

# Social Circles and Intersections: Creating a Peer-based Supportive Community Online

Russell Beale  
School of Computer Science  
University of Birmingham  
Edgbaston  
Birmingham  
B15 2TT  
UK  
R.Beale@cs.bham.ac.uk

## ABSTRACT

*In this paper, we present a design study that describes how we used a web-based bulletin board system to support children who suffer from cystic fibrosis. Their illness tends to make them feel socially isolated, and face-to-face group meetings are not possible, and hence we looked to the internet to provide a suitable infrastructure for us to build a supportive community dedicated to this patient group, which could provide support, information and a social meeting place of which they could feel an important part. We discuss the design issues that faced us in trying to create such a community for this group of users.*

## KEYWORDS

Social circles, community, cystic fibrosis, design study

## INTRODUCTION

Children with cystic fibrosis (often referred to in this paper as CF) have a multitude of problems to deal with, one of which is social isolation. They become quite knowledgeable about their condition, but are often not in a position to discuss this with other children or adults, either because they are embarrassed or because the other party does not know much or cannot empathize with them. One of the conventional ways to address this problem has been to provide group meeting sessions for the patients, allowing them to get together with other patients on a regular basis to discuss things. However, more recent medical research has shown that there is a significant risk of cross-infection between patients and so such meetings are not now possible (Govan et al 1993, Leeds 2001). In an attempt to reduce their feelings of isolation, we have designed a system for them in which we try to provide an online community on the web.

This paper discusses the design principles behind the web community, identifying the key points that have to be addressed in order to provide an effective, workable environment, and evaluates how well the system achieves its goals.

## GROUP MEETING REVIEW

The previously run group sessions in which the patients got together were reviewed by the design team and the medics and counsellors involved. Because these meetings no longer happen it was impossible to observe them, but they were discussed openly. We also involved some of the older patients who were better able to reflect back on the dynamics and content of those meetings. In review, the sessions were successful because the boundaries for them were very clear. The people involved were all either fellow cystic fibrosis sufferers, or were specialists able to offer advice and counselling. The confidentiality of the meeting was implicit yet clear, and the participants appreciated the opportunity to interact with others in their position, and both offer and receive support. Issues directly relating to treatments, illness and so on were discussed, but so were much more conventional things such as current television and celebrity news, and so on. These topics can be seen to build and maintain conventional friendships, and are significant since they mean that the people involved in the sessions are there with a shared purpose and common ground that is more than just their illness.

In designing a web-based community, we wanted to ensure that it was focused much more on the community and social aspects than on the medical ones (Preece 2000). We wanted it to address the social issues; their medical ones were already being treated in a comprehensive manner. This focus provides one disambiguating factor over the multitude of chatroom or web-based bulletin board systems that focus on medical issues, including cystic fibrosis (e.g. Cystic 2004). However,

whilst it is the social dimension that requires the infrastructure to support, there will clearly be a strong medical dimension to the discussion – the patients will want to talk to other patients with similar problems and issues, to support each other and to gain increased access to knowledge and information.

## **INTERLINKING SOCIAL GROUPINGS**

One of the first issues to address in the design of the system is to clearly identify the different social groupings and channels of communication within and between those groups that exist in the real world. There are a multitude of social contexts that we should ideally support, each having a slightly different role in the development of the community as a whole.

### **Inner circle**

Firstly, there is the closed circle of patients – those children that suffer with cystic fibrosis. Overlapping that grouping are the counsellors, who provide support and guidance and access to information for the patients, and the medics, who are charged with the care and health of their patients.

Each of these groups have different internal ethics relating to privacy and shared information. Collectively, these people will not share any of their information with the general world. However, counsellors will not pass information on to medics, and vice-versa, and there are certainly areas of discussion amongst the patients that no adults are, or should be, privy to.

### **Outer circle**

Outside of these groups, the patients must be remembered to be children too, and so exist within a family unit and have certain friendships with both other children and with adults. These friendships are often fractured and incomplete, however, because their condition and its treatment sets them apart. We need to realize that certain patients will discuss their problems with a few select friends, and that this is, in general, a good thing. There is therefore an individual, patient-controlled conduit of information out into a select group of friends.

### **World**

Beyond these groups is the outside world in general, which has both positive and negative impacts on their lives, much as for any other child. The outside, public world is a social sphere that has only one-way influence on the community. Information from that world – news, celebrity gossip, sports – becomes part of the fabric of conversation of the patients. However, their problems and issues do not find open expression in public. This is both a reflection of patient confidentiality, and the social exclusion they feel as a result of having their illness.

Additionally, we have to ensure that the patients are not visible to the general public in order to protect them from predatory or vicarious individuals taking advantage of them by pretending to befriend them or offering unrealistic hopes.

These social groupings and barriers are shown in Figure 1. The circles identify the different social groupings: e.g. the public are not co-patients, but some friends are. For the CF patient, information primarily flows from left to right – happenings in the world affect some of the public, some of whom are friends and who percolate this across into the group of co-patients and to individuals; information about individuals, on the other hand, doesn't go anywhere except in a one-to-one conversation with a doctor or counsellor.

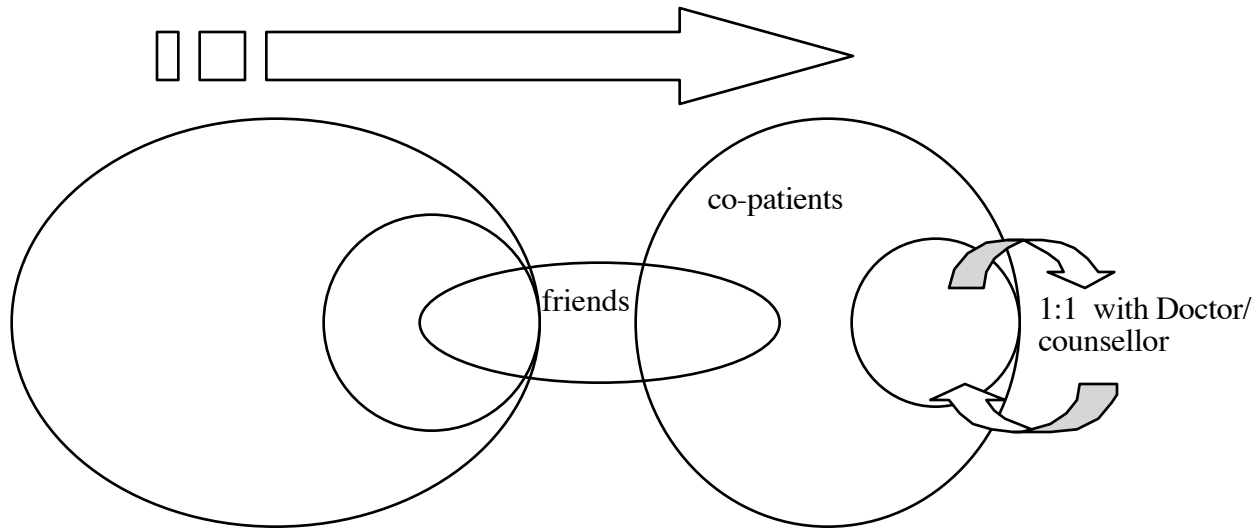


Figure 1: Social circles and intersections for CF patients

## DESIGN PRINCIPLES

It is critical that any system we design on the internet should reflect these social groupings and the existing flows of information, in order that the patients and staff can experience a sense of shared community and still understand and abide by the social protocols and implicit trust systems evident in real life. The system design does not have to mimic the face to face community approach that it is replacing, but it does need to reflect its values and priorities. We believe that the best software systems are those which use their technologies and media to best effect, and share concepts and goals, not those that merely mimic real-life.

### The basic community

This community takes the form of a bulletin board, where the children can post messages, reply to other people's posts, and generally share stories and experiences. The intention is to allow them to feel part of a supportive and caring environment, which is encouraged in a virtual world because it is simply not medically advisable in the real one. Making the bulletin board available over the internet allows a much wider participation, both geographically and temporally. Real-world group gatherings were often difficult for many participants to attend, reinforcing their social exclusion, whereas all patients can access the bulletin board wherever they happen to live. This is important, as at the Birmingham Children's Hospital, cystic fibrosis patients are taken from a wide catchment area. Most families tend to have computers with internet connections available at home, or at school, but if not then the local libraries provide a publicly available, free access point. The forum is persistent, so that people can log on at any time of the day or night and catch up on the material there. Its persistence makes it more accessible for new users, who can catch up on what is happening in this space. The asynchronous nature of the interaction means that they can use it as both an information resource and as a confidant even at 3am. It is restricted in users, in that only recognized patients and a few trusted adults are allowed to access the system.

The adults are there as guides and advisors, for whilst the system is designed to allow the children to help each other, there are times when specific questions require authoritative answers, or pointers to specific information needs to be given. The trusted adults play a watchful role, intervening in the discussions only to correct major fallacies or to address questions that others do not answer. They are not allowed to report the conversations to the children's specific doctors, and so act as counsellors, under counseling ethics of confidentiality. They provide a purely virtual presence that provides human contact and information to the patient.

## **Privacy**

Since privacy and trust is central to the community working effectively, we have taken a very clear principled approach to the notions of privacy that should exist within the system, and these are made explicit to all participants within the community. These exist on two levels; the first is social, in that people are reminded of the needs and rights of other participants. The second is technical, manifest in the access that is given to users to different parts of the system.

We have also kept in mind the underlying reason for the community in the first place – the space is for the patients, not the medics. This is reflected in that, for example, none of the conversations are passed back to the children’s own doctors – including the medical issues. Medical questions are dealt with by either the counsellors or by medics, but they will not be relayed on beyond the bulletin board. Medics or counsellors that are not part of the community are refused access in just the same way that the general public area.

### **One-to-one privacy**

We have designed the system to generally reflect the interwoven circles of existing social interactions. This means that there are areas that are closed to all except a patient and a medic, for directed personal question and answer interactions. There are private, closed areas for individuals to chat to other individuals in, allowing them to take aspects of more public conversations offline.

### **Restricted access areas**

The central closed area in which most discussions are expected to take place, which is accessible only to the patients and trusted adults, is the core of the site.

In order to allow a route for patient-controlled shared information we have provided a family and friends area, into which others can be invited by the patients. There is no general public access to the site at all.

The additional role of the family and friends area is to increase the sense of community that the children feel about their closed fora. By allowing them to invite friends and family in to see what they spend some time doing, they are encouraged to share a small part of their world with others they love and trust. This in turn means that the forum can become a shared experience for them, and because others know about it, it gains a certain status and importance.

## **SPECIFIC DESIGN**

Access to the site is limited to registered users only – there is no public access. There is therefore no anonymity allowed, which makes the forum safer for all and allows the counsellors to keep an eye on the postings to ensure the patients are not being groomed or harassed in any way. This makes it a more protected environment than in chat rooms or bulletin board systems that allow anonymous postings.

Patients are informed of the URL during clinics, and are given a username and password in order to access the site. They are also given a test username to first try out the system. Any unregistered people accessing the site are only able to view the registration page.

The site is loosely based on a street metaphor, since streets are regarded as cool places to hang out. The system is therefore known as “CF Street”, and is shown in Figure 2. Within this metaphor, we have to ensure that the multicultural, multi-ethnic nature of our patient base is reflected in the interface and naming conventions of the different fora within. We have therefore tried to give descriptive names to different regions of the site that express what they do without directly targeting specific social contexts – gossip about sports people and celebrities could have been put into a forum called “Whispers Wine Bar” or similar, but the implicit reference to alcohol is not appropriate for both a child-focused site and one with Muslim users.

### **Outer circles**

The site itself is split into different areas with differing levels of access. The most public area is called the “Rubbish Dump” – a practice area for users to mess around in and get used to the system, posting messages and replies to get the hang of the system. The rubbish dump is cleared out every few days. They are encouraged to log into this area using their test username, therefore disassociating themselves from any mistakes that they make in the initial few days. This

therefore tries to provide a safe place for people to make mistakes and generally get the hang of the technology, for many of our users are not hugely experienced web users.

At the same level of access is the family and friends area, called the “Public Park”. This is clearly marked as a public area, into which users can bring whoever they want. All friends and family are required to register, and once registered the patients can grant them access to the Public Park. By allowing patients control over who is allowed on and who isn’t we are able to give them a greater sense of ownership and control over their community, and are also able to associate family and friends with specific patients for auditing purposes, so that we can identify any problems or abuses and discuss them with the specific patients concerned. Patients are therefore responsible for the behavior of the people they invite to join the community, which makes for a greater value being ascribed to the community as well as a better quality of conversation and chat.

### **Inner circles**

The next level of restriction means that only patients and the counsellors can access the forums. Access is controlled by the moderator for the forums; patients cannot give access to anyone else. This private area is loosely split into arenas for different topics of conversation. “Café Chat” is designed for general discussions with fellow patients, whilst “Bike Sheds” are for gossip about celebrities, sports events and personalities, and so on. “Music Matters” is for rock, pop, rap and anything else relating to music. These groupings are arbitrary, and relatively unimportant, but they allow users to follow different conversation threads more easily and allow for simpler maintenance and management of the site than would one super-category. All these areas focus on the general social interactions that might happen in the real world.

We also support medical concerns in three different ways. “Corner Clinic” provides a forum for medical issues to be shared and discussed, with many of the responses coming from other patients. This provides both direct support for the concerned patient and a positive role for those providing the benefits of their experience, allowing them to contribute views of real value to the community. The counsellors more closely monitor this forum, providing guidance, input and information as needed. Their role is not to answer the questions (unless no-one else does), but to ensure that incorrect information is gently corrected, and to facilitate the provision of peer-to-peer support.

“Newsstand” provides the medics with a direct route into the CF community, as it is the outlet for information that they want to inform their CF patients about. Patients are able to comment and discuss the information in the Newsstand forum, but the medics, not the patients, create most new topics.

The final aspect to medical support is the “Help! 911” forum. This is not actually a bulletin board, unlike all the other areas, but provides a private messaging space for the user to communicate directly with a doctor or counsellor. Using this channel, they can raise any issues they wish on a one to one basis. In this area, none of the other patients can see what is posted or what the replies are – this represents the most confidential conversation supported by the system.

The system also supports private messaging (effectively, email written, delivered and accessed though the bulletin board system) between individuals, so that patients can take conversations away from the public space and have private discussions.

We are also investigating allowing patients to create their own groups of friends, which can then interact with each other as a group but away from the gaze on uninvited users. However, there are problems with this approach as it could lead to insulated cliques of users, with people only talking to their current set of friends. Whilst this may well reflect external social realities, it may not be the best thing for the individuals concerned, nor for those excluded from these gangs.

## **IMPLEMENTATION**

### **PhpBB**

The community is implemented using phpBB v 2.0.6 (phpBB 2004), a publicly available, free (GPL) bulletin board system. phpBB offers a highly customizable interface which allows you to set up and manage multiple forums, complete with administration and management tools, security profiles and messaging capabilities, and is written in php, running on a web server and accessing a Postgress database. Once the design principles and privacy issues were decided upon, these were mapped into the structure and security settings of phpBB, which provided nearly all of the required functionality without major modifications. Some minor changes were required, such as predefining parameters to the private messaging function to provide the “Help! 911” feature. The focus for the project could therefore be on the

principles necessary to create an effective community, rather than on specific implementation issues. The overall implementation of the system was completed within 6 days, with a further few weeks for testing and minor modifications.

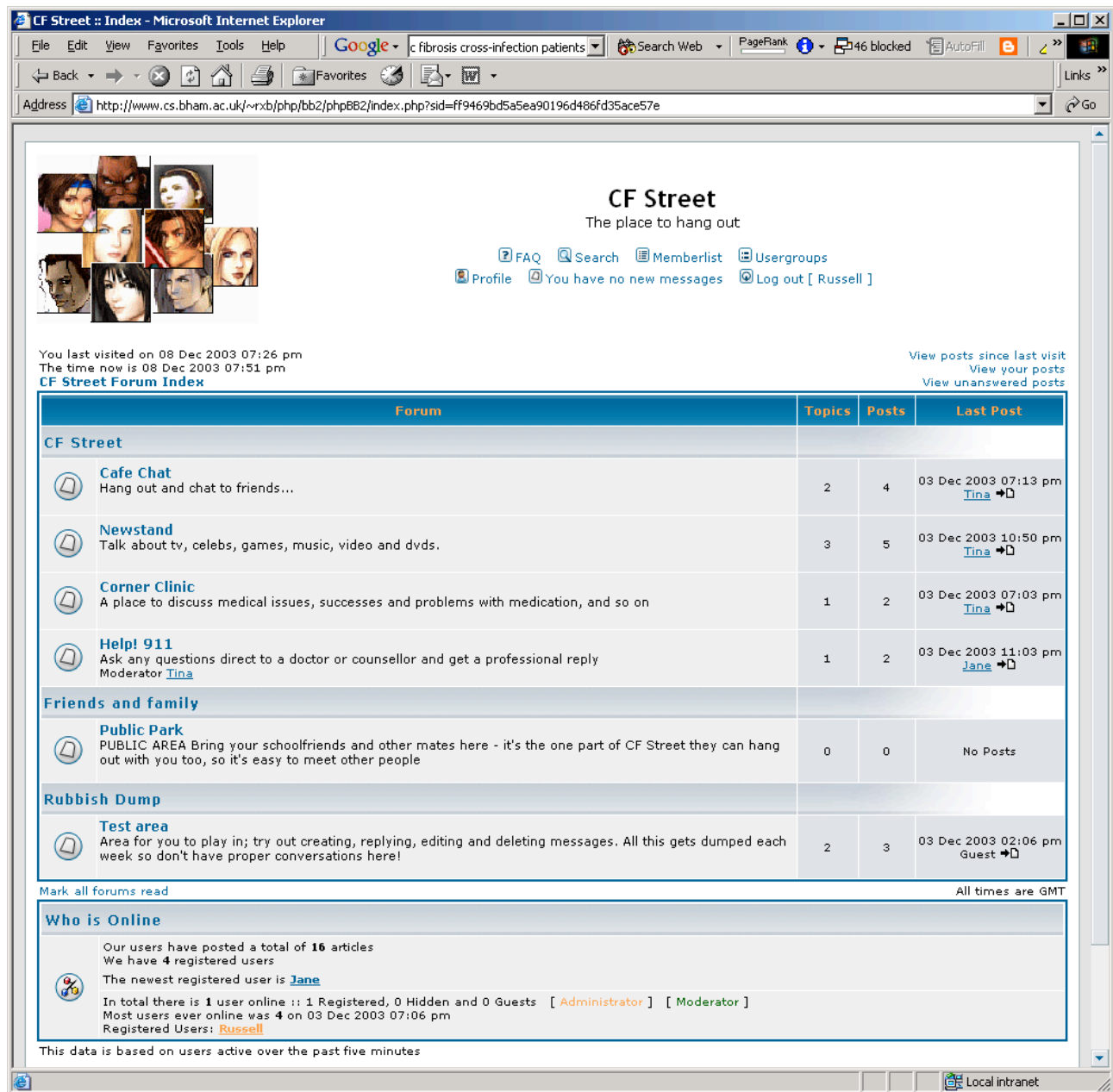


Figure 2: CF Street

### Inbuilt community features

PhpBB offers a number of inherent community-building features, which are worthy of note. It provides information on who is currently online, and allows users to send private messages direct to those people. Each user has a profile that describes them to others, and these are fully editable by the individual concerned. Each user can also associate an avatar (a small digitized image) with their name, which gets displayed in each of their posts. There are a large number of

(predefined for taste's sake) avatars available so that users can invest their postings with their personality, whilst their profile allows them to divulge as much or as little information about themselves as they wish.

One of the sharing behaviors that we would like to support is the ability to upload photographs and images onto the system, as we believe that this would be appreciated and valued by our users, and would in turn lead to greater use being made of the system. However, because patients could upload any images, inappropriate use of this could lead to problems, and we are considering options. One is to have forum moderators check all photos before they become publicly available, but this goes against the spirit of allowing the patients their privacy and freedom to discuss whatever they wish without too much adult censorship.

Normal social behaviours are allowed (swearing, mild abuse, etc.). Gentle steering by moderators and peer pressure is used if an individual is heading towards offensive material, with moderators allowed to delete particularly offensive postings. Management tools that can target single users are available within phpBB, so there is a way of restricting or denying access to individuals, a potentially useful sanction.

## **EVALUATION**

The system has been evaluated against its goals by the design team, counsellors and medics. Informal evaluations have been coupled with qualitative heuristic evaluation techniques (Nielsen 2004, Nielsen and Molich 1990) that assess how well the system meets its design goals. The results of the evaluations are given below.

### **Basic functionality**

CF Street offers a forum in which users can discuss both medical and general issues with a like-minded peer group. By posting messages and receiving replies, commenting on those replies and generally building up a threaded conversation, the system engenders a feeling of community; this is typical of any bulletin board system. Offering users the opportunity to customize their profiles and give more personal information is particularly useful for the children. In particular, having a choice from a multicultural avatar set, including cartoon and common television personalities, is attractive to our target audience.

### **Social interactions**

The different levels of access to the site provide the required layering of social interactions. The family and friends area was added after we realized that we needed to support the flow of information from parts of the community out into a wider context. It is also able to enhance the sense of belonging to something, since patients can now show others what it is they actually belong to. This demonstrates the interlinking of the different social circles that the patients move in, where the notion of control of information flow is highly significant in order for the patients to retain control and privacy.

With clear privacy policies, the system meets its goal of providing a safe place for patients to talk amongst themselves, and also meets the need for more personal one-on-one interactions through the personal messaging. The flow of information available using CF Street has strong parallels with the real world and meets our aim of supporting key flows, such as between patients, and between patients and their friends.

Despite a focus on patients and not medics, the system still provides functionality that wasn't previously so readily available; important information can be emailed or broadcast to all patients using the system, either through the Newsstand forum or through the administrative tools that the site provides.

### **Ease of use**

As far as patients are concerned, they simply log on to CF Street and can use it. They are not aware of security levels, permissions and policies, though as they invite family and friends they become aware that those people have less power than they do. Bulletin board concepts like moderators are not necessary, since the accepted and understood roles of counsellors and medics are able to take the same role.

Using Nielsen's usability approach we can demonstrate that the system is easy to understand, use and work with on a regular basis.

## **Technical considerations**

PhpBB has been extensively tested in the wider community and so is secure, reliable and fast enough for our needs. Access to the system only requires a web browser, and the site has not been overloaded with graphics making it perfectly acceptable when working under conventional modems on dial-up connections. For users without home access to computers, most schools provide a place where they could use CF Street from, but failing that the local libraries also have access points.

## **Community issues**

Since CF Street is designed to support the specific needs of a defined community, it does not have the same issues as many other more general communities do (Dorine 2002). It initially gets users because they are patients who are told about CF Street in their clinics. Publicizing and advertising the community is not necessary, since it is not for public access. Retaining users for any community is easy if the community gives them something that they need and cannot gain elsewhere; CF Street does exactly this, offering a replacement for the now defunct face to face group meetings of the past and addressing the social isolation felt by the children.

The persistence of the board allows new users to gain a lot of information and support initially without having to actively contribute, which is helpful, whilst a diverse user base who actively want such a community ensures that it develops and remains current.

PhpBB does have multiple language support, though Hindi is not yet available; once it is, we will offer a Hindi version of the system. This only affects the skin of the application, however – the language of the bulletin board is unchanged. Since we are targeting children, however, their acceptance and use of English is quite widespread. Moreover, as an asynchronous system, patients can take as long as they wish to compose their postings, allowing them to make their post as correct as they care to. This gives us another advantage over a chat-based system which requires some level of competence in both English and keyboard skills in order to be able to effectively participate.

One of the other benefits of CF Street is its cost-effectiveness. Not built with this in mind, it none-the-less offers some considerable savings. Ambulances are not needed to transport patients to group meetings. Counsellors and medics do not have to set aside specific times to work with the patients, but can respond during any slack time they may have. Space for gatherings does not have to be found, and information can be widely and quickly disseminated for practically zero cost.

## **CONCLUSIONS**

CF Street represents a particular solution to the needs of a specialized community. It has been built around strong principles of privacy and mutual support, blending the two in different ways to provide a space in which a variety of conversations can take place, from the widespread idle gossip to one-on-one consultations and counseling sessions. It has tried to build in features to give it a strong identity, one that the members can share parts of with trusted friends, but which remains uniquely their own. It offers an attractive, viable approach to friendship making, mutual support and advice that is infeasible any other way.

## **REFERENCES**

- Andrews, D., and Preece, J., (2001). A Conceptual Framework for Demographic Groups Resistant to Online Community Interaction, Proceedings of the 34th Annual Hawaii International Conference on System Sciences (HICSS-34)- 7, pp7013-
- Cystic (2004). Cystic Fibrosis Medicine – chatroom at <http://www.cysticfibrosismedicine.com/chatforum.html>
- Dorine C. A. (2002). Audience-specific online community design Communications of the ACM Volume 45 , Issue 4 (April 2002) Special Issue: Supporting community and building social capital. pp 64-68.
- Govan JR, Brown PH, Maddison J, Doherty CJ, Nelson JW, Dodd M, Greening AP, Webb AK (1993). Evidence for transmission of *Pseudomonas cepacia* by social contact in cystic fibrosis. *Lancet*. Jul 3;342(8862):15-9.
- Preece, J. (2000). *Online Communities: Designing Usability and Supporting Socialbility*, 1st edition, pp464 John Wiley & Sons, Inc. New York, NY, USA.

Leeds (2001). MRSA in Cystic Fibrosis, Miles Denton. May, 2001. Leeds University Teaching Hospitals, Leeds, UK.  
<http://www.cysticfibrosismedicine.com/htmldocs/CFTText/mrsa.htm>

Nielsen, J (2004) 10 Usability Heuristics, [http://www.useit.com/papers/heuristic/heuristic\\_list.html](http://www.useit.com/papers/heuristic/heuristic_list.html)

Nielsen, J., and Molich, R. (1990). Heuristic evaluation of user interfaces, Proc. ACM CHI'90 Conf. (Seattle, WA, 1-5 April), 249-256.

PhpBB (2004) PhpBB: creating communities. <http://www.phpbb.com/>

## **ACKNOWLEDGMENTS**

Thanks to the patients, counsellors and medics from Birmingham Children's Hospital for their enthusiasm, input and advice. A special mention must go to the authors of PhpBB for writing and making freely available a great piece of software. Particular thanks go to Dr. Tina Newton, Paediatric Registrar, BCH.

## **COPYRIGHT**

Russell Beale. © 2004. The authors assign to OZCHI and educational and non-profit institutions a non-exclusive licence to use this document for personal use and in courses of instruction provided that the article is used in full and this copyright statement is reproduced. The authors also grant a non-exclusive licence to OZCHI to publish this document in full in the Conference Papers and Proceedings. Those documents may be published on the World Wide Web, CD-ROM, in printed form, and on mirror sites on the World Wide Web. Any other usage is prohibited without the express permission of the authors.