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Gibson, Kerri; O'Donnell, Susan

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Challenges of Conducting Participatory User-Centred ICT Research With a Health Organisation

Kerri Gibson

*National Research Council of Canada
kerri.gibson@nrc-cnrc.gc.ca*

Auth Susan O'Donnell

*National Research Council of Canada
susan.odonnell@nrc-cnrc.gc.ca*

Abstract

The value of user participation when developing and assessing information communication technologies (ICTs) is undisputed. This paper discusses the challenges of conducting fieldwork on ICTs within a health organisation. The case study of a local health authority that wishes to develop best practices for multi-site videoconferencing is presented. The various complications we have encountered thus far in this participatory research are outlined, and the strategies that our research team has developed in addressing these issues are discussed. We conclude that the benefits of participatory research most definitely outweigh any complications that arise along the journey.

1. Introduction

Researchers often commit much time and effort, not to mention financial resources, to designing a well-thought out study. Depending on the context of the research, different amounts of control are awarded to the researcher. For example, in laboratory research, control by the researcher is maximized, some researchers may argue at the expense of external validity. In contrast, in fieldwork and participatory research with authentic user communities, the amount of researcher control within a study may be significantly less than that of an experiment. However, the gains of information and insight might be well worth the trade-off. Despite the uncontrollability of certain factors in participatory research, researchers can still plan their projects to the best of their ability, anticipate challenges, and choose responses to those challenges that maximize the potential of their project. What follows is an example of a case study illustrating what happens when a research design meets real life, and how the researchers responded.

2. Background

Telehealth has been defined as "the use of information and communication technology (ICT) to deliver health services, expertise and information over distance" [1] and

is a new and booming field within the health area. One of the main ICTs used in telehealth is videoconferencing. In our health authority's case, Tandberg units are typically used over an ISDN line. The organization plans to move to Internet Protocol videoconferencing within the next few years. Videoconferencing is defined as two or more locations connecting via audio and video in real-time; multi-site videoconferencing involves more than two sites and they connect via a bridge. Proponents of videoconferencing argue for its ability to save time and costs, a significant benefit in a health organization with serious human resource constraints, waitlists, and budget considerations. Benefits of videoconferencing also include its potential for the connection and inclusion of remote and rural sites in events.

Participation and engagement have been found to be key variables related to knowledge retention and central to successful videoconferencing experiences [2]. Participation and engagement, as conceptualized by our research team, involve such things as communicating and speaking via videoconference, and having a conversation about the topic with others during or after a session, or change or group action related to the videoconference [3].

A variety of social and technical factors that facilitate or hinder multi-site videoconferencing have been identified from our literature review [3] and several of these variables are being investigated in our study. Drawing upon research from several domains, we identified certain variables we will investigate to help us identify best practices to optimize the multi-site videoconferencing experience for these users. For example, from the human computer interaction research area, we are interested in how the technology acceptance model [4], with its constructs of perceived usefulness and perceived ease of use, might apply to our authentic user groups with their use of multi-site videoconferencing. We are assessing these variables through a questionnaire. From the group dynamics literature, we recognize how a sense of group membership can influence an individual's level of participation and engagement with the group and increase the likelihood of having a successful videoconference [5]. For example, individuals with a stronger sense of belonging to the group may participate more frequently during the videoconference. Cultivating

and maintaining a sense of group and team identity can be difficult under the best of circumstances but in the videoconferencing environment there can be unique challenges, such as teams never meeting in person, some individuals being off-camera more than others, and less social presence [6]. We are assessing group factors through the questionnaire and through observational analysis of the sessions.

3. Description of research project

This is a partnership project between a research institution and a regional health authority in a Canadian province. This health authority has an active telehealth department which seeks to maximize the potential of their videoconferencing use. The purpose of the research project, as was jointly agreed upon by both partners, was to investigate best practices for non-clinical multi-site videoconferencing in order to support the development and use of best practices for multi-site videoconferencing.

One of the major outcomes of the project will be an intervention for users of multi-site videoconferencing in this health authority. This intervention will be based on data collected from current users of multi-site videoconferencing in this health authority and will be grounded in the current literature on videoconferencing, informed by a good practices guidelines already developed by our team [7].

The main research questions guiding this project include:

- 1) to what extent are the people in the health administration groups in different locations participating and engaging using multi-site videoconferencing?
- 2) What constitutes "successful" participation and engagement by a health administration group in multiple locations meeting by multi-site videoconferencing?
- 3) What are the enablers and constraints to successful participation and engagement?
- 4) How can the design of the broadband audio-visual technologies be improved to facilitate participation and engagement?
- 5) How can the design of the visual communication process be improved to facilitate participation and engagement?

The project is currently in the first phase, where baseline data is being collected from groups who use multi-site videoconferencing in order to direct the design of the intervention. Data is being collected via a variety of methods and at a variety of levels, including questionnaires administered to participants of multi-site videoconference sessions, brief interviews conducted with telehealth support workers on their experiences and challenges with regards to their supportive role, focus groups with participants from the multi-site

videoconferences, and an inventory (e.g., types of equipment, types of technical support available, etc.) of the technical infrastructure of the entire health authority. The purpose of collecting these different types of information from a variety of sources is to paint a detailed picture of the current state of multi-site videoconferencing in this health authority, from the perspective of both users and telehealth support workers, and to identify the technical infrastructure that we are working with.

4. User-centred research

The current case study is undertaken from a participatory research approach, in the context of engaging in ICT fieldwork within a health organization by using a user-centred methodology. The objective of user-centred design is the creation of products that are deemed usable and useful [8]. Participatory research has three distinct features, namely, collaboration, mutual education, and results-informed action based on the data collected from the community at hand [9]. Fieldwork research on ICTs involves real users and has been recognized as a research approach advantageous for its ability to generate context-relevant and user-sensitive information [10]. The use of a participatory user-centred framework for an organization partnering with a research institution to develop and support the use of best practices for multi-site videoconferencing, seems most fitting. Participatory research has long been touted for its empowering potential, and thus is a good match for capacity building of users and their organizations.

According to Damodaran [11], the advantages of successful user participation and involvement in studies include:

- 1) improved quality of the system arising from more accurate user requirements
- 2) avoidance of costly system features that the user did not want or cannot use
- 3) improved levels of acceptance of the system
- 4) greater understanding of the system by the user resulting in more effective use, and
- 5) increased participation in decision-making within the organization. (p.364)

A recommendation for user-centred design involves engaging the users in the research design process as early as possible and consistently throughout the project [12]. For these reasons we have worked closely with our partner from the beginning, first in the design of the project proposal, and throughout the various activities involved in the research project, such as ethics approval, questionnaire development, selection and recruitment of participating groups, and many other tasks. We are also working closely with the partners to develop an e-learning type of intervention to help disseminate the best practices

on multi-site videoconferencing, and encourage the use of techniques to facilitate increased participation and engagement between the groups videoconferencing. The chairs of the groups who participated in this videoconferencing study are directly involved in the development of the intervention. Individuals and groups involved must feel some sort of ownerships and inclusion and this can be accomplished through participatory research.

Kujala [13] identified some common complications in user-centred studies, which include the difficulty of identifying appropriate users and obtaining access to these users, motivating users, and the fact that users were typically very busy. Thus far, we have had some of these challenges and some others, as we will outline next.

5. Obstacles and surprises along the way

Several challenges have been encountered thus far while working with our authentic user community. It is likely that these issues may arise when working with groups of users in general while engaging in this type of ICT research, though some issues are specifically relevant to health organizations. The issues we are about to discuss do not form an exhaustive list of the realities of working with user groups; they do, however, provide a flavor of some of our experiences thus far.

5.1 Ethics challenge

One of the first challenges that arose in this project was the ethical issue of videotaping and archiving videoconference sessions. In some cases information that was discussed by these health groups were confidential. The issue arose of what would happen if not all participants consented to the analysis of the video after it was archived. After a discussion with the ethics board of the health authority we were permitted to proceed given that we keep the data anonymous, confidential, and securely stored, and respect the rights of users. This meant that if even one participant from a videoconference site did not consent to the analysis of their video, then that's site video and audio information would be excluded from the analysis in the project.

5.2 Development of instruments

Certain restraints arose when developing the questionnaire. It was necessary to attempt to strike a balance between obtaining sufficient information to measure all the factors we deemed important, while at the same time taking into consideration the strict schedules of some of the attendees. Our partner suggested that the questionnaire should take 10 minutes or less to complete.

While developing the questionnaire, only the most valuable questions were left in, and they were refined and tested in a pilot study. Also, our partner from the health authority provided valuable feedback on the questionnaire and also piloted the questionnaire, helping us develop a context-sensitive and appropriate tool. Researchers that have explored multi-site videoconferencing in a community context have also come across some obstacles with regards to the development of assessment instruments. For example, in a different study we are conducting about multi-site videoconferencing and Aboriginal community development, certain adaptations to the data collection were made. Surveys were not always used; instead interviews, and focused discussions were conducted to obtain data, as questionnaire research was found to not always be culturally sensitive or compatible with a community's values.

5.3 Recruitment

Recruitment of the two educational groups and the two administrative groups for the study also proved to be a challenge. The majority of the groups who meet via videoconference only meet every month or so. This means that data collection needs to take place around the group's schedule. It also means that if there are any problems that arise during data collection - such as not enough sites connecting - then another data collection can only take place a month later.

A second issue with recruitment of participants is that these individuals are extremely busy. Most participants are healthcare employees (some are students), and their time and attention are in high demand. Therefore, asking that a group participate in a study which requires extra time at the end of a meeting for data collection, and possibly piloting an intervention and participating in a focus group as well, can be quite a demanding invitation. A complicating matter is that some of these groups are not well formed; for example, in the educational groups many of the attendants at the events are students, and so turnaround is quite high. Often the educational events only expect people to come when they have the time. When participation is not mandatory, it will clearly have an effect on the number of participants. In administrative groups, the people attending often have responsibilities to their fellow group members; in the educational groups, often participants come to listen to a presentation and are not expected to participate beyond active listening and some discussion.

5.4 Data collections

Thus far in the project, two data collections have taken place, though three events had been scheduled for data

collection. Questionnaires were administered to one administrative group and to one educational group. A data collection was scheduled for the second educational group but unfortunately no other sites connected to the main site, and so the event did not fit criteria for being a videoconference. At the first data collection, involving an educational group, only two sites were connected to the videoconference, and so a multi-site event did not take place, as it was only two-way communication. For the data collection of the administrative group, the Chair was aware that only two sites were going to be participating but wanted to make it a multi-site videoconference so that data could be collected. She went to a separate videoconferencing room within the same hospital to chair the meeting.

These dilemmas with our data collections have made us reflect on the research process, and also on the use and state of multi-site videoconferencing for these groups and for the organisation. We have asked ourselves the question, what is accounting for this low level of site participation? A few explanations have been suggested by our team members, our partner, and also by participants themselves.

During these videoconference events where sometimes no or very few sites connect besides the host site, linking up with the bridge and participating in the event is not mandatory. The opportunity exists for participation, but often other things come up (e.g. an emergency), and participants cannot attend. At the rural sites, which have been the least likely to participate in the events that have been hosted so far, staffing is likely to be less than at the urban centre, so demands on staff time might be higher. Furthermore, there are different incentives to facilitate participation, depending on the site. For example, at the urban site there are refreshments and door prizes offered at one of the educational groups- it should be noted that this is the group in our project which has so far drawn the most number of participants. The consequence is unequal participation and unequal treatment across sites.

An additional explanation for low site participation is related to the construction of a new hospital within the health authority. During the months when our data collection started, the move was beginning to the new hospital, and people were occupied with different tasks surrounding this. Another possibility is that multi-site videoconferencing technology is simply not being used as much as the health authority assumes. Or, could the perceived usefulness of the technology, and the interactions between the users and the technology not be optimal? These technical factors and the interactions between social and technical factors will be evaluated by the data collected in this project.

There could be multiple factors underlying the lack of participation. The issue, however, is one that needs to be

addressed and should not be overlooked. Section 6 will discuss this further.

5.5 Lack of stability in the work environment

At the time of final revisions to this paper, a new research challenge has emerged. The provincial government announced that the regional health boards across the province, including our partner organization, will be re-formed. Instead of eight health authorities, there will be only two. The jobs of several of the stakeholders in this research, and people who have participated in the project along the way, may be in jeopardy. With the future of non-clinical activities within the organization being unknown, it might be even more challenging to conduct the participatory research that we are doing. However, it is likely because of the change in structure of the health service delivery that multi-site videoconferencing will become even more necessary for communications between health organizations in the province.

6. How are we dealing with these challenges?

In working with an authentic user community in participatory research, certain compromises must be made along the way in the face of challenges, as in any type of research.

As was just mentioned, the first three attempts at data collections did not go as predicted – though some of the chairs of the groups did warn the researchers that this could be an issue, as they had faced lack of participation in the past. Therefore, we have had to contemplate how we would address this situation. It is certain that we need to continue collecting data. This will lengthen the time of the research project but is necessary. Some of the sites which will provide us with the most valuable feedback are the rural sites who only are able to participate through videoconference and have a different experience than the urban site which is usually also the host site. We have heard very little so far from these participants, and we need to learn their story as well. Another issue for consideration is whether perhaps we need to change the groups that are participating, or recruit additional groups. One important issue that we have recently decided needs to be addressed is that perhaps either the intervention, or the actual research process, needs to be modified to include a piece on promotion and awareness of the multi-site videoconferencing events and technology. Participatory research is empowering- it isn't top down – it is user-centered; this means we need to start where the users are at. And so, if very few sites are participating, and typically only the host site, which is the urban site, consistently participates, then maybe we have to re-evaluate our starting point for this project. For example,

perhaps more awareness-raising on the use of multi-site videoconferencing within this organization is necessary. After all, the goals of increasing participation and engagement are at the core of this project- and that starts with having people physically present. Previous researchers [14] have cited how human factors are key in successful multi-site videoconferences, and often work needs to be done on relationship-building, team integration, and "personalization of meetings." Clearly if the majority of the activity and participants are located at the urban site, then it is likely that the climate for participation and communication is not as encouraging and warm for remote, rural sites. This will be an issue that our intervention will address.

Developing and maintaining a strong relationship with the partner representative from the health authority has been a key factor in allowing the research process to move forward as smoothly as possible. Our partner was involved at all steps of the research process and we have bi-monthly meetings in order to remain up to date on all issues. Together we selected groups to invite to participate in the project, we learned the importance of the project from the partner's perspective, and we learned of the requirements and wishes of our partner for the potential intervention. The entire process has been collaborative above all.

Good relationships and rapport with the actual groups, participants in the groups, and chairs of the groups, also aid in the research process and are key to participatory research. When as many stakeholders as possible are working closely together for the same goal, and are engaged in the process, performance at all levels can be maximized. For example, it was the chair of the administrative group who suggested and followed-through on the idea of going to a separate room to chair the videoconference so as to enable data collection and make the event a multi-point one. What came out of this was not just a successful data collection, though albeit in an interesting circumstance, but the chair also gained interesting experience. The chair commented during the actual event of how everyone on her committee should have the experience of being at a remote site- that all kinds of things are different, body language and facial expressions are not as visible, and lags in audio can begin to affect the experience. Also, the very fact that these groups are involved in the research project makes them more conscious of their videoconferencing techniques and experiences, according to the participants' anecdotal experience that they shared with this researcher. Learning is taking place already, then, and will be continuous, even though an intervention has not even begun. Also, the learning is taking place not only with the user group but also our research group. Coming across these obstacles, and addressing them, gains experience as well.

Another key ingredient necessary in addressing these challenges is flexibility. Our research group appreciates the time commitment involved for all individuals involved in the project, and understands the constraints of working within a health organization. Adapting the research process to meet the needs of users then, to better enable and facilitate the whole process, including data collection, has been necessary. As was already mentioned, when developing the research tools the issue of time constraint for participants was taken into account when selecting items and finalizing the length of the questionnaire. Also, self-addressed and pre-stamped envelopes were made available for all participants at all data collections, in case someone wanted to participate but did not have time. Flexibility will be key in dealing with the uncertainty and challenges that will result from the recent turn of events that will see the reforming of the health authorities within the province.

7. Conclusions

Participatory research is arguably one of the most effective ways of conducting context-sensitive and user-centred quality research. As always, there are consequences to using a certain approach. In our project we are looking at supporting the use of best practices in multi-site videoconferencing in a health setting and we have experienced certain methodological challenges to date which have been outlined in this paper. These issues center on ethical challenges - a hot issue currently with regards to surveillance and the recording of videos - and recruitment, measurement tool development, and data collections. No doubt these will not be the last of our obstacles, and we still have work to do to address these challenges. Our experience of the research process so far matches well with Cornwall's [15] description of tasks central to participatory research, namely, reassessing, flexibility, and reflection. When challenges arise we assess and reassess the situation and our procedure, remain flexible in all of our proceedings, and reflect at all stages of the process.

It seems clear in this research project that the benefits of participatory research clearly outweigh the complications, and challenges are part and parcel of any type of research. The amount learned from a user community cannot be just measured in the data collected from the questionnaires. When working with users as equals instead of possibly in an expert-subject relationship, the outcomes can be invaluable.

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