NIHR Health Services and
Delivery Research programme

NHS
National Institute for
Health Research

HS&DR Protocol
Project Ref: 10/2000/40
Version: 1
Date18 January 2012

Meeting the support needs of patients with Complex Regional Pain Syndrome (CRPS) through innovative use of wiki technology

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Sponsor	University of Bath
Funder	HS&DR

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Summary: We propose to implement and examine two forms of online support for people with Complex Regional Pain Syndrome (CRPS): an online community and a patient-centred information resource. The team's previous research has shown that participation in online forums is potentially beneficial in terms of psychological support processes, especially by fostering the development of a positive group identity and self-validation. Whilst we expect these processes to occur naturally in an online message forum, there is no guarantee of a positive outcome: online interactions can be negative as well as positive. We want to facilitate positive engagement among members of a patient community through the innovative use of a wiki. A wiki is a technological environment that allows its users to work together to write web pages. Contemporary wiki tools incorporate discussion facilities akin to online forums, through which people can share ideas related to the pages they are collaboratively writing and editing. Using this medium, people with CRPS will participate in a structured collaborative writing activity intended to help them construct a positive collective identity. The collaborative writing task will culminate in the provision of a publicly accessible website – a patient-centred information resource - which raises awareness and understanding of their condition, thereby overcoming an impediment to offline support identified by this patient group. From a research perspective, a wiki has the added advantage of preserving all of the contributions, discussions and collective corrections and additions made to the document. In this way we extend previous research, by not only providing online support and a publicly available website, but also an analysis of processes through which they are produced.

Aims and objectives:

- To set up a peer support online forum in order to identify the nature of support provided and to explore its development over time.
- To facilitate the development of social processes implicated in psychological support by applying a technological innovation known as a wiki.

This will allow us to explore in greater depth the following questions:

- What constitutes support in newly developed online interactions?
- How does the process of giving and receiving support online evolve?
- Can the combination of an online forum *and* a collaborative writing task increase support as well as a sense of psychological and physical well-being relative to an online forum alone?

Background:

What is CRPS: Complex Regional Pain Syndrome (CRPS) is difficult to diagnose and is characterised by burning pain in one or more limbs, swelling, and temperature and color changes, with 15-20% of patients developing long term disability (Geertzen, Dijkstra, van-Sonderon, et al., 1998). The cause is unknown and there is currently no cure. It has an incidence of 5.46-26.2 per 100,000 person years (Sandroni, Benrud-Larson, McClelland & Low, 2003). For those patients whose symptoms do not spontaneously resolve within the first year, long term residual symptoms or impairment are common. Treatment is palliative rather than curative and so focuses on improving function. CRPS can be both distressing and debilitating and have a considerable impact on the lives of both the person with CRPS and those closest to them (Kelmer & Furnée, 2002).

What is the impact of CRPS?

Impact on person: CRPS can have a negative impact on the physical, emotional, social and financial aspects of patients' lives (Rodham, 2009). CRPS pain is often invisible and is difficult to explain to family, friends and colleagues. In addition, patients are faced with the frustration of no longer being able to do the things they used to and can lose their sense of identity. Furthermore, patients have reported that their health care professionals, lack knowledge of CRPS as a condition and this is a source of considerable frustration (Rodham, 2009).

Impact on carer: A study on the carer experience of CRPS (Lauder et al., submitted) demonstrated that they were disappointed to discover that CRPS was not well known or understood by health professionals. Furthermore, obtaining information from the Internet, which often displayed 'worst case scenario' accounts and pictures, created uncertainty and anxiety about how the CRPS might progress and what it meant for the future of their relative or friend. Sverker et al. (2007) suggested that providing relatives with better information might have the added benefit of improving the situation for the patient. The way in which significant others respond to the person with CRPS can impact negatively on the person's illness experience (Beugnot, 2002). Furthermore, there is a growing body of research which suggests that chronic illness may have profound effects on the well spouse (Maugham et al., 2002).

Coping with CRPS: The relationship between social support and physical and psychological well-being is well documented and includes positive adjustment and coping with illness (Holland & Holahan; 2003), increased positive health behaviors (Franks, Stephens, Rook *et al.*, 2006) and decreased physical disability (Beugnot, 2002).

Current NHS policy and practice: Multidisciplinary rehabilitation (including psychological interventions) is recommended for the management of CRPS (Harden, Swan, King, Costa & Barthel, 2006). Patients in the UK may be referred to an inpatient programme at the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath. This is the only specialist inpatient programme for people with CRPS in the UK. The programme at the RNHRD is multi-disciplinary, with a focus on physical rehabilitation (including physiotherapy, occupational therapy and hydrotherapy) and also includes sessions with health and clinical psychologists. Since treatment is palliative rather than curative, the main objective is to improve function and to encourage self-management implementation of skills developed on the in-patient programme (i.e. adherence to advice) is essential in order to lessen the impact that CRPS has on patients' lives. Furthermore, active participation in the treatment process by the person with CRPS is essential for successful rehabilitation (Bruehl & Chung, 2006). Online support can complement the rehabilitation process.

Online support: Online discussion forums are increasingly used by patients as a source of information, advice and psychological support for health related issues. While face-to-face support groups provide members with the opportunity to help each other, online forums provide similar opportunities, but also open up the possibility for discussing taboo topics and forms of self-expression that are often unavailable offline (Adams, Rodham & Gavin, 2005). There is growing evidence that forum participation can have a positive impact, for example, reduced sense of isolation, increased self-efficacy, and reduced anxiety (Coulson, Buchanan, & Aubeeluck, 2007). Of particular importance is the development of a shared group identity and consequently the validation of patients' thoughts, feelings and experiences (e.g. Adams et al., 2005; Mo & Coulson, 2008).

To date, research in this area has been conducted retrospectively on pre-established message boards. None have created a board from scratch and/or charted the development of support over time. Furthermore, the bulk of online support has been restricted to discursive online systems (such as online forums) and not made use of web technologies designed to encourage collaborative writing and joint accounts of feelings, experiences and other condition-relevant information. Wikis are community-centred technologies that were invented to support collaborative document production with minimal technical knowledge. They are, in essence, web pages with an edit button. MediaWiki is the most well-known example as it is the platform on which Wikipedia runs, and includes mechanisms for making community roles and behavioural norms visible (Butler, Joyce & Pike, 2008). The productions of community members include not only the equivalent of a web page but also the discussion behind it. The discussion is quite unlike other online forums because it is editable in the same way as the web page and permits community members to debate alternate viewpoints (Billings & Watts, 2010).

Previously there was an interactive forum for people with CRPS (known as ‘RSD UK’). However this has closed. Many people with CRPS in consultation with one of the applicants in her role as CRPS Health Psychologist have mentioned that they miss this source of support and would like to have such a forum resurrected. Currently people with CRPS who have been treated at the RNHRD are able to join an independently run peer support group for people with CRPS (crps@themin) which is currently a static resource providing information and downloadable text resources but with no capacity for online interaction.

This project will contribute to an area of significant and growing need and extend previous knowledge by: bringing together practising health professionals, academic psychologists and computer scientists to draw to provide innovative online support for patients. This will be achieved by following the development of an online forum *from its inception,* and investigating whether and how a wiki-based discussion system contributes to supportive activity. It will inform the planning and provision of better health services by: meeting expressed needs of patients; providing a publicly accessible website that raises awareness and understanding for health-care professionals, and the partners, family and carers of those with CRPS; providing a set of guidelines for a combination of cost-effective web-based support, designed specifically to encourage supportive interactions.

OUTCOME MEASURES

A key aim of our study is to explore what constitutes support in online forums and how such support develops.

We have noted above that rehabilitation and adaptation to CRPS can be enhanced if people with CRPS have adequate and appropriate levels of support. We intend to measure support through a qualitative analysis of the online forum and wiki interactions exploring whether elements of support (e.g. Information, Emotional, Esteem, Network and Tangible Assistance) as identified by Coulson (2005) are present. This typology has been successfully used in other studies of online support (Coulson et al., (2007). In addition to analysing the online interactions, we also intend to take measures of the participant experience at three different time points. A tool particularly suited to measuring this is the Patient Generated Index (PGI). Using the PGI in conjunction with generic measures of health status (Hospital Anxiety and Depression Scale, Short form of the McGill pain questionnaire, the brief COPE inventory) will enable us to ensure we address the key elements that the Department of Health (2008) suggest should constitute Patient Reported Outcome Measures (PROMs).

NEED

The importance of the proposed research is three fold:

- To extend the evidence base and current knowledge by exploring the conditions which facilitate supportive activities in an online environment
- To provide effective and relatively low-cost support for out-patients by combining innovative web-page and discussion technologies in an integrated and user-centred manner
- To provide the type of support and information for friends, family and carers explicitly requested by members of the CRPS patient support group attached to the Bath Royal National Hospital for Rheumatic Diseases (RNHRD)

METHODS

Design and theoretical/conceptual framework: This is a mixed methods research design conducted over three phases. In Phase 1 an online forum for people will be developed and all members of crps@themin will be invited to join it, subject to agreeing to the moderation policy we have developed in anticipation of this work (see ethical considerations below).

Phase 2 will commence after three months, when we will introduce a collaborative writing task using a wiki which will run alongside the forum. In this task, forum members will be invited to co-construct a web page presenting CRPS in a way that they feel addresses the misconceptions around the condition. This will be modelled on the Wikipedia page (http://en.wikipedia.org/wiki/Complex_regional_pain_syndrome) for the same condition but from the point of view of the participants themselves. We expect a 50% take-up rate, meaning that some participants will remain in the forum only, and others will participate in both the forum and the wiki task simulataneously.

Phase 3 will commence three months later, when this page will be made available to friends/carers of forum members and their feedback sought. After a further 3 months, participants will be invited to take part in an online focus group exploring the experience of participating in these online activities. The continual feedback provided by both the forum and wiki allow an iterative design process that can be adapted to patients' needs and experiences as required.

Sampling: The commencement of the project will be announced via a flier which will be sent to all members of crps@themin inviting them to participate.

Participants for phase 1 & 2 will be drawn from a convenience sample consisting of those members of crps@themin who indicate a willingness to take part. crps@themin is an independent support group formed by and for those who have been diagnosed as having CRPS and who have completed, or are currently undergoing the rehabilitation programme run by the RNHRD. This support group has been running for approximately one year. Each year the RNHRD sees approximately 80-100 new patients, all of whom will be informed of the existence of crps@themin. Participants will themselves recruit family and friends for Phase 3 of the study.

- Forum participants: between 30 and 50 members of crps@themin
- Wiki writing task participants: a subset of the forum participants consisting of 15-25 members
- Friends/family/carers: recruited by those completing the wiki writing task, n=15-25
- Focus groups: friends/family/carers who participated in phase 3 will be invited to participate in online focus groups. Each focus group will consist of between 4-7 participants.
- Focus groups: people with CRPS who have participated in the forum and/or the wiki will be invited to participate in online focus groups. Each focus group will consist of between 4-7 participants.

Rationale for sample size: CRPS is a rare condition. Its rarity is one of the reasons why people with the condition find it difficult to understand and difficult to explain to others. Our sample is intended to be representative of the patient experience in these respects and will be drawn from the small existing population of CRPS patient group members.

Setting/context*:* This study will take place in an online environment but will be followed up with focus groups and interviews at the RNHRD, a clinical environment with which members of the support group are already familiar.

DATA COLLECTION

Phase One: An online forum for people will be developed and all members of crps@themin will be invited to join it. Those who do so will be asked to complete a short online survey that will enable us to measure the participants experience of CRPS and of the support available to them. The survey will consist of: initial background questions on the use of the Internet, experience in other off- and online support groups, and an Internet self-report measure (Joiner et al., 2006); the Patient Generated Index (PGI); the Hospital Anxiety and Depression Scale; Short form of the McGill pain questionnaire; and the brief COPE inventory. This gives us a ‘start-point’ measure that we can use to compare against measures taken later in the research so that we can see how people’s quality of life varies over time.

Phase Two: After the forum has run for three months we will invite members to complete the online survey again. We will also analyse the conversations that have taken place on the forum so that we can begin to understand whether and how support is developing. At this point we will introduce the wiki writing task.

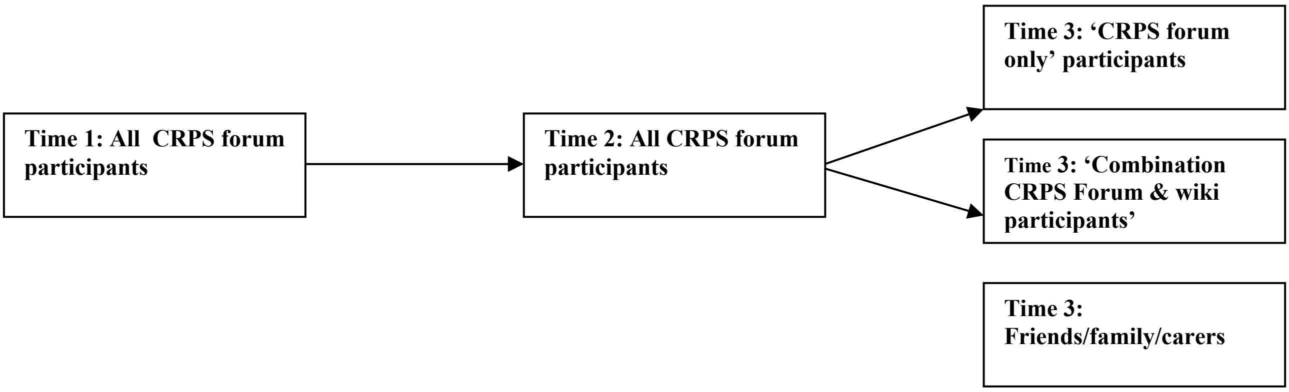
Phase Three: At this point, the forum will have been running for six months and the wiki for three. Participants will be asked to complete the online survey and the media wiki will be made available to friends and family. Three months later, friends and family will be asked to provide feedback through online focus groups about their perception of the wiki and subsequent understanding and responses to CRPS. In addition, members of the forum and those who contributed to the media wiki will be invited to take part in an online discussion led by the researchers with the aim of gaining in-depth understanding of the participants’ experiences of using the forum and developing the wiki. Both the forum and the media wiki will be designed so that they can continue to run beyond the life of the research.

ADDRESSING THE RESEARCH QUESTIONS

In summary, the research we are proposing is designed to answer the following three questions:

1) ***What constitutes support in newly developed online interactions?***
2) ***How does the process of giving and receiving support online evolve?***
   We will measure support through a qualitative analysis of the online forum and wiki interactions which will have been archived at the same time that participants complete the online survey. This qualitative data will allow us to explore whether elements of support (e.g. Instrumental, Informational, Practical and Emotional) as identified by Vaux (1987) are present and whether they change over time. In addition to analysing the online interactions, we will also have comparative data from the online survey that will have been completed at three different time points.

3) ***Can the combination of an online forum and a collaborative writing task increase support as well as a sense of psychological and physical well-being relative to an online forum alone?***



Data will be collected at three points, see above diagram. Baseline data will be collected at Time 1 from all crps@themin participants taking part in the CRPS online forum. Time 2 data will be collected from crps@themin forum participants after three months of forum activity. Time 3 data will be collected three months later. At this stage, the crps@themin participants will constitute two different groups: some participants will have been participating in the forum only, others will have taken part in a combination of the forum and the wiki task. The time 3 data will allow us to compare these two groups. In addition focus groups will also be conducted with the carers who have had access to the now completed wiki page.

DATA ANALYSIS

Online survey data: Assessed at phases 1, 2 & 3 of the study via online survey and archiving of online interactions. Data will be entered into an SPSS database and analysed using descriptive statistics – the aim being to identify any trends over time, rather than for statistical significance.

Forum Interactions and Development of wiki page (people with CRPS): Thematic analysis on the preserved texts (online comments, amendments, deletions & discussions) with the aim being to identify how participants worked collaboratively to reach consensus about what to include on their wiki page. In addition, types of support will be identified using the typology as set out by Coulson (2005). A content analysis will be undertaken using a coding framework based on the five categories of social support, using Cohen's kappa as a measure of inter-rater reliability.

Focus Group Data: The focus group data will be analysed qualitatively using Interpretative Phenomenological Analysis (IPA). Detailed IPA guidelines produced by Smith, Jarman and Osborn (1999) will be adhered to. In order to increase the "trustworthiness" of the findings, the transcript will be independently coded by another trained IPA analyst (NC), and checked for consistency. The final themes were chosen on the basis of the richness, universality and salience of the theme in the transcripts, rather than based on prevalence of the theme alone.

CONTRIBUTION TO COLLECTIVE RESEARCH EFFORT AND RESEARCH UTILISATION

There will be two key outputs from our study. The first being the online support resources (forum and wiki). These will be linked to the existing crps@themin webpage on completion of the study and will be available for people with CRPS, their carers, friends and family members as well as healthcare professionals who work with people with CRPS. The second output is more academic in nature and consist of a contribution to the theoretical literature concerning online support. This knowledge will also be utilised by the multidisciplinary team at the RNHRD who can incorporate relevant elements into their practice.

Output 1: online resources: The forum will be a source of online support and the wiki is designed to promote knowledge of CRPS amongst patients, the family, friends and health care professionals dealing with CRPS. This will be disseminated by:

- Annual National CRPS Conference held at the RNHRD to promote wiki
- crps@themin support group, can link from their web site, plus support group conference, link from homepages
- Reference in any publications or conference presentations derived from this study
- Presentation at in-house hospital research meeting
- Workshop to hospital IT support services
- The wiki and forum to be self-sustaining at the completion of this project. Members will be trained to moderate and administer the site, as well as to train future moderators and administrators. The cost of sustaining and self-managing the site will be negligible (£60-80 per year). The patient support group is involved in fund raising and will be in a position to budget for this cost.
- At the end of this project we will create a template for the system that could be used with a wide range of commercial hosting companies. This will allow the work to be taken-up by other patient groups in other settings. We shall also prepare a short 'Patient Guide' for using online forums and moderation, which will be supported by podcast linked to University of Bath

Output 2: an understanding of what constitutes support in online forums. This will be disseminated via academic papers and conferences. For example:

- International Association for the Study of Pain (IASP), British Society of Rheumatology conference, and Divissn of Health Psychology conferences
- Academic (e.g., Cyberpsychology, Behavior and Social Networking, and Psychology and Health) and professional journals (e.g. Musculoskeletal Care; Health Psychology Update)
- Stakeholder or user events such as crps@themin patient information days

PLAN OF INVESTIGATION AND TIMETABLE

Task	Month																	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Bi-monthly team meeting	▨		▨		▨		▨		▨		▨		▨		▨			▨
Liaise with CRPS support group	▨					▨				▨				▨				▨
Technical design of forum	▨	▨																
Create online survey	▨	▨																
Prepare ethics application	▨	▨																
Advertise for RA	▨																	
Steering group meeting			▨						▨				▨					▨
6 monthly report prepared & submitted						▨						▨						▨
Recruit RA		▨																
Submit ethics	▨																	
Launch forum					▨													
CRPS participants complete online survey					▨				▨				▨					
Forum runs						▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Forum moderated						▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Wiki designed				▨	▨	▨	▨	▨										
Survey data analysed						▨				▨				▨	▨	▨		
Wiki task									▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Wiki made available to friends, family etc													▨	▨	▨	▨	▨	▨
Forum/wiki data archived									▨				▨				▨	
Online focus group(s)															▨			
Analysis of focus group data																▨	▨	
Train users to self-manage forum																	▨	▨
Link forum to CRPS@themin																		▨
Write-up research									▨	▨	▨	▨	▨	▨	▨	▨	▨	▨

APPROVAL BY ETHICS COMMITTEES

The CRPS support group around which this study is based is independent of the NHS, and therefore the study does not require NHS ethics approval. The project needs approval from the University of Bath Psychology Ethics committee only. This committee meets monthly. The Chair of Central Bristol REC has confirmed that the project does not require review by an NHS REC. In line with our professional commitments, we will adhere to the ethical guidelines of the British Psychological Society (2009) and the guidelines for psychological research on the Internet (BPS, 2007). Ethical approval for the study will be obtained from University of Bath Psychology ethics committee. This committee meets monthly, and can approve the full three phase programme of research in a single application at the commencement of the study. Fully informed consent will be sought from all participants at every stage of this study. His is in part an observational study of user engagement, and users will be informed that we are analysing their discussions. Informed verbal and written consent will be obtained from both people with CRPS (Phase 1-3) and their carers (Phase 3).

Anonymity and confidentiality of focus group participants: As friends/family will be recruited via the person they support, they will have knowledge of each others' participation in the study. This will made explicit in the recruitment materials and on the consent sheet.

Access to Participants: Participants will be recruited via the crps@themin support group (Phase 1 & 2). Family and friends (Phase 3) will be recruited via the participants in the forum and wiki. All participants in Phases 1 and 2 will be emailed an information pack and asked to pass it on to a friend or family member who they think might take part.

Moderation, anonymity and confidentiality of online wiki and forum participants: Use of the site will be subject to the same terms and conditions that are in force for the online resources provided by NHS Choices (http://talk.nhs.uk/terms/houserules.aspx). These terms and conditions are intended to safeguard members from inadvertently exposing themselves to the risk of criminality, such as identity theft. They further protect those who run the site from prosecution in the case of the illegality of actions its users might carry out by clearly debarring any form of activity that might be in breach of criminal or civil law. We shall additionally make clear that the content that users create should not be read or used as any form of officially sanctioned health advice. Contributions to the community site will be moderated by broadly the same set of rules that govern contributions to the NHS Choices communities. Moderation will be undertaken by members of the research team on a rotating basis. We will check the site on a twice daily basis, first thing in the morning, and last thing in the afternoon. In joining the wiki and/or the forum, participants agree to abide by the terms and conditions we outlined in our protocol and as such we do not envisage moderating being an onerous task. All team members will be trained to undertake these editing actions by the technical support person. Future moderation will be undertaken by members of CRPS@themin. They will be both trained to moderate, and in turn to train others to moderate. This will ensure that they will have the skills to moderate the forum themselves, and to create accounts for new members. NC has experience at providing such training and will lead this phase of the project.

We do not intend to remove any contributions on the grounds that they promote a particular health perspective. However, we would remove contributions and retain the option to bar the relevant contributor, in the case that there is clear evidence that the contribution was offensive. Users will be free to use their own names, however they will be required to maintain the anonymity of any friends, family or health care professionals that they might discuss. If and when members fail to do this, the relevant identities will be edited out of the online text and the member reminded of their obligation to respect third parties.

PROJECT MANAGEMENT

Day-to-day management: Jeff Gavin (JG) will be project manager, and therefore responsible for overseeing the day-to-day management of the research. He will be responsible for overseeing the RA, and will hold one-on-one meetings to discuss a) the project (e.g., setting targets, meeting deadlines) and b) the RA's broader well-being . He will also hold monthly He will ensure ethics requirements are maintained throughout the project and will be the point of contact for users of the forum and wiki who have any problems, queries or complaints

Team Management: There will be bi-monthly team meetings chaired by JG. Team members will provide written updates of their activities, including progress towards to meeting targets and expenses claims. Interim meetings will be held when needed via skype. At the first meeting with the team and the RA, the protocols, responsibilities and targets for each bi-monthly period will be clearly outlined, and assigned to appropriate personnel. For example, Karen Rodham (KR) will be responsible for patient-group liaison; Leon Watts (LW) for liaison with technical support design, and technical set up of forum and wiki; Neil Coulson (NC) will oversee the moderation of the forum and wiki, the content analysis of user interactions.

Steering Committee: JG will establish a steering committee to provide guidance on the implementation of the project. It will meet at the beginning of the project, and then one month prior to the commencement of each new element of the study. In addition to the applicants, the committee will include members from the patient support group, as well as the university and hospital computing support team. This will enable users and stakeholders to have input into the design of each phase of the study.

SERVICE USERS/PUBLIC INVOLVEMENT

The participants in this study will be the service-users themselves. The commencement of the project will be announced via a flier which will be sent to all members of crps@themin inviting them to participate. Participants will themselves recruit family and friends for Phase 3 of the study.

Design of the online resources: The chair of crps@themin will sit on the steering group, and will therefore have ongoing input into the design of the project. In addition, the team will liaise with members of the crps@themin group who will be invited to comment on the proposed design of the forum and the wiki. This will ensure that the online resources we develop will be in a format that is acceptable to those who will be using them. We will build in a feedback loop to enable that any practical/design problems experienced by users with the online resources will be identified and addressed promptly by the team.

User protocol: At the start of the study users will be invited to contribute to the user protocol. Legally and ethically we must follow BPS ethical guidelines and adhere to the terms and conditions of online participation adapted from the NHS Choices guidelines. However, how this is achieved will be negotiated with users, who may request additions to the protocol.

Handing over: Towards the end of the study, we will train some members to become ‘expert patients’ and to take on the moderating role themselves.

Dissemination: In terms of dissemination, we will write a report that will be posted on the crps@the min web page, will present at a face-to-face meeting of the crps@themin support group. The actual process of participating in the wiki-phase will remain private, but the online resource developed will be publicly available. A crps@themin forum member will co-present at a national conference to disseminate a service user’s experience of the services.

EXPERTISE AND JUSTIFICATION OF SUPPORT REQUIRED

The multi-disciplinary project team was selected to bring together complementary strengths, skills and knowledge from health psychology (academic and practitioner experience) and human computer interaction. Through its synthesising of disciplinary areas, the project will contribute to knowledge and practice concerning online patient support, coping and self-management.

JG is a lecturer in Department of Psychology, University of Bath. He has extensive experience in qualitative research, and online methods. He investigates the social aspects of online communication including, identity management and construction in online settings, online support for health related issues, and the role of media in public health communication. He has worked for the National Centre in HIV Social Research in Sydney, Australia, and has conducted several projects on online communication and relationships for Match.com. JG and KR have collaborated on several projects investigating online social support and identity management in relation to several patient populations, including deliberate self harm and eating disorders. They have also have an interest more broadly in online methodologies, and have published several journal articles and book chapters on online ethics. JG will be overseeing the day-to-day running of the project and budget, liaising with co-investigators, and will act as line manager for the RA. He will also lead the write-up and dissemination of findings. It is anticipated that these tasks will require an average of half a day per week, and has been costed accordingly.

KR combines a practice role in the NHS with an academic role at the University of Bath. In her practise role she runs a health psychology clinic for patients who have CRPS and focuses on developing patient support and coping skills. In her academic role she contributes to the teaching on the Masters in Health Psychology. She also conducts research specialising in exploring the coping strategies employed by people when they are facing difficult situations, and has experience in administering and scoring the Patient Generated Index. Karen has expertise in the conduct of qualitative research and has published widely in respected academic and practice journals. Recently her focus has been on exploring how the Internet might be a means of obtaining support for groups who are marginalised, often because they have mobility issues. Her work and research experience are highly relevant to the proposed study which builds on an earlier analysis she conducted of how patients with CRPS sought support via an online message board. As a consequence of her dual role, KR will act as a point of liaison between the academic and NHS environment, with particular responsibility for patient-group liaison. She will supervise the administration of the Patient Generated Index and other patient experience measures, and will contribute to the writing up and dissemination of the research. KR has been costed at a quarter-day per week.

LW is a lecturer in the Department of Computer Science, University of Bath. He researches the relationship between technological mediation and participation in group activity, particularly in the context of open-ended or contested discussions. His research contributes to the interdisciplinary fields of Computer-Supported Cooperative Work and Human-Computer Interaction. His research on interpersonal awareness in conversation has shed light on the design of both text- and video-based technological environments from perspectives including linguistic grounding, social identity and, most recently, dispute resolution practice. LW will have responsibility for liaison with technical support design, and will technical set up of forum and wiki, and contribute to the analysis of the qualitative data. LW has been costed at a quarter-day per week.

NC is an Associate Professor of Health Psychology, University of Nottingham. His programme of research examines the role of online communities for those affected by chronic illness. He has undertaken projects across a range of common illnesses and conditions including: HIV/AIDS, infertility, Huntington’s disease, dental phobia, food allergy, breast and prostate cancer and Inflammatory Bowel Disease. His work focuses on two key aspects of the online community experience: 1) the provision of social support between group members and 2) the potential empowering effects of group membership and factors affecting the relationship between group experiences and psychosocial/clinical outcomes. NC has extensive experience in analysing online interaction/messages for social support, the development of the online surveys, and training moderators of online forums. NC will oversee the moderation of the forum and wiki, the content analysis of user interactions, and the development of the patient guide for new forum users and the training of ‘expert patients’ to self manage the sites at the completion of the study. NC has been costed at a quarter-day per week.

The RA will be employed at 50% time for 18 months at Research Grade 6. Will be responsible for archiving, inputting and analysing the data; construction of the survey material; conducting the focus groups, contributing to dissemination and bi-monthly reports, monitoring feedback from users. Will have qualitative and quantitative analytical techniques, experience working with online data collection, and will work under the direct supervision of JG.

A technician will set-up, technically maintain the forum and wiki. This includes initial installation, technical setup, user administration (creation of user accounts and issuing of passwords), testing of the sites, and ongoing maintenance and technical monitoring. We have costed this at 450 hours at Grade 6.

Conference attendance & Travel

Travel, subsistence and registration fees are requested to cover attendance of 2 investigators at an overseas conference (total £3,000), and 1 investigator and service user (forum member) at a national conference (total £1,700).

Train travel and subsistence are also requested for NC to attend 9 bi-monthly meetings of investigators in order to facilitate project management (total requested £1,000).

PLANNED OR ACTIVE RELATED RESEARCH GRANTS

JG is currently leading two University of Bath Teaching Development piloting the use of Virtual Environments as an aid to experiential learning (£6787) and the role of social networking sites undergraduate students' transition to university (£9382, with LW). KR is currently running a pilot study exploring why some patients with Complex Regional Pain Syndrome (CRPS) engage in deliberate self-harm funded by the Royal National Hospital for Rheumatic Diseases R&D Donated Funds & the Charitable Trustees (£6k). LW is preparing a bid for researching development of reputation in online communities to be submitted to EPSRC.

HISTORY OF PAST OR EXISTING NIHR PROGRAMME RESEARCH

None of the applicants has held an NIHR grant.

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This protocol refers to independent research commissioned by the National Institute for Health Research (NIHR). Any views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HS&DR programme or the Department of Health.