Towards designing for equity: active citizen participation in eHealth

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Abstract

Purpose – Reducing inequity in accessing healthcare among rural and remote populations remains a problem. Internationally, eHealth is now touted as a potential solution, with a range of diverse approaches and impacts. Yet, the equity gains of implementing eHealth are often not realized due to a lack of effective strategies for citizen participation. The purpose of this paper is to present the background to, and results of, a multidisciplinary eHealth assistance project in a remote region of the Brazilian Amazon, highlighting the importance of citizen participation within planning processes.

Design/methodology/approach – The project was conducted in three phases – pre-mission, mission, and post-mission. Discussions were held between health teams and local community leaders, and were coordinated by government health organizations in partnership with the Amazon State University. A multidisciplinary team visited five remote communities in the Brazilian Amazon, where participants underwent clinical assessment using eHealth technologies within pharmacy, cardiology, dermatology, and/or odontology. Analysis and second opinion were provided by relevant specialists and the results were delivered electronically to local healthcare teams.

Findings – A total of 111 patients were evaluated with an average age of 54 years. There were several important findings following specialist second opinion, which improved the quality of care they received. These comprise identifying drug interactions and patients requiring further investigation for cardiological and dermatological complaints, including suspected malignancy.

Research limitations/implications – Due to a breakdown in communication, data from the post-mission phase are lacking, particularly regarding treatment outcomes. Furthermore, the authors did not perform an analysis of cost-effectiveness. If eHealth technologies are to become part of routine clinical practice it is important that the financial implications are acceptable.

Originality/value – This project demonstrates how equity can be designed for with a multidisciplinary approach to eHealth activities in rural and remote environments within

Brazil. Such activities typically focus on one particular area, yet primary healthcare facilities see patients with a variety of problems.

Keywords:

eHealth; Equity; Citizen participation; Telemedicine; Amazon region; Health care; Brazil; Rural regions.

1 Introduction

The eHealth revolution is upon us. In its simplest form, eHealth is the use of information and communication technologies (ICTs) to facilitate clinical activities, research and education, as well as for monitoring public health. In recent times there has been an explosion in the number of eHealth projects around the world in both developed and developing countries, exploring myriad problems via innovative ICTs. Acknowledging the value of ICTs within healthcare, the World Health Assembly drafted Resolution 58/28 on eHealth (WHO, 2005b). It asserts the need for each state to define national strategy, develop regional partnerships, ensure low cost and system interoperability via the use of technical and semantic standards, and incorporate these solutions into existing health systems. Of particular interest is the potential of eHealth for improving medical practice and patient care in rural and remote locations (Gagnon *et al.*, 2006; Jordanova, 2007). Populations living in such areas are typically marginalized from healthcare systems and experience significant health inequities.

Citizen participation prioritizes mechanisms of civic engagement in political processes and policy formation, providing an opportunity for the public to express opinions and exert influence on a wide variety of issues. Arnstein's (1969) ladder of citizen participation relates this concept to citizen power, more specifically the redistribution of power that ensures a voice for those previously left unheard. Three broad themes – citizen power, tokenism, and non-participation – are analyzed within this model. One limitation, however, is the assumption that citizen control is more effective than citizen consultation. There is much debate over whether active citizen participation is best achieved through targeting individuals or organizations that represent individuals' best interests (Lavalle *et al.*, 2005). Overall, active citizen participation aspires to greater transparency and accountability with government, at local, regional, and national level.

The Alma Ata Declaration (WHO, 1978), with its emphasis on primary care, brought citizen and community participation to the forefront of public health policy, stressing that the involvement of communities will enhance the delivery and uptake of health interventions, thus tackling health inequities. It framed health as a socio-economic issue and a fundamental human right, compelling governments to lead the way on ensuring the provision of adequate health and social measures to reduce health inequalities.

The next major development arrived at the turn of the century with the drafting of eight Millennium Development Goals (MDGs), which aim to improve social and economic conditions in the world's poorest nations, thus encouraging development (UN General Assembly, 2000). The subsequent acceptance of this declaration by virtually every country in the world means that it is one of the most widely ratified set of goals ever signed. Whilst possessing several limitations (Waage *et al.*, 2010), they represent a unique example of multilateral cooperation on a previously unprecedented scale. Progress has been uneven – some countries such as China and India have made important advances, whereas many of the poorest regions where progress is even more vital, in particular sub-Saharan Africa, still have a long way to go (Beaglehole and Bonita, 2008).

Subsequently, the Commission on the Social Determinants of Health (Marmot *et al.*, 2008) gave recommendations for action to promote health equity based on three vital principles:

1. improve the conditions of daily life, i.e. the circumstances in which people are born, grow, live, work and age;
2. address the inequitable distribution of power, money and resources, which comprise the structural drivers of those conditions of daily life; and
3. measure the problem, evaluate action and expand the knowledge base.

Universal access to healthcare, whilst playing a leading role in the drive to reduce health inequities, is just one of the social determinants of health, which collectively represent the social and economic conditions under which we live (WHO, 2003).

Noncommunicable disease (NCD) now represents the majority of the global disease burden and carries serious economic and social implications, particularly in low- and middle-income countries (Alwan and MacLean, 2009). NCDs such as cardiovascular disease and cancer are responsible for 60 percent of global deaths (WHO, 2005a), 80 percent of which occur in low- and middle-income countries (WHO, 2008b). Although patients living with NCDs benefit from regular evaluation, optimal care requires a multidisciplinary approach, something that is often lacking in remote areas. Whilst the role of technology in facilitating effective chronic disease management has been evaluated (Siminerio, 2010), few studies exist assessing a multidisciplinary initiative. The eHealth approach we have implemented is intended to address this significant gap in the Brazilian context.

2 The Brazilian context

Brazil, a country with significant social and health inequalities, is currently undergoing an epidemiologic transition (Habib and Saha, 2010). Until the early 1980s, the country was under authoritarian rule and had suffered a history of exclusionary service delivery models – healthcare was almost exclusively delivered by the private sector, with a lucky minority being entitled to public-funded care (Costa, 2007). However, with the restoration of democracy, significant political reform occurred that emphasized increasing citizen voice within policy making. The Brazilian Citizens' Constitution of 1988, which focuses on “social and individual rights, liberty, security, well being, development, equality and justice as supreme values of […] society”, paved the way for several mechanisms of participatory democracy. Overarching decentralization of budgets and decision-making facilitated the implementation of one particularly resilient innovation – participatory budgeting. This is a process of democratic deliberation and decision-making, in which citizens decide how to allocate part of a municipal or public budget. It allows the identification, discussion, and prioritization of public spending projects, and gives citizens the power to control how money is spent. In Brazil, although several areas have also been explored, the focus has been on health and education.

Participatory budgeting typically involves the following basic steps:

1. community members identify spending priorities and select budget delegates;
2. budget delegates develop specific spending proposals, with help from experts;
3. community members vote on which proposals to fund; and
4. the city or institution implements the top proposals.

Participatory budgeting results in more equitable public spending, a higher quality of life, increased satisfaction with basic needs, greater government transparency and accountability, increased levels of public participation (especially by marginalized or poorer residents), and democratic and citizenship learning (Costa, 2007). The first full participatory budgeting process was developed in the city of Porto Alegre, Brazil in 1989 (Lavalle *et al.*, 2005).

Political reform brought with it a dream – universal access to healthcare. This dream quickly became a reality through the comprehensive family health program operating within the newly created, publicly funded Unified Health System, or Sistema Único de Saúde (SUS). This dramatic overhaul characterized by decentralization, universality, comprehensiveness, equity, and social oversight has resulted in increased primary care coverage and major progress in public health (Harris and Haines, 2010), so much so that Brazil has either already achieved, or is on course to achieve, the MDGs before 2015.

Despite overwhelming progress on important public health parameters however, access to specialist care outside of large urban centers remains poor and it is those living in remote areas that suffer this inequity the most. Specialists often avoid working in such areas due to professional isolation and poor resource availability. As a result, reference hospitals in urban centers have to cope with a large volume of referrals from these areas, leading to congested emergency and ambulatory departments.

The context presented above, combining general themes and those specifically relating to Brazil, sets the scene for the projects undertaken by our research group. Over the last four years, the Microgravity Center at the Pontifical Catholic University of Rio Grande do Sul (PUCRS) in Porto Alegre, Brazil, has been performing eHealth assistance projects in remote regions of the Brazilian Amazon. Biomedical engineers work alongside clinicians and academics to create user-friendly systems and new technologies that facilitate the delivery of healthcare to rural areas. In so doing, our research aims to reduce health inequities experienced by disadvantaged populations within Brazil, consulting with the relevant actors where appropriate. In the rest of this paper, we present data from the most recent project conducted in July 2010.

3 Methodology

The main objective of this project was to evaluate a multidisciplinary eHealth approach in remote areas without access to expert opinion. The eHealth approach was designed to provide assistance via telemedicine in locations without experts. The telemedicine comprised our own telemedicine data exchange software, incorporating electronic patient records (EPRs); digital camera; a skin illumination device; and digital electrocardiography equipment. A process model of our eHealth approach is shown in Figure 1. As the model shows, patients are assessed locally and all data is inserted into a database. This is then synchronized with the central database upon internet availability, which can be accessed securely by selected specialists. Information is then returned via an encrypted digital envelope to the local healthcare team to advise ongoing clinical care.

A multidisciplinary team consisting of dentists, doctors, nurses, pharmacists, biomedical engineers and medical, healthcare and engineering students was created to flexibly deliver second opinion about medical practice to local physicians in these five communities. The project incorporated three main phases: pre-mission, mission and post-mission. The researchers and participants studied the following focus areas: gerontology, pharmacy, cardiology, dermatology, odontology, and telecommunication engineering.

Secondary objectives of the project included:

1. validation of the software and equipment developed for providing assistance; and
2. assessment of the potential of second opinion delivery via telemedicine in locations without experts.

Ethical approval was granted by the research and ethics committee of PUCRS, Porto Alegre.

3.1 Pre-mission phase – May 1, 2010 to July 13, 2010

A partnership was established between PUCRS and the Amazon State University. This facilitated the selection of the areas of study and community locations. A multidisciplinary team was created, incorporating members from both institutions and a variety of professional backgrounds – dentists, doctors, nurses, pharmacists, biomedical engineers and medical, healthcare and engineering students. The tools and technical support for the project were provided by the biomedical engineers. Upon arrival in Amazonas the team received an induction into the local culture. Practical training was provided to ensure familiarity with the equipment and systems being used.

Remote areas of Brazil were chosen as receiving sites due to their lower population density and human development index (Table I), in order to enable a greater impact on local healthcare. The remote receiving sites were selected following discussions between the health teams and local community leaders. These discussions were organized and coordinated by government health organizations in partnership with the Amazon State University. The main topics considered were the lack of specialized healthcare in the remote communities, as well as the available resources and infrastructure required for the delivery of virtual second opinion. Community representatives were involved in deliberative discussions throughout all stages of the project.

In this project, the receiving site was Rio Preto da Eva, a small municipality located east of Manaus within the state of Amazonas. The delivering site was the Hospital São Lucas/PUCRS, Porto Alegre. We visited Rio Preto da Eva over a period of ten days. We identified five communities as ideal for the approach based on an explicit set of criteria – remote location; family physician responsible for all healthcare delivery; either basic, or absence of, healthcare facilities; and low standard of living. In these five communities, the availability of resources with which to work would typically range from a nurse's station in a healthcare centre to a more basic environment requiring a degree of improvisation to provide comfort and privacy for both patients and the eHealth team.

3.2 Mission phase – July 14, 2010 to July 29, 2010

All community members aged over 40 were invited to participate. The younger age of 40 was chosen, rather than 65, in order to maximize patient numbers and the impact on health within the communities. An initial assessment was performed and an EPR was created on the telemedicine system we had developed. All patients were included in the pharmacy evaluation. Information was gathered regarding current medications, use of medicinal plants and allergies. Patients were then triaged based on relevant systems review, past medical history and family history to one or more of the required areas of care: cardiology, dermatology and odontology. A patient interview was conducted regarding specific aspects of the presenting complaint and a relevant physical examination was performed. Information was uploaded to the EPR along with skin/mouth images or an electrocardiogram (ECG), depending on the referred area.

In order to acquire images of mouth and skin lesions, a Sony digital camera was used with an illuminator developed by the Microgravity Center, PUCRS. A standardized approach was taken for capturing images (Cardoso *et al.*, 2007). A digital ECG machine developed by Micromed Biotecnologia Ltda was used to record the electrical activity of each patient's heart. The Wincardio telecardiology software developed by Micromed was the platform used for storing each ECG on a notebook computer.

Data were transmitted to a secure database via a store-and-forward approach upon internet availability at a speed of 1 Mbps. The telemedicine system was programmed to connect to the Microgravity Center's main server, synchronizing all collected data. Transmissions included Plain Text (via database MySql), images (JPEG) and Digital ECG files (transmitted via File Transfer Protocol). Through using a password protected application on personal computers, the specialists at the delivering site were able to gain access to the EPRs via this server.

3.3 Post-mission phase – July 30, 2010 to November 30, 2010

Specialist healthcare professionals at the delivering site analyzed the data and provided an opinion on diagnosis and management, which was converted into an encrypted digital envelope and transmitted to the receiving site's local healthcare team via e-mail. Whilst the specialist provided a recommendation, the final decision regarding management was the responsibility of the local healthcare team.

4 Results

A total of 111 patients were evaluated during the course of this project. The majority of patients were over 40 years of age; however, due to local demand for health assistance, 19 patients (17 percent) under 40 were seen and included in the analysis. There were 55 males (49.5 percent) and 56 females (50.5 percent). The average age was 54 years (SD=19; range=2-95). Table II provides a breakdown of the number of consultations within each of the four main clinical areas and a summary of the key findings. Some patients were triaged into more than one area under evaluation and therefore the total number of consultations exceeds the total number of patients.

Tables III and IV provide a summary of the information gathered about past medical history and medications, respectively. The medical history of the interviewed patients indicated that the more prevalent diseases and medical conditions were related to metabolic syndrome, with hypertension and diabetes being the most common (above 50 percent – Table III). The most frequently prescribed medications for patients were found to be in accordance with these diseases (Table IV).

5 Discussion

This study adds to the current literature by highlighting the potential for a multidisciplinary eHealth initiative. On the whole, the project was successful and provided patients with an expert second opinion that they may not have otherwise received. Many patients required analysis by more than one specialist, highlighting the complex and varied needs of the average patient aged over 40 living in this remote part of Brazil. Those patients previously requiring referral for a specialist opinion would have been placed on a waiting list. Cases are prioritized according to urgency and a non-urgent case can expect to wait several months.

Within pharmacy, nearly 60 percent of patients were found to be taking at least one medicine or medicinal plant, perhaps reflecting the age of the population included. An adjustment to medication was recommended in 32 patients, suggesting that they may not receive regular reviews. Potential drug interactions were identified in five patients, an important discovery given the possibility of serious harm. The pharmacological care of these patients has been improved through this project.

Within cardiology more than 40 percent of ECGs were altered, displaying a variety of abnormalities. When placed into clinical context, the cardiologist recommended a medication change for three patients and further investigation in six patients. It is important to identify patients requiring further cardiovascular investigation given the significant morbidity and mortality caused by cardiovascular disease in Brazil (WHO, 2008a).

Whilst a variety of skin conditions were observed in the dermatology assessment, by far the most important finding was the suspicion of potentially malignant lesions in five patients. These lesions require urgent attention involving a biopsy and/or excision, since an early diagnosis can considerably improve the final outcome. Primary healthcare professionals often encounter skin lesions in the Amazon region and, when the diagnosis is uncertain, teledermatology can help prevent inappropriate referrals. Diagnostic concordance between teledermatology and clinic dermatology is acceptable and management concordance is moderate to very good, although there is insufficient evidence to suggest whether clinical course is affected by teledermatology versus clinic dermatology (Warshaw *et al.*, 2011). Whilst clinic dermatology remains superior to teledermatology, the latter will be of benefit in areas without dermatologists.

The results from odontology are less reliable and more difficult to interpret accurately. In addition to the small sample size, for some patients the specialist was unsure of the exact diagnosis and provided more than one explanation, predominantly due to a lack of information regarding the chronicity of the lesion in question.

6 Implications

A recent publication from the International Telecommunication Union (ITU, 2008) provides sensible advice for anybody involved in the planning and implementation of eHealth projects, specifically in developing countries. It advocates a thorough consideration of current and future public health issues and opportunities; incorporating the public sector, private sector, and non-governmental organizations (NGOs), where appropriate; ensuring sustainability with a well-considered business plan; promoting a strong commitment from all parties to a project; preparing for ongoing education and communication with partners; attempting to bring on board local politicians, health care staff, and financiers; and acting within appropriate administrative, legislative, and regulatory frameworks. Yet, this report failed to consider the importance of designing for equity to realize the full potential of eHealth on improving healthcare outcomes.

An ever present feature within the telemedicine literature is its potential use in remote and rural areas (Gagnon *et al.*, 2006; Jordanova, 2007). There are many isolated communities within the Amazon region that can only be accessed by boat or light aircraft; the former is often lengthy and unreliable in the dry season, whilst the latter is far beyond the financial capacity of the average Brazilian. The barriers to seeking specialist care in such areas are inherently greater and the potential of second opinion delivery via telemedicine may be of increased significance.

Our project fills a gap in the theory and practice of eHealth, where the potential for a multidisciplinary approach to eHealth activities has been relatively unexplored thus far. One successful example is the Réseau en Afrique Francophone pour la Télémédecine (RAFT) project in West Africa (Bagayoko *et al.*, 2006). The RAFT project is a collaborative, multinational, internet-based network that provides a linguistically and culturally appropriate environment through which doctors can:

- engage in educational activities; and
- seek second opinions through case discussions.

It focuses on low-bandwidth technology in order to promote accessibility, although is limited by local infrastructure. Overall, it has achieved great popularity amongst users and has encouraged many doctors to practice in rural areas.

Rural and remote locations bring with them both beauty and challenges. Upon arrival in Amazonas the digital ECG machine malfunctioned, probably as a consequence of a sudden increase in temperature and humidity upon leaving the airport. All other equipment and software functioned smoothly and without problems. Infrastructure enabling internet connectivity is an important issue which should be adequately addressed. Due to the proximity of the visited locations to Manaus, data were typically transmitted to the delivering site from the Amazonas State University within 24 hours of collection. However, in the majority of the Amazon region, satellite connection is the only available internet access due to a lack of mobile phone networks or wired internet services. Globally, internet connectivity is undoubtedly a major barrier to the widespread adoption of eHealth technologies in rural and remote areas. Mobile phone networks, on the other hand, are comparatively more readily available and mobile-based eHealth, or mHealth, is being increasingly explored (Klasnja and Pratt, 2012).

This project has some important limitations. It has recently been identified that within telemedicine there is a lack of good quality cost-effectiveness studies (Wootton and Bonnardot, 2010). A project may be feasible and may help to improve the quality of care delivered to patients in remote locations, but is it better than the next best alternative and is it sustainable? Furthermore, whilst we received positive feedback from the patients and staff involved, it would have been useful to perform a formal qualitative evaluation of their opinions and experiences; this may have provided an insight into the barriers currently obstructing the implementation of telemedicine projects into routine clinical practice in this region. A difficulty in the post-mission phase has been patient follow-up. Thus, far, due to a lack of communication from the receiving site, we have been unable to collect sufficient data summarizing the final management plans and outcomes for our patients.

In our experience, active participation of local community leaders and their interaction with health team members in each step of the organization and planning process facilitated team integration and data collection. The discussions resulted in a focused and culturally appropriate project that addressed the needs of the local population. Flexibility along the way was vital to ensure the validity of the project. As previously identified (Laverack and Wallerstein, 2001), there is no gold standard when planning community participation, and the same applies for eHealth interventions also; certain principles can be followed but adopting a cut and paste approach will inevitably fail. Active citizen participation, when carefully planned, can undoubtedly assist with the drive to reduce inequity, whether that is within eHealth or within a broader medical or social change framework.

7 Conclusions

In this paper, we have presented results from an eHealth project to design for equity that has wider applicability across contexts. Our project recognizes and addresses the critical needs of a country the size of Brazil for a more equitable distribution of specialized secondary care in order to improve health service delivery to its rural and remote populations. While eHealth initiatives have the potential to reduce health inequities, our approach suggests that the active participation of citizens and professionals of varying backgrounds is vital if Brazilians are to sustain eHealth. The establishment of basic communication infrastructure is fundamental to allow data transmission to take place in remote environments and therefore government and NGO involvement is vital to ensure the appropriate tools are available. The standardization of acquisition equipment and protocols, of transmission data security and reliability, and of visualization systems and methodologies must be defined and widely spread to ensure information exchange between different systems, platforms, and devices. Further research is needed on critically assessing the conditions for active citizen participation that result in meaningful and valid improvements in accessing equitable healthcare. Moving forward, we will draw on the findings from our study to continue refining and conceptualising our approach.

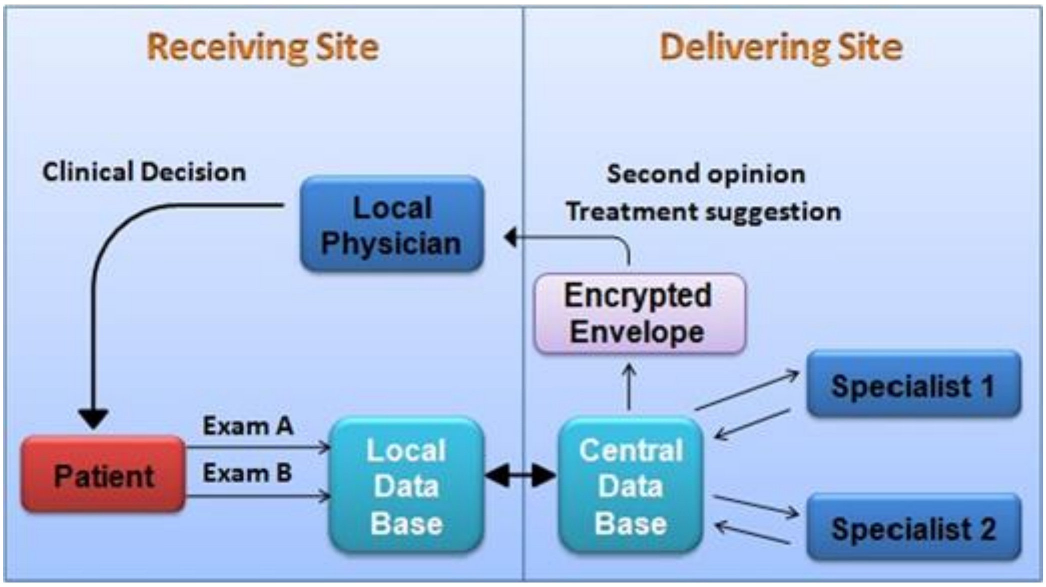

Figure 1
A schematic view of the roles of the receiving and delivering sites in the Brazilian Amazon project

City	Area (km^2)	Population	Population density ($/km^2$)	Human development index	GDP per capita (R$)
Porto Alegre	497	1,436,123	2,890	0.865	23,534
Manaus	11,407	1,802,525	122.5	0.774	10,427

Table I.
Comparison between Porto Alegre and Manaus

Table I
Comparison between Porto Alegre and Manaus

Area	No. consultations	Main findings
Pharmacy	111	66 patients (59.5 percent) were taking a medication and/or a medicinal plant. The pharmacist suggested an adjustment in 32 (48.5 percent) of these patients. There were 29 patients taking more than one medication. Of these, five (17.2 percent) had drug interactions
Cardiology	55	32 (58 percent) ECGs were normal, whilst 23 (42 percent) were altered. The most common alterations were ventricular repolarization abnormalities and ventricular hypertrophy. The cardiologist suggested an adjustment to medication in three patients (5.5 percent) and further investigation in six (11)
Dermatology	48	19 patients (39.6 percent) had evidence of mycoses, including pityriasis versicolor, tinea, onychomycosis and superficial mycosis. In five patients (10.4 percent) the dermatologist suspected malignancy and recommended further investigation
Odontology (stomatology)	8	Suggested diagnoses included: hemangioma, fibroepithelial hyperplasia, melanocytic maculae, leukoplakia or candidiasis, fibroma of oral mucosa and Peutz-Jeghers

Table II.
Summary of the number of consultations and main findings of the eHealth mission

Table II
Summary of the number of consultations and main findings of the eHealth mission

Condition	No. patients (%)
Hypertension	46/111 (41.4%)
Diabetes	14/111 (12.6%)
Dyslipidaemia	8/111 (7.2%)
Cerebrovascular disease	6/111 (5.4%)

Note: Pre-project

Table III.
Most common medical conditions

Table III*Most common medical conditions*

Drug (class)	No. patients (%)
Captopril (ACE inhibitor)	19/111 (17.1%)
Aspirin (NSAID)	11/111 (9.9%)
Glibenclamide (sulfonylurea)	4/111 (3.6%)
Hydrochlorothiazide (diuretic)	2/111 (1.8%)
Simvastatin (statin)	2/111 (1.8%)

Note: Pre-project

Table IV.
Most common medications

Table IV*Most common medications*

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