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RESEARCH ARTICLE

Disease surveillance and patient care in remote regions: an exploratory study of collaboration among healthcare professionals in Amazonia

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The development and deployment of information technology, particularly mobile tools, to support collaboration between different groups of healthcare professionals has been viewed as a promising way to improve disease surveillance and patient care in remote regions. The effects of global climate change combined with rapid changes to land cover and use in Amazonia are believed to be contributing to the spread of vector-borne emerging and neglected diseases. This makes empowering and providing support for local healthcare providers all the more important. We investigate the use of information technology in this context to support professionals whose activities range from diagnosing diseases and monitoring their spread to developing policies to deal with outbreaks. An analysis of stakeholders, their roles and requirements, is presented which encompasses results of fieldwork and of a process of design and prototyping complemented by questionnaires and targeted interviews. Findings are analysed with respect to the tasks of diagnosis, training of local healthcare professionals, and gathering, sharing and visualisation of data for purposes of epidemiological research and disease surveillance. Methodological issues regarding the elicitation of cooperation and collaboration requirements are discussed and implications are drawn with respect to the use of technology in tackling emerging and neglected diseases.

Keywords: Computer supported cooperative work, health information technology, healthcare in remote regions, user requirement analysis, mobile devices, disease surveillance, data compilation and sharing, information visualisation.

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1. Introduction

The phenomenon of global climate change is rapidly altering the patterns of land use and cover in the tropical forest areas such as the Amazon, and it is expected that it will continue to do so with growing intensity (Mooney *et al.* 2009). These changes are in turn contributing to the spread of diseases, such as American Cutaneous Leishmaniasis (ACL), and increasing the likelihood that diseases not yet transmitted in the Amazon region, such as bartonellosis (Carrión's disease), will reach it in the near future (Cesario *et al.* 2011).

The provision of healthcare services to populations located in remote regions such as the Amazon, who are often dispersed over large geographical areas, has long been considered a difficult issue from the perspective of health systems management (Dussault and Franceschini 2006). While specific telemedicine approaches have been employed elsewhere with some success for remote assistance to diagnosis and treatment of diseases (Hailey *et al.* 2002), in this article we argue that the situation of concern created by emerging and neglected diseases in remote regions entails needs that go beyond the usual functionality of telemedicine systems. Health management in such situations requires a more comprehensive approach capable of dealing with issues of human ecology and disease surveillance, in addition to patient care (Mayer 2000).

In terms of computer support for these activities, an accordingly broader perspective on information exchange also needs to be considered. That is, support for collaboration needs to be adaptable and provided at different levels, in aid of different though inter-related activities. At one level, primary care activities are often carried out in remote locations by nurses and community healthcare workers. The latter generally have 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 the performance of primary care providers. At a higher level, the healthcare system needs to collect and maintain patient records, and these may be accessed, among others, by epidemiological surveillance bodies which have the need to gather accurate information on disease occurrence, including patient location. These collaborations may also have a transnational character, as in the case of 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).

Our aim in this research has been to explore the possibility that an approach which combines mobile devices (for patient care and epidemiology research in the field), centralised databases (for modelling and alerting), and support for both synchronous and asynchronous communication may be suitable to address, at least in part, this set of needs. While our starting point was technical, we adopted a Computer-Supported Cooperative Work (CSCW) perspective (Schmidt and Bannon 1992) and strive to account for the sociotechnical complexity of the settings where the interactions among the main actors who face the challenge of controlling neglected diseases take place. We employed triangulation, a method advocated by McGrath *et al.* (1982) and others for the social sciences and also employed in HCI design (Mackay and Fayard 1997), which involves approaching the same question in different ways. Initially, fieldwork consisting of observation and interviews was conducted in the Southwestern Amazon region (see Section 4). Then actors, tasks and needs were identified and described. Based on that description, possible designs were explored through sketching and storyboarding (Buxton 2007). We allowed ourselves to explore a wide range of functions so as not to unduly narrow the focus too soon in the research. An initial high-fidelity prototype was then designed to allow us to explore the potential role this combination of technologies could play, both in patient care and in a broader system for surveillance of emerging diseases. This provided us with a basis to validate and further investigate a number of issues through the use of questionnaires and targeted interviews.

The relevance of this article is not only that it provides practical insights into a concrete situation of concern in healthcare, but also that it addresses a topical issue in CSCW. As Fitzpatrick and Ellingsen (2012) remark in their recent survey, "the developing world [is] especially under-represented in the [CSCW] accounts of healthcare work". The research presented in this article is intended as a contribution to remedying this situation.

This article is structured as follows. We start with a brief review of related work on mobile healthcare applications, with emphasis on applications that support fieldwork in remote areas and developing countries. This is followed by a discussion of the theoretical background against which our research is set, and an outline of its methodology. We then present the main actors in the context of disease surveillance and patient care in the region, an assessment of needs and requirements, and an outline of the perceived opportunities for technological support. Such opportunities are then explored through the use of a prototype, a concept video, questionnaires and interviews. The main findings are then presented, and the article closes with a discussion of the implications of the findings, general conclusions, and plans for further research.

2. Related work

Time and space can often be barriers between healthcare providers and their patients, as well as between healthcare providers themselves. Information technology has been seen as a tool for breaking down such barriers (Tachakra *et al.* 2003). Telemedicine has been a focus for CSCW research since its inception, in the mid-1980s. This led to development of a number of early telemedicine systems, generally for supporting collaboration between distributed teams of medical practitioners (Luk *et al.* 2008, Handels *et al.* 1997, Makris *et al.* 1998).

While applications of telemedicine, in various forms, have existed for many years, the use of mobile technology for supporting healthcare is relatively recent. In most cases mobile wireless technology is seen as a low-cost and rapidly-deployable solution to address common diseases afflicting developing regions (Smith *et al.* 2011). As such, these systems generally use mobile phones to provide the functionality of biomedical devices, such as a microscope or spectrometer, to assist healthcare providers with diagnosis of diseases such as malaria or tuberculosis (Breslauer *et al.* 2009, Smith *et al.* 2011), which are still common in many parts of the world. Other medical uses of mobile technology include training of health workers in rural areas (Ramachandran *et al.* 2010), emergency medical services (Orwat *et al.* 2010) and provision of home-care (Hägglund *et al.* 2007).

One important application area for mobile technology which has so far been somewhat neglected by researchers is its use for collection of public health information and monitoring the spread of diseases. This is despite the fact that such information is considered to be fundamental to public health, and the use of technology is widely regarded as an important part of data gathering and sharing in healthcare (Reidpath and Allotey 2009). As Vanden Eng *et al.* (2007) point out "[access] to good quality, up-to-date national and regional data on disease burden, needs assessment, or intervention coverage is essential to help inform national policy decisions; guide relief efforts; monitoring control programs; and evaluate their impact, progress, and cost-effectiveness". Vanden Eng et al. have themselves developed a system for mobile devices fitted with a global positioning system (GPS) which they have used for probability sampling and data entry in household surveys in Africa.

At present healthcare service researchers also perceive a need for systems that combine collected information about public health and spread of diseases with other relevant information, such as geographical and environmental data, to produce useful and effective data presentation for field use by researchers and carers on mobile devices. Interactive map visualisations, for instance, have been found to be invaluable in public health management and research (Koenig *et al.* 2011).

In addition, researchers have suggested possible uses of mobile devices to provide health workers with guided steps through established protocols for diagnose and treatment of common diseases. One of the few examples of such a system to be discussed in the CSCW literature is e-IMCI (DeRenzi *et al.* 2008), a prototype for Integrated Management of Childhood Illness (IMCI), jointly developed by the World Health Organisation and UNICEF. A pilot evaluation in Tanzania showed that the system leads to better adherence to the IMCI protocol, as well as greater speed and flexibility than the paper booklet version. The developers of e-IMCI note that there is a similar screening protocol for HIV, for which an expert system could be developed. A less explored alternative would be to provide health workers, particularly community health workers who have limited training, with access to formally trained medical professionals through the use of mobile devices such as smartphones and tablets.

Finally, there is also the underlying issue of the management and integration of health information from different healthcare providers and health programmes, particularly in developing countries, where there is a need for ICT infrastructure and common standards for sharing and exchange of information (Braa *et al.* 2007). As Braa *et al.* (2004) point out, development of Health Information Systems (HIS) in such settings need to take into account the challenges of *sustainability* and *scalability* — where sustainability refers to adapting the information system to the local context, cultivating learning processes, and developing usage routines that can persist over time, while scalability is concerned with making a working solution developed in one site adapted successfully over other sites. We share these concerns and, as will be demonstrated, aim to address them through active involvement of locally based actors and organisations we have identified.

3. Theoretical background

Although a CSCW approach is not explicitly adopted in most of the research reviewed in Section 2, they all evidence the cooperative nature of the work arrangements these research projects aim to support. CSCW is a relatively young research field when compared to the disciplines that contribute to its theoretical background, such as computer science, sociology and anthropology, psychology and organisational studies. It should then come as no surprise that there are different views on what the focus of the field should be. A clarification as to our motivation and perspective on CSCW is therefore in order. Multidisciplinarity, a core feature of CSCW, is also a characteristic both of our research group (comprising computer scientists, human-factors researchers, medical doctors and epidemiologists) and, as will become clear later in the paper, of the work situations and groups we investigate. While our work has a strong technological component, our analysis is not driven by technology alone. Rather, our perspective is close to that of Schmidt and Bannon (1992, p. 12), who characterise CSCW as "as an endeavour to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements". In this context, we view CSCW as a discipline oriented towards design, in the sense that the disciplines Simon (1981) calls "sciences of the artificial" are so oriented.

Therefore, the study presented in this article has involved fieldwork and observational techniques in order to enhance our understanding of the *cooperative work* undertaken by the heterogeneous group whose activities we wish to support, as well as more common requirements engineering techniques, including surveys and iterative prototyping, in order to devise effective interventions in these work arrangements through *computer support*.

We use the term *fieldwork* to describe work carried out by one of the authors (see Section 4) over a period of 5 years in the Amazon region which consisted in observing daily practices of healthcare providers, researchers (epidemiologists, social scientists), and managers in the region, and occasionally taking part in such activities at medical, organisational and policy-making levels. We place less emphasis on the connotation this term often has in some CSCW literature, namely, that of an activity requiring particularly specialised sociological training and a pre-existing conceptual grasp. Our perspective is thus in agreement with the view expressed by Randall *et al.* (2007, p. 19). In this investigation we adopted the meta-level approach proposed by Doherty, McKnight & Luz (2010) to structure the analysis of requirements based on the data collected through fieldwork and subsequently documented in notes and reports. This meta-level approach consists in employing key concepts from well-established CSCW frameworks and case studies of their application in mobile healthcare situations in order to facilitate requirements elicitation. More specifically, we focused on three key concepts and explored their implications with respect to the activities of health workers in remote regions. These concepts are: mobility work, coordination mechanisms and common information spaces.

Mobility work (Bardram and Bossen 2005a) regards the spatial aspects of cooperative work, and implies that actors involved in cooperative work (see the next section) need to gain access to the right configuration of people, places, resources and knowledge to accomplish their work. An analysis based on this concept highlights the movement required for such access to be obtained, and also the different characteristics of the places in which work is accomplished. This spatially focused theme also exhibits temporal facets, such as the acquisition and preparation of information prior to mobile activities and transfer or aggregation of information resulting from such activities. These aspects are also related to the concept of articulation work (Strauss 1988), which concerns the coordination work that enables the cooperative activities of actors who are distributed and semi-autonomous in their work, and the arrangement of tasks performed by such actors to assist work flow. This implies, in addition, facilitating access to appropriate communication channels and mechanisms of interaction, such as plans, standard operating procedures and organisational structures, designed to reduce the complexity of articulation work. Mobility work can therefore be regarded as a complement to the concept of articulation work.

The means to support and facilitate articulation work are conceptualised in CSCW as coordination mechanisms. In particular, this concept clarifies the role of artefacts as support for the articulation of distributed activities (both cooperative and collaborative, as discussed below) through conventions, prescribed procedures etc. Numerous examples of artefacts that embody coordination mechanisms have been identified in mobile healthcare contexts. In fact, some works place strong emphasis on the analysis of artefact use in hospital wards. Bardram and Bossen (2005b), for instance, investigate the use of artefacts such as worksheets, whiteboards and personal notes, in coordinating activities such as locating patients and staff, cooperative planning, scheduling, etc. Coordinative artefacts is also one of the original concepts identified in the method proposed by Doherty *et al.* (2010) as relevant to the analysis of mobility work in healthcare. In our analysis, we decided to focus rather on the more general concept of coordination mechanism, since the activities of medical professionals and researchers we studied are highly distributed, from a geographical point of view, which makes articulation work and communication through physical, non-digital artefacts such as the ones analysed in connection with work performed in hospital wards (Bardram and Bossen 2005a,b, Doherty *et al.* 2010) uncommon and to a great extent impractical.

The concept of common information spaces (Schmidt and Bannon 1992, Bannon and Bødker 1997) concerns the set of information objects produced and accessed by multiple actors involved in cooperative work. The issue that needs to be considered is not so much the fact that these information objects need to be collectively accessible — e.g. using CSCW technology to provide a shared view in synchronous interaction (Greenberg 1990), or database technology to facilitate distributed asynchronous access by a group of people (Schmidt and Bannon 1992) — but rather the joint interpretation and agreement on meanings (even if temporary) for those information objects. This process of interpretation requires jointly creating a common information space that extends beyond the individual personal information spaces of the actors involved in the creation and use of these information objects. The concept of common information spaces has been fruitfully employed in the analysis of healthcare work. Kane and Luz (2011), for instance, characterise the presentation and use of information at multidisciplinary medical team meetings in terms of this concept, describing the interpretation process of joint construction of the common information space by different specialists in the multidisciplinary team. Quantitative evidence for the attainment of common ground among these specialists has also been observed in the regular structure of turn taking during the meetings (Luz 2012). Heterogeneity of work and of the representations used by cooperating workers is also addressed by influential ethnographic studies of coordination in hospital wards (Reddy *et al.* 2001, Bossen 2002).

As noted before, beyond the heterogeneity of backgrounds, educational qualifications, and immediate goals and concerns that characterise the joint activities of those involved in healthcare and disease monitoring, wide geographical distribution of workers poses additional challenges to analysis. These challenges are not easily met by analytic frameworks originally developed for healthcare work that is confined to hospital wards. In particular, the activities performed by the healthcare providers in the context of disease surveillance and patient care in the geographical area on which our research has focused can be characterised along the lines of two interrelated group work processes, namely, *cooperation* and *collaboration*. Gaudin *et al.* (2012), drawing on a conceptualisation elaborated by Rogalski (1994) and others, consider cooperation to occur when the team members involved perform different activities but pursue a common goal. Collaboration, on the other hand, occurs when team members not only pursue the same common goal, but also work on the same task together to achieve it. Cooperation requires neither unity of time nor space, while collaboration requires unity of time, but not necessarily unity of space, so long as the team members have access to the appropriate support tools. We found this conceptualisation useful and complementary to the concepts of mobility work, common information spaces and coordination mechanisms and adopted its distinction of collaboration and cooperation in our analysis.

Methodologically, the structure provided by these concepts served to sensitise our analysis and design to the contextual underpinnings of the activities we wished to support.

Application of this method resulted in iterative refinement of the identification of actors, goals and requirements, which is consolidated and presented in the following section. It also served as a basis for the specification of the first prototype which, in turn, was instrumental to the next stages of elicitation (see Section 5), thus triangulating the findings.

4. Identifying actors and establishing requirements

An assessment of the needs of individual actors and organisations involved in treatment and monitoring of emerging and neglected diseases in the Southwestern Amazon region, including health professionals from Brazil, Peru and Bolivia was carried out through survey of the literature, fieldwork, and informal interviews. Preliminary results of this assessment have been reported in a conference paper (Luz *et al.* 2012). The text in this section extends and elaborates on that earlier report.

The fieldwork that provided the initial motivation for the study reported in this paper was carried out over a number years in Brazil by one of the authors, who lived and worked in the tri-national Southwestern Amazon region in the last decade. Over this period, as coordinator, in the state of Acre, of the Health Ministry's Health Work Internalisation Programme ("Programa de Interiorização do Trabalho em Saúde", PITS, in Portuguese), he had close contact with the health system of the region and was able to observe the effects of poor sanitation, the low educational level of the population and the scarcity of health professionals (due to distances and difficulty of access) on the epidemiology of diseases in the area. These factors, combined with the characteristics of the Amazonian ecosystem create the conditions for spread of a number of infectious diseases.

In the process of investigating ways to improve healthcare in this remote region, the research team headed by Dr Cesario conducted 14 semi-structured interviews with healthcare professionals in the state of Acre, as well as many hours of direct observation of the activities of local nurses and doctors in Brazilian towns close to the tri-national border (see Figure 1). As pointed out earlier, monitoring of the region shown in Figure 1 is relevant due to risk factors consisting of proximity to an area (in Peru) where bartonellosis is endemic, as well as the above mentioned socioeconomic characteristics. The research team also joined the MAP initiative (named after the department of Madre de Dios, the state of Acre and the department of Pando, shown in Figure 1) which aims to promote the sustainable development of the region. Through this initiative, they held two workshops with healthcare professionals and researchers from Brazil, Peru and Bolivia which identified concerns with the propagation of bartonellosis from other areas of Peru into MAP region, and the near complete lack of coordination among the health systems of the neighbouring towns near the border, not least due to the fact that these towns are located in different countries. Further research indicated that coordination efforts are hampered by a lack of effective mechanisms to encourage local healthcare professionals to collect and feed epidemiological data into the health system.

This initial fieldwork assisted us in gaining further access to the relevant stakeholders and their work settings, obtaining ethical approval and accessing medical data. It also guided the identification of the health professionals involved, the description of the tasks they perform, and their needs in the specified work contexts. The study reported here was approved by the Ethics Committee of the School of Computer Science and Statistics, Trinity College Dublin.

After identifying the main stakeholders, we conducted further semi-structured inter-

Figure 1. Map showing the area of Amazonia (top left) where the fieldwork was conducted, encompassing the Brazilian state of Acre, the Bolivian department of Pando and the Peruvian department of Madre de Dios.

views with two medical researchers involved in developing healthcare policy, a medical doctor and a nurse who practice in the region, and an epidemiologist working in the area. The region in question, to put it more precisely, comprises towns and rural settlements around the area marked with a black dot in Figure 1. The aim of these interviews was to delineate a situation of concern and define a design problem.

The prospective functionality of a system was then explored through sketching and storyboarding. This process involved exchanges of low fidelity prototypes and video-mediated meetings between the research team and two medical informants over a period of two months. Findings were then triangulated through the use of a concept video and questionnaires which were presented to 47 health professionals involved in primary care, epidemiological research and disease surveillance in Brazil (see Section 5).

4.1. *Main actors in disease surveillance and patient care*

Monitoring, prevention, treatment and research of emerging diseases involves a complex interleaving of actions by several actors of heterogeneous backgrounds. Building technology support for these various actors involves an understanding of their activities, knowledge and representations, as well as the articulation work needed to enable effective sharing and use of information. While this article focuses on support for health professionals responsible for primary care and local data gathering, we briefly outline the roles of the different groups involved in the more general setting.

Nurses and community health workers are generally responsible for day-to-day primary care in the Southwestern Amazon region. Community health workers (CHW, "agentes comunitários de saúde" in Brazil, or "agentes comunitarios de salud" in Peru and Bolivia) are members of the community who perform functions related to healthcare delivery. Although they receive basic training in the context of specific interventions, and may be provided with basic laboratory equipment, they have no professional degreed tertiary education (Lehmann and Sanders 2007), and at least in Brazil they are not allowed by law to diagnose diseases. CHWs also perform other developmental and promotional roles, acting as bridges between the community and formal health services. These local workers may interact with locally-based nurses, as well as medical assistants and doctors. Nurses have a level of formal training, which CHWs lack, and therefore perform a wider range of primary care duties. The scarcity of doctors in the area places extra demands on the work of nurses, including the task of coordinating and supervising the activities of CHWs and a role in epidemiology research, as discussed below. In the context of emerging diseases and epidemiological surveillance these primary care workers could also play important roles in recording details of suspected cases for notification, identification of disease vectors (carriers) which in the case of both bartonellosis and ACL are sand flies (Diptera: Psychodidae: Phlebotominae), and educate local communities.

Medical doctors and specialists are medical professionals who are often not available full time in the primary care units of the region. In addition to treating referred patients, they can provide guidance to the activities of local nurses and CHWs. Doctors and specialists from regions where a disease is newly emerging may need to seek information from colleagues from regions where it is endemic. This is the case of bartonellosis, for instance, which is endemic to Peru but it is not yet transmitted in the Amazonian parts of Peru, Brazil, or Bolivia (see Figure 1). In addition to the informal ties that may exist between doctors across national borders, formal mechanisms are starting to be put in place that might facilitate information exchange. The South western Amazon region has been experiencing not only the aforementioned MAP Initiative (which congregates local governments, universities, and civil society to address regional problems with a sustainable approach), but also several partnerships between academic groups. Although the MAP initiative provides a basic institutional framework for collaboration among researchers and policy makers, a common information space that allows for mobility work and coordination among doctors, researchers and local healthcare providers has not yet been established.

Epidemiologists and researchers devise models for disease surveillance. They rely on access to information from a variety of sources in order to assess risks and characterise eventual patterns of disease propagation. Of particular interest in the Southwestern Amazon region is the development of early warning systems to anticipate and manage the negative impacts of climate change on the spread of emerging or re-emerging vector-borne infectious diseases (Cesario *et al.* 2011). Such systems need to be able to aggregate data on climate, land use, the general geographic characteristics of the region, vector distribution and patient case distribution as well as their evolution over time.

Although epidemiology can be regarded as a separate research speciality, our study includes nurses who also perform data collection tasks that are normally performed by epidemiologists. In some cases, these nurses also have epidemiology training and research interest in the area. The need for mobility work in this type of activity is clear, but presents itself at different levels. Nurses based in rural communities would typically perform epidemiological data collection as a secondary activity, while researchers would do it as their primary task when in the field. These different actors will therefore attach different meanings of the objects manipulated in this task. This implies a need for the creation of a common information space in order to enable effective cooperation.

Policy makers and administrators rely, among other sources, on information and expert recommendations provided by physicians and epidemiology researchers in order to decide on prevention policies, tools and strategies to cope with possible outbreaks and epidemics. As in the case of information exchange among researchers and medical staff, there are both governmental agreements and non-governmental initiatives aimed at improving integration across the borders. Multi- or bilateral diplomatic agreements promote the free transit of people across the borders and support binational large infrastructure projects, such as road building. Such initiatives are likely to have significant impact on the work of policy makers and consequently on their requirements for collaboration support.

4.2. *Team collaboration and cooperation*

Although these various actors are dispersed across different geographical locations and often perform their tasks independently and asynchronously, from a CSCW point of view they can still be collectively regarded as a team. Teams have been defined as groups of people who deal with different sources of information and perform a number of activities as an integrated unit to achieve a common goal (Gaudin *et al.* 2012, Cooke 2004).

Figure 2 presents a diagrammatic overview of the interactions between actors involved in disease surveillance and patient care in Southwestern Amazonia as an instantiation of the scheme described in Gaudin *et al.* (2012). Although at present the level of collaboration and cooperation between health professionals involved is generally rather minimal, it is possible that with the introduction of CSCW technology, particularly mobile devices, both of these processes can be strengthened to improve the diagnosis and monitoring of neglected and emerging diseases.

4.3. *Technology support for collaboration and cooperation*

Although the collaborative and cooperative processes that take place in the context of disease surveillance and patient care presented in this article are not as intense as those that take place in other medical context such as hospital wards (Bardram and Bossen 2005a), our working assumption has been that they could nevertheless benefit from CSCW technology. In the context of medical interventions and surveillance of emerging diseases such as bartonellosis and ACL in the Amazon region, mobile devices could in addition support other activities identified in our study so far. These activities and their constraints are described below.

Collection of patient data: due to the remote and sparsely populated geography of the region, an important goal both from the point of view of healthcare services policy and patient management is to obtain consistent and accurate patient information. The mobility requirements for these activities also involve heterogeneity of linguistic cultural backgrounds due to the fact that the location where such activities take place (and monitoring is necessary) is within a tri-national region. Portuguese is the language most

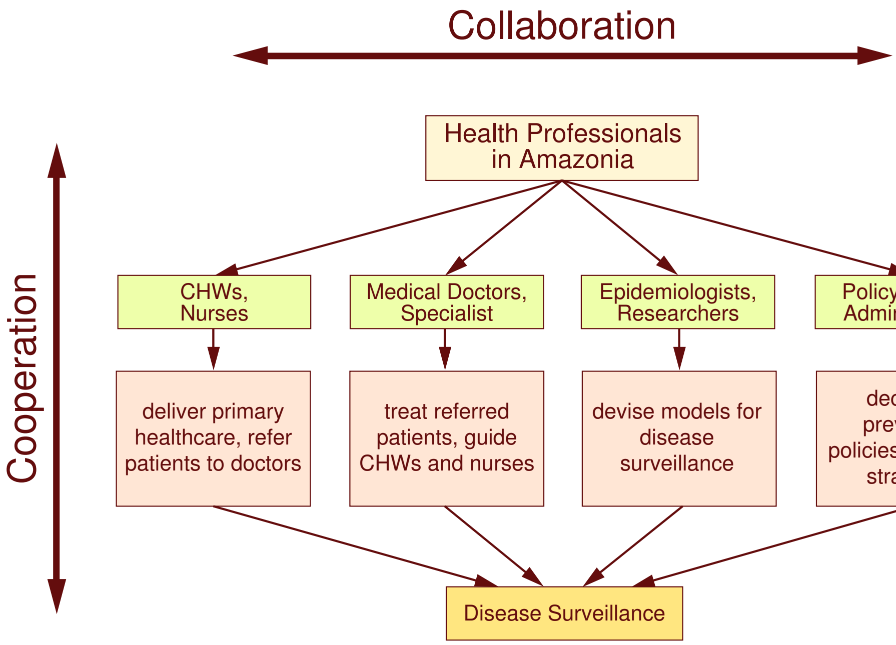


Figure 2. Collaboration and cooperation between health professionals. An instantiation of the diagram proposed in (Rogalski 1994) and reproduced in (Gaudin *et al.* 2012).

widely spoken on the Brazilian side of the border, whereas Spanish is the predominant language in Peru and Bolivia. In addition to these official languages, there are indigenous languages (grouped into three main linguistic families) that are spoken by different indigenous populations in the MAP region (Cesario *et al.* 2011). An integrated data collection approach for this region will therefore need to be localised to the particular area where collection takes place while building on a common schema. Mobility requirements also include location data, which could potentially be integrated into geographical information systems for the purposes of issuing early warning of outbreaks, as well as use by other healthcare professionals. A typical constraint on this activity is the irregular telecommunication coverage in the region. In the case of CHWs, literacy may also be an issue.

In addition to patient and geographical data possibly collected by nurses and CHWs, data could be gathered by researchers for the purposes of filling eco-epidemiological knowledge gaps on both bartonellosis and ACL, and for their surveillance. Such data include: time spent outdoors during sand fly 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 ACL parasite (Cesario *et al.* 2011)) kept at home, outdoor occupational and recreational activities, travel and household hygienic facilities.

One of the doctors we interviewed pointed out that, even though notification of infectious diseases to the health system is a formal requirement for doctors in Brazil, the data collected and stored on notification databases is often unreliable. There are both (1) problems related to the use of the notification form and associated procedures as a coordination mechanism and (2) socio-cultural issues. The former arise due to under-staffing and the resulting time pressures placed on doctors working in the region as well as the fact that they regard notification as mostly a form-filling exercise, leading to this task being delegated to nurses or even clerical staff. Two interviewees expressed the opinion that the lack of visibility of this information, or aggregated information of this nature for the entire region and specific neighbouring regions contributes to the relative lack of interest in the notification activity. The socio-cultural issues concern over-notification for economic reasons (e.g. more resources could be allocated to the area) and under-notification for fear of damaging the external perception of the town where the cases occur.

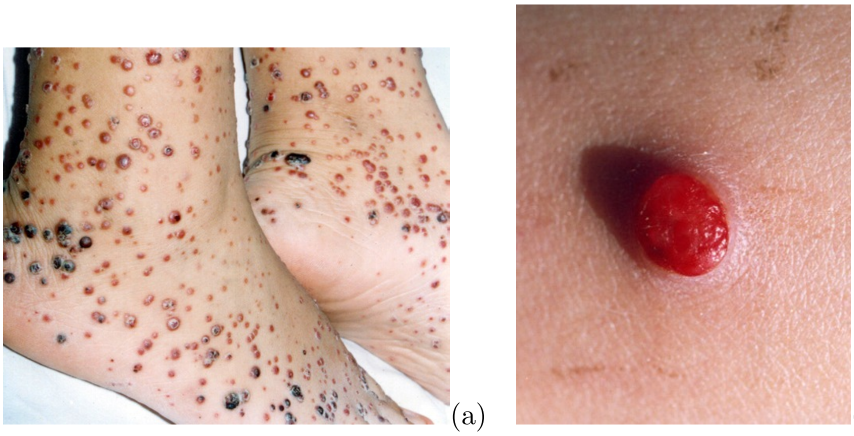
Diagnostic assistance: as noted above, primary care workers operating in the region are often members of the communities which they serve, and have only basic training on how to perform very specific interventions. However, emerging diseases may force these professionals to confront situations for which they are ill prepared. Further training and outside assistance would therefore be needed. Physical distance and mobility constraints make carrying of bulky laboratory equipment and instructional material impractical. Such materials could include, for instance, medical atlases for aiding differential diagnosis of cutaneous lesions, which characterise both bartonellosis and the non-visceral form of ACL (see Figures 3 and 4 for examples of lesions), and mobile microscopy for analysis of blood smears for diagnosis.

The medical doctors and researchers who participated in a workshop organised by our group noted that these mobile device capabilities could also be helpful to their research activities. One of the participants reported that he is currently building an inventory of Phlebotominae (the subfamily of vectors of both ACL and bartonellosis) and blood samples for laboratory analysis though informal contacts (i.e. contacts outside the formal coordination mechanisms implemented by the health service authorities) with local nurses and doctors. He raised the possibility that some of these data could be collected and analysed locally through mobile devices and transmitted electronically to him.

Figure 3. American Cutaneous Leishmaniasis (ACL) lesion. Photograph by M. Cesario.

Access to central knowledge sources: as with diagnostic assistance, mobile health-care workers may benefit from access to knowledge compiled from a variety of sources and stored centrally. These include not only patient records but also references, disease and vector distribution maps, as well as population data.

As noted earlier, effective access and visibility of these knowledge sources is an important factor in motivating collection and production of better quality information.



(a) (b)

Figure 4. Verruga Peruana (Peruvian wart) lesions caused by bartonellosis in its second (eruptive) clinical phase. Lesions shown in miliary form (a) and in mular form (b). Photos by Maguia *et al.* (2009), reproduced with permission.

Aggregated data can also help identify deficiencies in diagnostic and data gathering processes. An interviewee (a researcher) illustrated this point to us with a statistical analysis she conducted on data collected through the existing formal notification system which showed an apparently anomalous pattern of incidence of the mucous form of ACL among children (0 to 10 y/o). She attributed this pattern to deficiencies in data gathering and in diagnosis, since the mucous form of the disease is difficult to diagnose, particularly in children, thus implying that the high number of cases recorded in the database may be due to misdiagnosis (false positives).

Early warning: if patient, serum-epidemiological and population data can be successfully gathered by primary care workers and researchers working collaboratively at the local level and aggregated into databases and geographical information repositories, these data would provide a solid foundation for the implementation of an early warning system for the aforementioned emerging infectious diseases. Data analysis and machine learning techniques could then be applied in order to detect patterns of dispersion, risk modelling etc. In addition to being of research interest to epidemiologists, early warning was identified by participants as an important tool to healthcare service managers and policy makers in devising effective strategies for dealing with outbreaks.

5. Validating and further exploring fieldwork findings

A triangulation method (Mackay and Fayard 1997) has been employed in order to validate and further explore some of the needs and possibilities discussed above, which were uncovered by the initial fieldwork. This method involved developing a series of sketches and storyboarding with the participation of medical specialists, which eventually led to the implementation of an exploratory prototype, the production of a concept video based on this prototype, and the presentation of the concept video to representatives of the main actors identified above as a means of gathering their opinions on the prospective functionality, usability, priorities and risks of the proposed system. A survey and informal interviews were employed for this purpose.

5.1. *Prototyping*

After three rounds of paper prototyping and user interface sketching, a high-fidelity prototype called *nu-case* was created which runs on Android^{tm} smartphones and tablets[1]. This prototype aimed to explore support the following tasks: collection of patient data, diagnosis of common and monitored diseases, communication with specialists from regional hospitals and central data repositories, and spatiotemporal visualisation of case reports.

Data collection is supported though different modalities: the user can enter the data through the on-screen keyboard and add audio notes for transcription at a later time for incorporation into a multimedia patient record. Precise GPS coordinates can be easily added to the record. A photo of the patient and images of skin lesions can also be captured through the built-in camera and annotated though drawing and textual labelling. Figure 5 shows samples of the nu-case patient record selection and data input screens, with the location dialogue box open to acquire GPS coordinates.

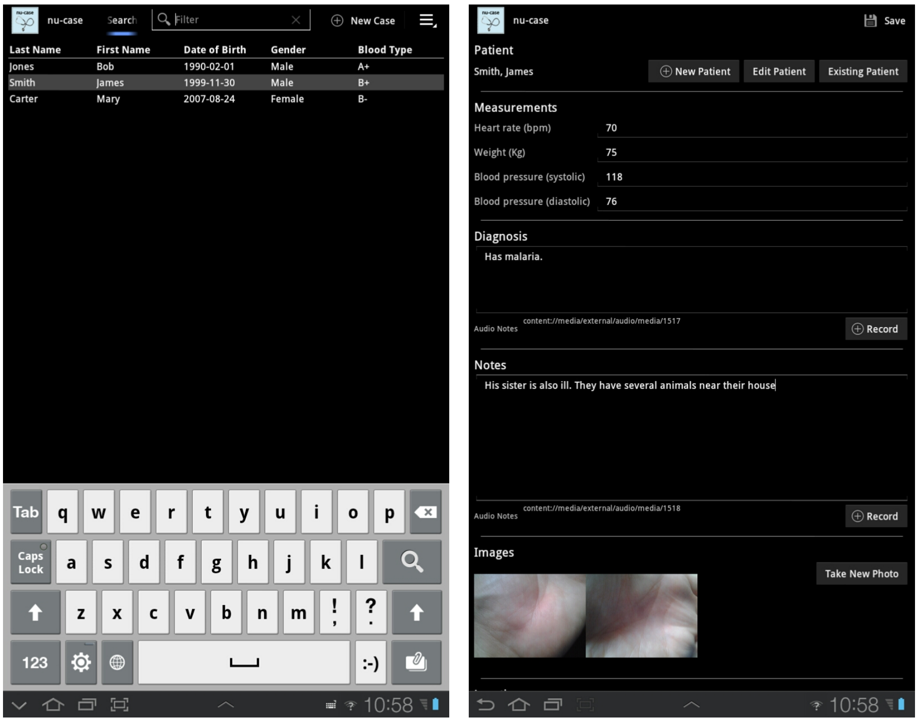


Figure 5. Screenshots of the nu-case prototype in (left) patient record selection and (right) data input modes on a Samsung^{tm} Tab 10.1.

Support for diagnostic has been implemented for illustrative purposes, to assist our discussions and interviews with the prospective users, rather than as a tentative approximation of a realistic diagnosis support system. The functionality implemented includes support for acquisition and basic image processing of photographs of skin lesions and visual comparison of features. The chronic form of bartonellosis is characterised by one or more reddish eruptive skin lesions (as shown in Figure 4). Since specific training is necessary for the differential diagnosis of these dermatological lesions, we have implemented a simple tool with which the acquired images of the patient can be compared with positive

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

and negative cases which the user can slide across the screen, while leaving the image of the lesion to be identified statically placed on the bottom half of the screen. It is possible that lesion identification algorithms based on machine learning methods such as the ones used with some success to distinguish nevi, dysplastic nevi and melanoma (Dreiseitl *et al.* 2001) can be employed in diagnoses of ACL and bartonellosis. The prototype has been designed so as to suggest this possibility, as well as the possibility of flagging a patient case and skin lesion images for further attention of a (possibly remotely-located) specialist when the classifier's confidence score falls below a pre-determined level. This would in effect establish a coordination mechanism (Schmidt and Simone 1996) between local healthcare workers and specialists in remote sites. Images may also be captured through a portable electronic microscope connected to the mobile device through its USB port. Similar image analysis methods can, in this case, be employed to aid diagnostic by examination of blood smears (Cesario *et al.* 2012b).

Assistance to diagnostic, perhaps via mechanisms such as the ones described in the previous paragraph, is not the only form of communication between local healthcare workers and specialists envisaged for the system. Communication can be synchronous and involve sharing of images and other medical evidence if network access is available, or asynchronous and involve gathering of data for uploading once the worker returns to their network connection point, if network access is unavailable or unreliable[1]. The asynchronous communication pattern can also be employed for uploading patient and epidemiological data collected in the field, as well as for downloading instructional and reference material (e.g. updated lesion images annotated by specialists) and the latest data on relevant geographical changes, disease propagation patterns etc.

Finally, the data collected locally and aggregated into a central repository can be returned to the local mobile device where it can be visualised on a graphical display along spatiotemporal dimensions (Cesario *et al.* 2012a). This information visualisation has been implemented so as to display a map of the region on which the reported cases are shown (see Figure 6). The patient cases used for development and testing of the prototype come from an actual database which contains instances of case notifications in the region, covering a period of eight years. Cases can be displayed by municipality of infection or municipality of notification (GPS coordinates are not available on this database). Circles with diameters proportional to the number of cases in an area are shown on the map. The user can alter the display by selecting, through direct manipulation, different date ranges and combinations of features from patient records (see Figure 7). It is also possible to set the initial parameters of the visualisation and then animate it to display progression over time, thus supporting trend analysis and identification of patterns of disease spread.

5.2. *Gathering feedback*

We have produced a concept video demonstrating the presumptive functionality of nu-case in order to gather feedback on the needs assessment described above, and to assess the perceived ease of use of the system, the usefulness of the different features implemented, their suitability to the tasks they are meant to support, and any potential pitfalls and constraints in its deployment. The use of this type of concept video is considered to be invaluable in involving potential users in the process of design (Buxton 2007).

This video was used in conjunction with a questionnaire and a series of interviews

[1]In Acre State, Brazil, where the fieldwork has been carried out, there is reasonable 3G network coverage. At the tri-national region, coverage is less reliable, but landline connection is available on all three sides of the border.

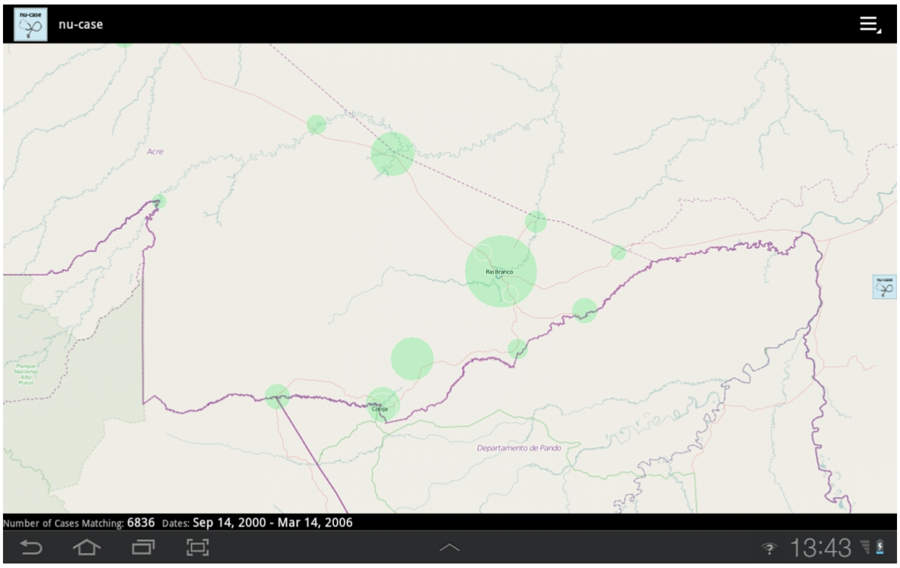


Figure 6. nu-case visualisation of reported patient cases.

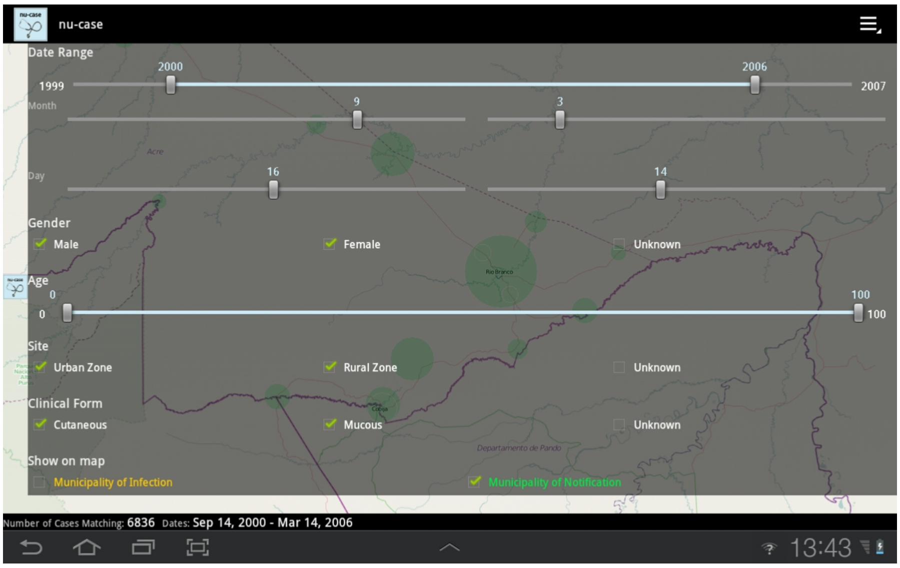


Figure 7. Dynamic query interface of the nu-case visualisation.

conducted with Brazilian healthcare professionals. The questionnaire consisted of two types of questions: a set of 7-point scale questions with bipolar anchor points to assess perceived ease of use and usefulness of features provided by nu-case, and a set of ranking questions to assess the relative importance of the different tasks to be supported by technology and the perceived risks and issues in its deployment and use. All questions were followed by comment boxes where respondents could enter general comments in free-form text. The content of these questions is detailed in the following sections, along with the results.

Once ethical approval for the study was granted, our collaborators in Brazil proceeded to recruit participants from amongst the healthcare community. A total of 57 participants responded. Of these, however, 10 did not fully complete the questionnaire (the participant's information sheet made it clear that participation was voluntary and that all questions were optional) and their answers were therefore excluded from subsequent analysis. The questionnaires were administered after the participants watched the concept video[1]. Participants were able to pause and rewind the video at will.

Of the participants who answered the questionnaire fully, the majority (62%) left extensive textual comments, indicating a good level of engagement with the survey. After a sufficient number of questionnaires were collected, we conducted interviews with representative members of the different professional groups who took part in the survey.

The answers of the 47 participants who fully completed the questionnaire (15 medical doctors, 15 researchers, 13 nurses/CHWs and 4 healthcare administrators) are reported below. Some researchers and healthcare administrators also had medical qualification and described themselves as members of two (sometimes three: doctor, researcher and manager) groups. In the summary of answers presented below only the specified primary occupation was considered. The respondents' age groups were 20-30 (17), 31-40 (13), 41-50 (10), 51-60 (6), and > 60 (1). The genders were fairly evenly balanced: 21 females, 25 males and 1 undeclared gender.

5.2.1. Ease of use and usefulness of diagnostic functionality to different user groups

Most respondents answered that the system appeared to be easy to use (mean 5.5, on a scale of 1=very difficult to 7=very easy). The mean ratings per groups were: 5.7 ($s = 0.9$) for doctors, 5.3 ($s = 1.6$) for nurses, 5.4 ($s = 1.5$) for researchers and 6.0 ($s = 1.1$) for administrators. Four participants commented that their ratings assumed that the user had a certain familiarity with the mobile device (tablet). These answers have, of course, to be qualified by the fact that the respondents did not actually use the system but rather formed their opinion based on the concept video. However, our aim here was not to assess the usability of the prototype as such, but rather to test a design concept based on a prior assessment of needs. The inclusion of this question was motivated by a study by Diefenbach *et al.* (2010) which suggests that videos elicit essentially the same judgements of pragmatic quality as real interaction with the prototype when used in testing of design concepts. The scenes depicting examples of user interaction with the prototype were storyboarded in collaboration with an epidemiologist who worked in the Amazon region and a medical doctor who investigates neglected diseases. The storyboards formed the basis for the creation of the video, which showed a user's interaction with the prototype in great detail, thus enabling viewers to form an opinion about the pragmatic quality of the system.

The questionnaire also explored the somewhat controversial issue of helping different prospective user groups (doctors, nurses and community health workers) in diagnostic tasks for neglected diseases. The results are shown in Figure 8, categorised according to the occupations of the respondents as a diverging stacked bar chart with neutral opinions split down the middle by the zero line, positive opinions shown to the right of the zero line and negative opinions shown to the left. Most respondents were very positive about the potential of the tool in helping *doctors* in diagnostic tasks ($\bar{x} = 5.7, s = 1.6$). They were less positive when it came to rating the usefulness of the diagnosis functionality to *nurses* ($\bar{x} = 5.4, s = 1.6$). The opinions in this case were divided according to groups: doctors tended to view it negatively or neutrally, while researchers, nurses and administrators were more positive. Opinions were markedly divided as regards perceived usefulness to *CHWs*, with mean score $\bar{x} = 4.5$ ($s = 2.0$). Doctors and administrators rated it more

[1] An English-language version of this concept video can be watched at http://bit.ly/YFpAun

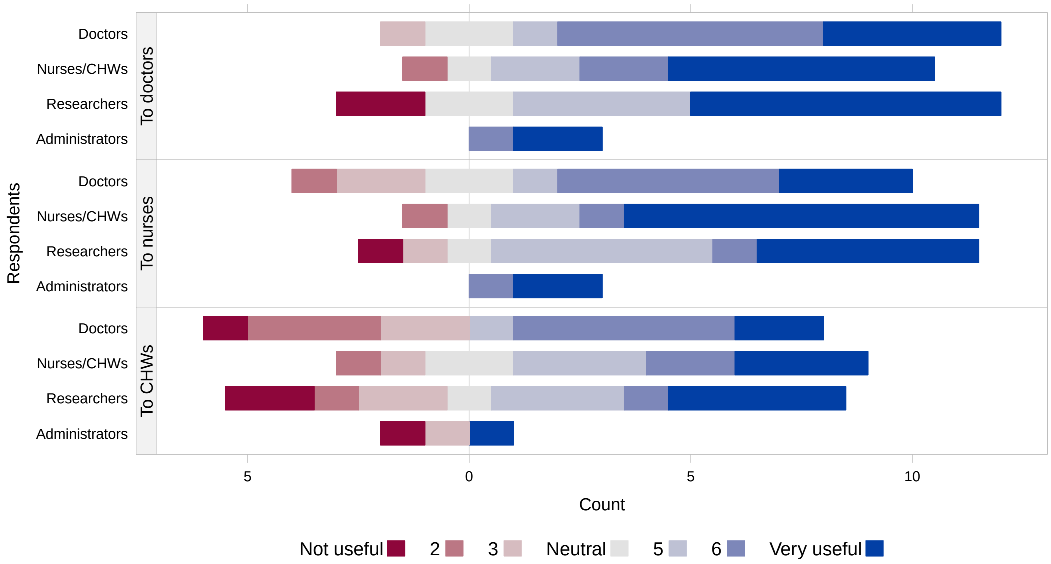


Figure 8. Perceived potential of nu-case as a diagnostic aid when used by doctors, nurses and community health workers.

negatively (not useful to CHWs), while researchers were somewhat divided (some rating the functionality negatively some rating it positively), nurses on the other hand, saw potential usefulness of the diagnosis functionality to CHWs.

From the written comments and post-questionnaire interviews it is clear that respondents saw the diagnostic functionality either as a visual aid to the task of a medical doctor ("it could help compare cases"[1]) or as supporting an ancillary task such as alert of suspected cases (which would then need to be properly diagnosed by a qualified professional) and triage, or as a telemedicine tool ("It could be useful, but poor if compared to a face-to-face consultation. In remote areas, due to the lack of [medical] professionals, it could be a solution"). A respondent thought the system would implement some kind of automated diagnosis and reacted against the idea ("no system is capable of replacing a qualified health professional"). The interpretation of the system as supporting a task that is ancillary to diagnosis *per se* seems to lie behind the fact that many participants rated the diagnosis functionality as useful to nurses, even though in Brazil by law only doctors are allowed to diagnose ("it would be very useful because it would facilitate collection of data in the place where the patient's nursing evolves").

5.2.2. *Components and possible task support*

Based on the video presentation of different components of the nu-case prototype, we asked how useful each of these individual components would be. Participants rated the components individually on bipolar 7-point scales. The responses were overwhelmingly positive, with most functions being rated *useful* or *very useful*. *Recording patient data* was rated on average 6.2 ($s = 0.8$), *taking images of skin lesions* was rated 6.4 ($s = 1.0$), *taking images of blood smears (with microscope attachment)* was rated 6.0 ($s = 1.5$), *recording geographical data (GPS)* averaged 6.4 ($s = 1.1$), *accessing other patient cases* was rated 6.3 ($s = 1.1$), *differential diagnosis* averaged 6.0 ($s = 1.4$), and *visualising case*

[1]All respondent quotations in this paper are literal translations from the original responses in Portuguese.

database topped the ratings with an average of 6.6 ($s = 0.8$).

We asked the participants to rank a set of possible applications of nu-case in order of importance in the context of neglected diseases. Figure 9 shows a diverging bar chart summarising the ranking distribution, classed according to respondent group and sorted from highest to lowest ranking. Disease monitoring and surveillance was consistently ranked among all groups as the most important task. Support for medical research and case notification and records were also highly ranked. It was pointed out that medical research and disease surveillance are inter-related tasks which involve a number of information seeking and data collection sub-tasks which could be facilitated by a networked mobile device deployed in the field.

With respect to the importance to diagnosis, one of the participants remarked that the system could also be used by doctors in urban areas, rather than only in remote regions, where cases of neglected tropical diseases can occur sporadically. Examples of such cases are travellers who get ill after returning home, a scenario that was not considered in the video ("I see this type of support for diagnosis as a reality that is closer to urban areas than to remote areas. I think the system could assist doctors based in areas that are distant from the zones of transmission of tropical diseases, either in their daily work or in medical research").

The cost of a tablet device needed to run nu-case was perceived as a barrier to its use in CHW training and diagnosis support, along with the above mentioned legal issues restricting diagnosis to doctors only, and the lack of training and low educational level of CHW. Consequently these tasks were ranked as having low importance.

5.2.3. Possible issues and challenges

Similarly to task importance, participants were asked to identify the most important issues in the implementation and deployment of a system such as nu-case. The stacked bar charts shown in Figure 10 summarise the responses. In this case, probably due to the diversity of the functions presented in the concept video, there was considerably more disagreement between the different groups of participants (doctors, nurses, researchers and administrators), and even within groups, than in the previous question. Yet, some trends could be identified. Medical doctors and researchers were mostly concerned about potential legal issues as well as dependability and accuracy. Nurses and administrators valued dependability and accuracy, but were less concerned than doctors about legal issues. Patient privacy did not consistently rank as highly as expected, but it is possible that some of the concerns respondents might have had in this area were subsumed under "legal issues".

Other potential issues identified by the respondents included network signal coverage and reliability, and the durability and battery life of the tablet devices when used in remote areas ("I am not sure the equipment would withstand the heat and humidity of the region."). A related issue was the cost of the equipment, given the likelihood that it will be damaged if used under adverse environmental conditions and the possibility of data loss ("Loss of data due to misuse, defects of the device [exposure to humidity, dropping etc] or theft [are serious issues]"). However, when asked about which hardware platform they would consider the most appropriate for the system, the majority of respondents, 33 (70%), chose tablets ("good compromise between portability and image size and detail", "ease of transport, operation and visualisation") , 5 (11%) answered notebook/laptop computers ("familiarity and low cost"), and 7 (15%) answered smartphones ("I think a 4- or 5-inch screen smartphone would be easier to transport and handle. I don't think the size of the tablet would be an advantage, even for comparing images. I believe this sort

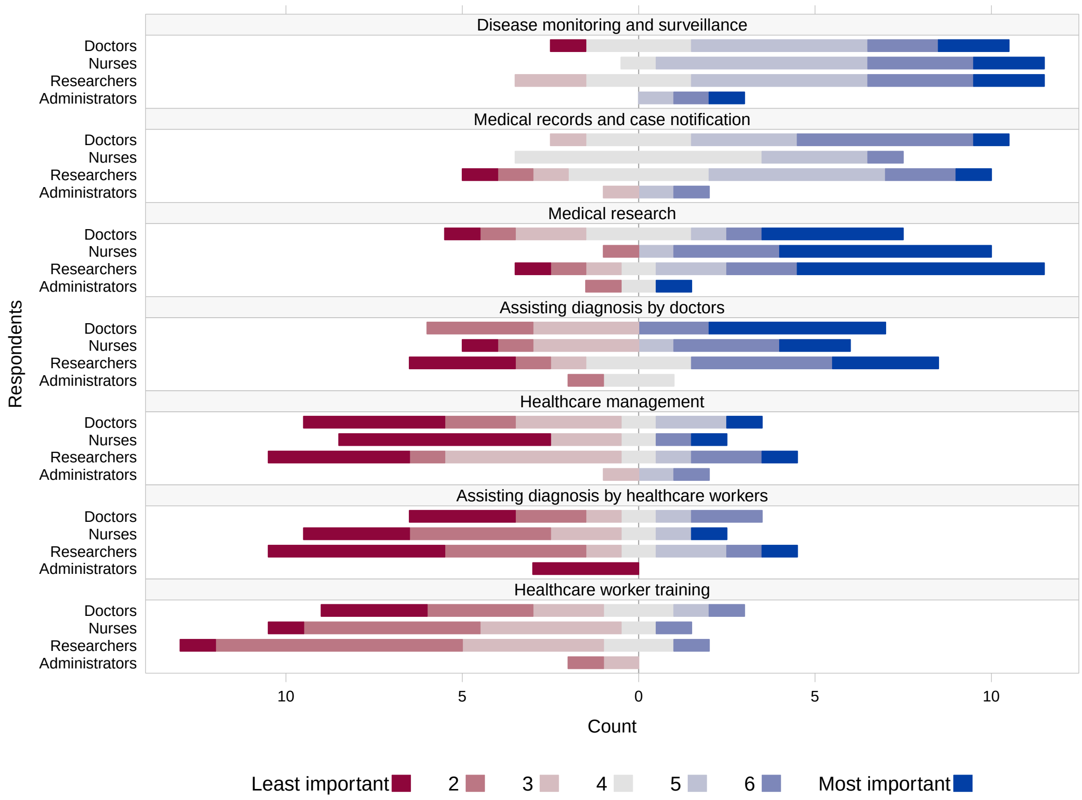


Figure 9. Diverging bar plot showing the distribution of ranking of different tasks in terms of the potential importance of nu-case, classed according to the four respondent groups. The ordering is from least important (1) to most important (7).

of more detailed analysis needs to be done on higher resolution monitors"). When asked about details, most participants remarked that the choice of platform would depend on the target user group and the place where the system would be used. There was, for instance, awareness of the greater suitability of certain platforms to mobile situations, such as fieldwork by researchers using tablet devices or smartphones. The functionality of the devices was also considered, with the fact that tablets have built-in cameras that are easy to use for fieldwork being cited as one of the reasons for preferring this hardware platform.

In terms of diagnosis, again the issue of the lack of training by local healthcare professionals was raised several times, along with the legal issues concerning diagnosis ("By law, diagnosis can only be performed by medical doctors. Nurses and [CHWs] can however help with triage and prioritisation. In such cases, image standardisation becomes an important issue"). Specific privacy issues mentioned included misappropriation of patient data by "hackers" and the possibility of causing embarrassment to the patient due to the use of photographs of facial lesions.

When asked what other functionality could be incorporated into nu-case, participants provided a number of suggestions, ranging from collection of certain data items to the use of specialised peripheral hardware. As regards data collection, researchers suggested collection of more epidemiology data and their display through tables and graphs as a complement to the map-based visualisation demonstrated in the concept video. One of the participants also suggested that synchronous communication capabilities would also

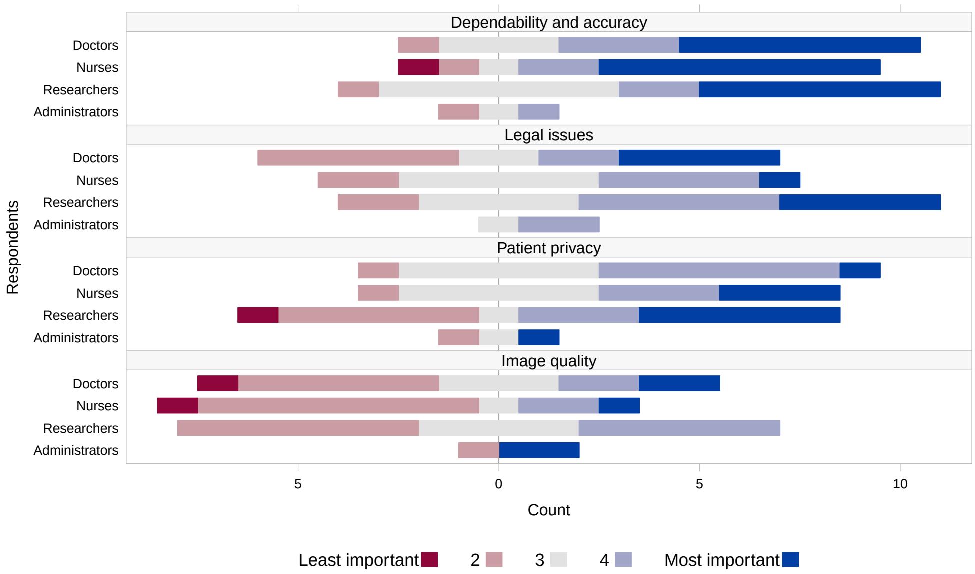


Figure 10. Bar plot showing the distribution of possible issues and challenges in using nu-case ranked in order order of importance (1 = least important, 5 = most important) by the four respondent groups. Counts for each category are shown at the bottom.

be useful ("while a healthcare professional is conducting an anamnesis[1] other professionals could participate in this process at the same time").

5.3. *Discussion*

The quality of the feedback obtained from our study participants demonstrates that the concept video strategy was successful in engaging the study participants, sometimes to the point of critiquing and suggesting improvements to the system functionality. For instance, regarding the visualisation feature, one of the participants observed that for the system to be useful to an epidemiologist, the area of infection rather than the area of notification should be displayed. The fact that the system showed area of notification was immediately detected, even though a distinction between municipality of infection and municipality of notification was made. Based on this observation we concluded that a finer level of granularity (e.g. GPS data) may indeed be required.

The high ratings given to the different components and functions of the system as demonstrated in the concept video also corroborated our initial assessment of tasks and needs of the main actors in this context.

However, the study also revealed potential issues and shortcomings which could have implications not only for the work presented in this article but also for the development of others systems for use in developing regions, such as the ones surveyed in Section 2. These issues concern legal and technical aspects of healthcare provision by nurses and CHWs, as well as attitudes to distance and to technology mediation. As mentioned above, respondents were generally sceptical about the usefulness of the system to CHWs. This was largely attributed to the lack of support by qualified professionals ("the CHW would need to be closely monitored by their coordinator in order to be make effective use of

[1]Process employed by a physician to obtain information that is useful in formulating a diagnosis by asking a patient or a suitable informant certain specific questions.

this technology") and the generally low educational level of CHWs ("In general, the CHWs I know have very low educational level. They would not be able to make the associations necessary for a diagnostic"). This is in marked contrast to the assumptions typically made in projects that have a strong technological focus. Breslauer *et al.* (2009), for instance, assert that "[combining a] mobile phone microscopy system with automated sample preparation systems could address challenges associated with use by minimally-trained health workers and the time involved in imaging multiple fields of view". Examples of such assumptions are also common in the medical artificial intelligence (AI) literature, sometimes with barely a reference to health workers. While it has been acknowledged that under certain circumstances, such as those in which healthcare must be provided in remote regions, CHWs can be empowered to perform simple diagnostic tasks which they would not normally be allowed (by law, in the Brazilian case) to perform (Yager *et al.* 2008), a number of obstacles remain.

A needs assessment exercise that focuses on human activity and is sensitive to broad collaboration and cooperation concerns as opposed to narrow technical issues may help overcome obstacles of that nature, or at least avoid the pre-conceptions and simplistic generalisations that all too often lead to software project failure in real-world socio-technical systems. In the case of diagnostic activities, our attention was drawn to the fact that it is necessary to distinguish the activities of nurses from those of CHWs in the delivery of primary care. Nurses have a greater level of training and often perform functions which might involve coordination of, and assistance to, CHWs. In remote areas where there is a shortage or lack of doctors, nurses, to again quote one of the respondents, "carry the health system on their backs", performing diagnostic and treatment functions out of necessity. System designers should therefore aim to provide these professionals with different levels of support for such functions, while catering for their coordinative activities. There are also other local groups with related coordination roles who could be better supported. Technology can alleviate tensions by establishing better communication channels between CHWs, nurses and doctors, and providing appropriate coordination mechanisms aimed at overcoming legal and cultural as well as technical barriers.

As regards attitudes of healthcare professionals towards technology mediation, less enthusiasm was felt towards the potential of the system as a tool to aid diagnosis, possibly mirroring common views of AI systems in the medical community (Miller and Masarie Jr 1990). There was scepticism about the ability of CHWs in the region to use the system. The use of machine learning in lesion identification was seen as too complex for use by local healthcare workers, and doubts were expressed as to the accuracy and dependability of such systems. On the other hand, the aid for differential diagnosis by image comparison on the device's screen was positively assessed, and it was suggested that this function could be invaluable in healthcare education, both by providing background study material and reference and by helping compile new medical atlases for emerging diseases out of images collected by healthcare workers in the monitored regions. In terms of data collection, however, the issues of legal requirements, image quality, accuracy and dependability were also raised.

With respect to the tablet hardware platform featured in the concept video, two different concerns were raised. The first was its physical appropriateness to the rural environment, and the second regarded "image issues". The general reactions concerning the former were that the tablet is not robust enough to cope with the environmental conditions (damp, heat, dust) and that a more portable and resilient device such as a smartphone may be preferable. A reaction concerning the latter was that the very choice of a high-end tablet itself suggests use by medical doctors close to urban centres rather than local healthcare workers. Interestingly though, this "image issue" served to elicit a requirement that had not been mentioned in the initial fieldwork and analysis of tasks, namely, the need for support for doctors located in urban centres in diagnosing neglected tropical diseases contracted by travellers (specially relevant in the cases of bartonellosis). This is another example of how the system could facilitate better cooperation between doctors located in urban centres, who typically have little knowledge of neglected diseases, and those located in rural areas who deal with such diseases on a more regular basis. The cooperation may even be across national borders, for instance between doctors in Peru who deal with cases of bartonellosis and their counterparts in Brazil and Bolivia who have not yet come across such cases.

In summary, the results reported above show that there is a great deal of good will and interest on the part of healthcare professionals in the use of technology to support and enhance cooperation and collaboration in the context of disease surveillance and research, as well as patient care, in remote regions. This is further evidenced by the fact that it was generally felt that the proposed nu-case system would be easy to use and could improve patient data collection in terms of efficiency and quality.

In terms of mobility, the study shows that a mobile system such as nu-case, with sufficient access to a central repository of dynamically updated disease case data and other related information, would be able to satisfy the requirements of access to people, places, resources and knowledge, so that monitoring and control of neglected and emerging disease in remote regions can be achieved. This is particularly true of at least three categories of tasks that our study participants rated as being very important: *disease monitoring and surveillance*, *medical records and case notification*, and *medical research.*

Finally, the study also highlighted the need for supporting temporal facets of mobility, defined as articulation work, which emphasises access to appropriate communication channels and interaction mechanisms. Unfortunately, as mentioned above, support for articulation work through coordination mechanisms is often ignored by developers of healthcare systems due to their narrow focus on technical issues.

6. Conclusions and further work

This article presented an analysis of work set against a background of collaboration and cooperation on disease surveillance and patient care in the Amazon region. The work presented here is part of our ongoing research towards the design, development and deployment of technology to assist the diverse but inter-related processes of diagnosing, treating and monitoring the spread of neglected and emerging diseases in the Southwestern region of the Amazon. It can be regarded as a real-life study on the application of fundamental CSCW concepts of mobility, common information spaces and coordination mechanisms to identify different actors involved in disease surveillance and patient care in the remote Amazonia, their primary activities and goals, and their specific task requirements for a healthcare system that needs to support the processes of cooperation and collaboration between them. The analysis was complemented by a prototyping exercise which acted as a focus for feedback from healthcare professionals. It has demonstrated the potential benefits of a triangulation method which combined the use of a concept video with surveys, interviews and fieldwork in the study of remote healthcare with its inherent complexities.

Further to the identification of the key actors, goals and requirements, and the development of a high-fidelity prototype mobile system, we plan to iterate the design process by conducting structured interviews and live prototype demo sessions. These interviews will be guided by the findings of the present study in order to refine and further specify user requirements, particularly in relation to the issues of concern and challenges already identified by our study participants. The next immediate goal is to bring selected functions of prototype system to a level where it can be used for field trials in Amazonia.

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References

Bannon, L. and Bødker, S., 1997. Constructing Common Information Spaces. *In*: *Proceedings of the Fifth European Conference on Computer-Supported Cooperative Work*, Shared Information Spaces, 81–96.

Bardram, J. and Bossen, C., 2005a. Mobility work: The spatial dimension of collaboration at a hospital. *Computer Supported Cooperative Work (CSCW)*, 14 (2), 131–160.

Bardram, J. and Bossen, C., 2005b. A web of coordinative artifacts: collaborative work at a hospital ward. *In*: *Proceedings of the ACM Conference on Supporting Group Work*, 168–176.

Bossen, C., 2002. The Parameters of Common Information Spaces: the heterogeneity of Cooperative Work at a hospital ward. *Proceedings of the CSCW '02*.

Braa, J., *et al.*, 2007. Developing Health Information Systems in Developing Countries: The Flexible Standards Strategy. *Management Information Systems Quarterly*, 31 (2), 381–402.

Braa, J., Monteiro, E., and Sahay, S., 2004. Networks of Action: Sustainable Health Information Systems Across Developing Countries. *Management Information Systems Quarterly*, 28 (3), 337–362.

Breslauer, D.N., *et al.*, 2009. Mobile Phone Based Clinical Microscopy for Global Health Applications. *PLoS ONE*, 4 (7).

Buxton, W., 2007. *Sketching user experiences: getting the design right and the right design.* Morgan Kaufmann.

Cesario, M., Cesario, R., and Andrade-Morraye, M., 2011. Environmental change and health impacts in Amazonia. *Human Health and Global Environmental Change*, 1, 26–33.

Cesario, M., *et al.*, 2012a. Time-based geographical mapping of communicable diseases. *In*: *16th International Conference on Information Visualisation, IV'12*, July. IEEE Press, 118–123.

Cesario, M., *et al.*, 2012b. Mobile support for diagnosis of communicable diseases in remote locations. *In*: *Proceedings of the 13th International Conference of the NZ Chapter of the ACM's Special Interest Group on Human-Computer Interaction*, CHINZ '12, Dunedin, New Zealand New York, NY, USA: ACM, 25–28.

Cooke, N.J., 2004. Measuring team knowledge. *In*: *In Handbook of human factors and ergonomics methods.*, 471–478 Boca Raton: CRC Press.

DeRenzi, B., *et al.*, 2008. e-IMCI: improving pediatric health care in low-income countries. *In*: *Proceedings of the twenty-sixth annual SIGCHI conference on Human factors in computing systems*, CHI '08 New York, NY, USA: ACM, 753–762.

Diefenbach, S., *et al.*, 2010. The impact of concept (re)presentation on users' evaluation and perception. *In*: *Proceedings of the 6th Nordic Conference on Human-Computer Interaction: Extending Boundaries*, NordiCHI '10, ACM, 631–634.

Doherty, G., McKnight, J., and Luz, S., 2010. Fieldwork for requirements: Frameworks for mobile healthcare applications. *International Journal of Human-Computer Studies*, 68 (10), 760–776.

Dreiseitl, S., *et al.*, 2001. A Comparison of Machine Learning Methods for the Diagnosis of Pigmented Skin Lesions. *Journal of Biomedical Informatics*, 34 (1), 28–36.

Dussault, G. and Franceschini, M.C., 2006. Not enough there, too many here: understanding geographical imbalances in the distribution of the health workforce. *Human Resources for Health*, 4 (1), 12.

Fitzpatrick, G. and Ellingsen, G., 2012. A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. *Computer Supported Cooperative Work (CSCW).*

Gaudin, C., *et al.*, 2012. Collective activities in a technology-mediated medical team. An analysis of epidemiological alert management. *Behaviour & Information Technology*, 1–10.

Greenberg, S., 1990. Sharing views and interactions with single-user applications. *In*: *Proceedings of the ACM SIGOIS and IEEE CS TC-OA Conference on Office Information Systems*, COCS '90, Cambridge, Massachusetts, USA: ACM, 227–237.

Hägglund, M., *et al.*, 2007. Bridging the gap: a virtual health record for integrated home care. *International Journal of Integrated Care*, 7 (2).

Hailey, D., Roine, R., and Ohinmaa, A., 2002. Systematic review of evidence for the benefits of telemedicine. *Journal of Telemedicine and Telecare*, 8 (suppl 1), 1–7.

Handels, H., *et al.*, 1997. KAMEDIN: a telemedicine system for computer supported cooperative work and remote image analysis in radiology. *Computer Methods and Programs in Biomedicine*, 52 (3), 175–183.

Kane, B. and Luz, S., 2011. Information Sharing at Multidisciplinary Medical Team Meetings. *Group Decision and Negotiation*, 20, 437–464.

Koenig, A., Samarasundera, E., and Cheng, T., 2011. Interactive map communication: Pilot study of the visual perceptions and preferences of public health practitioners. *Public Health*, 125 (8), 554–560.

Lehmann, U. and Sanders, D., 2007. *Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers*. Geneva.

Luk, R., Ho, M., and Aoki, P.M., 2008. Asynchronous remote medical consultation for Ghana. *In*: *Proceedings of the twenty-sixth annual SIGCHI conference on Human factors in computing systems*, 743–752.

Luz, S., *et al.*, 2012. Supporting collaboration among healthcare professionals and disease surveillance in remote areas. *In*: *Procs. of the 25th International Symposium on Computer-Based Medical Systems (CBMS'12)* Rome: IEEE Press, 1–6.

Luz, S., 2012. The non-verbal structure of patient case discussions in multidisciplinary medical team meetings. *ACM Transactions on Information Systems*, 30(3), article 17, 24 pp.

Mackay, W.E. and Fayard, A.L., 1997. HCI, Natural Science and Design: A Framework for Triangulation Across Disciplines. *In*: *Symposium on Designing Interactive Systems* Amsterdam: ACM Press, 223–234.

Maguia, C., Guerra, H., and Ventosilla, P., 2009. Bartonellosis. *Clinics in dermatology*, 27 (3), 271–280.

Makris, L., *et al.*, 1998. Teleworks: a CSCW application for remote medical diagnosis support and teleconsultation. *IEEE Transactions on Information Technology in Biomedicine*, 2 (2), 62–73.

Mayer, J.D., 2000. Geography, ecology and emerging infectious diseases. *Social Science & Medicine*, 50 (78), 937–952.

McGrath, J.E., Martin, J., and Kulka, R.A., 1982. *Judgment Calls in Research*. Sage Publications, Inc.

Miller, R.A. and Masarie Jr, F.E., 1990. The demise of the "Greek Oracle" Model for Medical Diagnostic Systems. *Methods of Information in Medicine*, 29, 1–2.

Mooney, H., *et al.*, 2009. Biodiversity, climate change, and ecosystem services. *Current Opinion in Environmental Sustainability*, 1 (1), 46–54.

Orwat, C., *et al.*, 2010. Adopting Pervasive Computing for Routine Use in Healthcare. *IEEE Pervasive Computing*, 9, 64–71.

Ramachandran, D., *et al.*, 2010. Mobile-izing health workers in rural India. *In*: *Proceedings of the 28th international conference on Human factors in computing systems*, CHI '10 New York, NY, USA: ACM, 1889–1898.

Randall, D., Harper, R., and Rouncefield, M., 2007. *Fieldwork for design: theory and practice*. Springer-Verlag New York Inc.

Reddy, M., Dourish, P., and Pratt, W., 2001. Coordinating heterogeneous work: Information and representation in medical care. *In*: *Proceedings of the* 7^{th} *European Conference on Computer-Supported Cooperative Work (ECSCW'01)*, 239–58.

Reidpath, D.D. and Allotey, P., 2009. Opening up public health: a strategy of information and communication technology to support population health. *The Lancet*, 373, 1050–1051.

Rogalski, J., 1994. Formation aux activités collectives. *Le travail humain*, 367–386.

Schmidt, K. and Simone, C., 1996. Coordination mechanisms: Towards a conceptual foundation of CSCW systems design. *Computer Supported Cooperative Work (CSCW)*, 5 (2), 155–200.

Schmidt, K. and Bannon, L., 1992. Taking CSCW seriously. *Computer Supported Cooperative Work*, 1 (1-2), 7–40.

Simon, H.A., 1981. *The Sciences of the Artificial*. second Cambridge, Massachusetts: MIT Press.

Smith, Z.J., *et al.*, 2011. Cell-Phone-Based Platform for Biomedical Device Development and Education Applications. *PLoS ONE*, 6 (3).

Strauss, A., 1988. The articulation of project work: An organizational process. *Sociological Quarterly*, 29 (2), 163–178.

Tachakra, S., *et al.*, 2003. Mobile e-Health: The Unwired Evolution of Telemedicine. *Telemedicine Journal and e-Health*, 9 (3), 247–257.

Vanden Eng, J.L., *et al.*, 2007. Use of Handheld Computers with Global Positioning Systems for Probability Sampling and Data Entry in Household Surveys. *The American Journal of Tropical Medicine and Hygiene*, 77 (2), 393–399.

Yager, P., Domingo, G.J., and Gerdes, J., 2008. Point-of-Care Diagnostics for Global Health. *Annual Review of Biomedical Engineering*, 10 (1), 107–144.