants (56.5%) talked about treatment regimes, with most having undergone a range of treatment options including physiotherapy, drug treatment, spinal cord stimulation and specialist courses.

**Physiotherapy:** Eight participants had undergone physiotherapy to help overcome motor limitations associated with CRPS. Although this approach did not work for everyone (“Physio was stopped because there was no improvement”, participant 11), some individuals found it beneficial to use the affected limb as much as possible (“I keep as active as I can but as it is now in both legs I do use a wheelchair when I want to be out and about”, participant 12).

**Drug treatment:** Seven participants described using medications to control pain levels, with limited results. Two individuals stopped taking pain medication because it did not work for them (“I gave up trying the painkillers after them just causing side effects with no positive effects”, participant 5). Others described their drug regime in various levels of detail, ranging from a brief summary (“I’m on all the meds, standard, all the pain, standard”, participant 17) to longer descriptions of specific medications (“I now manage with daily paracetamol and diclofenac. Then buprenorphine on top as and when required”, participant 12).

**Spinal cord simulation (SCS):** Two participants used SCS to control their pain levels with mixed results. SCS worked for one individual (“I was referred, to [hospital] for a spinal cord stimulator. It was wonderful the day it was fitted it was turned on and my pain level went down to bearable”, participant 8), but the other experienced difficulties using it to control her pain (“[I] am having real problems with my scs. This is my second scs as I burned out the first in 5 months”, participant 19). Additionally, a third participant was offered SCS but declined because she wanted to keep this available as a future treatment option (“My pain doc is in talks about giving me an SCS but I’m resisting because I’m managing and I still want options left for the future”, participant 12).

**Specialist courses:** Six participants had attended specialist pain management and rehabilitation courses. Two individuals were currently midway through a course (“I am currently at [hospital] on a four week pain management programme”, participant 1), and others indicated that these had helped them learn more about controlling their illness and setting realistic goals (“I was lucky enough to get

funding to stay at [hospital] as an inpatient for 2 weeks. Omg it was mentally, physically, and sometimes soul destroying. But I learnt so much”, participant 3).

### **3.3.5. Theme 5: Living with CRPS**

16 participants (69.6%) talked about their experience of living with CRPS and its impact on daily activities. There was a particular focus on good and bad days, loss of career, and the financial impact of CRPS.

Good and bad days: Fourteen participants described the challenges of CRPS. Several individuals mentioned pain-related difficulties (“I have learnt to live with my CRPS pretty well although I do have bad days when I get very frustrated and upset”, participant 13), some lost contact with family and friends (“CRPS ruined my marriage and friends slowly over the years dropped off”, participant 22), and others struggled with normal activities (“i can’t do my hobbies [...] i struggle with my gardening, i struggle with shopping and repairing my home”, participant 6). Despite this, participants described the importance of staying positive and focussing on what they can do (“[I] have stopped looking at life from the aspect of things I cannot do and now look at what I can do as an achievement”, participant 22), recognised how lucky they are (“as bad as it gets I thank god I'm here because it could have been so different I may not have been alive to see my gorgeous children grow up”, participant 7) and were inspired to help others (“I hit rock bottom and considered suicide, but then decided I'd got a fantastic wife, kids and friends and instead I am going to work towards setting up a charity”, participant 8).

Loss of career: Two participants mentioned not being able to work. This had a negative effect on self-identity through the loss of previously-important social roles (“I spent the first 2yrs in depression and mourning the loss of my career and life as it was”, participant 22), and led to frustration at being unable to find suitable employment (“One of my biggest frustrations is not being able to work [...] and not as yet being able to find a job I can sustain”, participant 9).

Financial impact: One participant talked about the financial impact of CRPS, which meant she faced higher living expenses while having a greatly reduced income:

“The entire illness so far as cost me all my savings in paying for diy help, decorating help, garden help. taxi fare, adaptations, heating costs, special footwear [...] and now looks like it may also cost me the family home as I can no longer afford the bills to keep warm [...] The dwp have me living on £97 a fortnight.” (Participant 6)

### **3.3.6. Theme 6: Reason for joining**

7 participants (30.4%) explicitly mentioned their reasons for joining the forum, with two individuals giving more than one reason.

Three participants wanted to contribute to scientific research (“I’ve joined to contribute to the research”, participant 15), four hoped to meet others with CRPS (“I live in [town] would be interested in meeting some more people around the area”, participant 17), and two were looking for support and advice (“[I] am now at a bit of a dead end. [...] Any advise would be grateful, as I don’t know where to go from here”, participant 11).

Interacting with others who understand the challenges of living with CRPS appeared to be particularly important:

“It is so lovely to see everyone supporting each other on here. It is a great idea to have a site where we can chat to others who truly understand what it is like to live with CRPS.”  
(Participant 18)

## **4. Discussion**

This study looked at engagement in a newly launched CRPS forum, and had three aims. Firstly, to investigate the number of people who join and use the forum by looking at membership growth. Secondly, using header analysis to investigate how members use the forum. Thirdly, to investigate how members introduce themselves by looking at the structure and content of their introductory messages.

### **4.1. Membership growth**

It was anticipated that membership growth might take the form of linear, exponential or burst growth. The number of participants grew in bursts, where some months had a large increase in membership while other months had very little increase.

The majority of growth took place in two distinct bursts, the first in June and the second in September and October. This coincided with the launch of targeted recruitment campaigns to increase awareness of the study and attract new members. The other months saw a gradual background increase of one or two new members per month.

This is consistent with research into how people discover online support communities. According to van Uden-Kraan et al. (2008), most individuals discover forums by chance while searching for health-related information, by hearing about them from family members or patient organisations, or through direct marketing by the community. The two growth bursts occurred in response to marketing

campaigns to recruit new members, while the background growth may have been associated with individuals discovering the forum by chance or hearing about it through word-of-mouth.

It appears that the success or failure of a new forum may partly be influenced by the promotional strategies used to recruit members. Growth is the third of Iriberry and Leroy's five key stages in the lifecycle of online communities (Iriberry & Leroy, 2009), following on from the group's inception and creation. Publicity campaigns promoting a new forum may generate interest and encourage new members to join by making them aware of the forum, its purpose, target audience, and any organisations it might be affiliated with. If enough members join then the forum may achieve the 'critical mass' needed for discussions to become self-sustaining (Jones et al., 2004; McCarty, 1992).

#### **4.2. Header analysis**

This forum had 23 participants who produced a mean of 1.0 message per day and 7.5 replies per thread. Established online support communities typically have more members, may produce more messages per day, but can receive fewer replies per thread. For example, an eating disorders group with 70 members produced 4.4 messages per day and 6.4 replies per thread (Winzelberg, 1997), and groups for arthritis (16,000 members), attention deficits (18,000 members) and depression (23,000 members) produced an overall mean of 74 messages per day and 3.5 replies per thread (Galegher et al., 1998).

It appears that smaller groups may produce fewer messages per day because there are less people to interact with. However, the relationship between membership size and number of replies may be more complicated. One possibility is that the number of replies may be unrelated to membership size but instead reflects the supportive intentions and behaviours of members, where a more supportive group may produce a greater number of replies. Alternatively, larger groups may produce fewer replies because of diffusion of responsibility.

Diffusion of responsibility (Darley & Latané, 1968) occurs when the presence of a large number of observers leads to a reduced likelihood of someone helping, and has been found to occur on the Internet. For example, help requests e-mailed to multiple recipients produce fewer and less helpful replies (Barron & Yechiam, 2002), and ListSrvs with a large number of members are less likely to help than those with a small number of members (Yechiam & Barron, 2003). Yechiam and Barron suggest two explanations why larger groups produce fewer replies. First, larger groups need an increased time commitment to read messages and compose replies, so individuals with limited time or resources will be less likely to respond to any particular message. Second, knowing that a group has lots of members may lead to the perception that replying is less important because others could reply.

The mode and median number of threads created was 0, showing that most participants contributed to existing threads rather than starting new threads to discuss their own problems. This suggests that supporting others may have been an important part of the forum; individuals may not have joined solely to discuss their own problems and instead used it to help others. Periods of inactivity were observed within threads, but it is unclear what caused this or if the same phenomenon occurs in other forums.

The forum was used throughout the day, evening and overnight. This finding is consistent with previous research conducted using established online support communities (Boberg et al., 1995; Winzelberg, 1997) suggesting that members have access to information, advice and support at any time (Malik & Coulson, 2008), therefore making it possible to fit their support needs around other obligations such as family, work or study commitments (Coulson & Knibb, 2007).

### **4.3. Introductory messages**

Nearly all participants introduced themselves by telling their disease story, with earlier introductions creating a 'how-to' template used by subsequent members for their introductions (Rodham et al., 2013). These richly detailed descriptions of CRPS-related experiences had six key features: personal details, precipitating event, symptoms, treatment, living with CRPS, and reasons for joining the forum.

**Personal details:** A limitation of forums is that non-verbal social cues like physical appearance, facial expressions and tone of voice are hidden (Coulson & Knibb, 2007; Finfgeld, 2000). Explicitly describing personal characteristics may be a substitute for not being able to observe them visually. Previous research indicates that forum members sometimes find it difficult talking to strangers about their illness (Coulson, 2013), so providing personal details may reduce anonymity and make it easier for participants to interact and share information about their experiences.

**Precipitating event:** The diverse range of causes leading to the onset of CRPS reflect the findings of epidemiological studies, which have identified fractures (49% of patients), soft tissue injuries such as sprains (20%), surgery (11%), tendon injuries (6%) and other types of injury (6%) as precipitating events, with 8% of cases occurring spontaneously (de Mos et al., 2008).

These precipitating events are similar to the concept of initiating events that LaCoursiere (2001) described in her theory of online social support. LaCoursiere proposed that a change in either perceived or actual health status could trigger the need for support, causing the individual to join an online support community subject to mediating factors like how the health condition affects their quality of life, their coping ability, feelings of social isolation, and how comfortable they are with using the Internet for health-related purposes. The present results demonstrate how being diagnosed

with CRPS may act as a trigger event that prompts the individual to join an online support community.

**Symptoms:** CRPS occurs most commonly in the upper limbs (de Mos et al., 2007; Sandroni et al., 2003) however, in the present study, CRPS occurred more commonly in the lower limbs, although the reasons for this are unclear. Nevertheless, the symptoms described by participants are typical of those normally associated with this illness (Turner-Stokes & Goebel, 2011). This could suggest that individuals who have CRPS in their upper limbs may experience greater difficulties accessing online support communities, which rely on being able to type and operate a computer. Further research could explore whether this is an impediment to accessing support, and whether individuals might benefit from technical solutions such as using speech recognition software packages to allow them to operate a computer using voice commands.

**Treatment:** Participants described physiotherapy, drug treatment, spinal cord stimulation, and specialist courses, which closely reflects the literature on CRPS treatment. Reviews of potential treatment strategies indicate that paramedical interventions like physiotherapy can be effective, drug treatment is often used but there is mixed evidence for its effectiveness, and invasive treatments like spinal cord stimulation can reduce pain but do not improve functioning (Cossins et al., 2013; Hord & Oaklander, 2003; Perez et al., 2010). Specialist rehabilitation programmes may be particularly beneficial to help individuals control their CRPS (Rodham, Boxell, McCabe, Cockburn, & Waller, 2012).

**Living with CRPS:** The difficulties of being in constant pain reflect the severe impact that CRPS can have on quality of life (Galer et al., 2000), and show how it can lead to social isolation (Rodham et al., 2009). Participants highlighted the importance of staying positive and focussing on what they can do (Rodham et al., 2009), but some individuals still mourned the loss of their career and suffered financial difficulties as a result of their illness (Kemler & Furnée, 2002).

**Reason for joining:** CRPS is an unpleasant and debilitating illness, and some participants expressed a clear desire to contribute to research studies. Meeting others and seeking support are acknowledged in the literature as common reasons for joining online communities (Coulson, 2013).

These reasons for joining an online support community appear to be distinct from the precipitating event of being diagnosed with a chronic illness. This expands the concept of initiating events that was introduced by LaCoursiere (2001), by suggesting that there could be at least two distinct trigger events that lead the individual to join an online support community: the precipitating event that causes them to suffer a particular health condition, and their subsequent reasons for deciding to join the forum.

Overall, telling their disease story may have served the wider purpose of creating legitimacy and establishing authority within the forum (Armstrong et al., 2012; Galegher et al., 1998). According to Galegher et al., anybody can join an online community but nobody has a duty to acknowledge or help new members. This means new members may need to demonstrate their legitimacy and show why they should be accepted by expressing real and genuine concerns. Telling their disease stories may have allowed participants to provide personal details about themselves to show they are real people, and also claim membership through behavioural statements about how they were diagnosed, what symptoms they experience, their treatment regime, the impact it has on their lives, and their reasons for joining the forum. Establishing their credentials in this way may have helped demonstrate authority, showing why others should read their messages, listen to their advice and take their comments seriously.

These results extend the findings of a previous study that examined introductory messages in the context of identity formation (Rodham et al., 2013), which identified five themes: journey to diagnosis, treatment, contact with health care professionals, looking for the positive, and hobbies. Most of the themes from Rodham et al.'s study are reflected in the current findings. Their 'journey to diagnosis' theme is conceptually very similar to our 'precipitating event' theme. Both themes describe the events leading up to the individual being diagnosed, with our theme building upon this by also looking at the precipitating event that triggered the illness. Their 'treatment' and 'contact with health care professionals' themes examined participants' experiences of various treatment methods and their encounters with healthcare professionals, while the present study focusses in greater depth on the different treatment options undertaken by participants. Their 'looking for the positive' theme was expanded to form part of our wider theme 'living with CRPS'. However, their final theme 'hobbies' is not reflected in the present findings because, although this was an important component of building a shared identity, it did not form an integral part of participants' disease stories.

#### **4.4. Limitations and future research**

This study has some limitations which lead to areas for future research. First, the number of members who joined each month was calculated from the date of their first message. Some participants might join the forum and 'lurk' until they feel comfortable posting (Colvin, Chenoweth, Bold, & Harding, 2004; Winzelberg, 1997), so the date of their first message might differ from the date they joined. Future research needs to examine membership growth using the date of registration.

Second, only a relatively small number of participants joined the forum, which can be partly explained in terms of sociability. The sociability of online communities depends on three factors: purpose, people and policies (Preece, 2001). The purpose of the forum was a research project, and while some participants cited this as a reason for joining, others may have been reluctant to join because they were not comfortable with being 'studied' (Eysenbach & Till, 2001). The policy of using



a closed forum meant individuals had to register before they could view messages and assess whether the forum was suitable for their needs, which may also have discouraged some individuals from joining. In relation to people, activity levels were lower than what has been observed in other groups (Galegher et al., 1998; Winzelberg, 1997), indicating that the forum failed to develop into a true community. This failure may have been partly due to low uptake, with the forum failing to achieve the 'critical mass' of members needed for discussions to become self-sustaining (Jones et al., 2004; McCarty, 1992), and partly because of the hacking incident that occurred midway through the study. The hacking incident severely disrupted communication within the forum, illustrating how incidents of this type may have an impact on members. Participants may have subsequently felt that the forum was no longer a 'safe' place for them to use, and the forum did not recover. Most group activity was produced by a core group of 6 high frequency posters. It is unclear how closely the data from these participants reflects the online activities of all participants, or if the results generalise to other forums.

Third, this study provided tentative evidence for diffusion of responsibility in forums, and research is needed to further explore how this might be expressed within forums. Fourth, participants used other social media outlets like Facebook groups alongside the forum. After the study ended they were offered the opportunity to continue running the forum but chose not to do this. This is partly because the forum did not recover from the hacking incident, but there might also be another explanation: individuals may have preferred the convenience of using Facebook on their mobile phone or tablet computer, rather than logging onto a PC to use the forum. Future research should investigate what social media platforms people prefer, and how this influences engagement with those platforms and what kind of online support that they receive.

#### **4.5. Conclusions**

Three aspects of engagement were examined in a newly launched CRPS forum. Membership growth occurred in bursts closely linked to the promotional strategies used to increase awareness of the forum, indicating that successful marketing may be crucial for membership growth. Header analysis showed that members joined to provide support as well as receiving it, they accessed support at all times of the day or night, and indicated that diffusion of responsibility may occur in forums.

Introductory messages may be crucial for engagement, and took the form of disease stories with six key themes: personal details, precipitating event, symptoms, treatment, living with CRPS, and reasons for joining.

## 5. References

- Armstrong, N., Koteyko, N., & Powell, J. (2012). 'Oh dear, should I really be saying that on here?': Issues of identity and authority in an online diabetes community. *Health, 16*(4), 347-365.
- Attard, A., & Coulson, N. S. (2012). A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behavior, 28*(2), 500-506.
- Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior, 24*(5), 1867-1883.
- Barron, G., & Yechiam, E. (2002). Private e-mail requests and the diffusion of responsibility. *Computers in Human Behavior, 18*(5), 507-520.
- Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Chan, C.-L., Bricker, E., Pingree, S., . . . Peressini, A. (1995). Development, acceptance, and use patterns of a computer-based education and social support system for people living with AIDS/HIV infection. *Computers in Human Behavior, 11*(2), 289-311.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- British Psychological Society. (2013). Ethical Guidelines for Internet-mediated Research. Retrieved from <http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf>
- Colvin, J., Chenoweth, L., Bold, M., & Harding, C. (2004). Caregivers of Older Adults: Advantages and Disadvantages of Internet-based Social Support. *Family Relations, 53*(1), 49-57.
- Cossins, L., Okell, R. W., Cameron, H., Simpson, B., Poole, H. M., & Goebel, A. (2013). Treatment of complex regional pain syndrome in adults: A systematic review of randomized controlled trials published from June 2000 to February 2012. *European Journal of Pain, 17*(2), 158-173.
- Coulson, N. S. (2005). Receiving social support online: An analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *CyberPsychology & Behavior, 8*(6), 580-584.
- Coulson, N. S. (2013). How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *JRSM Short Reports, 4*(8), 1-8.
- Coulson, N. S., & Knibb, R. C. (2007). Coping with food allergy: Exploring the role of the online support group. *CyberPsychology & Behavior, 10*(1), 145-148.
- Darley, J. M., & Latané, B. (1968). Bystander intervention in emergencies: Diffusion of responsibility. *Journal of Personality and Social Psychology, 8*(4), 377-383.
- de Mos, M., de Bruijn, A. G. J., Huygen, F. J. P. M., Dieleman, J. P., Stricker, B. H. C., & Sturkenboom, M. C. J. M. (2007). The incidence of complex regional pain syndrome: A population-based study. *Pain, 129*(1-2), 12-20.

- de Mos, M., Huygen, F. J. P. M., Dieleman, J. P., Koopman, J. S. H. A., Stricker, B. H. C., & Sturkenboom, M. C. J. M. (2008). Medical history and the onset of complex regional pain syndrome (CRPS). *Pain, 139*(2), 458-466.
- Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *British Medical Journal, 323*(7321), 1103-1105.
- Finfgeld, D. L. (2000). Therapeutic groups online: the good, the bad, and the unknown. *Issues in mental health nursing, 21*(3), 241-255.
- Galegher, J., Sproull, L., & Kiesler, S. (1998). Legitimacy, Authority, and Community in Electronic Support Groups. *Written Communication, 15*(4), 493-530.
- Galer, B. S., Henderson, J., Perander, J., & Jensen, M. P. (2000). Course of Symptoms and Quality of Life Measurement in Complex Regional Pain Syndrome: A Pilot Survey. *Journal of Pain and Symptom Management, 20*(4), 286-292.
- Gavin, J., Rodham, K., Coulson, N., & Watts, L. (2014). Meeting the support needs of patients with complex regional pain syndrome through innovative use of wiki technology: a mixed-methods study. *Health Services and Delivery Research, 2*(24).
- Holtz, P., Kronberger, N., & Wagner, W. (2012). Analyzing internet forums: A practical guide. *Journal of Media Psychology: Theories, Methods, and Applications, 24*(2), 55-66.
- Hord, E. D., & Oaklander, A. L. (2003). Complex regional pain syndrome: A review of evidence-supported treatment options. *Current Pain and Headache Reports, 7*(3), 188-196.
- Iriberry, A., & Leroy, G. (2009). A Life-Cycle Perspective on Online Community Success. *Acm Computing Surveys, 41*(2).
- Jones, Q., Ravid, G., & Rafaeli, S. (2004). Information overload and the message dynamics of online interaction spaces: A theoretical model and empirical exploration. *Information Systems Research, 15*(2), 194-210.
- Kemler, M. A., & Furnée, C. A. (2002). The Impact of Chronic Pain on Life in the Household. *Journal of Pain and Symptom Management, 23*(5), 433-441.
- LaCoursiere, S. P. (2001). A Theory of Online Social Support. *Advances in Nursing Science, 24*(1), 60-77.
- Leung, L. (2008). Internet Embeddedness: Links with Online Health Information Seeking, Expectancy Value/Quality of Health Information Websites, and Internet Usage Patterns. *CyberPsychology & Behavior, 11*(5), 565-569.
- Malik, S. H., & Coulson, N. S. (2008). Computer-mediated infertility support groups: An exploratory study of online experiences. *Patient Education and Counseling, 73*(1), 105-113.
- Malinen, S. (2015). Understanding user participation in online communities: A systematic literature review of empirical studies. *Computers in Human Behavior, 46*(0), 228-238.
- McCarty, W. (1992). HUMANIST: Lessons from a Global Electronic Seminar. *Computers and the Humanities, 26*(3), 205-222.

- Mo, P. K. H., & Coulson, N. S. (2010). Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of 'lurkers' and 'posters'. *Computers in Human Behavior*, 26(5), 1183-1193.
- Nonnecke, B., & Preece, J. (2000). *Lurker demographics: counting the silent*. Paper presented at the Proceedings of the SIGCHI conference on Human Factors in Computing Systems, The Hague, The Netherlands.
- Perez, R., Zollinger, P., Dijkstra, P., Thomassen-Hilgersom, I., Zuurmond, W., Rosenbrand, K., & Geertzen, J. (2010). Evidence based guidelines for complex regional pain syndrome type 1. *BMC Neurology*, 10(1), 20.
- Petrovčič, A., Vehovar, V., & Žiberna, A. (2012). Posting, quoting, and replying: a comparison of methodological approaches to measure communication ties in web forums. *Quality & Quantity*, 46(3), 829-854.
- Pfeil, U., & Zaphiris, P. (2010). Applying qualitative content analysis to study online support communities. *Universal Access in the Information Society*, 9(1), 1-16.
- Powell, J. A., Darvell, M., & Gray, J. A. M. (2003). The doctor, the patient and the world-wide web: how the internet is changing healthcare. *Journal of the Royal Society of Medicine*, 96(2), 74-76.
- Preece, J. (2001). Sociability and usability in online communities: Determining and measuring success. *Behaviour & Information Technology*, 20(5), 347-356.
- Ridings, C. M., & Gefen, D. (2004). Virtual Community Attraction: Why People Hang Out Online. *Journal of Computer-Mediated Communication*, 10(1), 00-00.
- Rodham, K., Boxell, E., McCabe, C. S., Cockburn, M., & Waller, E. (2012). Transitioning from a hospital rehabilitation programme to home: Exploring the experiences of people with complex regional pain syndrome. *Psychology & Health*, 27(10), 1150-1165.
- Rodham, K., Gavin, J., Coulson, N. S., Watts, L. A., & Heath, H. (2013, 24th May 2013). *Let me introduce myself: The role of first posts in establishing a common-identity community in an online support forum*. Paper presented at the Conference on Psychology and Social Harmony, Beijing.
- Rodham, K., McCabe, C., & Blake, D. (2009). Seeking support: An interpretative phenomenological analysis of an Internet message board for people with Complex Regional Pain Syndrome. *Psychology & Health*, 24(6), 619-634.
- Sandroni, P., Benrud-Larson, L. M., McClelland, R. L., & Low, P. A. (2003). Complex regional pain syndrome type I: incidence and prevalence in Olmsted county, a population-based study. *Pain*, 103(1-2), 199-207.
- Turner-Stokes, L., & Goebel, A. (2011). Complex regional pain syndrome in adults: concise guidance. *Clinical Medicine*, 11(6), 596-600.
- van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. F. J. (2008). Empowering Processes and Outcomes of Participation in Online Support Groups for

Patients With Breast Cancer, Arthritis, or Fibromyalgia. *Qualitative Health Research*, 18(3), 405-417.

Winzelberg, A. (1997). The analysis of an electronic support group for individuals with eating disorders. *Computers in Human Behavior*, 13(3), 393-407.

Yechiam, E., & Barron, G. (2003). Learning to Ignore Online Help Requests. *Computational & Mathematical Organization Theory*, 9(4), 327-339.

Zrebiec, J. F., & Jacobson, A. M. (2001). What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study. *Diabetic Medicine*, 18(2), 154-158.

**Table 1:** Number of members who joined each month

<i>Month</i>	<i>New members</i>	<i>Cumulative total</i>
June	7	7
July	1	8
August	1	9
September	5	14
October	6	20
November	2	22
December	1	23