Involving Geographically Distributed Users in the Design of an Interactive System

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Abstract

We report the process of designing an interactive system for use in disease surveillance and patient case management at remote communities in the Amazon region. The design aimed at coordinating and supporting the tasks of a distributed community of users in the region, and involved collaboration of designers and developers located in three continents, working on a common research project. In spite of this high degree of geographical distribution, both of users and designers, a participatory design approach was pursued. The challenges faced by this project as regards securing end-user involvement, eliciting requirements, generating and validating design ideas, and iterating the design process are discussed. A prototype which embodies the experience gained in applying these methods in this particular setting is also described.

Keywords: Mobile devices, disease surveillance, interactive geographical maps, medical information systems.

1 Introduction

Software engineering projects are increasingly being conducted by geographically distributed teams (Herbsleb, 2007; Cusumano, 2008). The challenges faced by such teams have been documented in a number of studies (Damian and Zowghi, 2003; Ramesh et al., 2006) which highlight issues such as how to best manage collaboration among team members of different cultural backgrounds, how to minimise communication problems, how to improve the technical infrastructure for cooperative work, and how to implement effective knowledge and information management mechanisms to support the work of the development teams and project leaders (Herbsleb, 2007).

Most of these studies, however, focus on large scale projects, often in the context of cross-border organisations, where the distribution of development is primarily driven by business considerations, such as the desire to exploit local market opportunities, the "need to capitalise on the global resource pool" (Herbsleb, 2007) and even the need to deal with time pressures by exploiting time-zone differences. Far less attention has been devoted to HCI issues in the distributed development of interactive systems. Such issues are typical of, for instance, research projects, where development is mainly motivated by scientific or applied research questions and spans multiple institutions. In these contexts, user-centred and participatory design methodologies are often preferred, placing additional strains on activities such as requirements elicitation which have proved challenging for distributed teams, even those working with more traditional development methodologies (Damian and Zowghi, 2003).

This paper reports the case of one such distributed project which has focused on exploring the potential of interactive mobile systems to assist local healthcare providers and epidemiology researchers in treating patients and monitoring emerging and neglected infectious disease in the Amazon region. We report our experience and the methods we employed in designing a system for this geographically dispersed user community while following a participatory design philosophy. This process has involved several iterations of requirements gathering, design, development and user evaluation.

2 Disease surveillance and Healthcare in remote regions

Management of healthcare in remote regions to serve populations located in large, sparsely populated extensions is acknowledged as a difficult problem (Dussault and Franceschini, 2006). In the Amazon region, this problem is compounded by the natural geographical obstacles, the consequent scarcity of human resources, and more recently, the phenomenon of global climate change. Climate change has altered the pattern of land use and cover in the region and it is expected to continue to do so (Cesario et al., 2011). These factors are contributing to the spread of diseases, such as American Cutaneous Leishmaniasis, and increasing the likelihood that diseases not yet found in the Amazon region, such as Bartonellosis, will reach the region. This situation creates requirements that are not addressed in conventional telemedicine systems, which focus mainly on issues of remote assistance to diagnosis and treatment (Hailey et al., 2002).

Health management in this context requires a more comprehensive approach capable of dealing with issues of human ecology and disease surveillance, in addition to patient care (Cesario et al., 2011). Cooperative work needs to be flexible and take localised diagnosis, data collection and data analysis tasks into account. Therefore the support of interactive computer systems needs to be provided at different levels in aid of diverse but inter-related activities (Luz et al., 2013, 2012).

At one level, primary care activities are often carried out in remote locations by nurses and community healthcare workers. The latter have generally little training and would therefore benefit from support, specially under circumstances involving the identification of diseases that are rare in the areas in which they operate. Communication with specialists and researchers might help improve primary care providers' performance.

At a higher level, the healthcare system needs to collect and maintain patient records which will be accessed, among others, by epidemiological surveillance bodies which have the need to gather accurate information on disease occurrence, including patient location, along with a number of other relevant environmental variables.

In the case of the project reported here, these collaborations can also cross country borders. One of the diseases targeted by our project is Bartonellosis, which is endemic in some areas of Peru, has spread in recent years, and risks reaching the disease-free Peru-Bolivia-Brazil tri-national borders (Cesario et al., 2011).

Within these complex practical work settings, we have explored a number of technological facets as possible ways of supporting the activities of healthcare professionals, researchers, policy makers, and administrators. These include:

- mobile support for epidemiological research and data collection,
- mobile assistance to disease identification and case notification,
- visualisation of cases and distributed activities reported to a central database, and
- support for synchronous and asynchronous communication among healthcare providers.

3 Geographically distributed design

Participatory design literature often cautions designers and developers of technology to be aware of their differences with potential users, who according to the principles of participatory design must be actively involved in the design process. Specific techniques, such as envisionment videos (Buxton, 2007), have therefore been developed to facilitate this process (Masoodian, 2000).

Further complexity arises when the design and development team itself consists of members from different cultural, scientific, and linguistic backgrounds. Due to the nature of contemporary research, where international and inter-disciplinary collaboration is encouraged, most projects tend to encompass such diverse backgrounds. This is of course the case of our project.

Given the characteristics of the problem described in Section 2, the proposed solution we have been investigating, and the activities it needs to support, our team encompasses researchers from two main disciplines, namely, medicine and computer science. However, within the discipline of medicine itself, our team members have different focuses and educational backgrounds. They include: a professor of medicine, a medical researcher and an epidemiologist.

In addition to diverse backgrounds, the team has had to cope with working and cooperating across geographical distance. The design and software engineering teams are located mainly in Ireland and New Zealand, while the medical specialists who act as co-developers and facilitators of end user participation are located in research institutes in Brazil. The distances make it impractical to hold frequent face-to-face meetings. Collaboration has therefore required not only the regular use of communication tools such as email and (audio and video) conferencing software, but also the use of participatory design artefacts (e.g. sketch interfaces and envisionment videos) that could be exchanged for asynchronous use to support requirement analysis and design ideation.

At the initial stages of the design process, sketches and simple storyboards, which could be easily scanned and distributed among the groups and used as support material for presentation, proved quite effective at helping establish common ground among the different specialist areas and sensitise the designers and engineering team to potential situations of concern. As a shared understanding developed, more elaborate tools were introduced. A valuable experience in this context has been the production of the envisionment video itself, as a design sketching tool, involving all the team members. As part of this process our team worked together remotely to sketch the initial storyboards, develop the script, film, and then iteratively edit and produce the final video.

A similar process has been followed for the design and development of our software prototype (discussed later). This has involved dividing the system into different functional components (patient case data collection, computer-assisted diagnostic, and visualisation), each of which have been designed and developed iteratively through the involvement of interaction designers, software engineers and specific medical expert team members.

4 Geographically distributed users

Early on in the design process it became clear that supporting a complex activity such as disease surveillance would necessarily mean supporting the tasks of local healthcare providers and mobile researchers who act as gatherers and users of epidemiology data. This posed the initial challenge of identifying the main actors, their background knowledge and their work patterns.

As mentioned before, the geographical area covered by the prospective users of the system spans a region of the Brazilian Amazon that borders two other South American countries: Peru and Bolivia. Within these countries, the project stakeholders are located in places that are themselves separated by great distances (Figure 1). In particular, the focus of data collection is within a sparsely populated rural area whose healthcare needs are served by community healthcare providers and nurses.

4.1 Overall Strategy

Due to the complex and distributed nature of healthcare and disease surveillance in the region, we employed observational and qualitative methods to help the team reach common ground as to the context of the activities that might be supported by technology, the main actors involved and their typical tasks.

Once a shared overall picture of the context of the project was formed, the team sought to secure the

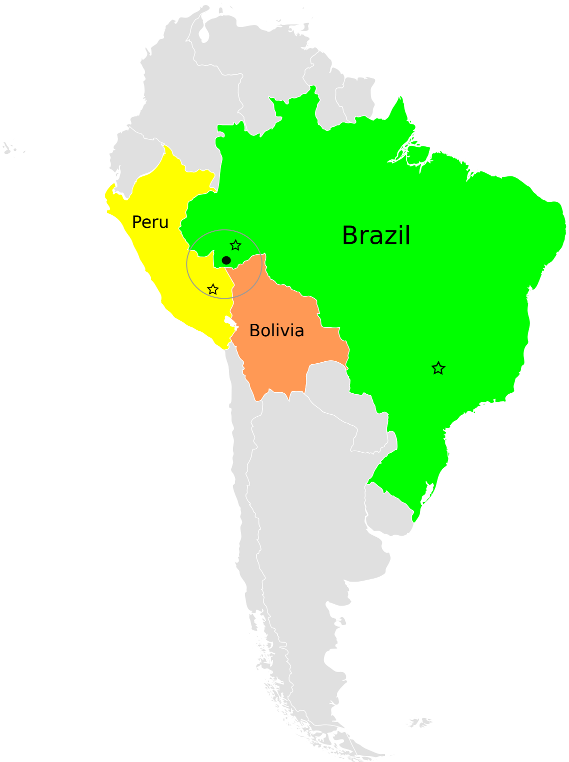

Figure 1: Map of South America showing the areas over which the user group is distributed. The larger circle indicates the region where patient data are collected. The stars indicate the locations of project participants and the filled circle the municipality where fieldwork has been conducted.

involvement of the prospective user group by recruiting *informants* who acted as the main contact points between the developers and the users. These informants are researchers who have conducted investigations on different aspects of disease surveillance, prevention and treatment in the region, independently of this project, but have an interest in tools and technology that might improve such tasks. These informants were briefed on the nature of the project and the possibilities of technology support. They contributed to the refinement of use cases, provided feedback on the sketched interfaces, and participated in interviews.

As the project evolved, key informants were kept abreast of the developments and employed the above mentioned techniques in their cooperation with the international members of the design team, including low-fidelity prototyping and envisionment videos. They also employed these tools to test design ideas with the local user groups. We also gathered feedback across a larger user population by means of questionnaires. These key researchers have also played an important role in the design of a high-fidelity prototype which currently serves as a basis for further development iterations.

In the following sections we describe these methods and their outcomes in further detail.

4.2 Fieldwork: main actors and their tasks

The fieldwork has been conducted by two members of the project team over an extended period. They have medical and epidemiology backgrounds and lived in the Amazon region for the duration of the initial fieldwork. Contacts with local health workers were established and information exchanges with medical experts from Peru and Bolivia were initiated. This qualitative research produced a comprehensive document which outlined the disease surveillance and healthcare situation from a general perspective, and documented the work practices of the prospective users in great detail. This document was circulated to the international partners, along with the relevant medical and healthcare policy literature. The design team then structured these data in the light of existing analytic frameworks, paying special attention to issues of mobility in healthcare contexts (Doherty et al., 2010; Bardram and Bossen, 2005), in order to identify main actors and plausible design statements, and devise a strategy for requirements analysis. This qualitative analysis was complemented by surveys and focused investigations of specific issues, along the lines of the methodology proposed by Kane and Luz (2011) in the context of information sharing among specialists from different disciplines.

Fieldwork revealed that the various actors involved in healthcare provision within the groups represented in this project perform different but complementary sets of activities and make use of specialised but interrelated knowledge and representations. Our efforts therefore focused on supporting the articulation work (Schmidt and Bannon, 1992) necessary in order to improve the activities of the different stakeholders though effective information sharing and use.

Closest to the patients, and performing most of the primary care in the region are *community health workers*, *local doctors* and *nurses*. Community health workers are members of the community who have no tertiary (university) training in healthcare but nevertheless perform essential functions related to healthcare delivery, receiving basic training in the context of specific interventions. They also perform other developmental and promotional roles, acting as bridges between the community and formal health services (Lehmann and Sanders, 2007). Their activities are complemented and assisted by the activities of trained nurses, medical assistants and doctors based in local health centres. Due to geography of the region, and also to the nature of their job, it is in the work of community health workers that mobility requirements are most apparent. This level of mobility and the lower levels of medical training of these workers suggest a need to support coordination between (mobile) community healthcare workers and nurse, their more direct but less mobile counterparts in primary care. This type of asymmetry (of mobility, training and educational level) observed between community health workers and nurses is even more pronounced between the former and medical specialists and researchers.

At the levels of secondary and tertiary care, one finds *medical specialists* who treat patients referred to them by the local health centres. In addition to treating patients, doctors often provide guidance to the primary care agents and engage in research activities. While this type of guidance is rarely formalised, reflecting legal and institutional constraints, it relies nevertheless on certain coordination mechanisms (Schmidt and Simone, 1996) which could, in principle, be reinforced through technology. Doctors from regions where a disease is newly emerging will typically seek information from colleagues from regions where the disease is endemic.

Two types of actors use the patient data gathered by healthcare providers: *healthcare service managers* and *epidemiology researchers*. The former are concerned with prevention policies, tools and strategies. The latter are concerned with modelling and assessment of risks for the purpose of disease surveillance. In this particular setting, the epidemiologist members of the team aim to aggregate data from several sources, including climate, land use, disease vector distribution and terrain features, as well as the medical data pertaining to the spread of cases, both geographically and temporally.

Through the identification of these potential user groups it became clear that they have different but somewhat interrelated needs for interactivity and data. Healthcare workers working in the field need mobility, access to local data (maps, residences visited etc) and, occasionally, assess to specialist assistance. Epidemiology researchers and managers need global, compiled data. The following use cases illustrate the nature of these needs.

4.3 Use cases

In the following sections we outline potential use cases which emerged from the initial observational studies. These use cases have been further investigated through the prototyping activities reported in Section 4.4.

4.3.1 Diagnostic assistance

Due to their limited resources and medical training, local health workers can benefit from assistance in identifying conditions and triaging patients. Since physical distance and mobility constraints make carrying of bulky laboratory equipment and instructional material impractical, such assistance could take the form of electronically stored medical atlases for identification of the cutaneous lesions that characterise diseases such as Bartonellosis and Leishmaniasis, and support for synchronous or asynchronous communication with experts. A typical scenario would involve the use of a mobile device to photograph the lesion, attempt automatic identification against a precompiled statistical model, fallback to identification assisted by image (medical atlas) comparison in case of uncertainty, and transmission of image and patient data to a specialist centre for further investigation.

4.3.2 Data collection and epidemiological surveillance

In the context of diagnostic and treatment of emerging diseases and epidemiological surveillance these primary care workers could also play an important role in recording details of suspected cases for notification, identification of disease vectors (carriers) which in the case of Bartonellosis and Leishmaniasis are sandflies, and educate the local communities. Other stakeholders with a local presence, such as field researchers, may also contribute to gathering different facets of epidemiologically relevant data from visits to local families. This includes accurate location data (GPS coordinates), data about time spent outdoors by family members during sandfly feeding times, insect bite prevention measures, history of insect bites or infestation and places where insect bites occurred, number and type of domestic and peri-domestic animals (known reservoirs of the Leishmaniasis parasite) at the home, outdoor occupational and recreational activities, travel and household hygienic facilities. These data can be integrated into early warning systems and shared among fieldworkers.

4.3.3 Mapping, visualisation and coordination tasks

Information collected by researchers would help in coordination tasks such as mapping of at-risk families to be visited by a healthcare provider, a record of households visited, statistics regarding the effectiveness of specific interventions etc. As these data have spacial and temporal facets, covering a number of different categorical and numerical variables, geographical visualisation can potentially play an important role in supporting awareness and coordination of activities among the various stake holders.

4.4 Prototyping

Our analysis of the use cases discussed above identified four categories of tasks that could be supported using technology. As mentioned earlier, these related broadly to patient case data collection, disease identification, visualisation of cases, and communication between healthcare providers.

The requirements of each of these categories of tasks in terms of their scope and the type of functionality that needs to be supported by technology have changed over time as we have worked with our users in refining them iteratively. The initial design iterations involved sharing of hand-drawn sketches (Figure 2) and storyboards (Figure 3) illustrating tentative functions identified in the observational studies and fieldwork. These sketches and storyboards formed the basis for four initial meetings and various email exchanges encompassing healthcare professionals, system developers and other stakeholders. They were essential in helping establish an initial common ground and in giving the prospective users of *nu-case* an idea of what was possible in a fairly unconstrained manner.

These initial low-level prototypes were then refined. The consensus that was emerging on the range of possible and potentially desirable features of the system was incorporated into a concept video which showed scenes of the prototype then under development in use in a series of scenarios that illustrated the above described use cases[1]. Frames of this concept video are shown in Figure 4. The video contained short verbal descriptions (in the form of captioned voice-overs) of the scenarios. It was presented to a diverse group of stakeholders, including medical doctors, healthcare service managers, nurses, community health workers, medical researchers and epidemiologists. Following the presentation, participants were given questionnaires designed to elicit their opinions on the usefulness of the functionality described, on potential risks, on the perceived usability of the system, on the suitability of the devices for the region and tasks, and on the potential utility of the system's functions to different healthcare providers. A detailed analysis of the feedback gathered in this phase of the project is presented in (Luz et al., 2013). In addition, the concept video has been used in a separate activity designed as part of the training of medical students in health informatics (Carloni et al., 2013).

From a development perspective, as the design and development team itself is geographically distributed, it has been necessary to develop each component of the prototype individually by different members of the team over time, while making sure that those components are integrated effectively. This has required careful selection of the development platform, data structures, map format etc.

[1] The full video is available at http://bit.ly/YFpAun

Figure 2: Parts of the initial sketches, illustrating patient case data collection using *nu-case*.

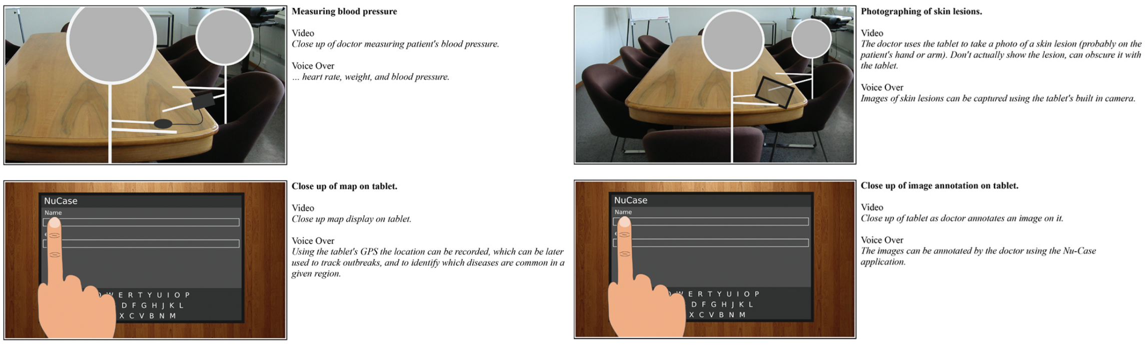

Figure 3: Parts of the storyboards, illustrating patient case data collection using *nu-case*.

User feedback was gathered at each prototyping iteration. The initial iterations focused on key actors and co-developers, while higher fidelity prototyping was used to elicit feedback from a broader user group.

4.4.1 Patient case data collection

Initially the type of functionality we had envisaged for this component was to allow collection of simple patient data, generally in text format, which would be used mainly for record-keeping purposes. Discussions with our users, and medical science team members, however, indicated that there was a need to expand the functionality supported by this component to include a range of data such as audio notes, precise GPS coordinates, photographs of patients and their skin lesions, images of slides for laboratory tests (e.g. blood smears) and other image-based diagnostic exams (e.g. X-rays).

These requirements are motivated by the fact that collection of accurate patient data is not currently carried out by our users working in the remote region, and such data is much needed not only for better diagnostic support, but also for notification of cases, and more effective visualisation and monitoring of the spread of neglected and emerging diseases.

Clearly mobile devices, with their extensive data collection capabilities (audio, video, photographs, GPS), are well suited for this purpose. We have therefore developed our prototype for Android™ smartphones and tablets[2]. Figure 5 shows a screenshot of part of the data collection component of our mobile system, called *nu-case*.

[2] http://developer.android.com/

4.4.2 Disease identification and notification

Providing diagnostic assistance to primary healthcare providers was among the first functions that we considered prototyping. The initial idea was to allow the user to attach a portable microscope to the mobile device and use it to take images of blood smears, which could then be automatically compared with blood smear samples of specific diseases (e.g. Bartonellosis and American Cutaneous Leishmaniasis) by the system to provide diagnostic advice. We therefore developed the necessary image analysis and machine learning functionality to support this process (Cesario et al., 2012). Comparison of blood smear images with malaria cases, as acute Bartonellosis can sometimes be misdiagnosed as malaria.

Despite some success with this work however, during the second iteration of prototyping, medical users suggested that a more useful approach would be to allow the user to make visual comparison of skin lesions that characterise diseases such as Bartonellosis and Leishmaniasis with photographs of existing cases using the system. This would have the advantage of resembling an accepted practice (consultation of medical atlases) while adapting it to the mobility requirements. The system could also be improved if the user could add photographs of skin lesions collected in the field during diagnosis to the image database and aggregated on a central server for curation by specialist and eventual use for future diagnostic assistance.

4.4.3 Visualisation of cases

Visualisation of geographical disease data using maps is an important component of epidemiology. Therefore, support for geovisualisation of patient case data was considered to be an essential requirement.

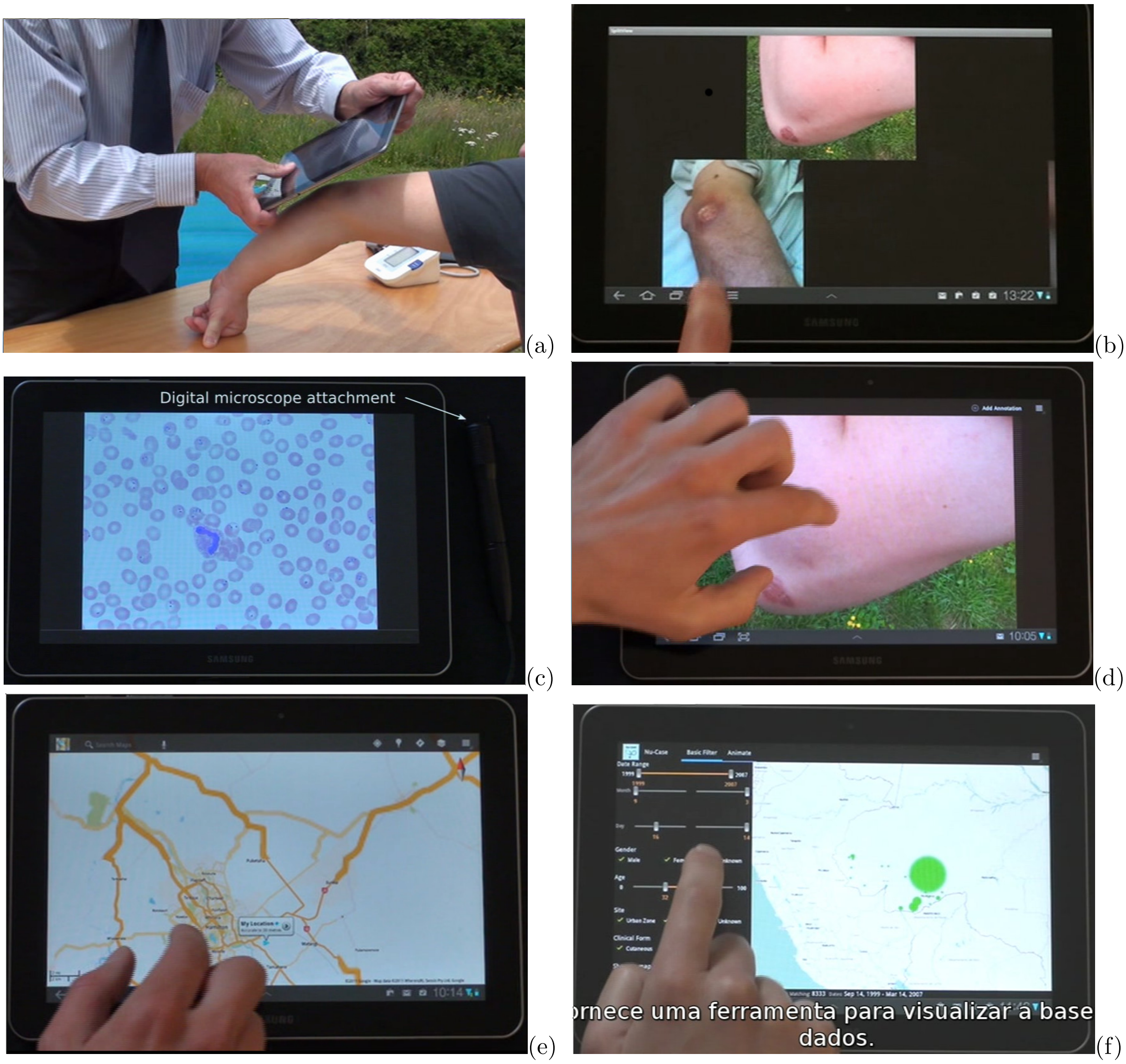

Figure 4: Frames of the video produced as part of the *nu-case* prototyping activities: (a) a doctor taking an image of a skin lesion for the electronic medical record, (b) support for image-assisted differential diagnosis, (c) blood smear image collection and machine-assisted analysis, (d) annotation of collected images for the medical record, (e) coordination of data collection through geographical information, and (f) visualisation of epidemiological data.

Since initially we did not have any data collected by the prototype system itself, we focused on the use of historical data made available to the project by the medical science team members. These data, collected over a decade, did not provide precise GPS location of reported cases, but had information about the municipality of infection and the municipality of notification for each case. We therefore developed a spatio-temporal visualisation of quantitative case data over the map of the region of interest. The evaluation of this visualisation in turn led to several improvements to the prototype.

We are currently working on the next version of the visualisation component which utilises more comprehensive patient case data newly collected in the region by a collaborating field researchers, based in the Amazon region. This data set not only includes the precise GPS data, but also other details such the patient's occupation, place of employment, type of employment, type of dwelling, family composition, proximity to rivers, presence of domestic animals etc. These data requirements were elicited through use of the first version of the visualisation prototype in user workshops. Figure 6 provides an example of the visualisation component of our *nu-case* prototype, showing several cases from the new data set.

4.4.4 Communication among care providers

The prototype system includes support for synchronous and asynchronous communication modes. One form of communication envisaged is between local healthcare providers and medical specialists to provide diagnostic assistance. This communication could be synchronous, and involve sharing of medical images and other data when reliable internet access is available, which may not be the case when working in the field. Alternatively, the communication could be asynchronous, and involve gathering of patient case data when there is no network connection, and uploading them to a central data repository later, as network access is restored (for instance when the

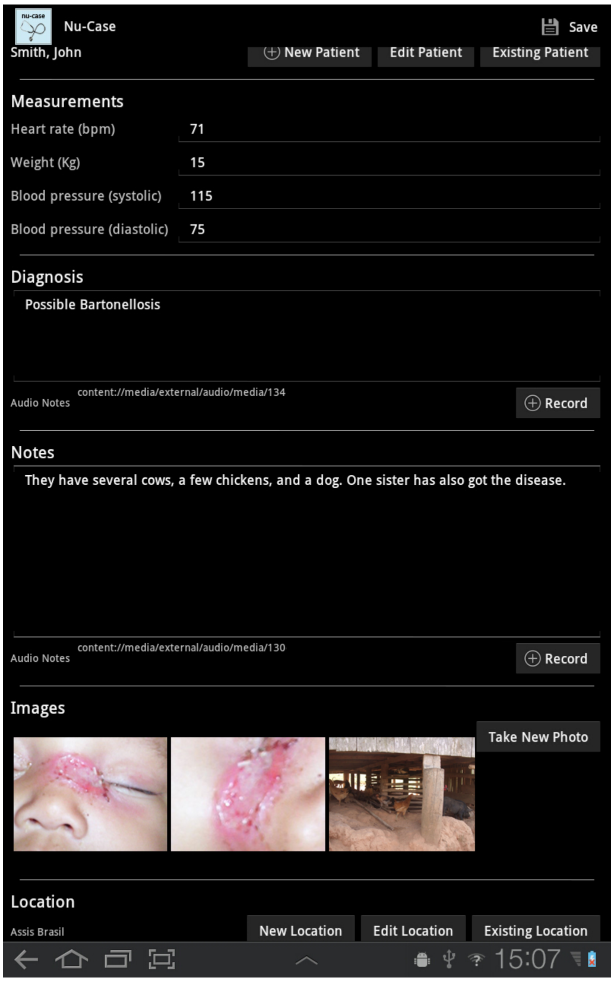

Figure 5: An example of a patient case in the data collection component of *nu-case*, which includes textual data, audio annotations, photographs, and GPS location data.

healthcare provider returns to their clinic).

Over several iterations, based on the feedback provided by our users and medical team members, our system has evolved to included a range of features to support more asynchronous communication, particularly for diagnostic assistance.

The system also aims to provide support for instance for downloading instructional and reference material (e.g. updated lesion images annotated by specialists, as shown in Figure 7) and the latest data on relevant geographical changes, disease propagation patterns etc.

5 Conclusion

In this paper we have described the design of an interactive system for assisting healthcare providers in remote regions with the task of diagnosis and monitoring of neglected and emerging infectious diseases. A distinguishing feature of this design process is the fact that it has been conducted by an interdisciplinary team of geographically distributed researchers and practitioners, for a group of users who are themselves geographically distributed.

Our experience has shown that although projects such as this are often complex in their nature, they can benefit from methodologies such as participatory design and related techniques. It has also shown that iterative prototyping can be successfully employed in

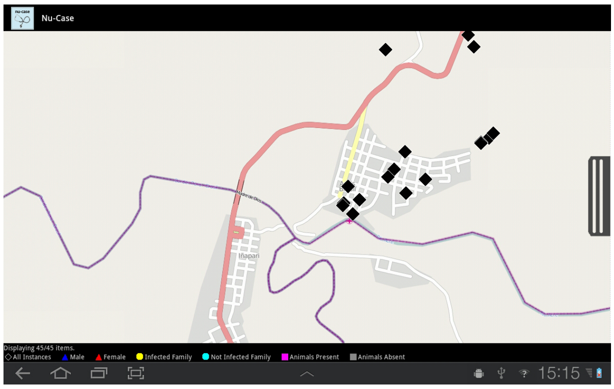

Figure 6: Visualisation component of *nu-case*, showing several individual cases on the map of the region of interest. Shown cases are selected by the user based on a number of case data attributes.

Figure 7: An example of the image annotation facility provided by *nu-case*, showing a lesion area on a photograph annotated by a specialist.

distributed development of interactive systems, provided that there is sufficient involvement of local informants and co-developers.

Our project is an ongoing one, and we aim to run field-trials of the *nu-case* prototype system with close involvement of our user group, once further development and testing of the various components of the system have been carried out.

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