THE PROMISE OF NEW TECHNOLOGIES IN AN AGE OF NEW HEALTH CHALLENGES

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The Promise of New Technologies in an Age of New Health Challenges

Selected Papers from Global Telehealth 2016

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Preface

The 5th Global Telehealth Conference was held in Auckland on 1st and 2nd November 2016, hosted by the Health Informatics New Zealand (HiNZ) organisation. The choice of venue allowed a return to the Asia-Pacific arena for the conference, following its previous two years in South Africa (2014) and Canada (2015). It is hoped that the event will continue to find new locations year by year, in order to bring the benefits of globally-relevant research in Telehealth and associated areas to new audiences.

This volume provides a record of contributed papers presented at the above conference. The 18 papers included here were accepted on the basis of a blinded peer-review process which provided independent expert appraisal by members of the Scientific Programme and Review Committee. The acceptance rate for the conference was approximately 60% of papers submitted, ensuring publication of the highest quality of work. These papers cover a wide variety of topics, from theoretical and abstract contributions through to discussion of practical projects and highly specific applied contributions. In addition, two invited papers are included, which were also accepted through the reviewing pathway. These detail some recent contributions towards two global issues in which Telehealth plays a major role: universal health coverage and personal health monitoring.

The theme chosen for Global Telehealth 2016 was "The Promise of New Technologies in an Age of New Health Challenges." This reflects a change in emphasis which can be noted in many health services, where conventional pressures such as budget and workforce constraints are being augmented by indirect forces of social change and strategic direction, which portend longer term and more flexible approaches. Telehealth, as well as many other technology-based health care assistive elements, offers demonstrably effective and sustainable solutions to issues such as access to care and quality of care, by enabling different models of care and care delivery channels to be employed.

New Zealand was a fitting choice of venue for the conference, as it has held a longstanding commitment to Telehealth as a mechanism for health care delivery nationally and in the wider Pacific region. This position was reaffirmed earlier this year with the release by the New Zealand Ministry of Health of the document entitled "New Zealand Health Strategy: Future Direction". This refreshed national health strategy acknowledges the need to work differently to meet changing health needs, with Health IT including Telehealth identified as a key enabler of such change. The strategy endorses the direction set by New Zealand programmes in electronic referral, shared care planning and tele-consultation as enablers of efficient and well-coordinated health delivery. Furthermore, the strategy emphasizes the ability of Telehealth – especially as exemplified by patient portals, and mental health and well-being tools – to strengthen health consumers' direct role in the healthcare system.

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Passive RFID Localisation Framework in Smart Homes Healthcare Settings

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Abstract. In recent years, Smart Homes have become a solution to benefit impaired individuals and elderly in their daily life settings. In healthcare applications, pervasive technologies have enabled the practicality of personal monitoring using Indoor positioning technologies. Radio-Frequency Identification (RFID) is a promising technology, which is useful for non-invasive tracking of activities of daily living. Many implementations have focused on using battery-enabled tags like in RFID active tags, which require frequent maintenance and they are costly. Other systems can use wearable sensors requiring individuals to wear tags which may be inappropriate for elders. Successful implementations of a tracking system are dependent on multiple considerations beyond the physical performance of the solution, such as affordability and human acceptance. This paper presents a localisation framework using passive RFID sensors. It aims to provide a low cost solution for subject location in Smart Homes healthcare.

Keywords. Localisation, smart homes, healthcare, RFID, personal monitoring

Introduction

Life expectancy has been increasing dramatically over the last few decades and the trend is expected to continue into the future. Nine percent of the population are aged over 60 in developing countries and this figure may reach 19 percent in 2050 and 27 percent by 2100 leading to an excess of this group over the number of children [1]. In developed countries such as Australia, there is pressure on the population due to the increase in life expectancy and lower levels of fertility [2]. With the ageing population, there has been increasing demands on healthcare facilities globally that aim to improve health services for the elderly.

It is important to maintain monitoring of older individual' behavioral patterns and general health conditions on a daily basis to prevent health risks. Healthcare services are usually expensive and they often require the patients to stay at healthcare accommodation that adds further running costs for the amenities and for training health specialists. Smart Homes have been increasingly considered as a feasible option for healthcare monitoring and services for the elderly as well as for disabled people who prefer to stay comfortable in their homes.

The Smart Homes concept is defined as places of residence that are outfitted with computers and technological devices [3]. Smart Homes aim to provide not only comfort, convenience and a safe environment, but also the improvement of life quality, and assistance to, occupants on a daily basis, as well as connecting them to the world beyond [4]. Research in Smart Homes focuses in part on building advanced technological systems. Smart environments include applications that monitor the elderly unobtrusively via connecting sensors, and that warn them or their healthcare providers about abnormal conditions [5].

Indoor localisation systems based on underlying technologies such as RFID [6], Bluetooth [7], Zigbee [8], UWB [9] and Infrared [10] have been designed and employed to locate the movement of objects and subjects in the indoor environment. These technologies have been used in various indoor localisation applications such as healthcare and assisted living in the smart environment. Ambient assisted living systems help to recognize daily life activities and behavioural movement by measuring a set of their specified activities, such as standing, sitting, lying, walking and interacting with furniture or objects.

In this paper, we propose a cost-effective Passive RFID location framework for Smart Homes for localising subjects using an inexpensive passive RFID tag. The proposed system could help improve pervasive computing in healthcare by applying overlaid smart healthcare solutions to connect the subjects with external healthcare facilities and to enhance the quality of health services in residential settings.

1. Related Work

Tracking stationary movable objects and individuals is a problem which has interested researchers due to the challenges in implementing and optimizing of indoor positioning systems. Radio Frequency Identification (RFID) has been considered a promising technology in indoor positioning environments [11]. Several RFID-based systems have been exploited in the last decade by researchers in the areas of Smart Homes for finding favourable indoor positioning solutions for healthcare facilities, such as [4, 12-13] and others have explored pure RFID location awareness such as [14-19]. However, most systems have provided low performance in accuracy and efficiency while others have a relatively high cost. We discuss most related and noticeable works as follows.

LANDMARC [14] was a novel approach that introduced the concept of localisation using tag references at certain planned locations. Similarly VIRE [17] used the principle of LANDMARC in locating objects using the virtual reference elimination (VIRE) method for location estimation. The authors reported the least error estimation of 0.47m when compared to the LANDMARC system.

Zhang et al [18] implemented a localisation system named Tag-free Activity Sensing (TASA) using a hybrid approach (passive tags and active tags) which was more cost effective. They attempted to reduce the localisation error of tracking moving subjects caused by infrequent trajectories (abnormal activities) [18]. To achieve higher accuracy, the authors proposed a technique to reduce the error in RFID readings and recovery trajectories in an online manner with reference active RFID tags. Chawla [19] developed a localization framework that relied on a variation of the power level of antennas using the power modulating algorithm for location estimation. They used multiple tags to track moving robotic in real time. The system reported real-time accuracy of reasonably high (25cm and 18cm) for stationary tracking.

The aforementioned systems they have used multiple tags and more complex solution in a number of the tracking resources as well as the cost beyond these resources such as in deploying more active RFID for accuracy optimization. In our approach we provide a very simple solution to track movable entities using a single passive tag and three antennas to track the location of movable objects. Our objective is to provide a low cost solution with minimum tracking resources.

2. Framework

We introduced approach using a minimum antenna and only one single tag we receive reasonable good results in term of accuracy. Further, we have developed a framework for object localisation in Smart Homes health. This includes using various devices and technologies supporting localisation and tracking objects in Smart Homes. At the current stage, our system provides the ability for tracking stationary objects using single passive RFID tags. The system has been analysed in detail for stationary and is being extended to cater for moving subjects that can be applied to Smart Homes health care settings. Figure 1 shows our framework for the proposed tracking system using passive RFID tags. The three processes of the framework are presented as follows.

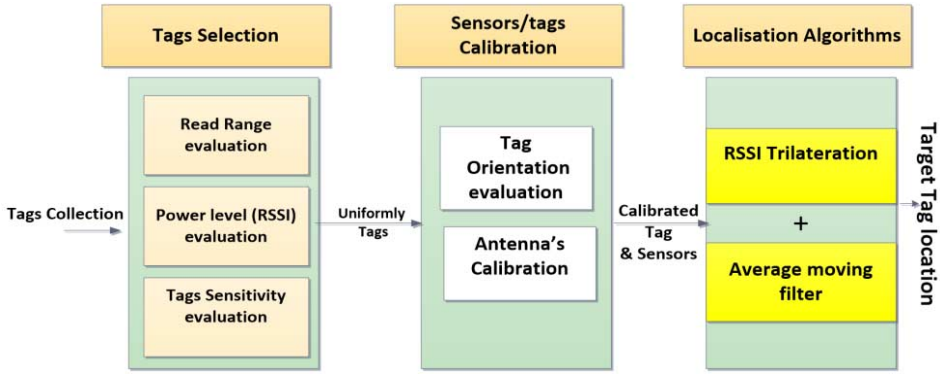

Figure 1. Localisation Framework for Smart Homes.

2.1. Tags Selection

The first stage of the localisation framework is to evaluate tags in the selection procedure to determine the most suitable and readable tags for localisation purpose. This involves two systematical sets of tests to define the candidate tags for the following processes. In the first set of tests, reading-range evaluation is examined for each type of tags according to various distances from the antenna. This process systematically determines the most far-reaching and most accurate tags for different type of antennas and tag readers. The following set of tests analyses sensitivity of the tags according to different power levels of the readers where the tags were set at fixed locations from the antennas. The tags' sensitivity tests determine the most suitable tags on various readers' power levels.

2.2. Tags Calibration

After the selection process, the candidate tags are tested further using various stationary locations and orientations to evaluate tags readings at different directions toward the antennas. This procedure is essential to select the suitable tags as the orientation is important in deciding the performance of a tag. In our experiment, all the antennas are located in fixed positions on a gridded floor. The three antennas are facing the target tags at the same height. Various power levels were set to find the optimal power level of each antenna. Other factors such as tags orientation and antenna angulation were examined to obtain the proper settings of our localisation platform.

2.3. Localisation Algorithms

Our localisation approach targets passive tags (i.e. movable and non-expensive) that can be easily attached to impaired individual assistive devices such as wheelchair, walker stick, etc. To achieve this goal, multiple algorithms have been studied including Trilateration algorithm [23, 24] for distance estimation and filtering algorithms. We now present the localisation algorithms.

To determine Received Signal Strength Indication (RSSI) values, loss path propagation model [20] derived from Friis Transmission Equation [21] was studied to estimate the tag backscatter signal power received (PR). In experiments, Friis equation converted to an approximate linear logarithmic distance equation [22].

After measuring the distance of the passive RFID targeted tag using the above-mentioned methods, the well-known Trilateration algorithm [23, 24] is applied to estimates three distance-points from each antenna in relation to the targeted tag. The system performs the trilateration to estimate the location of the targeted tag in real time. The position of target tag is calculated by the intersection of the three circles.

Due to the noise and the major changes in RSSI values, filtering is essential to ensure the quality and smoothness of the reading signals. Although there are many different types of available filter algorithms, at this stage, we only apply moving average filter to reduce the noises from the readers. The filter takes the average of every (N) of sequential from each RSSI sample. Then it reduces the mean of the distance variance of each estimate and the actual position [19].

3. Experimental Evaluation and Results

To evaluate our RFID localisation framework, we have implemented an experimental setup using *Impinj Speedway R420* development kit with UHF RFID Reader running in 920-926 MHz frequency. The location system was deployed in our Smart Home infrastructure at the Telehealth Research & Innovation Laboratory at School of Computing, Mathematics and Engineering (SCEM), Western Sydney University. The experimental area for testing was 2.75m × 3.0m. We used the passive Gen2 tag of type (MONZA 4D) as a target tag. The floor was divided into several grids for better measurement where each grid size is 0.6m × 0.6m. Three antennas were set using adjustable stands. The antennas were faced to each other at the same direction as a triangular shape.

3.1. Experimental on Tag Selection and Sensors Calibration

The experiments were carried out to examine the performance of Gen2 passive tags. The results showed that each tag has a different level of performance over the three tag selection measurements (see Figure 2). We have noticed that the tags with small antenna circuits generally give a poorer reading performance according various distances, power levels and sensitivity level tests. To ensure that the tags statistically meet the selection procedure requirement, we verified this by several tests, including tags distance reading range, tags RSSI readings and tags sensitivity test. From the experiments we found the tag Monza 4D type A, has the most desirable reading range over different positions from all antennas. It also provides various orientations from the antennas. We have considered the Tag (Monza 4D) as the most suitable tag for our localisation experiments.

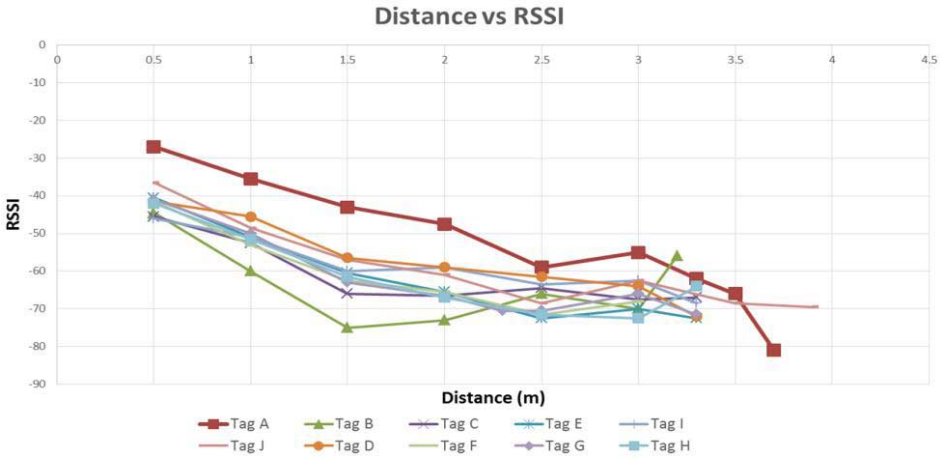

Figure 2. Performance of the tags at various distances over variations in power level (dBm) where Tag A = Monza 4D type 1, Tag B = Monza 4D type 2, Tag C = Monza 4E type 1, Tag D = Monza 4E type 2, Tag E = Monza 5 type 1, Tag F = Monza 5 type 2, Tag G = Monza 4U type 1, Tag H = Monza 4U type 2, Tag I = Monza 4D type 3, Tag J = Monza 5 type 3.

3.2. Localisation Experiments

Due to the limitation of passive RFID tags, it is challenging to produce accurate results due to factors of tag's orientation, tag's spatiality, metal and liquid occlusion, and ambient interference [24]. We applied a diversity of tag location tests on various tag's orientation from the RFID Antennas as well as different tag's placement on an attached object (e.g. an assistive walking stick). We also carried out several experiments to determine the best position of the tags in stationary localisation. We found that the closer tag to centre of the platform, the higher accurate results we got. From our experiments we experienced interference issues caused by the other environmental surroundings (e.g. desks, chairs and mobile signals etc.). We also calibrate the amount of power level going through the antennas as well as the antenna's height so that the best results could be reached. We found that the power level of 31dBm was the most reasonable for the localisation platform, and (0.5m) antenna height from the floor was the ideal height of our platform when the tag was located around 0.2m from the ground.

Systematical tests were carried out to determine the accuracy of the localization system. In these tests, the tag was positioned on varying points, mostly the central area. Estimated location coordinates were programmed and simulated with a graphical interface using JAVA programming language. The coordinates were calculated and then were compared to the real position in order to determine the accuracy.

Figure 3 shows the average performance in accuracy of the tag according it different positions, illustrated the performance of our localisation platform. The results indicate that high accuracy points are located in the central area of the gird. The green dots represent the average accuracy above 90% with (Mean M = 94.27%, Standard Deviation SD = 2.08%) in an average error of 16.5 cm. The highest accuracy is 98% which is at the central point of the grid (e.g. with less than 2 cm of error). Dark blue and light blue dots are mostly located in the outer area of the gird. These dots represent accuracy of 80% to 90% (M = 84.81%, SD = 2.81%) and 70% to 80% (M = 76.45%, SD = 2.83%) respectively. Yellow, orange and red dots represent the accuracy 60% to 70%, 50% to 60% and below 50% respectively. These dots are mostly located at the far outer of the grid.

This figure also indicates the limitation. The far outer areas are filled with red dots representing the low accuracy area. These are the blind spots. This is caused by the limitation of the coverage area for each antenna. If the tag is placed at the edge of the coverage area in the grid, the RSSI reading of the tag will change rapidly or even unreadable by at least one of the antenna. The trilateration method requires tag location coordinates from each antenna in order to calculate the actual location of the tag. If one of the coordinates is missing, the accuracy will be significantly decreased.

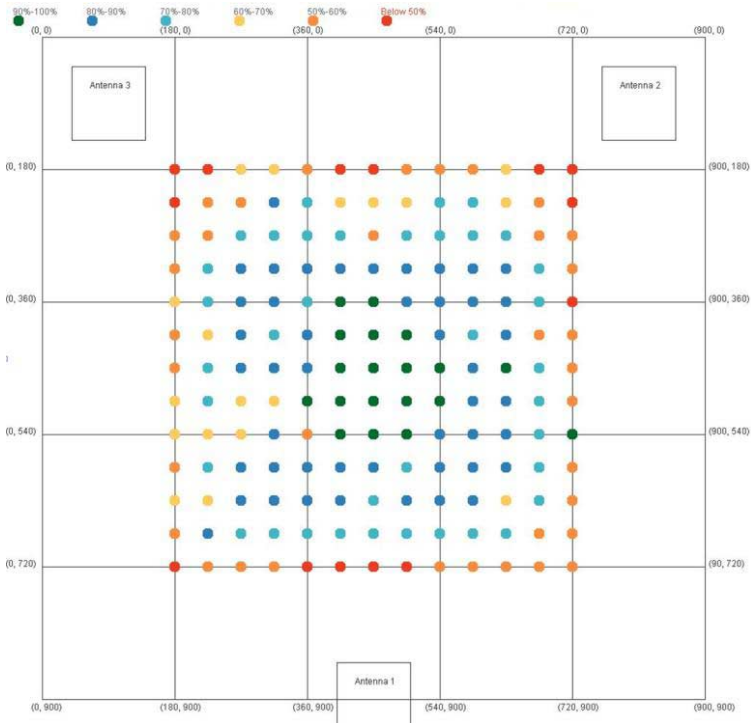

Figure 3. Accuracy distribution of tracking a passive RFID tag over various locations in the localisation area.

4. Discussion

Observing from the experimental tests, low accuracy results were recorded outside central area as well as the blind spots. The current localisation configuration consists of only three antennas in a triangular format that results in blind spots, not covered with antennas. The orientation of the tags and the antennas also plays a significant role in the accuracy outputs. The current configuration only uses one passive tag so that the orientation of the tag affects significantly the RSSI readings. Results showed that the relationship between RSSI and AoA (Angle of Arrival) varies significantly during the measurement. The results indicate that the RSSI reading gets its peak performance when the tag is facing directly towards the corresponding antenna (i.e. AoA is 0^o or 180^o). When the tag is facing the antenna's sideways, the reading decreased dramatically. This suggested that this type system is suitable for operations that track subjects within the area of 1.10m × 1.20m.

Despite the challenges that we faced during the experiments, our proposed framework was able successfully to track subjects' movement. We applied a RFID tag on a walking stick in the space of 60cm × 60cm. A person is acting as an elder and moving the walking stick slowly in the area. We visualized the movements on the JAVA platform and determined its accuracy. Results suggested that the accuracy is still over 90% in the central area, even with human and objects interferences. However, there were a few spikes during the experiment. This could be resulted by the sudden change of movement from the person moving the walking stick. The experiment positively shows that our system performs well with high accuracy in the central and near central areas. Reasonably good results were achieved considering the simplicity of our system that uses minimal tracking resources: three antennas and one "almost nil cost" passive RFID tag. We have validated our hypothesis in real experiments and we have received a promising results compared to the existing systems. We also carried out a successful tracking experiment that used one passive RFID tag which was attached to an assistive walking tool. It did not require the individual person to wear it or attach the tag to his/her body. In addition, by using passive tag, our system does not need frequent maintenance compared to the active tags that use of the battery.

Conclusion

In this paper, we have introduced a low cost tracking system using a single RFID tag and three antennas with promising results in term of accuracy. We proposed a potentially cost-effective localisation framework to localise movable subjects and to perform subject or object location determination at stationary settings. The used passive tags are significantly cheaper and less obstructive (i.e. much smaller and less weight) than the active tags. Although there are still limitations in the current system, the results are reasonable and promising. We are going to improve our location system by addressing localisation blind spots and improve the accuracy by using more antennas and RFID tags. We will also implement more advance filtering algorithms to enhance the signal processing. Finally, we will optimise the localisation of mobile subjects in real-time and tracking individuals in real-life scenarios.

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Reviewing the Evidence: In Pursuit of a Framework for Parkinson Disease Rehabilitation with Games

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Abstract. Exercise gaming has been receiving a significant interest from both consumers and researchers. Be it for the purposes of weight loss, physical fitness or even just enjoyment, the potential of games to support rehabilitation has also been under investigation for a while. Due to our aging society, game based therapies could be a solution for optimizing resources and reducing rehabilitation costs. This paper aims to discuss the potential capacity of games as systems to enhance the relation of physical exercise and cognition for the rehabilitation of Parkinson Disease. Our investigation demonstrates that there is no established methodology for games in rehabilitation of Parkinson's addressing how games can encapsulate physical exercise strategies while providing safety, continuous monitoring and cognitive development exercises in facilitation of rehabilitation. Since rehabilitation with games is trending, yet to be developed rehabilitation strategies would benefit from new insights into the relationship between game worlds, physical exercise and motor-cognitive training. Therefore, it is useful to do further research into realizing (1) a relational model that demonstrates the relation between game world (composed of game features including formal game elements, audio-visual features, mechanics and dynamics), motor skills, cognition and physical exercise for both generic and specific rehabilitation purposes, (2) a structured task creation approach for game features that reconciles specific rehabilitation outcomes, correct level of engagement, task difficulty and safety requirements for target demographic.

Keywords. Parkinson's disease, rehabilitation, exercise games, cognitive training, motor training, tasks, methodology

Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disorder with an increasing prevalence across the world [1]. The primary symptoms of PD are motor symptoms; tremor (trembling fingers, hands etc.), rigidity, bradykinesia (slowness in movement), and postural instability (balance impairment) caused by the deterioration of muscle strength. Although subtle bradykinesia is also observed in healthy elders with declining capacity for repetitive movements, the scale of bradykinesia caused by PD is the most common neurodegenerative cause of parkinsonism. Besides the motor-symptoms, there

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are also non-motor symptoms including depression, cognitive impairment, visual disturbances and sensory abnormalities, autonomic dysfunction, fatigue, apathy and sleep disorders. These non-motor complications lead to decreased quality of life and decreased independence as PD progresses with combined motor and non-motor symptoms. At the later stages of the disease, many patients need continuous assistance to maintain their daily living activities besides continuous treatment. The economic impact of PD in USA exceeded $14.4 billion in 2010, expenditure comprising the costs for medical treatment and surgery, compensation for income, and social security payments [1]. While the age group for diagnosis is mostly between 40-70, prevention strategies reducing the progress of cognitive decline with lower costs are important.

Game based interventions look promising as individualized rehabilitation tools that can potentially reduce the rehabilitation costs [14]. However, there is neither enough development on how game based exercise rehabilitations should be structured for a higher clinical validity and reliability nor enough discussion into the selection process of game elements. The question we pose is how games can encapsulate physical exercise strategies, contribute to exercise-cognition relationship positively, and provide appropriated game elements as a safe and reliable system; in particular, for PD rehabilitation. Therefore, it is beneficial to develop (1) a relational model demonstrating the relation between game world, motor-cognitive skills and physical exercise and (2) a task creation framework that reconciles specific rehabilitation outcomes, correct level of engagement, task difficulty and safety requirements for target demographic.

This paper presents a perspective by reviewing the existing game based and physical exercise strategies in the rehabilitation of PD. As a preliminary step towards formulating a relational model and a framework to inform future game based exercise rehabilitation strategies for PD, this paper comprises the following sections: exercise strategies and rehabilitation of PD, cognitive training and games, game based exercise interventions for PD and discussion.

1. Exercise Strategies and Rehabilitation of PD

Recent studies have been demonstrating exercise therapy to be an effective complementary therapy for the rehabilitation of PD while creating positive effects and supporting symptom management [2]. Regular exercise with moderate to high intensity is commonly advised as a supporting therapy by both physiotherapist and occupational therapist [3]. In fact, there is strong evidence supporting the positive effects of high cadence aerobic exercise [4, 5] with several studies noting that moderate to strenuous exercises, such as cycling, leads to a significant improvement in symptom progress. After an exercise intervention of 16 weeks, Goodwin et al. [4] observed that aerobic endurance exercise (utilizing a treadmill, bicycle, or elliptical trainer) improved overall function, balance, and movement efficiency for patients with mild to moderate PD.

Several reviews evaluating the further potential of exercise based rehabilitation approaches concur that there is a lack of structure in establishing a validated intervention clearly and consistently reporting on the severity of the disease, progression of the conditions, retention and safety measures [2, 4, 6, 7]. Although exercise therapy is known as beneficial, patients do not really seem motivated for physical rehabilitation because of the fear of injury, pain and discomfort [8]. Considering that muscle strength degradation and balance impairment are common

conditions among elders and PD patients, high consideration for falls and protective adjustments to the intensity of the exercise to prevent injury become very important [9]. On the other hand, there is evidence suggesting that motor improvement may not be driven purely by cardiovascular or metabolic mechanisms but with high-cadence low-intensity composition [5]. This could be a useful insight for exercise games targeting PD rehabilitation for clearly identified tasks in relation to the role of exercise and progress of symptoms.

2. Cognitive Training and Games

Abilities that drive the execution of human behaviors are called executive functions and are vital for quality of life. These behaviors require both motor and cognitive skills to be in harmony. Several studies have investigated the cognitive benefits of exercise training, yet the direct relation between physical activity and cognition has not been clearly understood. Even though physical exercises that do not require any cognitive skills are expected to have no contribution to executive functions [10], a former study by Duchesne et al. [11] stated that significant improvement was found for inhibition component of executive function after a three-months aerobic exercise training regimen. However, flexibility component of the executive function was not improved at all. Therefore, when discussion refers to physical exercise and cognitive training, their relation needs to be understood further so that games can be integrated into their connection for a more effective system.

A literature review for cognitive training by Kueider et al. states that videogames can affect global cognitive functioning as well as improving specific cognitive domains for elders [12]. Based on eight studies reporting cognitive performance after training with a variety of commercial videogames, they conclude that "videogames appear to be an effective means of enhancing reaction time, processing speed, executive function, and global cognition in older adults", emphasizing on reaction time and processing speed as the largest impacted aspects. However, their analysis does not present evaluation for the games, their features or effectiveness for a particular cognitive skill. When a specific cognitive training software and Nintendo Wii[2] games are compared via a parallel controlled randomized user study aiming to compare their ability to enhance cognitive performance, researchers concluded that non-specific computerized training, aka. Wii Sports games, at least has the same degree of cognitive benefit as training with the cognitive training tool [13]. Moreover, game based training showed a higher success in transferring the training into the real world.

3. Game Based Exercise Interventions for PD

Most of the studies evaluating the use of games for PD are reporting the use of commercial games in particular Wii Fit games with the Wii balance board peripheral [14]. Although none of these studies explicitly take into account the special requirements for PD patients (requirements related to motor and cognitive demands or any special conditions), a few of them identified potential cognitive benefits in their user studies. Mendes et al.'s controlled trial [15] pointed out the similarities and

[2] http://wiifit.com/

differences between the conditions of early stage PD and aging symptoms of healthy elders. They demonstrated that despite the progressive nature of the disease, PD patients and healthy elders display similar improvements in transferring motor abilities trained in the games to similar untrained tasks. On the other hand, in some games, there were certain barriers preventing patients from performing as effective as healthy elders. They were observed in actions that require fast reaction and dual tasking with further cognitive demands including response inhibition, decision-making, divided attention and working-memory. These cognitive demands are listed among executive functions, and are affected with the development of PD. Although physical exercises were only shown to improve inhibition component of executive functions [11], there could be potential to provide training with a physical exercise strategy that is combined with a game environment posing challenges to train other components of executive functions.

A number of studies, as seen in Table 1, explored motor-cognitive training with the Nintendo Wii platform. Some positive results were obtained in these studies, yet there is not much discussion into the other aspects of motor-cognitive training targeting any specific symptoms, game selection criteria or the relation of game elements to the training. Esculier et al.'s work [16], among all, was the only home-based balance training program, showing that moving the rehabilitation out of the clinic/lab is possible. However, neither was the difficulty of play reported for the selected games, nor were they discussed in connection with rehabilitation purposes identifying their relation with the training.

Some custom games were also developed in a few studies. Assad et al. [17] developed a set of mini games utilizing the Sony EyeToy for whole body interaction to promote upper body exercise with circular/horizontal arm movements and big hand gestures with the idea of motor and cognitive training. However, the connection between the games' features and training was not clearly identified, and no progress monitoring or customization was present. Galna et al.'s [18] participatory design workshop empowered patients to help in designing a game for their own rehabilitation. Their design and the tasks were informed by an existing theoretical model of balance dysfunction and focused on specific aspects inherited from this model. However, the discussion about the relation between game features, exercise regimen and specific symptoms (both motor and non-motor) was insufficient.

Hermann et al. [19] presented a local multiplayer game with the Kinect SDK to understand the cooperation aspect of gaming referring to group training sessions for PD. Since their study was aiming to look into multiplayer aspects of play (perhaps towards the motivation via social play) rather than the game design, there was no explicit discussion regarding the task creation, difficulty consideration, appropriateness of actions or how those actions were related to the rehabilitation.

There are also a few game based exercise studies for elders [20, 21], mostly investigating fall prevention by targeting balance and upper body movement. Although some of these contain training and assessment features more so than game features, the investigation into the potential of home based rehabilitation deserves recognition. However, no work has been done on motivational factors to encourage long-term use of a game based exercise that also combines cognitive and physical training while assessing and ensuring patient safety.

Table 1. Studies that employ the Nintendo Wii platform and Wii games for game based rehabilitation of PD

Study	Games	Platform & Peripherals	Objectives of the study	Notes
Mendes et al. [15]	TT, PS, SH, TTw, BS, BRP, TC, RP, OC	Wii Fit + Balance board + Wii Mote	Motor and cognitive training with tasks that require planning, sequencing, flexibility, physical motion, weight shifting and inhibition.	Mendes et al. reported that PD patients were unable to improve their performance in SH, BRP and OC. SH was especially reported difficult because of quick decision making and inhibition of action.
Pompeu et al. [22]	TT, PS, SH, BS, BRP, TC, RP, OC	Wii Fit + Balance board + Wii Mote	To verify performance improvement on Wii Fit games and comparison of motor-cognitive training with Wii against balance exercise therapy for activities of daily living.	Cognitive demands of the games were attention, working memory and performance management, while further discussion was referred to Mendes et al.'s study [15]. Nonetheless, they reported that Wii-based motor-cognitive training and balance exercise therapy showed similar gains in activities of daily living; also, Wii based rehabilitation potentially improved motivation.
Esculier et al. [16]	TT, BB, SJ, SS, PS	Wii Fit + Balance board	To improve balance and functional abilities of PD patients via improving muscle strength.	No specific discussion was provided regarding the games or play sessions. The study concluded on the potential of improvements in static and dynamic balance.
Zettergren et al. [23]	TT, BB, PS, RP, FS, IC, OC	Wii Fit + Balance board	Effects of Wii training on gait speed, balance, functional mobility, depression.	IC was discontinued due to difficulty, yet no discussion or reasoning was provided. RP was also discontinued because participant found it very difficult due to the fast paced rhythm. OC was discontinued because the participant found the required series of stops and starts difficult to perform.
Zimmermann et al. [13]	Table Tennis Archery Swordplay Air Sports	Wii Sports Resort + Wii Remote + Nunchuk	Non-specific training for cognitive purposes compared against specific cognitive training	Researchers reported that specific cognitive training did not provide greater cognitive benefits than Wii training for attention, working memory, inhibition, and planning as followed up with neuropsychological assessment. However, there is no discussion regarding games' features or selection criteria.
Herz et al. [24]	Bowling Tennis Boxing	Wii Sports + Wii Remote + Nunchuk	Effects of training with Wii on motor and non-motor symptoms of PD.	They stated that the selected games required logic, visio-spatial function, sequencing and motor planning with correctly timed action. However, there is no explicit discussion on which features are fulfilling these requirements. No significant difficulty was reported.
Mhatre et al. [25]	BR, Skiing, MT	Wii Fit + Balance board	Improved balance, decreased postural sway, and improved quality of life. Also, balance confidence.	No discussion regarding the game selection is present despite mention of the need of specificity through the selection of games.
Liao et al. [26]	Football MB, BB, SS	Wii Fit + Balance board	Improve muscle strength, sensory integration ability, and walking abilities in comparison with traditional exercise.	No discussion regarding the selected games, their features or any difficulties in playing those. They found that Wii Fit training is as effective as traditional exercise.

TT = Table Tilt; PS = Penguin Slide; SH = Soccer Heading; TTw = Torso Twists; BS = Basic Step; BRP = Basic Run Plus; TC = Tilt City; RP = Rhythm Parade; OC = Obstacle Course; BB = Balance Bubble; SJ = Ski Jump; SS = Ski Slalom; RP = Rhythm Parade; FS = Free Step; IC = Island Cycling; BR = Bubble Rafting; MT = Marble Tracking; MB = Marble Balance.

4. Discussion

A common factor that is missing in many of the aforementioned studies is consideration of the game world. A game world is composed of game features including audio-visual elements, game mechanics and dynamics. Considering the relation between mechanics, dynamics and aesthetics as a useful model to motivate game design [27], it is important to realize the relation of the design with physical and cognitive training approaches. Some design principles already emerged through Assad et al.'s [17] development. These principles were based on the specific needs of patients, comprising appropriateness of movement, positive feedback, simplicity, adaptability, rhythm, and familiarity. Although these principles are very sensible as usability guidelines, they present limited insight for the design regarding the relation of game elements and cognitive aspects, or a relation of game elements to active physical exercise. They may be useful to inform the design of mechanics and dynamics; however, they are not detailed enough to enable a deeper understanding of how physical and cognitive training can inform the design of specific game features for specific conditions. Also, neither audio-visual aspects of the games nor aesthetics imposed by the design have been considered so far.

4.1. Need for a Relational Model

A relational model regarding the mediating effects of exercise on cognition was suggested by Etnier [28] in order to identify the nature of the exercise-cognition relationship; *mediation* as the explicit relation, the *mediators* as the influence mechanism, and the *moderators* as the elements influencing the properties of the relationship. Common pitfalls of game based interventions are inconsistent measures, lack of monitoring, suitability of game elements and psychology of feedback mechanisms [14]; a further insight into the relation of games to both physical and cognitive training would be beneficial. This insight can be developed via a model that explains what games can offer in relation to exercise-cognition relationship. An example of this is a classification framework for clinical decision making in pediatric rehabilitation to facilitate the selection of appropriate equipment [29]. Similar to this classification framework [29] and Rego et al.'s [30] serious games for health classification, a methodology to identify and select or develop appropriate games for specific training purposes is needed. By using Rego et al.'s taxonomy, a recent study [31] looked at some existing game platforms, yet there was no consideration of any games/products coming with the platforms under investigation, and even no elaboration on how to apply the classification points. Therefore, it is not possible to know whether a particular platform that seems appropriate based on its capabilities identified in the classification framework is going to be useful or not because the motor and cognitive load of the game/environment provided with the platform is undefined. Besides, there are contrary perceptions about the mini-games provided in the Wii Fit library: some studies were using a game for just targeting motor or cognitive skills while some others were using the same game for both [13, 15, 31]. For an effective rehabilitation, the connection of game elements to motor-cognitive training and executive functions is as important as the gaming platform. Hence, a model that demonstrates the relation of game system, game features, task sets, physical exercise and target motor-cognitive

skills would help to establish a grounded structure for both developing game based customizable rehabilitation strategies and utilizing existing gaming platforms.

4.2. Need for a Task Creation Framework

Almost all game based interventions have been employing existing commercial games without much explanation about why these games are chosen or how the features of the selected games are serving the particular purpose. Most of the time, the reasons of selection have been about the peripherals and equipment being aligned with the purpose of the rehabilitation, such as using a balance board for balance training, as seen in Table 1. As an exception, Mendes et al.'s study [15] is quite explicit about the target symptoms of the disease, and how these are targeted with certain mechanics in the selected games. However, due to the commercial off-the-shelf nature of these games, there is no possibility of adjusting difficulty based on the various conditions of the participants. Further study into customizable systems and systems that can adapt to the participant's status would improve the quality and effectiveness of interventions. Moreover, established safety precautions including but not limited to considerations about the risk of fall, heart rate, potential injury to joints should be taken into account for further studies, especially the ones reaching up to aerobic exercise levels [24].

In order to develop adaptive, safe, effective and consistent game systems, a task creation framework should address constraints and their impact on symptoms, incorporate exercise principles, enhance symptom improvement and potential activities, and inform the design for appropriate game features. Considering the constraints with regard to visual stimuli and the sensitivity to sensory input (in some cases even causing freezing) [3], games developed for PD rehabilitation should take such sensory complaints into account as well. In addition, task creation must be informed with the relational model for an established game based exercise intervention framework. The relation between a specific game feature and a specific condition of the disease can be very effective, e.g. visual cues making a greater effect than auditory cues on gait initiation in PD [24].

Many of the aforementioned studies target activities of daily living (ADL) through the interventions. ADL is composed of both motor and cognitive abilities, most of the time combined abilities, such as obstacle negotiation while walking or buttoning a shirt. So far, literature does not contain a clear and structured task creation framework for composite tasks, nor game features. Nevertheless, studies with commercial games help to identify the potential of game mechanics and their success for different conditions.

Game based interventions can provide a motivational contribution to the traditional physiotherapy approaches since repetition —especially under the stress of a health condition— can be psychologically demoralizing and demotivating. Taking into account that there is no definitive structure/approach or methodology to target specific positive outcomes [14], exercise games must implement approaches to provide positive feedback and motivation, adaptable challenge to a specific patient's condition and inbuilt safety across all game features. In pursuit of a framework for game based exercise intervention, task creation methodology should build a bridge between established motor-cognitive training tasks and game features.

Conclusion

In this paper, we discussed our perspective on the state of the art towards the development of effective game based rehabilitation systems for PD. Since physical training for PD rehabilitation is more established than game based interventions, we discussed potential lessons from studies in both areas. The evidence shows that games are capable of motivating cognitive and physical exercises for PD rehabilitation, yet there is limited work to inform such therapies for suitability and effectiveness of game elements. As discussed in section 4, there is a significant gap in the literature for game-based therapies that are customizable and adaptive; that have established safety precautions, clear goals and well-structured tasks targeting specific symptoms; and, that utilize game features to enhance the benefits of physical and cognitive training. Iterating from this review towards establishing a methodology, further research needs to be done to find out how games can encapsulate physical exercise strategies while providing safety, continuous monitoring and cognitive training. We believe that further development in this area can hugely benefit from (1) a model explaining the relations of physical exercise, cognition and game features, and (2) a methodology for task creation in conjunction with game features that are suitable for specific conditions.

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The Promise of New Technologies in an Age of New Health Challenges
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Emergency Data Management – Overcoming (Information) Borders

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Abstract. Background: In order to improve access to critical patient data in case of emergency, many countries have begun or intend to implement emergency datasets. In Germany, the German Medical Association developed a medical emergency dataset (MED), which provides the possibility to store information on prior diagnoses, medications, allergies and other emergency-relevant information on the German Electronic Health Card. Objectives: The aim of the study is to evaluate how the MED can be used internationally. Methods: A total of 64 paper-based emergency data sets were completed by primary care physicians in Germany, and were then evaluated by German clinicians, emergency physicians, and paramedics on the basis of fictitious emergency scenarios. Thirty randomly selected MEDs were then translated into English and will be evaluated by international emergency physicians and paramedics. Results: In Germany, clinicians, emergency physicians and paramedics rated the emergency data set as very useful or useful in more than 70% of the reviewed cases. The international evaluation will start in September 2016, so these results are pending at this time. Conclusion: The first study results from Germany indicate high potential benefits of the emergency data set in real patient care situations. The subsequent tests will show whether the MED is also suitable for international use.

Keywords. Electronic health records; health information exchange; emergency treatment; evaluation of telehealth

Introduction

Pre-existing patient information can be critical to the provision of safe and efficient emergency care. Several studies have shown that providers of emergency medical care have a strong interest in obtaining vital patient data at the point of care [1-3]. However, this information can be challenging to obtain or even lacking [1, 4]. Even if the patient

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data is in the form of electronic health record, accessing or using it may not be straight forward.

One such situation is for emergency health professionals to electronically access medical history of patients from other countries. Factors contributing to this problem include: language barriers, difficulty in accessing the dataset over the world wide web, differences in expectations around content of the data, and usability and workflow differences between emergency departments between countries.

In order to improve access to crucial patient data in case of emergency, many countries have begun or intend to implement emergency datasets. In Germany it is defined by the law that, starting 2018, physicians should create emergency datasets on request of their patients [5].

As a basis, the German Medical Association developed a medical emergency dataset (MED), which contains the following items:

- Diagnoses (amongst others ICD-10 code, free text, date of diagnosis)
- Medication (amongst others name, agent, dose)
- Allergies (amongst others allergen, reaction)
- Medical implants (amongst others type specification, date of implantation)
- Special Needs (pregnancy, wandering, communication disorders)
- Contact information (family, physician)
- Special information if requested by the patient (e.g. blood type)

The MED is intended to be physically stored on the German Electronic Health Card (EHC) by authorized health professionals (e.g. primary care physicians), so that it can only be decrypted with an electronic health professional card [6]. Consequently, access to MED will be limited to the area of Germany, and this electronic dataset will not be accessible by foreign health professionals when individuals are traveling abroad. In view of the rapidly increasing worldwide travel activities – for 2030 1,8 billion international tourist arrivals are forecasted worldwide [7] – this is a major limitation of the utility.

Therefore, the aim of our international study group is to evaluate how the MED may be used internationally in two dimensions: is the MED content useful for non-German health professionals, and in what fashion they would like to access MED electronically. This paper reports our current findings and their implications.

1. Methods

Within a project funded by the European Union and the Federal Ministry of Health, Emancipation, Care and Aging (MGEPA) of North-Rhine Westphalia a multi-phase study is conducted to test the possible use of the MED in different countries. The basis of this study is a validation study, which was conducted in Germany in 2014 (please see chapter 2.1).

1.1. Completion and first evaluation of the MED in Germany

Initially, 13 primary care physicians were asked to complete the MED for four of their patients who met at least one of the following inclusion criteria:

- cardiac insufficiency
- chronic respiratory disease
- special permanent medication
- implant

In addition, physicians were asked to select freely one further patient who could benefit from emergency data. The13 participating physicians completed a total of 64 medical emergency data sets.

Afterwards, the usability and benefit of the completed data sets were assessed by emergency care providers (14 clinicians with experience in emergency care, 14 emergency physicians[2] and 9 paramedics) on the basis of the following fictitious emergency scenarios:

- acute dyspnoea
- unconsciousness of unknown cause
- thoracic pain
- stroke
- acute abdomen
- craniocerebral injury.

Every completed emergency data set was reviewed five times on the whole (by at least three different persons and on the basis of at least two different emergency scenarios). In order to standardize the review process structured questionnaires, which were previously subjected to a pre-test, were used. These included questions concerning the perceived benefits of the different items of the MED and about its completeness.

The evaluating physicians and paramedics were selected on a voluntary base from the University Hospital Muenster as well as from the emergency medical services Muenster and Steinfurt. Participation was enabled until all positions were filled.

Before starting the study, the approval of the local ethics committee in Münster (Germany) was obtained, and written informed consent was secured from each patient.

1.2. Future research: Evaluation of the MED in Canada

To evaluate whether the MED can also be used in an international context, in 2016 / 2017, a second evaluation unit will be carried out in Vancouver and Victoria (British Columbia, Canada).

Since the medical emergency data sets were first created in German, for the international part of the evaluation 30 randomly selected MEDs were translated into English by a doctoral student of medicine. Likewise, the questionnaires and fictitious emergency scenarios were translated from German into English.

Every translated MED is to be reviewed on the basis of at least two different emergency scenarios and by at least four different persons (emergency physicians and paramedics), resulting in 120 assessments.

[2] In Germany the term “emergency physician“ is used for physicians, who work in emergency medical services and perform along with the paramedics preclinical emergency care.

In addition, a focus group of emergency physicians and family physicians will be conducted to get more information about their perception of the utility of the MED. Furthermore, possibilities and requirements for setting up a globally available emergency data set and how best to provide electronic access to non-German health professionals will be discussed within the focus group.

The international evaluation will start in September 2016, so the results are pending at this time. We will present the first results of the evaluation process and the underlying methodology at the Global Telehealth Conference 2016.

2. Results

2.1. Evaluation of the MED in Germany

For all the 64 patients a total of 476 diagnoses, 458 medications, 39 allergies, 43 implants and 11 communication disorders were documented in the emergency data sets. There were no documented pregnancies and no wandering patients.

Of the 64 emergency records, 63 were presented to clinicians, emergency physicians und paramedics for evaluation; one data set was used for training purposes. Since each emergency data set was reviewed five times, a total of 315 assessments were performed.

As shown in figure 1, in more than 70% of the reviewed cases, all three groups rated the completed emergency data sets as very useful or useful.

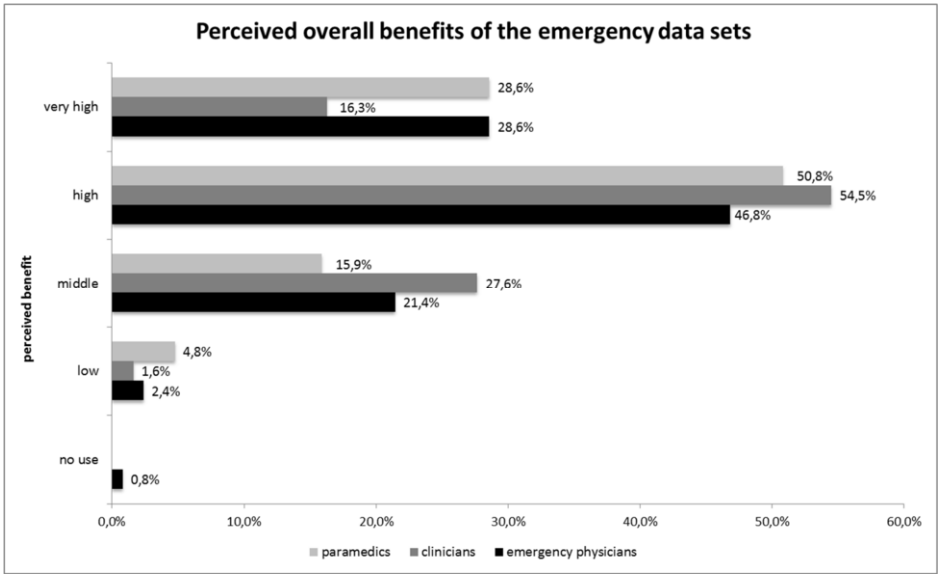

Figure 1. Perceived overall benefits of the emergency data sets from the perspective of emergency physicians (n = 14), clinicians (n = 14) and paramedics (n = 9)

The greatest benefit was attributed to the information on diagnoses and medication (Table 1).

Table 1. Rating of the different items as very useful or useful by clinicians, emergency physicians and paramedics (in percent)

Type of Information	Clinicians (n = 14)	Emergency Physicians (n = 14)	Paramedics (n = 9)
Diagnoses	69.6%	75.4%	77.7%
Medication	75.6%	70.8%	73.0%
Allergies	46.2%	12.5%	40.0%
Implants	69.9%	63.8%	37.5%
Special Needs	41.8%	36.2%	38.4%

Conclusion

Our present study provides a scalable method not only to test and validate the MED in the German context, but also expand this validation in Canada. The findings obtained and reported in this paper will help us to enrich the MED in Germany, and refine it to be useful for non-German health systems. Also, we will gain insights as to how health professionals from other countries would consider accessing the MED database. We intend to replicate this evaluation method in a non-English speaking country (e.g. Netherlands) to gather further data to add to our understanding. These findings will guide us in our next step in the development of a secure technical solution that makes it possible to access emergency data across borders.

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The Promise of New Technologies in an Age of New Health Challenges
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How Nurses Use Telehealth to Support Health Transitions of Older Adults

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Abstract. When people with long term health issues transition from illness to health, or move from hospital to home after an exacerbation they feel vulnerable, unsafe, uncertain, lost, and unsupported. Transitions are life experiences that result in change. Telehealth gives easier access to care and increases patient involvement and self-awareness for self-care and improved outcomes. The purpose of our research was to explore how telehealth tools and processes lend themselves to nursing of patients through transitions. *Methods* A multimethod study with before and after questionnaires consisting of validated questionnaires. These were triangulated with nurse field notes, nurse assessment of each participant, exit interviews with participants, and questionnaire for referring clinicians about their experience of the service. Twenty patients, their five doctors, and two telehealth nurses, participated. *Results* PACIC questions revealed that participants felt more involved in decision making, self-care planning, referrals to other services, and understood more clearly their health issues. The Quality of Life questions showed improvement, and their health issues bothered them less after telehealth. The Perceived Health Competence questions showed an improvement in how they rated their health, and their ability to influence their health. Clinicians indicated that the service worked well, was appropriate and useful, and should continue. The interviews revealed that participants learned how to do self-care with insight, made the transition from hospital to home and from illness to a new way of being well, and referred the service to others like them. *Discussion and conclusion* We conclude that our experienced nurses used the tools of telehealth (monitoring of self-care and videoconferencing) to coach, supervise, guide, and accompany patients through an organizational transition for half our participants (from hospital to home) and all the participants through an illness to a new way of being well.

Keywords. Telecare, telemonitoring, nursing, health service, aged care, transitions

Introduction

The transition from hospital to home, or recovering from repeat exacerbations of long term health issues, can leave people feeling vulnerable, unsafe, unsupported, lost, and disempowered. This is particularly true if people are elderly, and have one or more long term health issue. Transition, as defined by Meleis and Trangenstein [5] is 'a passage from one life phase, condition, or status to another' (p. 256). Transition is both the

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process and the outcome of complex interactions between person and environment [6]. It involves a different kind of self-awareness, re-identifying oneself, becoming different [5-7]. Transitions are life experiences that result in change, e.g. adapting to a long term health issue (health-illness transition) or discharge from hospital to home care (organizational transition) [6]. Care transitions are defined as 'hospital discharge or movement from one health care setting to another'[7]. Nursing is concerned with assisting people who are undergoing transitions with well-being as the goal [5].

The Chronic Care Model (CCM) [8] frames how healthcare professionals should be prepared and proactive, and 'patients' (people with long term health issues) should be informed and activated so that 'productive interactions' can happen. These 'productive interactions' are integral to transitions. Gee et al [9] have modified the CCM to accommodate ehealth, framing the entire model in ehealth terms, which includes telehealth.

Telehealth (defined as technology-mediated healthcare from a distance) [10] shows promise in helping people with long term health issues to track and record their healthcare plan, and progress and outcomes [11, 12]. It gives easier access to care, e.g. videoconference and telemonitoring, in order to improve overall wellbeing. Telemonitoring is defined as 'an automated process for the transmission of data on a patient's health status from home to the respective health care setting' [13]. Telemonitoring is a component of telehealth. People with long term health issues, especially older adults, are at risk of avoidable hospitalisations, and reduced life expectancy and quality of life [12]. Telemonitoring has been shown to have an impact on preventing hospital admissions, reducing length of stay, and improving health outcomes [14], but not its role in facilitating care transitions.

Not all research shows unequivocally that telehealth makes a difference. A systematic review by Wootton [12] reveals that by 2012 health outcomes had not improved dramatically, and in many instances did not merit the adoption of telehealth services [12]. Recent research based in New Zealand settings (urban hospitals and rural primary care) shows that quality of life, self-efficacy, and disease-specific measures did not improve significantly. What was significant was that patients became more active in self-care as a result of raised self-awareness and the sense of safety and feeling more cared for [15]. It is this increased involvement and self-awareness that are of interest for nurses assisting patients in transition [6].

In New Zealand, health and care services are primarily provided by the government, and free at the point of care, i.e. in hospitals and associated services. Primary care is semi-private and patients pay a co-payment for services. Non-government organisations (NGOs) supplement these services. Private aged care services are available. Some of the services provided by such organisations include rest homes, hospital care, medication management, falls prevention, and care giver services [16].

Our research question is, 'How do telehealth tools and processes lend themselves to nursing of patients through transitions?' The question was not how effective or viable the service was, but how the nurses utilized the tools and processes for patient transitions to a new way of being well.

1. Methods

1.1. Recruitment and equipment installation

An NGO aged care organisation provided a telehealth service for six months. Five referring medical specialists and primary care physicians identified and recruited patients for the research. Of the 20 referred patients, ten had been discharged from hospital. All were dealing with changes in self-care resulting from exacerbations or changes in their long term health issues. People were recruited if they were over 60 years old, cognitively able to consent and learn to use the equipment, living in an area where broadband was available, and deemed by their physician to be clinically appropriate for telemonitoring.

Ethical approval was granted by the Health and Disability Ethics Committee on 20/5/2015, reference 15/NTB/84. The research was conducted between July and December 2015.

The equipment was installed in participants' homes according to their needs and the nurse assessment. Participants were shown how to use it. A wireless tablet for recording responses to telehealth questions was installed in each participant's home. Monitoring equipment was installed according to need, and included electronic thermometers, weighing scales, pulse-oximeters, and blood pressure measuring equipment. Schedules for regular measurement and video call appointments (via the tablet) were set up.

1.2. Data collection

This was a multi-method study as depicted in Figure 1. There were three stages: assessment and set up, service delivery and before and after questionnaires, and post service feedback. In addition to the data indicated in Figure 1, referring doctors and nurse specialists were asked to provide clinical diagnoses of their participating patient/s and any other data deemed clinically relevant. They defined the vital signs parameters to be used in the telehealth service.

In total 81 devices were installed in 20 homes. Most participants received a combination of devices. Field notes were kept about incidents, technology support requests and repairs of technology problems, and observations about how participants were coping. Participants completed self-monitoring activities and their data was sent to the telehealth nurse, who printed reports for their doctors. The data was used for their care. The nurses communicated with participants' doctors if and when clinically required.

1.3. Data analysis

The multi-method approach in Figure 1 aimed at triangulation to expand understanding [17], which resulted in comparing and contrasting the quantitative and qualitative data that were collected. Statistical analysis of the questionnaires was not practical because of the wide range of possible responses, i.e. most questions had five Likert scale answer options. The Central Limit Theorem states that statistical analysis is best performed on studies with large numbers of participants, preferably more than 25 [18]. Since our pilot study did not contain sufficiently large numbers for statistical analysis,

the quantitative data are presented descriptively and triangulated with the qualitative data. The interviews were thematically analysed [19].

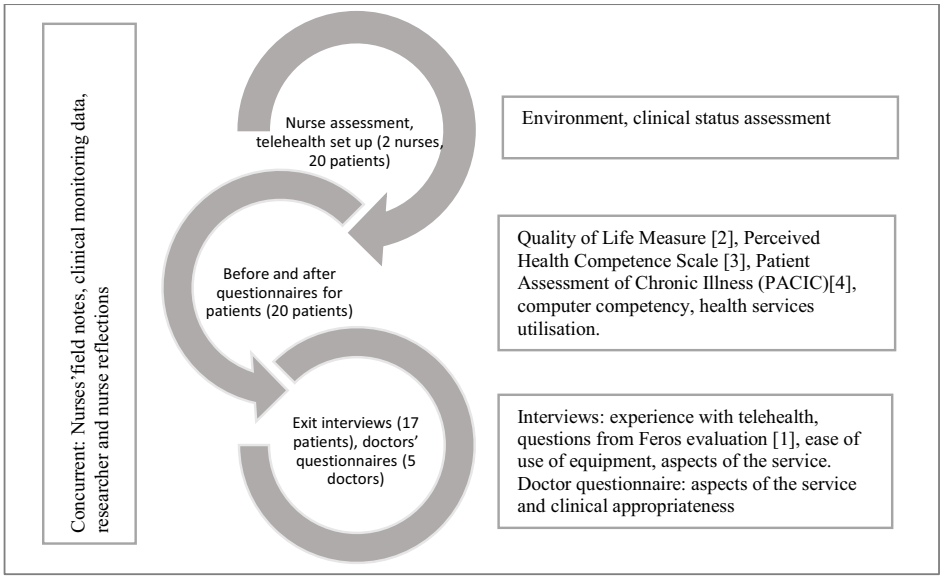

Figure 1: Study design

2. Results

2.1. Demographics and health profile

Seventeen women and three men enrolled in the study. The ages ranged between 61 and 90, with most participants in the 70 – 84 age range. Twelve were New Zealand European, four were Maori, one was Indian, one was Samoan, and one not specified. All spoke English except for the Samoan person who requested an interpreter. They either lived alone (12), with their spouse (5), spouse and child (1), child (1), spouse and grandchild (1), or daughter and grandchildren (1). The 20 participants had 54 health issues (co-morbidities) including combinations of hypertension (13), cardiac issues (6), heart failure (7), airways disease (15), diabetes (5), and other (8). Nine participants were taking five or more medications (polypharmacy).

The nursing assessment about participants' senses, mobility, and cognitive status revealed that three participants had macular degeneration (one was 'legally blind'), one had cataracts, and 12 wore glasses. Three participants had issues with hearing. One had tinnitus and two had hearing loss but were not using hearing aids. In terms of ability to move around without assistance, there were combinations of limited movement, weakness, stiffness, and unsteadiness. One person could not use the weighing scales, and weighing was excluded from her care plan. One person was cognitively borderline and forgetful, requiring some reminder calls from the nurses. Her care plan was simplified and only one measurement (her weight) was prioritised.

2.2. The effects of participating in the telehealth pilot

The shortest enrolment in telehealth was eight days, and the longest was five months and two weeks (156 days). Almost a third of participants (seven) used the service for four and a half months (120 – 134 days). Responses to the PACIC questions revealed that participants felt they were more satisfied with how their care was organized, were shown how their healthcare actions influenced their health, and invited to discuss their health goals. They indicated a difference in being helped to make a treatment plan to fit into their daily activities, and were referred to additional services, e.g. dietitian. Participants shifted from 'almost never' to 'almost always' in the question about being told how their visits to other doctors/specialists helped their treatment. Participants indicated that there was more discussion on how to elicit support from family and friends, and that they were given ways to record daily measurements.

In response to the Quality of Life questions, participants had a low sense of health competence that improved towards the end of the programme by one level of improvement from very poor, up each level of the Likert scale. Two people rated their health as 'very poor' and no-one rated their health as 'excellent' before (Figure 2). Five participants who could not do physical activities before became one person after the service. Two people were not affected by their health issues before. After participating in the service eight said they felt unaffected by their health issues. Similarly there was a shift from six participants saying they could not do daily work, to one. Seven respondents had severe to very severe pain and this number did not change – it was not clear if the people with pain 'before' were the same as the 'after' people. Participants indicated that they could participate more socially after. This aligns with the positive shift in their energy and confidence in their health. Thirteen people were not significantly bothered by their emotional limitations 'before' and 18 'after'.

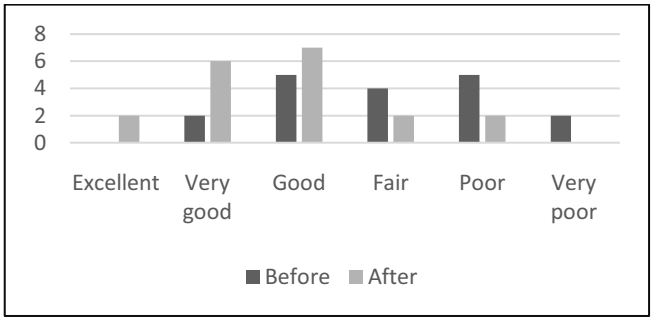

Figure 2: Rate your health, before and after

The Perceived Health Competence questions revealed that there was no change before and after except a one level shift to improvement for the questions about succeeding in projects they undertake about their health, generally being able to accomplish health goals, and able to do things about their health as competently as other people.

Half the participants had never used computers, while the other half had used their phone as a computer, tablet, laptop, or desktop computers. Nine participants were confident about using computers. In the 'after' questionnaire, participants revealed that they found the equipment easy to use (17), and did not find it intrusive (15). They indicated that the discussions with the nurse prevented serious problems (16), they

could manage their health better with the equipment in place (17), and they felt more secure and safe (17).

The three doctors who completed the clinicians' questionnaire revealed that they felt that daily monitoring improved the standard of services to their patients and elaborated to say that their patients felt supported, safe, and confident. They agreed that involving patients in their care via telehealth was useful for early intervention, increased patient insight, reduced anxiety (if used under the right circumstances), prevented hospitalization, and was a meaningful way of conducting a clinical consultation 'but not for everything'. They would recommend the service to their peers, and saw it as an adjunct to usual care. To improve the service, 'keep it going'.

Participants who were interviewed commented on how the telehealth service had affected their awareness of their health issues and how they responded to their state of health, rather than if the programme resulted in improved outcomes because they had incurable long term health issues. As their awareness grew, so did their ability to learn how to make different decisions about seeing a doctor or going to hospital, resulting in fewer visits and/or admissions. One participant said that when her 'dropsy' resulted in swollen feet, she 'just thought it was part of my health and I couldn't do anything about it,' and the nurse taught her when to go to the doctor. Aspects of their condition that they had been unaware of were raised and handled, e.g. fever. Exacerbations and aspects of their health that were difficult to self-manage were handled under nurse supervision, e.g. dealing with a COPD exacerbation without going to hospital. They stated that the nurses' abilities to solve their health problems and assist them into better health, were related to experience, background and expertise, and making self-care fun. This resulted in the ability to trust the nurses when their health took a downturn.

They found it easy to use the technology once they had got used to it and built it into their routine. Customer service was considered to be good in light of the responsiveness of the nurses, and the expertise and ability of the technical support team. They would recommend telehealthcare to others, saying that they are already recommending it to people like them.

Discussion and conclusions

Our research question was, 'How do telehealth tools and processes lend themselves to nursing of patients through transitions?' The tools were telemonitoring, videoconferencing, and nursing competencies. Other tools that emerged included telehealth competencies such as using the technology, addressing unexpected exacerbations and conditions that affected their patients' health, and being well-connected in a clinical network, nurse maturity, and advanced abilities to coach, supervise, and accompany patients through transitions.

People go in and out of transitions as part of long term health issues, and the nurses in our study accompanied, supervised, coached, and intervened via telehealth, to help the participants with their transitions. The transitions we examined were illustrated by a hospital to home care transition and transitions from one state of illness-health to another (described by Meleis et al [6] as organizational and illness/health transitions respectively). The transition for half the participants began before discharge from hospital, while for the others it began during an exacerbation of their long term health issue. They were aware of being in this transition, as evidenced by their answers to the questionnaires (supported in the interviews). Most participants felt ready to discontinue

telehealth when the nurse indicated that their need for it had ended. Some participants initiated the ending when they felt ready.

Factors that contribute to rehospitalisation include unclear expectations, lack of continuity of care, communication breakdown, and incomplete/inaccurate understanding of self-care actions (including medication) [7]. Our findings show that patients benefited from nuanced, regular conversations with their telehealth nurse, who in turn communicated with the associated clinicians when clinically indicated. Patients learned from doing their own daily measurements, and therefore clarified the meaning of their own data and understood what was expected of them. Under guidance from the telehealth nurse, patients were able to learn when to contact their doctor and why earlier rather than later, thus preventing a significant exacerbation of their illness and hospitalisation. Consequently, participants became more involved in their self-care and more socially outward in their activities as they perceived their own developing mastery of self-care associated with their new way of being 'healthy' within the confines of long term health issues.

Role ambiguity and incongruence between ideal and actual roles of clinicians during times of transition for patients can result in poor outcomes [20]. Participants appreciated that their well-connected and experienced telehealth nurse was able to link them to appropriate clinicians in their circle of care, or link clinicians to one another when appropriate. Telehealth competencies for nurses include communication and coaching skills, and the combination of clinical and technology skills, and supportive attitude were evident in how the nurses leveraged telehealth to assist participants through transitions [21]. Telehealth nurses therefore have the potential to reduce the effect of ambiguity and incongruence.

This pilot study's limitations were mostly associated with the small number (20 patients, two telehealth nurses, and five doctors). This was mitigated by structuring a multi-method study aimed at triangulation of results, and the use of validated questionnaires in the before and after patient surveys. Since this was a small pilot study and cannot be generalized to a larger population, although the conclusions can be used in similar settings (transferability) [17].

We conclude that our experienced nurses used the tools of telehealth (monitoring of self-care and videoconferencing) to coach, supervise, guide, and accompany patients through an organizational transition for half our participants (from hospital to home) and all the participants through an illness to a new way of being well. These productive interactions as described in the CCM [8] assist patients in making illness to health transitions. The duration of the transitions was determined by the participants' degree and complexity of illness, and their raised self-awareness, involvement in self-management activities, and willingness to learn new ways of taking care of themselves. Herein lies an opportunity for nurses to leverage the tools of telehealth to achieve the core function of nursing as defined by Meleis and Trangenstien [5], i.e. nursing '…is concerned with the process and the experiences of human beings undergoing transitions where health and perceived well-being is the outcome.' In the words of a participant, 'I couldn't put a value to this, its' too valuable.'

Acknowledgements

We would like to thank the hospital and primary care clinicians who recruited participants, and the participants themselves for their contributions to our research.

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Current Trends in Electronic Medication Reminders for Self Care

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Abstract. Poor adherence to medication can lead to negative health outcomes and increased financial burdens. We present a literature review on electronic medication reminders used for medication adherence in self care settings, to identify current and possible future trends. A structured PubMed search based on extracted MeSH terms provided a total of 45 publications which were identified as most relevant. Three main categories of electronic solutions were identified: mobile phone reminders, in-home electronic reminder devices, and portable reminder devices.

Keywords. Reminder systems, medication adherence, self care

Introduction

The problem of poor adherence to medication regimens occurs all around the world, and various strategies have been developed and applied in order to address this. Improved medication adherence helps to achieve better health outcomes for the patients and reduce financial burdens on the healthcare system by reducing adverse health incidents [1]. Forgetfulness in taking medication is a common cause for poor adherence; additionally as a person ages, the list of medications prescribed by healthcare professionals grows, and so does the number of times per day at which they must be taken.

Existing evidence-based medication adherence interventions for self care settings requiring human carer involvement are often disadvantaged by high-resource delivery needs and impracticality for everyday clinical practice settings [2]. Consequently a recent popular strategy has been the use of technology-based interventions to improve medication adherence. These interventions are generally realized through the use of information and communications technology-driven electronic reminders to inform patients of the time to take their medication, and sometimes also the dosage. Electronic reminders are defined as automatically generated or sent reminders, without personal human contact between the healthcare provider and the patient. These reminders may occur independently of the actual medication or may be associated with various medication storage and handling devices.

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This paper aims to provide a literature review on electronic medication reminders used for medication adherence in order to identify the current and future trends. This paper only reviews contributions in the scientific literature and so materials and research produced by organisations outside of the associated commercial or academic publishing channels were not considered.

1. Background

Inconsistent and interrupted adherence behaviour can lead to negative consequences on the subject of care, especially for elderly patients and patients with serious health conditions. Studies have shown that the true rate of medication adherence in self care settings in developed countries is typically only about 50% [3, 4].

Non-adherence to medication is considered to be a major public health problems, which can lead to financial burden upon the healthcare systems [5], as non-adherence can result in hospitalisations, re-hospitalisations, and nursing home admissions [6]. Among the population, elderly people are more at risk of the consequences of non-adherence in comparison to younger people due to their age and health complications. The diminished visual acuity, decreased physical strength, poor coordination, and other cognitive deficits associated with ageing makes their daily activities, including medication taking, increasing laborious [7]. Most non-adherence (especially with elderly people) is presumed to be unintentional, often caused by forgetfulness or carelessness. However younger adults can also forget their medication unintentionally, due to busy lifestyle. Unintentional non-adherence is often influenced by patient characteristics, age, treatment factors, and patient-provider issues [8].

Drug-related factors and patient-related factors play an important role in medication adherence are [9]. Drug-related factors include complex medication regimens, adverse effects and the number of concurrent drugs. Patient-related factors include cognitive ability, health knowledge and beliefs about the drugs [10]. It is important for healthcare professionals to determine the cause of non-adherence in order to apply the most suitable strategy to help to improve adherence. Often this involves applying a combination of strategies instead of a single strategy, in order to achieve the best adherence outcome.

2. Methodology

The goal of this paper was to collect and analyse publications on electronic medication reminders used for medication adherence in self care settings, to identify the current and possible future trends. PubMed was used as the primary tool for searching the publications, and all of the publications included were published since 2007, ensuring that the most current trends were considered. The choice of limiting the search to PubMed was made on the basis that terminology for the topic of interest would be more consistent in this environment, as compared with very broad related vocabulary likely to occur in the more general science/engineering arena.

MeSH was used to refine the search terms for use in PubMed. Three primary concepts that were related to the scope of this research were identified as initial query construction terms: “medication reminder”, “medication adherence” and “self care”. The term “medication reminder” did not occur directly in MeSH, but when this was reduced to “reminder”, MeSH suggested the term “reminder systems” defined as “systems used

to prompt or aid the memory". The qualifier "electronic" was not used to limit "reminder systems" as it is not used in this context within MeSH. By examining the paths to the terms in the MeSH terminology, it was found that "reminder systems" was related to communication and information systems (and not to healthcare), "medication adherence" was related to patient compliance (through health behaviour and patient acceptance), and "self care" was related to therapeutics and rehabilitation (through health services). Table 1 shows the terms and paths discovered.

Table 1. MeSH Search terms and paths

MeSH Search Term	Paths
Reminder Systems	1. Information Science Category/Information Science/Communication/Reminder Systems 2. Information Science Category/Information Science/Medical Informatics/Medical Informatics Applications/Information Systems/Reminder Systems
Medication Adherence	1. Psychiatry and Psychology Category/Behavior and Behavior Mechanisms/Behavior/Health Behavior/Patient Compliance/Medication Adherence 2. Health Care Category/Health Care Quality, Access, and Evaluation/Delivery of Health Care/Attitude to Health/Patient Acceptance of Health Care/Patient Compliance/Medication Adherence
Self Care	1. Analytical, Diagnostic and Therapeutic Techniques and Equipment Category/Therapeutics/Self Care 2. Health Care Category/Health Care Facilities, Manpower, and Services/Health Services/Rehabilitation/Self Care

Once these preferred MeSH search terms were determined, PubMed searches were conducted (at 1-Jan-2015) using them to find publications to provide a baseline for future searches. Since "Reminder Systems" is the primary topic in this review, it is regarded as a compulsory term, and it is accepted that additional terms might be from either of the two groups "Medication Adherence" and "Self Care". A search requiring all three MeSH terms in this combination only resulted in 228 papers, as shown in Table 2.

Table 2. PubMed search results based on MeSH terms

PubMed Search String	# Publications
Reminder Systems [MeSH Terms]	2330
Medication Adherence [MeSH Terms]	8475
Self Care [MeSH Terms]	41001
Reminder Systems [MeSH Terms] AND (Medication Adherence [MeSH Terms] OR Self Care [MeSH Terms])	228

By examining the titles and abstracts of the first 500 papers in the query results of the three independent MeSH term searches in Table 2, commonly used related terms were obtained for each group. These terms were verified by two expert reviewers to ensure accuracy and were then used to conduct PubMed Title/Abstract searches. Table 3 shows results found from these searches, compared with the initial MeSH based searches. From this table, it can be seen that all of the most common related terms produce substantially fewer results (all below 23%) for Title/Abstract searches, compared with the searches based on the preferred MeSH terms. Addition of further (less common) related terms would be most unlikely to yield higher rates than these. It was therefore decided to adopt the original MeSH based search results for further analysis.

Table 3. Title/Abstract related term search results.

	Related terms	# Publications (% MeSH)
Reminder system	Medication reminder	35 (1.5%)
	Clinical reminder	83 (3.6%)
	Electronic reminder	44 (1.9%)
	Computerized reminder	49 (2.1%)
	Automated Communication	12 (0.5%)
Medication adherence	Medication compliance	1130 (13.3%)
	Drug compliance	698 (8.2%)
	Drug adherence	407 (4.8%)
	Patient autonomy	1576 (18.6%)
Self care	Self-management	9190 (22.4%)
	Self-monitoring	4337 (10.6%)
	Self-medication	2486 (6.1%)
	Self-treatment	1008 (2.5%)
	Self-administration	7082 (17.3%)
	Home-based care	501 (1.2%)

As a result of the combined MeSH based search a total of 228 publications were found. Limiting the search to publications within 10 years resulted in 201 papers being retained. Within these, analysis of the titles of the paper revealed 108 papers were irrelevant, as the titles were either related to only general medication adherence issues, or related to reminder techniques but not specifically electronic reminder systems or devices: this resulted in 93 relevant publications based on title. These 93 publications were then further analysed based on reading of their abstracts, from which 53 papers were excluded as they either lacked hands-on trials of actual implemented reminder systems or devices in order to determine their effectiveness, or the reminder techniques were not related to the scope of this paper. This resulted in a set of 40 publications being chosen as most relevant to the review.

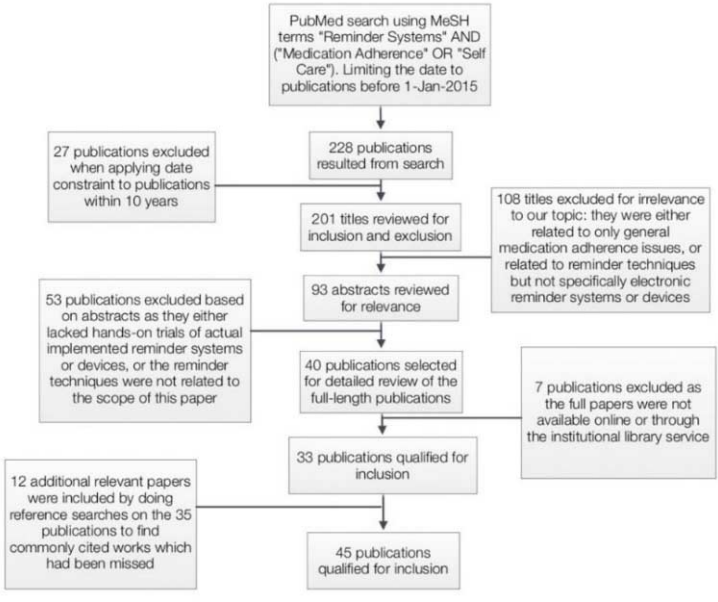

Figure 1. Diagrammatic view of the selection process

Within the 40 publications, 7 of the full publications were not available through the institutional library service. Of the remaining 33 publications, 7 were systematic reviews related to electronic medication reminders [15, 30, 31, 32, 37, 45, 55]. It was noted that all of the 33 publications chosen were published after the year 2007 without additional date constraints applied to the PubMed search, which further ensured that the most current trends were considered. Detailed content analysis was then conducted based on reading of the full papers for these 33 publications. Reference searches were also done on the 33 publications to find any commonly cited works which had been missed, which located 12 additional relevant papers to be included in the overall analysis (i.e. 45 papers in total). Figure 1 above shows the diagrammatic view of this selection process.

3. Analysis

Based on the results from the PubMed search and reference search, 45 publications related to electronic reminder systems for medication adherence in self care were read and analysed. This led to a broad summary of the current trends into 3 categories: mobile phone reminders, in-home electronic reminder devices, and portable reminder devices.

3.1. Mobile phone reminders

Mobile phones are devices that can support electronic reminder systems, as they allow constant access to communication and information and can perform many computational tasks. Their popularity has grown exponentially over the past few years so it can be assumed that they are now widely available and used across the population. Mobile phones provide ubiquity, accessibility and familiarity for users, which in turn has the ability to make their long-term use more sustainable over other electronic devices [11], and as such can be used as very convenient reminder devices that allow various degrees of personalization based on preferences [12]. One study has shown that a mobile-phone-based medication reminder system contributed positively to improving medication adherence [13]. Recent mobile phone contributions in the field of interest have focused on usage with internet connectivity. There are 3 types of reminding services that can be use with mobile phones: phone call/SMS services, reminder apps, and built-in alarms.

Phone calls and SMS (Short Message Service) reminder services were widely used even before mobile phones became popular. They are typically done by calling or texting the patients on to remind them to take their medications, often automatically from a service provider [14]. SMS reminding is currently increasingly being implemented in interventions aimed at improving medication adherence, due to high mobile device penetration and cheap cost [15]. One study on the effectiveness of SMS reminders shows that the rate of missed dose was decreased by 90.1% for participants in an intervention group that received SMS medication reminders [16].

Various studies targeting a variety of health situations have shown that SMS interventions help to improve medication adherence and behaviour and can be useful in measuring adherence. Studies on the effects of SMS reminder on medication adherence for patients with chronic diseases, such as diabetes, Parkinson and mental illness have shown to improve medication adherence [17, 18, 22]. SMS-based medication reminders have also shown to improve adherence for patients with infectious and viral disease, such as HIV/AIDS and tuberculosis [19-21, 23, 24, 31, 32].

One study focused on the effects of daily SMS reminder on patients with asthma, and the result shows that daily text message reminders are associated with increased adherence to anti-asthmatic medication [25]. A study on automated telecommunication-based reminders with once-daily glaucoma medication show that daily text or voice message improve adherence rate from 53% to 64% [26]. SMS is considered personal, socially acceptable, inexpensive and is accessible to patients irrespective of their geographical or socioeconomic barriers [27].

Personalized SMS reminders sent at a pre-set time have been shown to improve medication adherence significantly and reduce rejection episodes for paediatric recipients of liver transplants [28]. Interactive text message response (ITR) is an example of text messaging reminding where patients receive personalized daily short message system reminders with a follow up message about an hour later asking if they have taken their medication and directing a response via return text message [29].

One systematic review on the effectiveness of interventions using electronic reminders on patients taking chronic medication claimed that SMS intervention help to improve medication adherence [15] while another on the scope and effectiveness of text messaging for HIV/AIDS care showed that SMS reminders helped to improve adherence to HIV/AIDS medications [21]. A systematic review on the effectiveness of mobile phone messaging for facilitating self-management of long-term illnesses concluded that these interventions may provide health benefits [30]. However the use of such a service can also have disadvantages, including the risk of inaccurate data input, lack of understanding or misinterpretation of the information, and difficulties in reading for those with poor vision or literacy problems [30]. Another systematic review concluded that SMS reminders help to improve anti-tuberculosis medication adherence [32].

Mobile phone apps are a novel approach to improving medication adherence and behaviour, as they are constantly accessible, easy to use and learn, and have the ability to educate patients and provide medication specific information. Apps are downloaded into a mobile phone, so patients do not need to carry a separate reminder device to remind them to take their medication [33]. The apps can be obtained with little to no cost, and have been proven to be very useful for patients with complex medication regimens [34].

The number of such adherence apps is increasing across platforms such as iOS and Android, and the most popular features are medication reminders, refill reminders, data logs that record adherence which can be uploaded to healthcare professionals, and medication information. One study on the effectiveness of an iPhone app showed that most participants were comfortable sharing information via the app with a health professional, and deemed it useful in reminding and managing their medications [35].

Sometimes users will use only the built-in alarm features of a mobile phone to remind them to take their medication. However this does not work very well for patients who need to take a number of different drugs and doses every day, as they can get confused over which medication to take and how much to take, when the alarm rings.

It has been claimed that combining in-person with automated reminders produces the most effective results for improving medication adherence, clinical outcomes, patient and caregiver satisfaction, as well as improvement in patient-doctor relationship or person-centeredness of care [36]. One systematic review paper concluded that all studies in the review suggest that reminder systems such as text messages, automated phone calls and audio-visual reminder devices help to increase patient medication adherence [37].

3.2. In-home electronic reminder devices

Reminder services can be built into a home environment, such as smart homes, for health management and monitoring purposes. It can be beneficial to both the patients and healthcare providers, and especially useful for elderly patients who live alone and have difficulty managing their medications. For the providers, an automatic monitoring system with sensors will free up labour from 24/7 physical monitoring, thus reducing labour costs and increasing health service efficiency. In-home sensors and wearable sensors can monitor changes in the environment and patient's vital signals such as heart rate and blood oxygen levels, which human carers might overlook. The data collected from the sensors can be stored and integrated into a patient's health records for use by healthcare professionals to adjust diagnoses and treatments [38].

The Home Automated Telemanagement system was developed for the computer-guided management of patients with ulcerative colitis to monitor their symptoms, medication compliance, quality of life, and educating them on their disease. The system can also be adapted for other diseases such as hypertension, where the same principles can be applied to aid patient adherence in self care. The response of patients to the system within the pilot tests has been positive as it is easy to use and convenient [39].

Recent advances in telehealth technologies have enabled the development of connected devices that can be used in home settings in order to assist with medication management and monitoring [40]. Automatic pill dispensers are sophisticated, computer-based monitoring systems that can be programmed to perform a variety of functions, such as emitting audible or visual alarms, separating medications into compartments and dispensing the correct medication dosage. Some can contact a caregiver by telephone if a medication dosage was not taken within a predefined period. By using an automatic pill dispenser, the medication is locked away so the patient cannot accidentally overdose [41]. One major disadvantage of this device is that it can cost up to $1000, which is expensive compared to other type of reminder devices. [41]. In a randomized controlled trial of 61 elder patients with chronic illness, an automatic pill dispensing device with an audible medication-taking prompt was found to be superior in enhancing medication adherence in comparison with pre-filled pillboxes after a 6 months trial [42]. An example of such device is the MD.2 medication dispenser, a device that automatically dispenses the pre-loaded medication and gives alerts to patients when it is time to take their medication [43, 44]. A study has shown that dose-dispensing aids, including automated dose dispensing with monitoring system, help to improve adherence in polymedication [45].

Two-way interactive video technology can also be used to monitor medication compliance. Such technology brings virtual medication monitors into people's homes. The virtual caregivers can help to increase social interactions, thus adding to the quality of life. A study of the use of such technology over a sustained period on subjects with mild dementia found that the video-monitored participants' compliance remained stable at a rate of 81% while unmonitored patients' compliance fell by 12% [46].

3.3. Portable reminder devices

Portable reminder devices have an advantage over in-home reminder device due to their portability which makes them popular amongst busy individuals. These devices are often small in size so the users can carry the device with them everywhere they go, therefore the reminder service is not restricted to only the in-home environment. Simple reminders

provided by a portable medication reminder device have been reported to improve medication adherence [47]. These portable devices often work by sounding an alarm and sometimes flash lights to remind the patients when it's time to take medications [48].

The electronic pillbox is a widely used and simple portable medication reminder device and is suitable for patients who are not 'tech savvy'. Med-eMonitor is a smart pill container that is capable of cueing the taking of medication, warning the patients when they are taking the wrong medication, recording side effects complaints, and alerting carers of failures to take medication [49, 50]. A study has shown that Med-eMonitor help to improve medication adherence and achieve high satisfaction ratings [51].
The Helping Hand is an electronic monitoring tool that is suitable for blister packages. The reminder system within the Helping Hand consists of LED lights that provide feedback to the user regarding their medication behaviour within the previous week. It also yields a beeping signal to remind patients to take their medication at the correct time. It is easy to use and widely accepted by patients and clinicians [52, 53].

The Alarm Watch is a wristwatch that allows a patient, especially those away from home, to keep track of when their medications are due. The system allows the patient to make multiple daily alarms and an optional alarm instructional text message can also be displayed across the face of the watch. The watch has a vibrate mode so that only the wearer can know that it is time to take medication. There is also an emergency medical alert that can speak for the patients if they are unable to speak for themselves [44].

MedSignals is a device that is smaller than a desktop phone, and can signal pill usage in four different ways: beeps, flashing, text or voice. It can also verbally announce how many pills the user should take and how to take them, and can track patient's medication usage and upload the information to patient's file for use by healthcare professionals [44].

TimeCap fits a conventional prescription medication vial, and contains a digital timepiece that displays the time of day and day of the week when the container was last opened. This helps the patient who forgets when or if they took their most recent dose as they can find out by simply checking the digital timepiece on the cap. The timepiece also contains an alarm that beeps when a dose is due [54].

Results from a systematic review study shows that simple devices that monitor and store adherence records and devices that combine digital displays with audible reminder alarms appeared to be the main characteristics of Electronic Medication Packaging devices most useful for improving medication adherence [55].

Conclusion

Increasing medication adherence through a reminder system is one of the most common types of behavioural intervention: it targets and is helpful for patients who forget to take their medication unintentionally. Based on the above analysis, mobile phones, in-home electronic devices and portable devices used to communicate reminder messages have been shown to be useful in improving medication adherence and achieve a high user satisfaction, as summarised in Table 4. Based on the three different types of reminder systems identified, we can see that electronic reminder technology has evolved in several parallel streams over the past 10 years. Simple text messages are now moving towards interactivity through interactive voice response messages. Mobile phone apps are also becoming increasingly popular as an effective and convenient way of dose reminding.

Table 4. Overview of the technology and its success factors.

Technology	Success Aspect	Criteria offering success
Mobile phone	SMS [15-32]	Short, simple, effective, inexpensive, personal
	Phone call [31]	Personal contact, relationship building
	Applications [33, 34, 35]	Variety of functions, graphic images, cheap
In-home device	Smart Home device [38, 39]	Integration to smart homes, automated 24/7 monitoring, reduce labor costs, increase efficiency, data storage
	Automatic dispenser [42-45]	Standalone device, effective, multi-medication dispenser
	Video monitoring [46]	Virtual caregivers, increase social interaction
Portable device	Electronic pillbox [49, 50]	Portable, suitable for non-tech-savvy people, easy to use
	Alarm Watch [44]	Small, portable, wearable
	Helping Hand [51-53]	Portable, suitable for blister package
	TimeCap [54]	Portable, fits conventional medication vial
	MedSignals [44]	Variety of reminder functions, tracking medication usage

Medication reminding services are now being integrated into smart homes, which could become widely adopted in the future due to the many advantages associated with them. Automatic pill dispensing is also a desirable in-home reminder system, especially for the growing population of elderly people living along in the community, as it not only reminds patient to take their medication, but also helps to avoid accidentally overdose.

Various specialized portable devices like the ones discussed above could become a popular trend in the near future as they are easy to use and learn compared to other technologies that require some level of IT knowledge. Technologies like phone apps, smart home devices, automatic dispensers and video monitoring are also able to link to external systems, for example the pharmacies for medication refill information, or link to their healthcare centre and notify healthcare professionals when needed.

In conclusion, electronic reminder technology provides many benefits such that it is portable, effective, simple, accurate, and can include multiple functions. Each reminder technology has its success aspects and the criteria that enable such success. This paper shows that the current trends of electronic medication reminders should lead to improvements in medication adherence in self care settings, and the increasing opportunities in newer Information Communication Technologies will allow more patients access to such reminder solutions.

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Improving Patient Safety, Health Data Accuracy, and Remote Self-Management of Health Through the Establishment of a Biometric-Based Global UHID

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Abstract. Healthcare systems globally continue to face challenges surrounding patient identification. Consequences of misidentification include incomplete and inaccurate electronic patient health records potentially jeopardizing patients' safety, a significant amount of cases of medical fraud because of inadequate identification mechanisms, and difficulties affiliated with the value of remote health self-management application data being aggregated accurately into the user's Electronic Health Record (EHR). We introduce a new technique of user identification in healthcare capable of establishing a global identifier. Our research has developed algorithms capable of establishing a Unique Health Identifier (UHID) based on the user's fingerprint biometric, with the utilization of facial-recognition as a secondary validation step before health records can be accessed. Biometric captures are completed using standard smartphones and Web cameras in a touchless method. We present a series of experiments to demonstrate the formation of an accurate, consistent, and scalable UHID. We hope our solution will aid in the reduction of complexities associated with user misidentification in healthcare resulting in lowering costs, enhancing population health monitoring, and improving patient-safety.

Keywords. algorithms, biometrics, health information and safety, telehealth, unique health identifier, national provider identifier

1. Introduction

In recent years we have witnessed healthcare's expansion of electronic medical records (EMRs) [1], electronic health records (EHRs) [2], and personal health records (PHRs) [3], providing an electronic means of access to an individual's health data, such as medical history, insurance information, and demographic data. Likewise, technology continues to advance in the areas of improved hardware, application development, and mobile platforms, such as mobile health applications, creating a potential ubiquitous computing environment for healthcare delivery and monitoring. This progress has led to a paradigm shift from what we have known as traditional healthcare, to a redefinition or an evolution of com-

puting in healthcare. Advancing computer-based healthcare delivery services will only prove beneficial if healthcare data is accurate, secure, and accessible across healthcare networks which query or populate the health-related information.

One of the largest health information technology issues surrounds the accuracy and efficiency of identifying a patient. A local system with a poorly maintained or 'dirty' patient Master Person Index (MPI) will contaminate all other systems in which it links, significantly increasing the inaccuracy of patient records, while simultaneously lowering a patient's safety and quality of care potential [4]. As remote self-management technological advances and telehealth opportunities expand, accurately identifying a patient remotely and aggregating their remote health data with existing clinical data from the EHR is critical when assessing health outcomes. While many countries have implemented National Provider Identifiers (NPI) for their respective populations, no country has developed a biometric solution for identification and health record linkage. As electronic records continue to expand for PHRs and computing in health becomes increasingly ubiquitous, the need to establish an efficient, accurate, and secure form of identification is critical.

According to the report *IDENTITY CRISIS: An Examination of the Costs and Benefits of a Unique Patient Identifier for the U.S. Health Care System*, a unique patient identifier (UPI) would significantly improve patients' health record record linking, as matching capabilities of medical records to accurately identify a record being searched have a success rate of 85% to 92% [5]. Although the ASTM's International standards for identifiers E.1714 *Standard Guide for Properties of a Universal Healthcare Identifier* and E.2553 *Guide for Implementation of a Voluntary Universal Healthcare Identification System* provides guidelines of a UHID [6] [7], there exists no current standard for data elements used in algorithmic record matching. The development of a unique identifier would help establish and enforce a large-scale authorization of patient data, permitting collected data to be valuable in helping to improve health outcomes of a patient.

We introduce a new technique using our developed algorithms to establish a Unique Health Identifier (UHID) based on the user's fingerprint biometric, with the utilization of facial-recognition as a secondary validation step before health records can be accessed. Biometric captures can be completed using standard 8 megapixel minimum smartphones and Web cameras in a touchless method using our solution, permitting user identification of both patients and medical personnel to occur within a clinical environment or remotely, such as the user's home. A traditional username and password can be used as an alternative to the biometric UHID, however it contains a lower identification accuracy and security. We present a series of experiments to demonstrate the formation of an accurate, repeatable, and scalable UHID.

2. The Proposed Solution

Our solution, which we have named, Unique Medical Biometric Recognition Enforcement of Legitimate and Large-scale Authentication or UMBRELLA, provides a potential solution for large-scale architectures and ubiquitous computing

environments, including home-health and remote health self-management. The individual research areas, which are the pillars of the proposed architecture, can be divided into four distinct areas, shown in Figure 1.

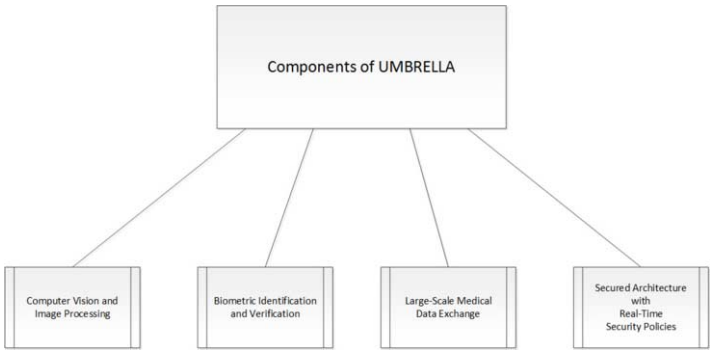

Figure 1. Components of the UMBRELLA Architecture.

3. Biometric Capture and Image Preprocessing

A key component of our solution is to accurately capture the user's fingerprints and facial features during the initial enrollment or when an enrolled user attempts to access the system. To avoid issues associated with touch fingerprint sensors, such as hygienic problems [8] and uneven finger pressure on a touch-based scanner leading to the problem of duality between fingerprint terminations and bifurcations [9], we introduce a touchless method using cameras in common devices such as Web cameras and smartphones. This provides a potential solution which does not depend on proprietary hardware, costly equipment, or single-use machinery.

3.1. Fingerprints Capture

Our developed application captures both the user's fingerprints and facial features using an overlay to the camera preview class written in Java code. The approach to capturing the user's fingers is structured, leading to consistent finger distances and fingerprint visibility. The user places their four fingertips, excluding the thumb, into the respective finger position markers, where all four fingerprints are captured simultaneously. Capturing the left and right hand results in a total possible of eight fingerprints captured. An illustration of the overlay capturing the fingers of a user's left-hand is shown in Figure 2.

3.2. Fingerprint Image Preprocessing

The fingerprint image preprocessing phase is a critical component to ensure accuracy of our system by preparing fingerprint images for minutiae extraction. Unlike past research, our solution captures four fingers of a hand simultaneously, using a variety of backgrounds and lighting conditions.

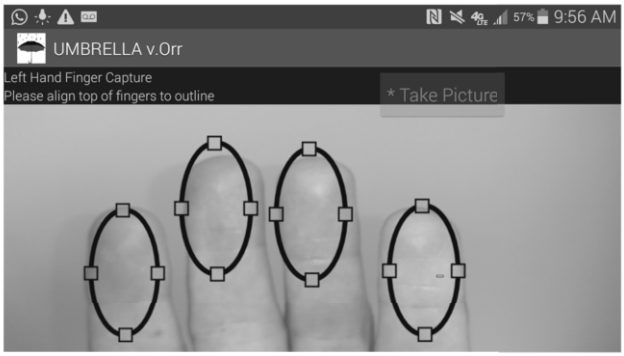

Figure 2. Fingerprint Capture - Left Hand

Our proposed algorithm is separated into three distinct parts. First the *Image Acquisition* phase, which captures images from the proposed application to perform local normalisation and RGB separation. Secondly, is the *Segmentation* phase, which conducts edge detection on the fingers before binary masking and cropping of the fingerprint region of interest is applied. Finally, the *Enhancement* phase is implemented. In this phase additional filters such as anisotropic diffusion, adaptive histogram equalization, ridge filtering, binarization, and thinning are conducted.

Experimental tests were conducted using the Goodness Index to evaluate the preprocessing algorithm. Results displayed a consistent average improvement of .31 in the image quality of the fingerprint after the algorithm was applied. False Non Match Rate (FNMR) and False Match Rate (FMR) were also calculated based from the minutiae mapping score within a given threshold. Results confirmed the images' quality and minutiae matching accuracy with a FNMR of 0.00 and a FMR of 0.016. With validation of the image preprocessing method, fingerprint images are prepared for the UHID process.

4. Development of the UHID

The establishment of a UHID for patients offers a paradigm shift from traditional identification measures used in healthcare and many other sectors of industry. It protects patient safety, reduces duplicate patient health records, and helps diminish healthcare costs associated with healthcare fraud, insurance fraud and correcting inaccuracies of health records due to patient misidentification. Likewise, the establishment of a biometric-based UHID allows authorized medical personnel to access patient health data without the requirement of usernames and passwords, however these forms of traditional identification can be utilized if needed. Through a medical personnel's unique identification, records are enforceable using the fingerprint biometric identification of the patient, where it is

validated through facial recognition, enhancing the security of patient identifiable information (PII).

At the time of this writing, only Krawczyk et al. has proposed a solution to secure electronic medical records using biometric authentication [10]. Their research, fused the biometrics of online signature and voice recognition to determine a user's authentication to their respective electronic medical record. This solution was based on a one-to-one matching environment and did not investigate the design of a UHID, nor did it take into account a large-scale architecture searching for multiple records within a one-to-many network.

4.1. Unique Identifier Parameters within the Medical Field

The discussion of creating a UHID has been debated extensively within recent years. As a result of the potential advantages sought from an established UHID, the American Society of Testing & Materials (ASTM) published a Standard Guide for Properties of a Universal Health Identifier in 2006, with re-approval confirmed in 2013 [11]. The ASTM's E1714-07 standards document stipulates thirty-one recommended criteria measures for an established UHID.

The ASTM document does not contain any text regarding protocols, examples, or linkage to a biometric UHID. The document only stipulates the technology used, must be scalable for the world population and its foreseeable future. Therefore, the document contains a loosely-coupled formation of guidelines and parameters in establishing and maintaining a UHID system. However, the premise of the ASTM's UHID standard brings about a common-sense logic in helping to structure one's approach in the development of a UHID system. We demonstrate our solution's design of an identification system in healthcare and its formation of a UHID to satisfy and comply with the suggested parameters brought forth by the E1714-07 document.

4.2. Triangulation

Fingerprint triangulation has proven to be a reliable method of establishing consistency within fingerprint analysis as it provides immunity against noise and distortion [12]. Experiments from Fengling Han et al. proved that minutiae points closest to the fingerprint's core are relatively stable, while points further from the core tend to produce more uncertainty [13]. Angles within the triangles are invariant under translation, rotation and scale, which was validated by work conducted by Bhanu and Tan [14][15].

Our solution develops an algorithm to capture the most stable minutiae points within each finger's already captured image. It then strategically creates a fictitious triangle to begin the process of marking key minutiae points, however our design differs from research conducted by Han et al. and others by several instances. First, the algorithm developed in our solution to create an existing UHID from the user's fingerprints is constructed to make certain no minutiae points are used more than two times in the selection of the lines of the fictitious triangle. Extensive testing concluded possible failures in forming the triangle and therefore calculating a unique identifier when the same minutiae point is used more

than twice. Secondly, the proposed solution performs a check to ensure no other minutiae points are in close proximity before a point is chosen. Due to possible saturation consisting of multiple minutiae points clustered together in a common space within the fingerprint, it becomes difficult for an algorithm to choose the same minutiae point each time when creating a fictitious triangle. The solution proposed chooses minutiae points based on stability and close proximity to other minutiae points, helping to ensure the same points are chosen each time. Third, the solution presented concatenates each finger's identification output sequentially by indexing each finger position, enabling a greater degree of uniqueness and scalability. Finally, no other solutions discuss methods of securing the UHID. The solution presented within UMBRELLA uses encryption of the UHID, adhering to the ASTM's traits of being *secure* and *disidentifiable*.

5. UMBRELLA's UHID

As a method of enforcing consistency and stability to achieve correctness in every digit of a UHID, UMBRELLA has focused on providing an algorithm using the methods of triangulation. The algorithm, and its associated User Interface (UI), was written in Java using Neurotechnology's Verifinger software developer kit (SDK). Verifinger was chosen due to its accurate matching capabilities between fingerprint samples and templates, along with its wide use within the academic research environment [16], [17] [18], [19]. Please note, the maximum number of fingers from a user is eight, while the algorithm used to define the unique and repeatable attributes from each of the user's individual fingerprints is nine. Therefore, each of the eight fingers contain nine unique attributes or digits. An explanation of this process is provided below.

To begin the process of establishing a UHID, five minutiae points with the closest proximity to the core, cores, or delta are selected, using each captured fingerprint's processed image. The distance between each selected minutiae point is calculated and the longest three lines between each selected minutiae point is determined. After the completion of locating the longest three lines between selected minutiae points, a fictitious triangle can be formed by calculating the coordinates of where the three lines intersect. Figure 3 illustrates the triangulation of the longest three calculated lines on one of the fingerprint images used within the research test images. With the triangle formed, the algorithm uses geometric properties of the triangle to establish the longest side of the triangle, known as the maximal side or x_1. Also, the angle between the angles of the two vertices of this line is labeled as the medial angle (αmed) and the other angle as the minimal angle (αmin).

The calculation of angles within the fictitious triangle of the fingerprint is the final step before being able to map the user's fingerprint to a unique identifier. As there are three sides, a total of six minutiae are present to end the lines of the triangle. Therefore, the process begins by marking each minutiae as a 1 if it is bifurcation or a 0 if it is an end. Digits 1-6 of each fingerprint's identifier would be a binary series of data populating the first six fields.

Fingerprint digits 7-9 are used to further extend the identifier within each fingerprint and assist in accounting for any discrepancies due to deformations,

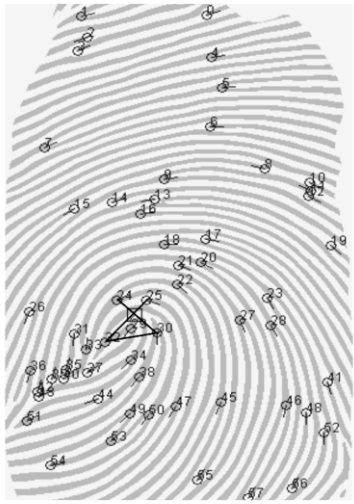

Figure 3. Triangulation of Selected Minutiae Points with Longest Three Lines

unforeseen shadowing or additional blurriness of the image resulting in change. Han et al. calculated a variance from their test results to determine average values of x_1, αmed, and αmin. Based on their findings of these values and their respective variations, a transformation was calculated to ensure the quantity each all three values would remain consistent during multiple captures of the same finger, producing the same values. Therefore, digits 7, 8 and 9 were based on previous error-tolerant transformation work by Han [13] and advanced through our research to produce more accurate results. Additionally, our proposed solution uses hexadecimal values instead of the 0-9 numbering system, providing a greater degree of uniqueness and scalability of a user's UHID through the use of 16 possible values instead of 10. Therefore, a total of nine alphanumeric digits are derived from each fingerprint image. While previous work cited the generation of an identifier by a single fingerprint, the proposed solution extends a UHID by combining each of the user's fingerprint image value output into single health identification attribute.

5.1. Concatenation

The current solution permits a total of eight fingers to be captured, or four fingers per hand. Each fingerprint is configured to generate nine digits, representative to the uniqueness of the minutiae within that respective fingerprint, and totaling a possible thirty-six digits from one hand or seventy-two digits from each. Using concatenation, fingerprint identification values can be presented together as a single UHID. This is possible due to the placement labeling of each finger position during the capture and image processing method. Images are aligned according to hand and finger position, producing a concatenated UHID.

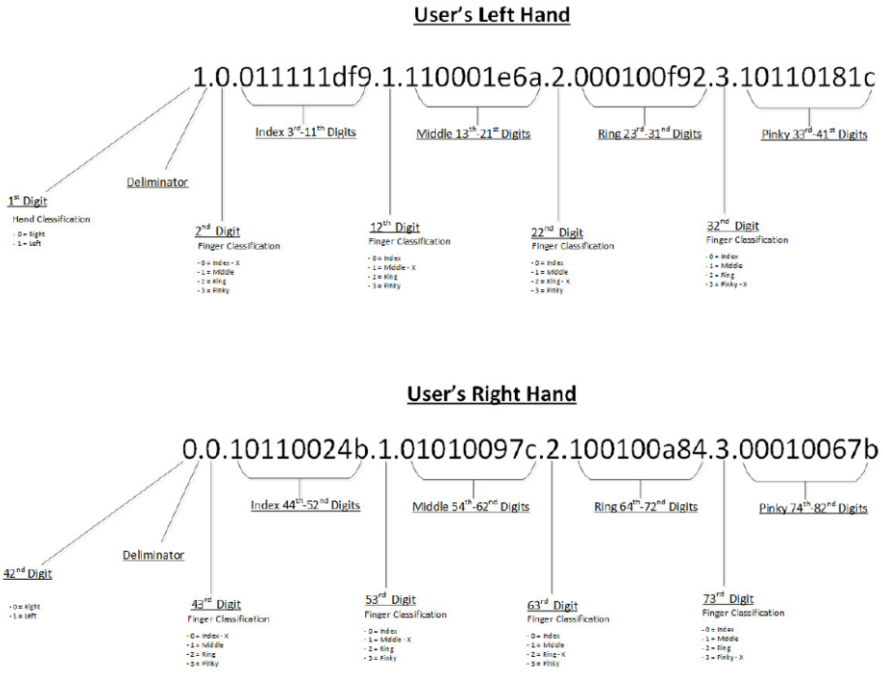

Figure 4. UMBRELLA's UHID Digit Classification

Figure 4 displays UMBRELLA's methodology of concatenating the four fingerprints from both the left and right hand. The concatenated UHID has a total of eighty-two digits, seventy-two stemming from the eight fingerprint images' identification output and an additional ten digits used for classification of hand and finger position. A delimiter is used to separate the classification of hand, finger position, and each fingerprint identification values from each other.

An accurate concatenation process offers several enhancements to user identification. First, it improves the uniqueness attribute of the UHID. Increasing the amount of digits of the identifier, subsequently will increase the variance between UHIDs, helping to provide a truly unique and scalable identifier. Secondly, an extended UHID identification value, which will become encrypted, increases the difficulty of capturing a user's identification number and using it for malicious purposes, such as medication fraud. Finally, the concatenation of a user's fingerprints helps in achieving a potential global UHID facilitating accurate user identification and health record exchange on a large-scale platform.

To secure the UHID, we encrypt it upon its initial creation, along with its use anytime within the system using the Advanced Encryption Standard (AES)

256-bit encryption seen in Figure 5.

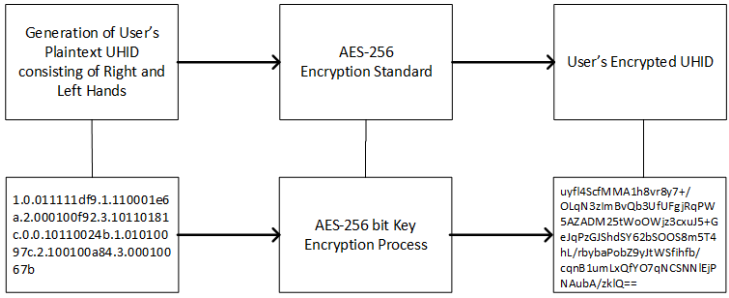

Figure 5. UHID Encryption of User's Concatenated Fingerprints

6. UHID Experimental Results

To perform experiments in developing a repeatable UHID, images captured from the four impressions of each hand for test participants were processed within our image preprocessing algorithm and used within our tests for a total of 420 images. An additional four impressions of each users' hands were taken and processed, permitting them to be used as a comparison in our verification process, creating another 420 images or a total of 840 images used within performance evaluation.

The average time to transform a single fingerprint into a portion of the UHID was 3.11 seconds, and totaling 24.88 seconds for all eight fingerprints and the concatenated user's UHID. To test, each of the user's eight fingerprints, consisting of four impressions for each finger were calculated. The remaining four impressions consisting of a separate capture process were used to validate the algorithm's consistency and repeatable UHID. Per Finger UHID Match is calculated by the following equation:

$$PerFingerUHIDMatch = \frac{UHIDMatch}{TotalUsers} \tag{1}$$

Results from our experiments are shown in Table 1. One finger from a user within our participant group did not match it's original UHID, the left-hand pinky. Upon investigation, although the algorithm was able to correctly choose the appropriate minutiae positioning as in the original template for the user, the third digit was incorrectly labeled as a *termination*, when it was actually a *bifurcation*. Due to the user's angle of their pinky finger's position with heaving shadowing in natural light, the single minutiae point classification was too difficult to determine for our algorithm. Although the facial recognition would have properly denied an incorrect user during the secondary biometric verification phase, we plan to continue in improving our algorithm even further to ensure a greater level of accuracy and consistency.

Table 1. UMBRELLA captured images' UHID match results

Finger Position Per Hand	Digits 1-6	Digits 7-9
Left Hand - Index	1.00	1.00
Left Hand - Middle	1.00	1.00
Left Hand - Ring	1.00	1.00
Left Hand - Pinky	0.93	1.00
Right Hand - Index	1.00	1.00
Right Hand - Middle	1.00	1.00
Right Hand - Ring	1.00	1.00
Right Hand - Pinky	1.00	1.00

We also conducted UHID on images from the Fingerprint Verification Competition (FVC) 2004 fingerprint database. The FVC 2004 database, consisted of eight impressions of a user's single finger. Using four impressions for each user to establish a UHID based on a single finger, the remaining four impressions of each finger was used to establish a separate UHID. The two UHIDs for each user were compared. Table 2 displays the results. One individual's, user 7, single finger UHID doesn't not match on digits 1-6. After further analysis of the image, we determined the issue was attributed to the very poor quality of the user's fingerprint involving the area around the fingerprint's core. As a result, the algorithm is not able to determine the distinction between several of the minutiae points clustered together and falsely chooses the incorrect minutiae.

Table 2. FVC 2004 database UHID match results

FVC 2004 Database	Digits 1-6 Matched	Digits 7-9 Matched
User 1	Yes	Yes
User 2	Yes	Yes
User 3	Yes	Yes
User 4	Yes	Yes
User 5	Yes	Yes
User 6	Yes	Yes
User 7	Yes	Yes
User 8	No	Yes
User 9	Yes	Yes

7. Conclusion

We have introduced a new technique of user identification in healthcare in a design which is scalable, promotes interoperability on a large-scale architecture, and secure. The proposed architecture offers a potential solution capable of patient identification, health data exchange and security. Our research has developed algorithms capable of establishing a UHID based on the user's fingerprint biometric, with the utilization of facial-recognition as a validation step before health records can be accessed. The design is flexible and does not require the current NPI's to be replaced. Rather, a user's UHID may be cross-mapped to their existing NPI, therefore not requiring existing records to be remapped to a new health identifier.

Experiments conducted show promising results. Both UMBRELLA captured images and fingerprint images from the FVC's 2004 Database show a high accuracy. Using a standard deviation of 9% digits 7-9 matched perfectly in both tests. While the facial biometric would have detected a non authorized user trying to access a record for the two failed cases, there remains continued development in the UHID algorithm to further improve its accuracy and consistency. We anticipate this solution to aid in the reduction of complexities associated with user misidentification in health care resulting in lowering costs, enhancing population health monitoring, and improving patient-safety.

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Applying the Resilient Health System Framework for Universal Health Coverage

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Abstract. Since the 1978 Declaration of Alma-Ata affirming health as a fundamental human right, policy-makers and stakeholders have proposed many different strategies to achieve the goal of 'health for all'. However, globally there still remains a lack of access to health information and quality health care, especially in low- and middle-income countries (LMIC). Digital health holds great promise to improve access and quality of care. We propose using the "resilient health system framework" as a guide to scale-up digital health as a means to achieve universal health care (UHC) and health for all. This article serves as a call to action for all governments to include population-based digital health tools as a foundational element in on-going health system priorities and service delivery.

Keywords. Digital health, Universal Health Coverage, resilient health system

Introduction

The 1978 Declaration of Alma-Ata at the International Conference on Primary Health Care affirmed health as a fundamental human right [1]. In order to attain 'health for

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all', the World Health Organization has endorsed Universal Health Coverage (UHC) as the means to achieve this ideal goal [2]. UHC encompasses health promotion, education, prevention, protection, treatment and palliative care. The WHO formally defines UHC as "…ensuring that all people have access to needed promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services" [3].

Modern information and communication technologies (ICT) hold great promise to improve access and quality of health care delivery – known variably as eHealth, mobile Health, telehealth and collectively grouped under "digital health". This article, transpired from an international collaboration between clinicians, academics, and health system and technology leaders gathered at the Global Telemedicine 2015 conference in Toronto, Canada, and proposes an evidence-informed "resilient health system framework" as a guide for policy makers to scale-up digital health in their national, regional, and global efforts to support UHC. The objective was to consider the literature to date and discuss the role of digital health as a facilitator to achieve UHC, with a particular focus on low- and middle-income countries (LMIC).

1. Sustainable Development Goals and Universal Health Coverage

The lack of access to quality care globally makes achieving UHC a tremendous challenge. Achieving equitable health for all depends on our ability to identify effective ways to improve health care access and quality, share health practices to improve global tracking of population health and manage the spread of diseases [4]. Aligning with the recently developed Sustainable Development Goals (SDG) that calls for all countries and states to ensure healthy lives and well-being for all at all ages, SDG goal #3 – "Ensure healthy lives and promote well-being for all at all ages" – directly addresses the principles of UHC.

2. Digital Health to Achieve Universal Health Coverage

Digital health – using ICT such as telephone, computers and mobile digital devices for health – represents the integration of health and information technology to create strategic value to improve access, quality and cost effectiveness for nations and their citizens, and is recognized as essential to the global attainment of UHC. In addition to supporting the values and practical delivery of UHC, digital health facilitates collaboration amongst health professionals towards patient-centred care, partnership between patients and health professionals and public engagement. As digital health continues to evolve through modern technologies and infrastructure, it strives towards attaining SDG #9 – "Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation".

However, the integration of digital health in LMIC countries, regions and communities is uneven and dependent on the local needs, context, and people. While there are successful examples of digital health initiatives to support remote communities to access healthcare, scaling-up these initiatives are challenging. Using a "resilient health system framework" will facilitate the progressive and judicious

implementation of population-based digital health tools in support of health system priorities through evidence-informed and policy-supported strategies.

3. The Resilient Health System Framework in Digital Health

The components of "the resilient health system framework" (Figure 1) to scale-up digital health are based on the literature and group members' own experiences and exposure to successful digital health deployment models.

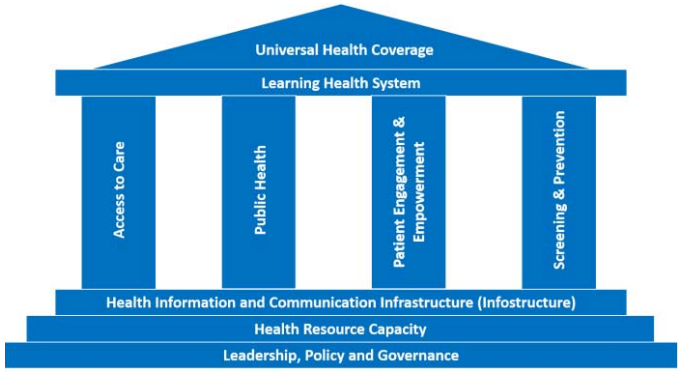

Figure 1. Framework structure

3.1. The Foundation

This framework is built on three interlocked platforms which together support the entire health care system: 1) leadership, policy and governance, 2) health resource capacity, and 3) information and communications infrastructure (infostructure).

3.1.1. Leadership, Policy and Governance

Accountable leadership, powerful policy, and effective governance are critical to achieving health equity [5]. Health governance steers the participation, performance, accountability and equity of stakeholders towards a common vision for UHC through:

- Defining the foundational components of a national digital health infrastructure, and engaging accountable and responsible stakeholders to co-create this united vision;
- Facilitating consistent access to health services from urban to rural areas, leveraging digital health tools where required;
- Improving quality of care across the healthcare continuum with improved decision support and access to health data and contextually related information for patients and care providers;
- Achieving gains in productivity and sustainability through equitable distribution of existing resources to extend the reach and capacity across communities, nations and regions with the support of ICT; and,
- Monitoring critical information to assess and continually improve health program effectiveness.

3.1.2. Health Resource Capacity

The success of digital health is contingent on establishing the necessary capacity and resources to build, use, and support access to high quality health services, and harvest useful information in the health system. The resource capacity requirements stretch beyond health professionals and technology specialists across the continuum of care to include business analysts and project managers - from health information managers to information security professionals and health network managers. There is a notable disparity in the availability, distribution, capacity and performance across the health system workforce. Countries will need to identify the range of skills, competencies and roles required at the regional, national and local levels to support a digital health ICT structure [6]. A strategic approach to build capacity should also take into consideration building human and institutional capacity, nurturing clinical and community champions, and developing the base of knowledgeable users to drive appropriate adoption of digital health in settings where care occurs.

Many countries have been taking steps in capacity building in digital health. Inter-professional residency programs and other health science communities and special interest groups leverage desktop and traditional videoconference technologies to enable learning and collaboration from all parts of the world. Conventional and online courses are offered in both European countries and North America [7] as well as in developing nations. The following is a short listing of some of these examples. Harmonization and sharing of these and other educational initiatives, and the establishment of a global directory of training facilities in Digital Health world-wide, would be worthwhile.

- The Telemedicine & Biomedical Informatics at Lucknow (India) run full time one-year diploma courses in five disciplines - Telemedicine, Hospital Information System, Nursing Informatics, Public Health Informatics and Digital Medical Library [8].
- The National Research and Education Networks (NREN) worldwide expand health resource capacities through programs such as the Academic Telehealth Community Collaborations, which bring together health scientists from a range of sub-specialties, including Science, Technology, Innovation, Education, Research, Communication, Assistance and Health Federal Authorities to discuss, finance and work together. Similar approaches are being implemented in Brazil [9] and India [10].
- The Brazilian Telemedicine University Network (RUTE) runs a three-month Capacity Program for Preceptors in inter-professional residency serving 50 institutions and 600 preceptors nationwide weekly by videoconference, yielding $3.5 million USD by averting unnecessary travel.
- The Asian eHealth Information Network [11] promotes best practice and knowledge exchange among Health Informatics Professionals through 'AeHIN Hour' webinars. AeHIN has focused on building capacity for countries to govern and manage their national eHealth programs.
- The Telemedicine Development Centre of Asia (Temdec) [12] shares leading edge medical information across Asia and Latin America, integrating the Asia Pacific Academic Network (APAN) and the Latin American Cooperation of Advanced Networks (RedClara Cooperación Latino Americana de Redes Avanzadas).
- The Government of Ethiopia launched WoredaNet in 2011 to connect 600 national agencies through [13] a national wide area network for the exchange

of video conferencing and other electronic information that can be routed locally within country. The policy, which connects a number of public hospitals and public universities, in each of the districts (woredas) across the country. One of the primary purposes of the network is to support video conferencing between government employees from the district up to the state level. One of the current uses of the network is for video conferencing to teach basic science courses for undergraduate medical education at three Ethiopian medical schools via a fourth medical school located in Addis Ababa.

The African Virtual University is an example of a multi-national collaborative. Sponsored by the African Development Bank, this innovative education institution services 57 eLearning centres in 27 African countries to provide academic programs and short courses as well as digital library resources to African students and academics. In 2014, AMREF Health Africa trained of 227 diploma-level health students including 95 nurses through eLearning across Ethiopia, Ghana, Kenya, Malawi, Nigeria, Tanzania, Uganda and Zambia [14].

3.1.3. Health Information and Communication Infrastructure (Infostructure)

The infostructure is an important instrument of policy as it operationalizes and rationalizes the design and focus of digital health investments that enable the country to achieve its health system goals and objectives, including UHC [15]. It consists of not only physical technology infrastructure, but also knowledge and insights that inform the functional design of the architecture underlying technology infrastructure. The infostructure supports health organizations and other health care partners in planning and delivering effective UHC through wise health decision-making at all levels. It encompasses the processes to manage the flow, integrity and security of health information as a strategic health system resource, and defines the architecture and standards required to enable information to be shared and technology to interoperate.

The infostructure should also connect and engage patients, families and communities by making possible the collection of and access to population-level data for health surveillance systems. In addition, the structures and terminologies are needed to enable consistent, contextualised and interoperable eLearning services and applications across settings and devices. For example, the Pan American Health Organization (PAHO) eHealth Strategy specifically addresses the need for, and quest to obtain, the standards required to ensure interoperability across organisations and countries within the region as a core requirement to build the knowledge economy and to provide the competencies needed to achieve UHC. The infostructure should also support scalability, making it possible to provide most appropriate and effective health interventions targeted to meet the needs of underserved populations as part of universal access of care. Properly architected and supported infostructure is not only more cost effective than solutions in silos, but is much more capable in leveraging new technologies in supporting emerging health care system priorities and managing costs.

3.2. The Pillars

The pillars represent dependable health service delivery arms, which both generate and consume digital health information to meet the health needs of the population, and support the resilient health system framework in achieving UHC. These pillars include:

3.2.1. Access to Care

Digital health provides new avenues to improve access to care and enhance continuity of care. These approaches transcend geography to optimize health service delivery by improving both the quality and cost effectiveness of health care. Improving access to care includes extending its reach to all populations, accessing new information about patients and their care needs, providing additional options for health services, and enabling access to vaccines, medicines, education and training. ICT interoperability is necessary to connect disparate collections of digital data, enhance collaboration towards mutually shared health goals and priorities across stakeholders, facilitate access to services, and rapidly respond to health needs of constituencies. Interoperability also enables the collation of data from many dimensions of the health environment which allows for better decision-making and can serve as a catalyst for public-awareness and buy-in. The growing ubiquity of cellular networks when combined with applications in health opens avenues for access to care that heretofore were closed.

3.2.2. Public Health

Public health refers to all organized measures by public or private organizations to prevent disease, promote health, and prolong life among the population as a whole. As such, public health examines the total system of care and is not concerned only with the eradication of one particular disease [16]. Tracking and measuring national progress towards UHC is critical to identify, implement and realize the success of priority actions to improve population health and well-being. Digital health makes it possible to track population-based service delivery and outcome data against the Global Reference list of 100 standardized Core Health Indicators [17] prioritized by the global community to provide concise information on the health situation and trends. This effort can help identify service gaps, alleviate inequities in access of care, and illuminate resource wastage to ensure timely service, equitable social protection, and optimal health system productivity. Examples of digital health contribution to public health may include: epidemiologic surveillance of infectious diseases, specific work flows and processes, disease-focused patient registries and decision support to fight particularly prevalent or costly diseases.

3.2.3. Patient Engagement and Empowerment

Patient engagement can be defined as "actions individuals must take to obtain the greatest benefit from the health care services available to them" [18]. Digital health creates opportunities for patients to improve their own health by becoming more aware of and involved in self-care and decision-making in treatment approaches. Ideal patient engagement requires:

- Patient involvement at all levels of care, including shared leadership and decision-making;
- Communication and collaboration based on mutual respect and honest conversations leading to informed and involved care choices; and
- Valuing the experiential knowledge of patients and families and caregivers.

The key to success to patient engagement is the establishment and nurturing of a strong partnership between patients, caregivers, formal and informal care providers, health practitioners, professionals, policy makers and other health stakeholders. However, factors such as complex advice, lack of resources, poor communication and interaction, and paternalistic medicine can disengage the patient, thus limiting the achievement of effective patient engagement. Health professionals are encouraged to help patients in understanding their medical conditions. Nevertheless, the idea that doctors or health professionals know best might diminish patient's opinion about their own health, thereby leaving patients disengaged.

3.2.4. Screening and Prevention

Digital health holds significant promise for disease screening and prevention in LMIC. Benefits of digital health to support disease screening and prevention include timely access to health and patient information, early and rapid case detection, disease surveillance and population health [19]. Low-bandwidth and cost-efficient internet and mobile health solutions can assist to extend geographic access to clinical support for patients and health workers, while social media and global positioning systems (GPS) in digital communications devices can support disaster communications and crisis management [20]. Digital tools enable disease outbreaks monitoring and real-time surveillance of emerging public health threats. Technology-enabled immunization programs can support appropriate and consistent administration of vaccines, while digital systems can also assist public health providers to track the distribution and availability of vaccines in across regions. Access to electronic health records provides patient-centric information to support clinical decision making while providing data to inform both policy and health service planning. Internet connected devices can assist patients in low-income, remote environments, to send digital samples to on-line systems for immediate diagnosis and care planning [21]. Digital monitoring tools can support real-time oversight of maternal labour by obstetric care attendants, reducing the risk of complications and mortality during pregnancy and childbirth, simultaneously encouraging the development of a skilled maternal-fetal workforce in developing countries.

3.3. The Ceiling

3.3.1. The Learning Health System

The "Learning Health System (LHS)" [22] constitutes a powerful and overarching canopy to support all aspects of UHC implementation and continuous improvement in health service delivery. The LHS paradigm denotes a health system where new insights and knowledge are continuously generated using information and evidence accumulating within the system itself. Its core driver is to strive towards delivering better, more efficient medical practices as a continuous journey of longitudinal patient care.

The foundation of a sound learning at the health system level depends on health workers on accurately recording and synthesizing patient data to guide decision support. Through continuous monitoring and effective data visualization, a sound evaluation of processes and actions can be effectively captured to support the continuous learning cycle. With the availability of trusted information to understand population characteristics, morbidity and mortality burdens, geographic variation, and strategic

resource allocation and tracking, digital health supports accountability, transparency, and ultimately the values of UHC through the dynamic process of continuous quality improvement.

Learning at the individual level must include continuous and evolving educational and training opportunities to enable ongoing absorption and implementation of quality improvement opportunities by actors themselves in the health system. The organizational culture and leadership of the LHS needs to build system-wide awareness and buy-in for on-going learning and improvement amongst all stakeholders. Technology enabled learning can support the education and experiential training of students, patients, and health sciences professionals. An effective health system infostructure should incorporate real time and asynchronous educational tools accessible via the internet to deliver cost-effective delivery of educational content, practical learning, and hands-on experiences. Examples include but not limited to telehealth-enabled simulation using trained actors as patients to provide feedback to learners, electronic medical record simulation exercises, personal health applications which support patient engagement and learning, and online educational opportunities which are able to reach vulnerable communities.

3.4. The Roof: Universal Health Coverage

All parts of this framework – from the foundation to the pillars and the ceiling - work synergistically towards supporting the roof structure. Optimizing existing ICT infrastructure and making strategic new investments in digital health solutions contribute to the acceleration of achieving UHC. The health system captures the evidence and works towards UHC through iterations in optimizing access, quality and productivity of care delivery universally. The resulting solutions will lead to innovative models from LMIC countries to high-income countries (HIC) and vice versa. Measuring UHC with ICT-enabled monitoring systems can also enhance evidence -based health policies and decision making with more reliable and sufficient data in formats and frequencies that ensure better health systems performance and prioritization of efforts [23].

Conclusion

While digital health is rapidly evolving globally, a thoughtful and cohesive strategy to guide local and global development will be essential to achieve UHC. The SDGs and their synergy towards supporting UHC in achieving health for all is a clarion call for multi-modal efforts to work towards this goal. Achieving UHC requires that we harness the data that spawns from our efforts to bring improvements in human development that are globally achievable, measureable, shareable, and replicable.

We call on nations to align digital health policy with governance that optimizes its ability to support UHC. Now more than ever, robust and resilient health systems will increasingly rely on digital health, and our neighborhoods and nations depend on interoperable and exchangeable data. We believe that this resilient health system framework, supported by digital health and information exchange, will support us on our journey towards attaining Universal Health Coverage.

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The Promise of New Technologies in an Age of New Health Challenges
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Family and Practitioner Perspectives on Telehealth for Services to Young Children with Autism

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Abstract. Telehealth offers the potential to address inequalities in autism service access for young children living in regional and rural areas with limited access to autism specialists. Our aim was to explore parent and practitioner uses of technology, and views about telehealth, including perceived barriers, for autism early intervention service delivery in a regional town in Australia. Fifteen mothers and 19 front-line autism practitioners completed surveys distributed by local autism service and support providers in the regional town; eight front-line practitioners from one service participated in interviews. Mothers and practitioners had access to technology that could be used for video-communication, but had little or no experience with telehealth. Mothers appeared more willing to try telehealth for receiving autism services than practitioners appeared to believe, and practitioners preferred to use it for consulting with other professionals and professional development. Barriers to telehealth included limited experience and practitioners not knowing what a telehealth service would look like, poor access to reliable and high speed internet, lack of skill and technical supports, and practitioners believing families preferred face-to-face services. The success of telehealth in this regional town will rely on better infrastructure, and upskilling practitioners in evidence-based autism interventions so they can provide the required support remotely. Use of telehealth to upskill practitioners in evidence-based practice could provide a first step in ensuring equitable access to expert autism services to regional and rural families.

Keywords. Telehealth, autism, early intervention, rural service delivery, evidence-based practice

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Introduction

Early intervention for children with autism is essential for ameliorating pervasive social-communication and behavioural impairments [1]. Yet, globally, few children access early interventions, particularly those based on current best evidence [2]. At particular risk are children living in low-income countries [2] and/or rural areas [3, 4] because of limited access to autism expertise. Telehealth could provide a solution. A recent projection that 6 billion smartphone users will be from developing nations by year 2020 [5] together with an initiative by Google to increase internet access for all [6] means that telehealth could be a key resource across communities. The feasibility of using telehealth to deliver autism services has been demonstrated in a number of studies [7-10], including those in which remotely located specialists have coached parents in evidence-based strategies while in their homes [4, 9].

Barriers to telehealth service delivery

Despite the promise, current access to the required technologies and associated costs can impede the widespread use of telehealth, particularly in rural communities [11, 12]. In previous telehealth evaluations for children with autism, families needed good internet access [7-9]. Such access may remain problematic for disadvantaged communities, despite overall increases globally. In particular, people in rural areas, even within middle-to-high income countries, continue to be disadvantaged by lack of mobile coverage, resulting in greater costs for smaller data packages in comparison with people in metropolitan locations [13].

A further barrier to the use of telehealth appears to be reluctance on the part of practitioners [11, 12, 14]. This reluctance has been found to stem from limited experience with telehealth, concerns about disrupting the dynamic of interactions, and relationships with children and their parents, and a belief that parents would reject it as a form of service delivery [11, 12, 14]. Recent research has started to debunk these beliefs [15].

Aims

Access to services and technology, and concerns and considerations of service providers and families of children with autism are features of the real-life context for translating research findings about autism evidence-based interventions, and the potential role of telehealth in supporting their implementation. We aimed to explore readiness for telehealth in terms of parent and practitioner uses of technology, and views about telehealth, including perceived barriers, for autism diagnostic and early intervention service delivery in a regional town in Australia. The results presented here were part of a larger study that focused on understanding the community context of this regional town for a planned program to embed evidence-based early autism intervention [16]. In particular, we aimed to explore the potential role of telehealth in this program.

1. Methods

1.1 Design and Ethics Approval

Data were obtained from practitioner and family surveys, and interviews of practitioners. Approvals were obtained from three Human Research Ethics Committees (References FHEC 14-063, FHEC 14-237; LNR/14/BHCG/58; Scope #89/15).

1.2 Study Setting

As documented in our related study [16], 14 services from five organisations served families with autism from a population of 185,000 across a geographic area of 7,486 km^2. This area was characterised as having a high level of disadvantage [17]. As has been found in a large Australian study [18], children with autism in this town tended to be diagnosed late. Families travelled up to 2.5 hours to access autism services (on average 50 minutes each way) [16], which were limited to one hour a fortnight on average, dramatically short of the 15-20 hours recommended to achieve optimal outcomes [19].

Regarding access to the internet, a National Broadband Network (NBN) is being rolled out across Australia, but the timeline for completion and strategies for connecting individual homes and businesses have been debated for some time [20]. The timing for the roll out for this town remains unknown, resulting in reliance on mobile wireless technology, satellite broadband, and for some, telephone dial-up through copper wires [21].

1.3 Participant Recruitment

Autism service providers and a support group in the town distributed surveys to their front-line practitioners and families. Interview participants were practitioners recruited from one intervention service. This service was chosen for interviews because the installation of a new videoconference unit in their workplace provided a timely opportunity to further explore the study aims.

1.4 Surveys

Parents and professionals completed separate surveys (available online and in hard copy). The family survey comprised 35 questions regarding demographic information, access to services (previously reported [16]), use of and attitudes towards technology and telehealth, and information about internet access (reported here). The professional survey comprised 29 questions regarding demographic information, assessment and intervention practices, and professional development needs (previously reported [16]), and use of and attitudes towards technology and telehealth.

1.5 Interviews

Structured interviews were conducted face-to-face or over the phone and lasted approximately 30 minutes. The questions focused on the study aims (see Appendix). Interviews were audio-recorded and transcribed verbatim.

1.6 Analysis

Survey data were analysed and reported descriptively. Interview data were analysed by coding according to broad explicit themes of relevance to our aims [22]: that is, use of technology, views about telehealth for delivering services, and perceived barriers.

2. Results

2.1 Participant Description

Survey participants were 15 mothers of children with autism (aged up to 6 years) and 19 front-line practitioners. Most mothers were full-time carers (*n*=9, 64%), and 20% (*n*=3) were single parents. Practitioners were mostly speech-language pathologists (*n*=5, 26%) and occupational therapists (*n*=4, 21%); others were psychologists, social workers, early childhood teachers and a mental health nurse. They had practiced from 1 to 34 years (mean=10 years, 10 months, sd = 9;11).

Eight early intervention practitioners participated in interviews. Three were early childhood advisors, two were occupational therapists, and three were speech-language pathologists. They had worked in early intervention for 1-25 years (mean=13 years).

2.2. Access to and use of technology

2.2.1 Surveys

All 15 mothers reported having access to a device that could be used for video-communication: mobile phones (*n*=7, 46.7%), tablet devices (*n*=10, 66.7%), laptops (*n*=5, 33.3%) or desktop computers (*n*=2, 13.3%). Some respondents had never used video calls (*n*=6, 40%); those who had, rated the quality of the connection as poor (median score of 2.5 on a scale of 1, very poor to 5, very good). Most had some form of broadband internet connection (*n*=12, 80%) (not NBN); one mother had data on her mobile phone only, and another used a pre-paid mobile with wireless capability. Only three (20%) were on plans providing unlimited data, with the others having 2-200 gigabytes (average = 100.8). Most were on monthly plans, which ranged in cost from AUD$40 to $120 (average = $89).

Most practitioners reported some experience with video-conferencing (*n*=11, 57.9%) using freely available programs, such as Skype® *n*= (5, 26%) and FaceTime® (*n*=3, 15.8%), as well as dedicated videoconference units (*n*=4, 21%). Telehealth was used by few practitioners for assessments (*n*=1, 5.3%) or client reviews (*n*=2, 10.9%), but more used it for intervention (*n*=2, 15.7%) and consultations with other professionals (*n*=4, 21%). None of the practitioners used freely available videoconference programs for assessment or intervention services, but rather for consultations with other professionals and follow-up with families.

2.2.2 Interviews

Technology usage for work purposes for these practitioners included (a) emails to families to set up appointments and send information; (b) digital cameras, picture-making computer software, and Google® images to create materials for therapy and

reports; and (c) iPads® with apps for therapy tasks, child reinforcement, and to video-record clinic sessions. Consistent with the survey data, some practitioners used videoconference software, Skype® and FaceTime® for conversations with friends and family members, but none used these for communication with client families. Most had smartphones, but tended to use them for personal use in limited ways, such as to take photos or videos.

2.3 Views regarding telehealth

2.3.1 Surveys

Aggregate responses for each service type and whether mothers anticipated problems if they were delivered by telehealth are provided in Table 1. Most mothers were either undecided or willing to consider telehealth for their child's assessment (*n*=12, 80%) or intervention (*n*=10, 67%), and were unsure about potential problems. Most (*n*=9, 60%) thought the reduced need for travel would be an advantage, as well as minimising children's anxiety by being able to stay in a familiar environment (*n*=4, 26.7%) and not having to interact with new people (*n*=5, 35.5%) in a face-to-face session.

Table 2 provides aggregate data from practitioner surveys. Respondents fell along a continuum in terms of seeing the benefits of telehealth, with most agreement clustering around potential benefits to families in relation to travel. Responses about possible benefits aligned with those to a question about barriers they thought families face in accessing services, with nine (47.3% of all practitioners)[2] indicating distance and travel time, with associated costs and disruptions for family. Still, even on the issue of disruptions to families, almost a third of respondents were undecided.

Practitioners tended to rate the quality of videoconference experiences as 3 (1-5 scale). Only one (5.3%) would use it for assessment, four (21%) for regular intervention, nine (47.4%) for reviews, 12 (63.2%) for follow-up support to families, nine (47.4%) for consultation with other professionals with the child and family present at the remote location, and 16 (82.4%) for such consultations without them being present. Most practitioners believed their employing organisation would (*n*=9, 47.4%) or might (*n*=7, 43.8%) be willing to use telehealth for autism services and provide the technology required, but many (*n*=10, 52.6%) were unsure if they would also provide training in using it. Many practitioners (*n*=10, 52.6%) did not think telehealth would reduce their workload; three (15.7%) believed it would increase it and six (31.6%) were unsure if it would increase it.

2.3.2 Interviews

Practitioners who were interviewed valued technology, reporting it had made a difference to how they worked. When asked to consider its possible use in supporting clients at a distance, one practitioner indicated that although she saw benefits, it was not going to change how she or others worked, stating it would not replace the value of "connecting with families, getting on the floor." Further, they were unclear how telehealth could work for them or families. One practitioner suggested telehealth would develop in her practice, and had much potential, but she did not know what that service

[2] For items in which there was missing data, percentages are reported according to all 19 practitioners.

would look like. It was noted that not having to come into a centre would have advantages for families who had children who could not tolerate even short drives, and competing demands.

Rather than for use with clients, these practitioners indicated that the videoconference equipment would help them access professional development activities without needing to travel. One participant stated "What interested me was the training, for us to go to [name of city] is massive, it's expensive and time consuming and exhausting."

Table 1. Summary of family survey responses (n = 15) regarding use of telehealth for receiving autism services

	Response		
Item	**No**	**Maybe**	**Yes**
Would you be willing to use telehealth for assessment?	3 (20%)	7 (46.7%)	5 (33.3%)
Would you be willing to use telehealth for intervention?	5 (33.3%)	5 (33.3%)	5 (33.3%)
Do you think there could be problems in using telehealth for either assessment or intervention?	3 (21.4%)	8 (57.1%)	3 (21.4%)

Table 2. Practitioner views about telehealth for autism service delivery.

Statement	**Rating** **5 Strongly Agree**	**4**	**3**	**2**	**1 Strongly Disagree**
Telehealth provides an effective and efficient means to conduct an autism/ASD diagnostic assessment*	0	1 (6.7%)	7 (46.7%)	3 (20%)	4 (26.7%)
Telehealth provides an effective and efficient means to deliver intervention service*	0	3 (20%)	9 (60%)	2 (13.3%)	1 (6.7%)
Telehealth can provide useful addition to face-to-face diagnostic assessment	3 (18.8%)	6 (37.5%)	3 (18.8%)	3 (18.8%)	1 (6.3%)
Telehealth is disruptive to the clinician – client relationship or rapport	1 (6.3%)	6 (31.6%)	4 (25%)	4 (25%)	1 (6.3%)
Telehealth can provide a useful addition to face-to-face intervention	1 (6.3%)	8 (50%)	5 (31.3%)	1 (6.3%)	1 (6.3%)
Telehealth is suitable for the conduct of diagnostic assessments only if there is a local clinician with the child/family^	2 (14.3%)	6 (42.9%)	4 (28.6%)	1 (7.1%)	1 (7.1%)
Telehealth provides a lower quality service for families than does face-to-face	2 (12.5%)	5 (31.3%)	5 (31.3%)	3 (18.8%)	1 (6.3%)

Statement	Rating 5 Strongly Agree	4	3	2	1 Strongly Disagree
Telehealth is suitable for the provision of regular intervention only if there is a local clinician with the child/family*	3 (20%)	5 (33.3%)	7 (46.7%)	0	0
Telehealth saves the child/family from having to travel	6 (31.5%)	8 (42.1%)	1 (5.2%)	1 (5.2%)	0
Telehealth allows the child to stay in their familiar environment	6 (31.5%)	8 (42.1%)	2 (10.5%)	0	0
Telehealth provides less disruption to other family members	5 (26.3%)	6 31.5%)	5 (26.3%)	0	0
Telehealth provides less disruption to scheduled family activities	4 (21%)	7 (36.8%)	5 (26.3%)	0	0

n=16, **n*=15, ^*n*=14; percentages calculated for 19 participants.

2.4 Perceived barriers

2.4.1 Surveys

Some mothers provided reasons for responses about their willingness to receive telehealth services (Table 1), including concerns about internet access or quality and the need for practitioners to directly interact with their children. Practitioners reported concerns about (a) access to the required technology for themselves and families, skill in using it, and reliability (including of the internet); and (b) the appropriateness of telehealth when working with children with autism, with many indicating it would interfere with building rapport and sustaining the relationship with the child, or it would not be useful for demonstrating clinical strategies. One respondent queried whether telehealth could be rebated under Medicare (the national health scheme), and another noted logistical issues in finding a common convenient time for a remote and local practitioner, and family.

2.4.2 Interviews

Barriers to using technology for service delivery included limited access to equipment and participants' own skill and confidence in using it. Many described problems with poor quality and unreliable connectivity, resulting in frustration and a reluctance to use videoconferencing with families. There was concern that children would act differently if they knew they were being observed remotely, or that a camera would not be able to follow them as they moved around.

Major perceived barriers for families related to their access to resources, including the internet, their skill in using technology, and whether they would see telehealth as equivalent to a face-to-face service or would value it. One practitioner described the differences in the situation of two families on her caseload, who lived a distance from the centre:

> …I have a couple of clients in [name of town] who I think would be great to use [telehealth with], one in particular, they are quite IT-savvy. The other, it wouldn't work, because they are quite poor really, they've often

> not got credit … often they can't even afford petrol to get to [town where centre is located].

Other access issues included many wireless dead spots and slow internet speeds in the area, which would disrupt the signal, and in turn, sessions. It was suggested that families in small communities who had to travel to receive services and were most likely to benefit from telehealth were least likely to have reliable internet because of its lack of availability and cost. One practitioner wondered how much internet data would be required, which was relevant to many people on limited internet usage plans.

Practitioners also reported problems with engaging families in early intervention, broadly, noting further difficulties in encouraging their participation in telehealth. Some families were described as very private, declining home visits. These families, one practitioner suggested, would be unlikely to accept telehealth into their homes. One wondered about some families' ability to think about telehealth in light of the complex challenges they faced, including for some, having more than one child with a disability.

Practitioners also wondered about the support they would receive to use the equipment, given their organisation had only limited technology support staff. Logistical issues were identified in terms of accessing the equipment and having back up support if there were problems. One practitioner was concerned about a family not having skill or support at home, and her own ability to provide the technical support that would be required to assist or to troubleshoot problems.

3. Discussion

The potential for telehealth to provide a means to connect families in this regional town to autism specialists [4, 9] was tempered by a number of factors. These factors related primarily to (a) practitioner experience with, and understanding of how, telehealth could be incorporated into services, (b) practitioner and family access to reliable technology and confidence in using it, and (c) parent and practitioner preferences and views regarding service delivery.

For both practitioners and families, there was little experience in using telehealth, although many had used video-call programs for personal communication. Our findings reflect those found previously, including that practitioners used technology largely for managing work tasks [11, 12] and saw telehealth as a poor alternative to face-to-face interaction [14, 15]. Rather, they saw telehealth as more useful for consulting with other professionals, even though a videoconference may not provide benefits beyond those of a telephone meeting.

As found by Dunkley et al. [12], also in a rural Australian context, families were more open to telehealth than practitioners. Most mothers were, or might be, willing to consider telehealth to receive autism services, with few being certain it would entail problems. Of most concern was the quality of the internet connection, a reality for many residents in this regional town and surrounding areas. Discrepancies in internet access across Australia may be addressed with the roll out of the NBN, but interim solutions, such as government subsidised access to satellite broadband has resulted in high demand, which along with latency problems, has led to poor performance [21]. Further, residents relying on mobile connectivity, as was the case for some families, have had to deal with WiFi deadspots [21], further compromising the potential to rely on telehealth.

Both the survey and interview data indicated that practitioners were uncertain about the usefulness of telehealth in delivering regular services, even if connectivity issues were resolved. Lack of previous experience created uncertainty about how telehealth would work [14, 15]. Access to equipment was not a barrier given that many families had tablet devices, with both video and internet capabilities, but their use for real-time interactions with families were not considered by the practitioners. Concerns about maintaining child attention, rapport or simply being able to follow a child with a camera have not been borne out in research in which telehealth has been used effectively to engage children and parents [7-9].

Although telehealth for autism service delivery is an emerging research area, previous studies have shown that success relies not only on access to reliable equipment and willingness to use it, but also that the delivered interventions are based on strong evidence, and with skilled practitioners providing the remote coaching and support [7-9]. In our previous study, we did not find evidence of skill in evidence-based interventions amongst practitioners, nor opportunities to develop them [16]. In this context, then, rather than using it for training parents, telehealth may be more useful in upskilling practitioners, which has been found feasible and effective in extending delivery of evidence-based interventions to community settings [23]. Extending coaching to parents using telehealth may be the logical next step. However, access to equipment and reliable internet connectivity may be an ongoing barrier, at least until the NBN reaches all parts of Australia [21], thereby contributing to the disadvantage that characterised this regional and rural area [16]. Certainly, families relying on limited usage plans and slow internet will not be able to take advantage of telehealth. These are likely to be the very families who are most reliant on service delivery models other than those available in light of the distance to services and transport costs incurred, or having to rely on infrequent home visits by service providers [16].

3.1 Limitations and Research Directions

The main limitation in the study was that there were few survey respondents, especially families, precluding the generalisability of findings. Interview data did provide greater insight into practitioner perspectives reflected in survey responses, and including families in interviews similarly would have contributed to understanding their attitudes and ability to make use of telehealth. Nonetheless, the combined data converged to provide a picture of limited potential to implement telehealth, albeit with some willingness to do so, and reflect previous findings [11, 12, 14, 15]. Extending the current study across rural and regional Australia would provide more robust and generalisable results. On the other hand, there may be greater value in providing both families and service providers with positive experiences of telehealth [15], and then determining their willingness to use it for delivering services to children with autism. Telehealth does hold potential to increase the availability of evidence-based intensive interventions for young children with autism [4], but there has been a lack of research into using telehealth for diagnosis [4]. Research with other client groups [24] has indicated that assessments conducted remotely can yield reliable and valid results, but accuracy in autism diagnosis is an area ripe for future research with the need to facilitate earlier diagnosis.

Conclusions

The promise of telehealth to redress problems with accessing autism services for young children is unlikely to be realised unless infrastructure, training, and attitudinal issues are addressed. For families in rural and regional Australia, delays in the roll out of a national infrastructure to support efficient and low cost internet access is contributing to their experiences of disadvantage. Children with autism have a small window of time in which to optimise their potential to overcome developmental delays. Those living large distances from specialist autism services rely on upskilling both local practitioners and parents, and telehealth could provide a means to do this effectively if barriers can be overcome.

Appendix

Practitioner Interview Questions

1. Can you tell me about your role and work with young children with autism and their families?
2. How do you utilise information and communications technology in your general work life at present?
3. Have you ever, or do you currently use any form of technology for the delivery of services to families?
4. If not, have you ever thought about using technology in supporting families? How?
5. How do you utilise technology in other aspects of your life at present?
6. If you were to use technology in your role to deliver services to families, what might be some of the barriers that would first need to be overcome?
7. What might be some of the enablers that might help to facilitate use of technology, in your role, to deliver services to families?

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Assessment of Computer-Assisted Screening Technology for Diabetic Retinopathy Screening in India – Preliminary Results and Recommendations from a Pilot Study

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Abstract. *Background* Diabetic retinopathy (DR) is regarded as a major cause of preventable blindness, which can be detected and treated if the cases are identified by screening. Screening for DR is therefore being practiced in developed countries, and tele screening has been a prominent model of delivery of eye care for screening DR. *Aim* Our study has been designed to provide inputs on the suitability of a computer-assisted DR screening solution, for use in a larger prospective study. *Methods* Computer-assisted screening technology for grading diabetic retinopathy from fundus images by a set of machine learning algorithms. *Results* The preliminary recommendations from a pilot study of a system built using the public datasets and retrospective images, showed a good sensitivity and specificity. *Conclusion* The machine learning algorithms has to be validated on a larger dataset of a population level study.

Keywords. Screening, computer-assisted, algorithms, diabetic retinopathy

Introduction

More than 50 million people in India are at risk of developing sight threatening eye diseases. Blindness due to chronic eye disease such as diabetic retinopathy (DR), can be averted if detected early through regular eye check-up. Early identification by screening is the key step in addressing treatable blindness, in the face of India's dual challenge of huge population and limited availability of experts.

The gold standard in DR screening is digital photography of the retina, and image-based tele screening methods such as ophthalmologist-based and ophthalmologist-led [1] have been used for epidemiological studies to find the prevalence of DR in India. Such studies have identified around 5-6% of diabetic population needing sight-threatening, treatable DR. An ophthalmologist-led telescreening has been considered as a suitable and cost-effective model for India.

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The advancement expected in telescreening includes introduction of improved equipment, better communication infrastructure, and introduction of computer-assisted screening technology. The images acquired during different screening models can be digitally processed and analysed using image computing – and there has been good amount of research to create computer-assisted screening technology in developed nations [2][3][4]. Introduction of computer-assisted image analysis for screening can enable wider deployment and empower minimally skilled technicians to participate in the care delivery process, thereby auguring greater penetration with existing telescreening setups, and outreach at a national scale.

This study reports an assessment of computer-assisted technology by building a DR screening software based on methods selected from the known art, and provides analyses from a pilot study of the system in a retrospective assessment conducted to assess the applicability and value of such technology for introduction in a larger prospective study, and steps towards incorporating such technology in routine telescreening in India.

1. Research on computer assisted DR screening

The technology for screening and grading diabetic retinopathy from fundus images is driven by a set of machine learning algorithms. These algorithms detect normal anatomical structures and clinical pathological signs in the given retinal image. The typical sequences of operations within an algorithm are pre-processing, image segmentation, feature extraction and pattern classification. Pre-processing is used to normalize image brightness, perform correction for non-uniformity in the image, reduce noise, and reduce image artifacts. Segmentation identifies candidate objects of interest (lesions, anatomical structure and others). Feature extraction computes quantitative information such as size, appearance, color, texture from the segmented candidates.

A categorized review of techniques used in digital color fundus image processing in Diabetic Retinopathy is presented in [5] under 5 categories: 1) Image enhancement, 2) Localization and segmentation of optic disc, 3) segmentation of retinal vasculature, 4) localization of fovea and macula, 5) Localization and segmentation of retinopathy.

Diabetic retinopathy referral decision is produced by two broad approaches. The first is a rule-based system, where in the number and location of detected lesions is used, and a set of rules are applied to provide the decision/grade of the image. E.g. the minimum requirement for performing grading according to American Academy of Ophthalmology ICDR scheme requires the count of micro aneurysms, hemorrhages in different quadrants, and exudative lesions, with respect to fovea position. Though this approach is intuitive and simpler to implement, it is not grounded on sample statistics and relies on the accuracy of lesion detection algorithms. Further, this approach might not provide parameters for controlling the sensitivity and specificity of the decision.

The second approach uses machine learning algorithms that learn the referral decision based on several samples provided along with expert annotation. This approach is more popular, since several frameworks are available to train the system, and the system can be improved by increasing the training set.

1.1. Publicly available datasets for system development and evaluation

For the purpose of this study a computer-assisted DR screening system was built, adhering to the data-driven approach, comprising of modules for determining gradability, normal anatomy detection, pathological signs detection, and analysis for computing the screening decision. The block diagram of the system is shown below:

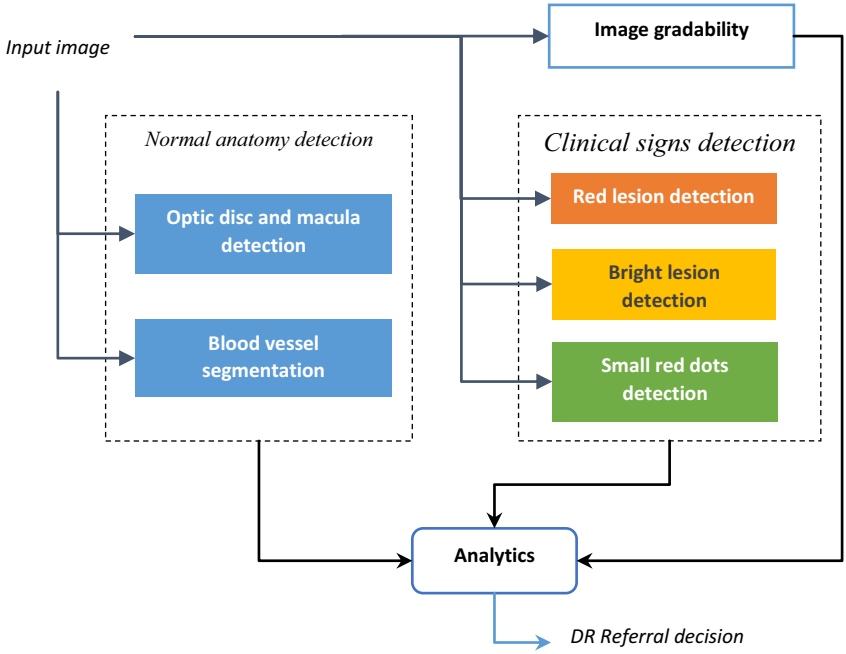

Figure 1. Block diagram of system for diabetic retinopathy screening from fundus images

The image gradability module determines parameters like image clarity, illumination uniformity, blur and provides a numeric score of gradability. Low gradability images would generally not succeed in further processing steps. Also blurred images and images with unclear media might indicate other conditions such as cataract and bleeding. Such cases might need referral. Hence the gradability score is vital during the DR decision analytics.

Normal anatomy detectors localize the 3 main anatomical structures: optic disc, blood vessels and fovea. These regions in the image are to be processed differently: e.g. optic disc should be disregarded by bright lesion detection algorithm. Blood vessels need to be suppressed for red lesion detection algorithm. The position of fovea, macula and temporal arcade structure are important for the DR decision analytics.

Three main categories of lesions have been handled in the system: small red dots (including micro aneurysms and dot hemorrhages), red lesions (blot hemorrhage, flame hemorrhage, pre-retinal hemorrhage), and bright lesions (small hard exudates, circinate exudates, cotton wool spots, ischemic zones). Each of the detectors finds lesions and assigns a confidence score for the detected lesion at every detected position. This provides a control parameter for selecting the sensitivity of each detector. Sensitivity

can be increased by selecting a low confidence threshold and specificity increases at higher confidence thresholds.

Given the output of the lesion detection modules and the anatomy detection modules the screening decision is learnt by training against several manually graded images.

In order to develop these modules and verify the functionality of the modules, publicly available retinal fundus image datasets have been used. Table 1 gives the names and details of the public image databases used for developing the corresponding modules. The two classes of information available in the public datasets are lesion-level manual annotations of various individual signs (such as DiaretDB) and image level readings which provide the screening and grading ground truth for each image (such as Messidor).

Table 1. Public datasets used for developing and verifying the modules of the system. The references are given in numbers and indicate the source of the data.

Module	Databases	Number of Images	Description of dataset
Image gradability	HRF[6]	36	Folder of good and bad quality images
Optic disc and macula detection	Stare[7]	81	Location of optic disc
	ReviewDB[8]	99	
Blood vessel segmentation	Drive[9]	40	Manual segmentation of blood vessels
	Stare[7]	20	
	Aria[10]	143	
Red lesion detection	DiaretDB[11]	89	Location of lesions
Bright lesion detection	Hei-Med[12]	169	Location of lesions, regions of exudates
	DiaretDDB[11]	89	
Small red dots detection	ROC[13]	100	Location of lesions
	DiaretDB[11]	89	
DR referral decision	Messidor[2]	1200	4 grades of DR severity

It is known that publicly available datasets have been acquired in clinical settings and therefore might not capture population level statistical distribution of DR prevalence. Therefore the study included a first pass observation of performance of the developed system on a selected set of images sampled from an epidemiological study followed by refinement of the algorithms to adapt to observations in Indian images, and a pilot study to evaluate the system on limited scale field data from Indian settings.

1.2. Objective of the study

The study has been designed to provide inputs on the suitability of a computer-assisted DR screening solution for use in a larger prospective study. Two specific outcomes from this study are:

- Identification of protocol to be used for prospective study
- Recommendations on capabilities needed in computer-assisted solutions for successful deployment in screening setups in India.

2. Study design

The first pass study of the designed system was done with retrospective images selected uniformly from an epidemiological study. The sample size selected was 100

cases where each case has images of one or both eyes captured in multiple fields. The subject details were anonymized and images were renumbered so that the file names indicate the field of view captured. The images selected were acquired using mydriasis, with 45 degree magnification and had been jpeg-compressed with quality factor ranging from 75% to 95%. Images with media opacity, severe pathology hindering imaging and low quality of capture were earmarked and included to observe the performance of the image gradability step in the system. The gold standard grading performed in the epidemiological study was taken as is, and it consists of consensus readings classifying each image into 5 levels of DR severity grades, and an image gradability flag. For the purpose of the study, an image was considered as referable if a consensus reading of 'moderate', 'severe' or 'proliferative DR' was given.

2.1. Anatomical and lesion level annotations

A resident clinical expert performed annotation of DR lesions in the selected set of images using a specially developed tool, based on marking of hand-drawn polygons and small regions of interest for lesions. The types of lesions annotated are:

- Red structures: small red spots, blot, flame, vitreous haemorrhage, neovascularization
- Blood vessels: up to 3rd order branching – this was done on normal images
- Bright structures: optic disc, cup, small hard exudates, confluent plaque, soft exudates, ischemic areas
- Indication of presence of IRMA, fibrous proliferation

2.2. Evaluation metrics

The design of DR analyzer software as a data-driven system provides specific task-related metrics for evaluation. Performance compared to human expert drives the algorithm refinement process.

Module evaluation: the lesion-level performance of DR analyzer software detectors can be evaluated by comparing algorithm outputs against lesion annotations provided by clinicians. Two methods of evaluation are used:

- FROC analysis (TPR vs FPPI): for lesion detectors and
- ROC analysis (TPR vs FPR): for normal anatomy detectors and DR referral analytics module.

Metrics used: AUC (area under ROC curve), sensitivity, specificity, precision, accuracy, confusion matrix

3. Study outcomes

The performance of the built system for different modules was observed. The image gradability module showed a sensitivity of 85.9% at specificity of 83%.

The performance of anatomy detectors was also evaluated against the prepared annotations and is given in the figures 2.a and 2.b.

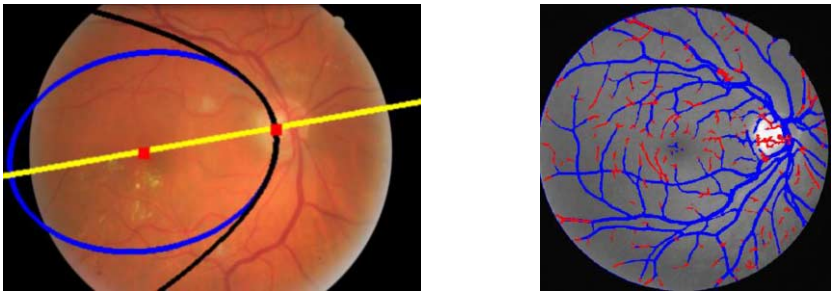

Figure 2.a. Outputs from the normal anatomy detectors. **2.b.** Output of blood vessel segmentation

The image-level performance observed on the Messidor public dataset is shown in Fig.3a. The performance of 83% sensitivity at 80% specificity is seen in this dataset. However direct evaluation on Indian data showed a reduction in performance to 70% sensitivity and specificity. This shows the need for refinement of the system for Indian data. After refinement, a high level of specificity is attained as shown in Fig. 4. Inspection of the DR severity scores reported by the system indicates that images of advanced stages of the disease receive higher severity scores.

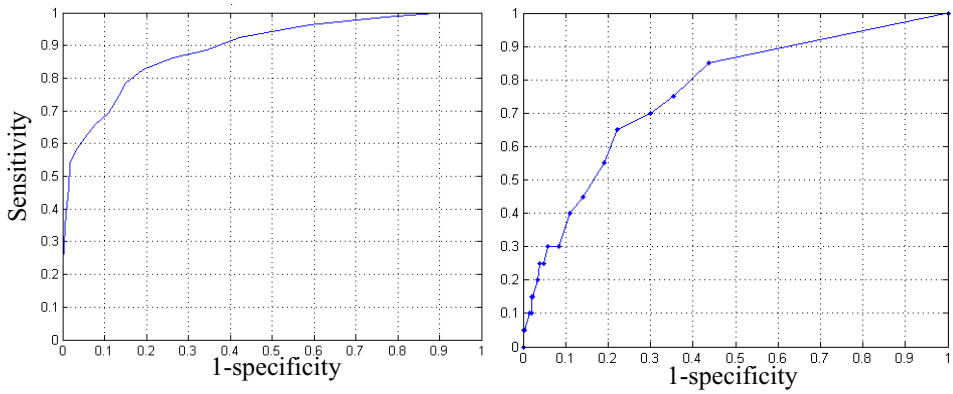

Figure 3.a. Image level decision performance on MESSIDOR dataset, and **3.b** cross-validation in selected Indian data from epidemiological data

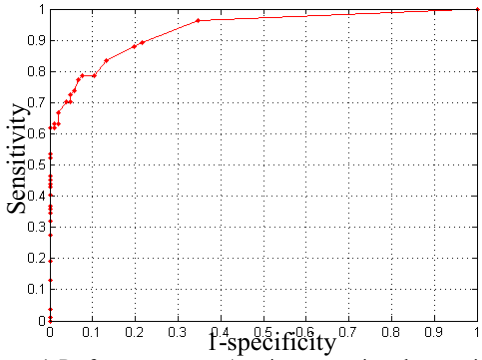

Figure 4. Performance curve (receiver operating characteristic curve) after refinements

The software system has been developed and evaluated using mydriatic imaging with 45 degree magnification and 7 field photography, which adheres to the globally accepted protocol [14].

Conclusion and recommendations for prospective study

The computer-assisted DR screening system has been shown to perform at a satisfactory level of sensitivity and specificity on the limited study and hence similar protocol would need to be followed for a prospective study.

The prospective study could have the following aspects for study:

- Inclusion of non-mydriatic imaging: The performance of the system on images acquired with a non-mydriatic camera for the same subjects could be included, which will help in studying if enough information can be derived by the software from non-mydriatic images, having the mydriatic images for comparison.
- Inclusion of separate analytics for diabetic macular edema: expert reading of macular edema should be taken and a separate module should be built which provides a grade of severity of diabetic macular edema.
- Analysis of treated DR images: Though the prospective study is intended to find new cases of DR the software should have the capability to identify treatment indications such as laser marks. Also advanced stages of DR such as neovascularization and fibrous proliferation should be treated as highly critical and separate modules in the system should be designed for identifying these. Though the prevalence of these in screening population is expected to be few these are signs for which a false or negative could be unacceptable.
- Study of the grading capability of the system and evaluation of observer variability between system outcome of grade and expert grading.

Based on this limited scale experiment the performance of the DR screening system on epidemiological data has been studied and the need for image quality check and pre-filtering for dust particles in software has been identified. The system is a data-driven system and the current performance is comparable to state of art methods showing that the technology used in the software is verifiable and needs to be validated on larger data with the inclusion of non-mydriatic images.

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WhatsApp in Clinical Practice: A Literature Review

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Abstract. Several spontaneous telemedicine services using WhatsApp Messenger have started in South Africa raising issues of confidentiality, data security and storage, record keeping and reporting. This study reviewed the literature on WhatsApp in clinical practice, to determine how it is used, and users' satisfaction. *Methods* Pubmed, Scopus, Science Direct and IEE Expert databases were searched using the search term WhatsApp and Google Scholar using the terms WhatsApp Telemedicine and WhatsApp mHealth. *Results* Thirty-two papers covering 17 disciplines were relevant with the most papers, 12, from India. Seventeen papers reported the use of WhatsApp Groups within departments, 14 of which were surgery related disciplines. Groups improved communication and advice given on patient management. Confidentiality was mentioned in 19 papers and consent in five. Data security was partially addressed in 11 papers with little understanding of how data are transmitted and stored. Telemedicine services outside of departmental groups were reported in seven papers and covered emergency triage in maxillofacial, plastic, neuro and general surgery, and cardiology and telestroke. *Conclusions* WhatsApp is seen to be a simple, cheap and effective means of communication within the clinical health sector and its use will grow. Users have paid little attention to confidentiality, consent and data security. Guidelines for using WhatsApp for telemedicine are required including downloading. WhatsApp messages to computer for integration with electronic medical records.

Keywords. WhatsApp, data security, consent, confidentiality, record keeping

Introduction

Global uptake of telemedicine has been slow, especially in the developing world, where the need is greatest. Barriers to its use in the developing world are the high costs of infrastructure and telecommunication [1] and the extra work required of already overburdened health professionals to participate in a videoconference consultation or to submit patient data for store and forward telemedicine [2]. Governments of poor countries have low tax bases with resultant limited health budgets [3]. They rightly weigh up the opportunity costs of providing either videoconferencing or computer equipment, with associated training, support and maintenance costs, to rural hospitals and clinics for telemedicine. There is little hard economic evidence of the benefits of telemedicine over, for example, provision of mosquito nets, better cold-chain management of vaccines or training of community health workers.

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Much has been written about mHealth and the development and use of mobile phone applications for medicine, surveillance, behaviour change, appointment and treatment reminders and the use of social media apps for support groups and delivery of medical services. The telephone has been a means of communication between patients and doctors and between health professionals since at least 1879. Doctors were quick to realise its potential and Einthoven transmitted ECG's over the telephone in 1906 while others transmitted heart and lung sounds by telephone in the 1910's [4]. The smartphone has introduced a new dimension, functioning as a pager, computer, camera, videoconferencing unit, audio recorder, data storage device and telephone. While much has been published about health specific mobile phone applications, what of the use of apps not intended for healthcare delivery?

Over the past three years we have noted the evolution of spontaneous, unplanned telemedicine services in KwaZulu-Natal, South Africa, using a mobile phone app, WhatsApp, designed for text, voice and image transfer. WhatsApp is a proprietary, free, mobile messaging client for smartphones using Android, iOS and Windows operating systems with support for Blackberry and Nokia operating systems to end in 2016 [5]. It is widely used with over one billion active users in February 2016 [6]. Without the need for expensive videoconferencing equipment or computer networks, doctors in the developing world have found practical use for it in clinical and administrative settings because the service is ubiquitous, free and easy to use. [7, 8].

As with any eHealth clinical service, data security, confidentiality and privacy issues need to be addressed. Data security during transmission of information, its subsequent storage on smartphones, and record keeping of chat messages are serious concerns and the process of data transmission needs to be understood. To send a WhatsApp message, an Internet connection is required, either through a wireless connection or a data connection through the phone eg 3G. The message is routed to a WhatsApp server, which may or may not be in the same country as the sender, and the server attempts to send the message to the recipient. If and when the recipient's smartphone is available i.e. has an Internet connection, the message is forwarded and deleted from the server. If, after one month, the message has not been forwarded it is deleted from the server. Data security during transmission to the server and recipient has long been considered a problem with WhatsApp with reports of programmes to hack into WhatsApp users' accounts. This was resolved in April 2016 and now, when using the most recent version of WhatsApp, all messages including text, images, video, audio and file sent for one to one communication, "chat", or one to many, "chat groups" are end to end encrypted for Android, iOS and Windows operating systems [9].

Such is the level of encryption that it is a problem for security agencies who are not able to access decrypted messages. In Britain, the Prime Minister and MI5 have called for WhatsApp to be banned [10], with similar concerns in India [11]. This year in Brazil, the service was blocked for 72 hours by court order and a Facebook executive was arrested for failing to provide decrypted messages for a drug related court case [12].

In the developing world issues such as confidentiality and data security, while noted, are frequently not adequately regulated. For example, "There are no clear guidelines for patient confidentiality from both the Dental Council and Medical Council of India and as such is less of an issue in India as compared to the developed countries" [13]. With improved encryption WhatsApp is a viable option for clinical

telemedicine services and has the potential to improve telemedicine uptake in the developing world.

The aim of this study was to review current literature on the use of WhatsApp in clinical practice, to determine how it is used, and users' satisfaction.

1. Methods

The following electronic databases and search terms were used, PubMed - WhatsApp[All fields]; Scopus - WhatsApp (All fields); Science Direct - WhatsApp(All fields); IEE Expert - WhatsApp, and Google Scholar - ("WhatsApp" AND "Telemedicine") or ("WhatsApp" AND "mHealth"). The first one hundred hits for the two searches of Google Scholar were reviewed. The search was up to the end of December 2015. Inclusion criteria were that the paper was in English and described the use or potential use of WhatsApp in clinical services. Papers reporting use of WhatsApp solely for education, behaviour change or patient reminders were excluded. Data were extracted on the year of publication, country of origin of the paper, discipline involved, nature of the service reported (clinical telemedicine services, intradisciplinary chat groups, case reports, research projects), perceived advantages and disadvantages of using WhatsApp, consent, confidentiality, data security, encryption and IT Governance.

2. Results

Fifty-eight papers including pre-prints were found from 2013 to 2015, 32 of which met the inclusion criteria. They originated from ten countries India (12 papers) [13-24], UK (5) [25-29], Italy (4) [30-33], Saudi Arabia (3) [34-36], Spain (2) [37, 38], Turkey (2) [39, 40], Brazil (1) [41], Netherlands (1) [7], Philippines (1) [42], USA/South Africa (1) [43]. They were made up of 13 papers, eight letters (three of which were responses to a paper), seven case reports and four abstracts. Disciplines reported were orthopaedic surgery (7) [16-19, 38, 41], surgery (5) [25-28, 31] (three of which were letters in response to a paper) [25-27], maxillofacial surgery (3) [13, 22, 40], plastic surgery (2) [20, 34], urology (2) [29, 42], dermatology (2) [35, 36], cardiology (1) [39], critical care (1) [14], cardiac surgery (1) [32], stroke (1) [24], palliative home care (1) [15], paediatric surgery (1) [43], neurosurgery (1) [30], diabetic retinopathy screening (1) [21], oral medicine (1) [33], allergy (1) [37], and laboratory services (1) [23].

The use of WhatsApp groups for intradisciplinary communication was reported in 17 articles three, of which were letters in response to a paper [25-27], one service was reported twice [18, 19] and one paper reported a survey of dermatologists who were members of different WhatsApp groups [36]. Of the thirteen remaining reports all were in surgical disciplines except for the survey of dermatologists. All of the services were confined to intradepartmental communication across a range of aspects, including second opinion [13, 19, 23, 30, 34], updates of patient admission and changes in treatment plans[13, 16, 19, 28, 30, 31, 34, 38] which also facilitated daily staff handover meetings [16, 30], theatre scheduling [13, 28, 34, 38], sharing of XRays and photographs (on admission and pre and postoperative) [13, 16, 19, 20, 23, 34], scheduling of academic meetings, and sharing of educational materials such as papers

[28, 29, 34]. Five were from India [13, 16, 19, 20, 23], two from the UK [28, 29], two from Italy [30, 31], two from Saudi Arabia [34, 36] and one each from Spain [34, 38] and the Phillipines [42]. Seven of the services reported routine use of WhatsApp for communication with three in India, two in Italy, and one each in Spain and Saudi Arabia [13, 19, 20, 30, 31, 34, 38].

There were seven case reports, six of which were from India and one from Saudi Arabia. Six clinical services other than intradepartmental groups included a diabetic retinopathy screening service in India that used a fundal camera attached to a smartphone [21], a triage service for oral and dental pathology in Italy [33], an afterhours second opinion service for emergency maxillofacial injuries in Turkey [40] an emergency cardiology programme in Turkey [39], and patients in Spain using WhatsApp to contact their allergist [37]. An overview of use of surgical apps in clinical practice mentioned the use of WhatsApp by a paediatric surgeon in South Africa [43].

Eight papers were reported as trials or audits. There were two concordance studies in orthopaedics [41] and urology [42], five audits of the use of intradisciplinary chat groups[16, 18, 28, 29, 34] and a report of the use of WhatsApp for one to one telemedicine referrals to improve time to reperfusion in patients with ST segment elevation myocardial infarcts [39].

Satisfaction with WhatsApp was gauged by perceptions of advantages. Advantages were noted in 11 papers and disadvantages in eight with three papers listing both advantages and disadvantages. (Table 1)

Table 1. Perceived advantages and disadvantages of using WhatsApp.

Advantages	Disadvantages
Improvement over voice only communication [13]	Frequent interruption [16,23]
Less disruptive than a pager [28,29]	Disparity in the sense of urgency [16]
Reduces need to be in hospital [31]	Worsens professional relationships [16]
A computer not required [33,40]	Leads to unprofessional behavior [16]
Faster than email [23,36]	Requires staying online 24 hours a day [19,34]
Permits immediate response [31,35]	Unable to print a record of chat [34,19]
Reduces clinical incidents[30]	Not part of the medical records [34,19]
Ameliorates surgery performance [30]	Difficulty identifying patients in chats [34,19]
Reduces consultation time [30,35]	NHS against instant messaging [26]
Increases level and improves supervision [28]	Possible issues of privacy [31]
Flattens hierarchy[28]	Possible issues of confidentiality [22]
Involves more senior staff in decisions [23,28,29,36]	Cost of device[22]
Encourages junior doctors to seek help [29]	Increased work using WhatsApp [23]
Improves team perception of effectiveness [18]	Risk of reducing autonomy of registrars [28]

Consent was discussed in only five papers. Three were group services [19, 20, 34], one a survey of dermatologists [36] and the other an overview of WhatsApp use [7]. Only three papers reported actually gaining consent for clinical photography [19, 20, 34] with consent for sharing information within a group noted in two [19, 34]. Consent to transmit and share other patient data via WhatsApp was raised in an overview of the use of social media on radiology [7]. A survey of dermatologists involved one or more groups noted that ideally consent should be obtained [36] and an overview paper noted that patients “should be able to provide consent” [7]. Two of the papers reported plastic surgery groups, with one dermatology and one orthopaedic group; all specialties that commonly take clinical photographs [19, 20, 34, 36].

Some papers referred to confidentiality whilst others used privacy, and although they are different they are often erroneously used synonymously. Confidentiality was addressed in 19 papers, nine of which identified this as a challenge or proposed ways of

maintaining confidentiality [7, 13, 15, 22, 23, 27, 31, 36, 44]. In the 10 services that discussed confidentiality, nine were in WhatsApp groups. Actions taken to maintain confidentiality were to: de-identify patients [18]; minimise patient identifiers [16, 29]; use patient's initials [28]; identify patients by ward, bed number, procedure and specialist, by date of surgery and place on the operating list [19, 34, 38]; password protect the phone or phone and WhatsApp [29]; restrict communication to within the group [20]; and 'protected' with no further information given.[41] Another group considered that they maintained privacy by only sending messages to their group over the hospital's secure wireless network or Internet [28, 41]. With messages about multiple patients in a chat group it was noted that it was sometimes difficult to identify to which patient the message referred [34].

Data security was addressed in 11 papers. Concern was raised about data security on the WhatsApp server during its transmission [25] but this has now been resolved with end-to-end encryption. Some felt that data transmission was secure if sent over a wireless network and would be more secure if access to the network was password protected [28, 41]. Different approaches were taken for security of data received on smartphones such as password protection of the phone and the application [16, 22, 23, 29], and deleting all messages after one week [28]. This was considered ineffective as it was thought that messages were still available on a WhatsApp server [27]. Others felt that there was no need to delete chats as they were a form of electronic medical record, "...lost xRays are a thing of the past." [13]

In an evaluation of WhatsApp in an orthopaedic service in Spain, the messages were downloaded from phones after 8 months for evaluation [38]. Confining the messages to group members was considered a way of maintaining confidentiality [19, 29, 42].

Little was mentioned of record keeping. It must be assumed that in most groups the doctor sending the messages and acting on the responses was entering the information into the patient's file. Johnston [28] recommended downloading and storing a hardcopy of messages when deleting them from the phone after one week. Others noted that they were unable to print a record of the chat and the chat did not form part of the medical record [19, 34].

IT governance was identified as a means of addressing issues of confidentiality, privacy and data security in four papers [7, 25, 26, 28,], three related to the use of group messages in a surgery service in England [25, 26, 28] and the other to the use of social media in radiology from the Netherlands [7]. Examples of IT governance included requiring devices used to store patient safety data be approved by the information governance services [25], restricting storage of data on mobile devices to one week, de-identifying patient data and keeping adequate clinical records [28], forbidding the use of mobile devices for exchange of clinical information [26], and forbidding visitors and personnel from taking photographs on mobile devices that have immediate access to social media [7].

Patient and or family communication with health professionals was reported for palliative homecare [15], orthopaedic pin tract care undertaken by the patient [17], communication with allergists [37] and oral medicine [33].

Concordance studies looked at the quality of xRays and CT images transmitted by smartphones and images taken with smartphone cameras and transmitted by WhatsApp. There was strong agreement in the assessment of xRays and CT scans sent for assessment of tibial fractures, (kappa 0.75 – 1.0) [41], the quality of images used for management decisions after cystoscopy or ureteroscopy (85% concordance) [42],

diabetic retinopathy screening (82% specificity and 98% sensitivity) [21], and oral medicine (82% concordance) [33].

Several papers reported surveys of the way in which WhatsApp was used and the users' perceptions of its worth. A small study found that orthopaedic residents had better recall of patients' diagnosis and management after introduction of a WhatsApp group [16] and also a significant improvement in the perception of communication within the group [18]. Junior doctors were more likely to pose clinical questions and pass information while consultants/attendees were more likely to give instructions [28, 29]. Types of communication included administrative questions, clinical questions, giving information or instruction, handover, education, theatre scheduling and ordering surgical implant [28, 29, 38].

3. Discussion

WhatsApp is being used across a range of clinical services, mainly to facilitate communication within intradisciplinary groups, and mostly in the developing world. There are few one-to-one telemedicine consultation services and those that exist are triage services or in one case a screening service. Doctors appear to have been able to incorporate WhatsApp into their everyday practice without the need for additional training, either technical or vocational. In general the practical advantages of using WhatsApp outweigh the disadvantages. There is poor understanding and misconception of how WhatsApp encrypts, transmits and stores text messages and associated files. Consent, confidentiality, patient privacy, data security and record keeping have been poorly reported.

It should be noted that all the papers reviewed were written prior to the introduction by WhatsApp of end-to-end encryption of all message formats across all operating systems. Prior to April 2016 it would appear that only one-to-one text message chats using the Android operating system were end-to-end encrypted but not group chats, image, audio, video and other files. Messages sent using other operating systems were not end-to-end encrypted. Before adequate encryption was introduced there were reports of ways to "hack" WhatsApp accounts [45]. It would appear that most clinicians were not aware of the potential security and confidentiality breaches that could occur. Some erroneously believed that using a wireless connection to the Internet (preferably password protected) rather than the phone's GSM service, or that confining messages to the chat group overcame security issues, [20, 42]. Ideally there should be no patient data stored on a phone. Some have advocated deleting messages after a given period [7, 28] while others have noted the benefits of having patient data permanently stored [13]. WhatsApp data stored on phones remain encrypted but can be 'read' if the phone is unlocked. Reasonable precautions are to password protect the phone, preferably using biometrics, and password protect the application.

Local information technology governance would help clinicians better understand the issues, especially with the growing number of health professionals bringing their own devices into healthcare services. Few services were reported from the developed world with none from major OECD countries suggesting greater clinician awareness of the legal, regulatory and ethical issues around data security, confidentiality and privacy. Even with end-to-end encryption there are still security concerns. The server to which the message is initially sent may be in another country and thus jurisdiction, and illegal in those countries requiring health data be stored in-country.

Without a unique patient identifier, maintaining confidentiality is a problem. De-identifying the patient information makes knowing who is being discussed in a chat group difficult, with potentially dangerous sequelae. Providing minimal identifiers, using patient initials, or using the patient's ward, bed number, procedure and consultant allows possible identification. Patients can also be identified from photographs and no paper reported blocking out identifying features. This cannot be done within WhatsApp but there are other apps available that enable areas of photographs to be blurred or blocked.

There were few reports of consent being gained to photograph and then send patient information on WhatsApp to a group of doctors. This may be indicative of a more laissez-faire approach to consent, seen in some developing countries with few or no relevant regulations. Ideally a patient should be aware of and consent to their information being sent to a doctor or group of doctors, over the Internet, using a social media application, and then possibly being stored on the doctors' phones. They should also be told what steps are to be taken to maintain confidentiality and security of their data [7].

Record keeping and integrating WhatsApp messages with an electronic medical record was identified as a problem. Electronic and hardcopy records can be made by emailing chats from WhatsApp, including images and other attached files, ideally to a secure server. A problem then remains with identifying a patient from a chat. Whether the emails sent by WhatsApp are encrypted is not known.

The concordance studies in effect, looked at the ability to determine the clinical features in a transmitted image. This then is an issue of screen size and resolution, image resolution and photographic knowledge and skills. There have been many such studies and modern smartphones provide images of good quality. An advantage of WhatsApp is that all the image data are transmitted and the small image seen on the screen can be enlarged to view areas of specific interest.

WhatsApp is seen to improve communication within groups although some felt that it was too intrusive and that the degree of urgency was sometimes overplayed [16, 23]. Junior doctors sought advice more readily and received advice from more of their seniors [29]. This was considered to flatten the vertical hierarchy of decision making and provide a wider range of opinions and better supervision [23, 28, 29, 36], but may however reduce the autonomy of registrars/residents who would normally be called before the problem was escalated to a consultant/attending [28]. No outcome studies were reported although improvement in surgical outcomes was noted [30].

As in the South African experience, a neurosurgical service began using WhatsApp when a junior doctor was unable to send CT scan and xRays by email [30].

Conclusion

The ubiquity of WhatsApp, its simplicity, low cost and improved encryption make it an attractive proposition for developing telemedicine services in resource constrained settings. There are however few reports of consultation over distance as opposed to intradisciplinary group in hospitals. The advent of end to end encryption reduces security concerns but may face regulation in some countries. What is required now is development of guidelines for the use of WhatsApp for intradisciplinary groups and one to one telemedicine consultation. These can begin as generic guidelines that can be adapted to meet local legal, regulatory and ethical needs.

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Health Behaviour Change Through Computer Games: Characterising Interventions

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Abstract. Recently games in the form of video, computer, or mobile apps have been utilised as an effective component of interventions for health behaviour change. This paper provides an overview of related projects reported in peer-review literature in the period 2006 to 2016. Nine highly relevant references were considered for analysis. The findings are presented according to 3 dimensions of characterisation: health intention, behaviour change principle, and health purpose.

Keywords. Health behaviour, behaviour change, computer games, video games, mobile apps

Introduction

Health behaviour change refers to adoption of healthy life style choices and habits, in order to prevent illness. Common examples of health behaviour change include encouragement of positive life style, such as increased physical activity, and discouragement of negative life style, such as smoking cessation. As well as these preventive purposes, health behaviour change can also be applied retroactively for management of chronic conditions [3, 4]. For example, the modification of personal nutrition and exercise practices can assist diabetes sufferers to better manage their health status and slow the advance of their disease [7]. A wide body of literature exists in this area and a comprehensive framework approach to characterising associated behaviour change principles has been proposed.

Various types of computer-mediated and computer-delivered "serious" games have been developed as health behavior change mechanisms for dealing with specific health intentions [1]. The results are often positive and can be maximized with some design optimisation and customisation efforts [1]. Such games can provide a means to elicit significant health behaviour change, due to the depth of engagement with human subjects that is provided by their interactive nature and challenge aspects. This makes computer games potentially an important medium for inclusion in future health behaviour change interventions and associated activities such as health education and health promotion [6].

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An open question concerning such games for health is: what aspects of design lead them to be most effective as health behaviour change agents? This paper contributes a perspective on this question by conducting an eclectic review of computer games reported in recent health behaviour change publications. We first describe our filtering methodology to identify the most relevant papers, then present a summary of the interventions and associated findings. The overall characterisation of these sources is provided according to 3 dimensions: health intention, behaviour change principle, and health purpose.

1. Review Methodology

1.1. Search

The literature review we conducted spanned the last 10 years. i.e. 2006 to 2016. This period was deemed the most suitable because it covers the large scale deployment of contemporary consumer internet/web services and mobile computing, including the proliferation of smart phone and tablet devices, which has provided wider scale and easier access for users of online and interactive technologies.

Searching was initially focused on papers dealing with health behaviour change in some form (e.g. behaviour modification; habit formation; lifestyle improvement). This is a problematic topic to search because there are many synonymous terms denoting concepts in this area, such as "behaviour modification", "habit formation", "practice improvement". For expedience, "health behaviour change" was adopted as the primary search term as it is widely used across a range of health disciplines.

The secondary element of the search strategy was to find instances where the health behaviour change used computer-related games as a substantial element of the intervention. The terms "Game" and "App" were used in order to find as many games related papers as possible, whether they were computer games, serious games, video games or mobile games (apps), accepting that some would not be computer-related.

Scopus was used for the purpose of identifying candidate papers, using the following search attributes:

Search by title, abstract, and keywords:
"health" AND
"behaviour change" AND
("game" OR "app") AND
PUBYEAR > 2005

Results were then sorted by citation count.

This search resulted in 254 papers being identified directly. Of these, 51 were regarded as potentially relevant, or marginally relevant, on the basis of their title. Many of these papers dealt with apps, but were only considered relevant if they were either a game in app form or an app with gamification elements. This led to the reduction in the number of relevant papers to 30, based on brief inspection of the contents. These remaining papers were subjected to further scrutiny to determine their eligibility for detailed consideration in this review, by applying the filtering criteria described below.

1.2. Inclusion/Exclusion Criteria

Remaining papers were considered further for inclusion by first reading their abstract, and if this was perceived as insufficient, then reading the full text. Any literature review papers on games for health behaviour change were automatically included (3 papers). Only 1 formal review was discovered during the search process [1].

Papers describing research projects were included if they involved a formal analysis through review or trial (or a comparable systematic deployment) of a computer gaming artifact to facilitate health behaviour change (4 papers) [2-5]. Papers that discussed concrete game design (or app design) concepts and/or game implementation issues for the specific purpose of supporting health behaviour change, and which argued for likely better health outcomes associated with use of these elements although not validated by a formal analysis, were also included (4 papers) [6-9].

Papers dealing only with higher level concepts or principles for computer gaming, which it was speculated by their authors might contribute to achieving effective health behaviour change, were excluded.

2. Review Results

The finally selected 9 papers were scrutinized in detail for their contributions, and the findings are tabulated below in Tables 1 and 2. Table 1 presents the range of types of papers according to their most obvious properties arising from the search selection process. Table 2 summarises the papers according to coverage of fundamental aspects of the paper contents, including research methods and sample sizes.

2.1. Paper Summary

For the purpose of this summary, a 'game' is defined as software which is used interactively by a user with an ultimate goal of an intended health behaviour change effect. An 'app' in this context is software implementing a simple game or with some gamification features, developed specifically for mobile users. A 'concept' is an idea or theory to better improve a 'game' or 'app' in order for users to reach the intended health outcome. 'Analysis' is a formal and systematic approach to determining the effects of the game on anticipated aspects of health behaviour change.

Table 1. Summary of included papers

Paper #	Game?	App?	Conceptual?	Analytical?
[1]	✓	-	-	✓
[2]	-	✓	-	✓
[3]	✓	-	✓	-
[4]	✓	-	✓	-
[5]	✓	-	✓	-
[6]	✓	-	✓	-
[7]	✓	-	-	✓
[8]	-	✓	-	✓
[9]	✓	-	-	✓

Table 2. Coverage of included papers

Paper #	Topic	Study Type	Sample Size
[1]	Health-related behavior change promotion through video games	Literature Review	27 papers
[2]	Young adult perspectives on behavior change apps	Focus Groups	19 participants
[3]	Conceptual model for serious video games for self-management	Design Synthesis	N/A
[4]	Serious video games for behavior change leading to decreased obesity and type 2 diabetes	Design Synthesis	N/A
[5]	Multiplayer health behavior change among youth	Long term empirical study	>200 participants
[6]	Gamification and how it fits into health behavior change	Design Synthesis	4 gamification taxonomies
[7]	The effectiveness of diabetes self-management video games	Artifact Review	14 diabetes self-management games
[8]	The extent to which gamification is used in health apps	Artifact Review	132 Apple App Store apps
[9]	User embodiment in a 3D virtual world to increase health self-efficacy in overweight adults	Randomised Controlled Trial	90 participants

3. Discussion

Games have been reported to be an "engaging and entertaining format" for health behaviour change, for people of all ages [1]. Paper [1] was a literature review of 27 articles covering 25 video games that were intended for the promotion of health-related behaviour change. It was found that most of the articles considered did result in "positive health-related change" through the use of games.

Paper [2] discussed young adults' (13 females, 6 males) perspectives on health behaviour change apps in regards to weight loss and dieting. The self-motivating goal setting nature of the apps reviewed within the focus groups was seen as one way in which apps can be gamified to increase user interest in using them. It was found that the greatest influences were "accuracy and legitimacy, security, effort required, and immediate effects on mood". However, functionality that was either deemed unnecessary or disliked, was "context-sensing capabilities" and social media features.

Paper [3] discussed a conceptual model of how serious video games, for the promotion of diabetes self-management among youth, could be supported by a behavioural science-informed framework. Goal setting was deemed essential for focusing users and changing their efforts. Goal monitoring helps users to track their progress and reinforces their behaviour changes. Problem solving skills learnt from this process allow users to overcome barriers as a result of goal setting and goal monitoring methods. Games developed in this way show promise but further research is necessary to determine how effective it is in practice.

Paper [4] further discussed the concepts mentioned in [3]. Behavioural principles can be adopted in the development of games for reducing the risk of obesity and type 2 diabetes. Through observational learning and personalised experiences to the user, it is more manageable finding the balance between "fun" and "seriousness" to the user. The idea of "personally relevant messages" was proposed, suggesting how a user's attention

would be better maintained when personally relevant messages were utilised. This would increase chance of success of a users' behaviour changing in a positive way.

Paper [5] explored group-based competitions in a multiplayer game setting. The effectiveness of group interventions is questioned at an individual level. Whilst a group intervention may be successful in overall health behaviour change, it may not be as effective for each individual within the groups. Five different player types were reported on with the dimensions of "motivation", "behavior", and "influence on others". The five player types are as follows: achievers, active buddies, social experience seekers, team players, and freeloaders. "Achievers" are characterised as setting themselves "game-related goals" and setting out to achieve them. "Active Buddies" are small groups of close friends who are able to create and enjoy physical activities together. "Social Experience Seekers" are players that use the communicative functionality and role-play in the context of the game to communicate with other players. "Team Players" are those that are "most motivated" by achieving goals as a group and working on their ranking through improving their team's performance. "Freeloaders" are players whom are signed up to a group but do not contribute to their group and this affects the group's performance. Game design suggestions are given on how to better integrate group functionality into multiplayer game interventions to increase effectiveness.

Paper [6] presented a behavioural science perspective on using gamification for health behaviour change. This relied on using a set of specific gamification strategies, achieved by a range of nominated gamification tactics. A potential framework was introduced to use in the design of "digital health interventions", which provided criteria for the use of gamification in health. The criteria proposed contain 7 aspects, as follows:

1. users' personal attributes
2. users' social or community context
3. psychological and behavioural outcomes being pursued
4. fit of intervention logic model or change theory with gamification persuasion
5. nature of interactive product or platform being planned
6. compatibility of interactive product, users, and community with the gamification strategies
7. compatibility of interactive product, users and community with gamification tactics.

Paper [7] covered 14 diabetes self-management games and whether they are effective in diabetes self-management behaviour change. The games reviewed span a wide range of different genres with the most common characteristics among the games being player involvement in problem-solving and decision-making simulations in regards to diabetes self-management. This was managed in one particular randomised-controlled trial by asking the players to "balance food and insulin" in order to maintain their character's blood glucose levels within an acceptable range. This was intended to encourage players to use the same skills on multiple occasions to become better at it in order to "win the game". This serves as an example of cause and effect as well as providing the player with the basic knowledge of how to better manage their diabetes independently. It was concluded that further studies similar to this could emphasize the effectiveness of game based self-management modalities for those with diabetes and lead to better health outcomes.

Paper [8] analyzed 132 health and fitness apps that have gamification elements. The review looks at the influence gamification has on the user's health behaviour with

the apps. A regression analysis was conducted which allowed the correlation between health behaviour constructs, gamification components, and effective game elements to be measured. It was found there is "widespread use of gamification principles" across the health and fitness apps. It was also found there is "low adherence to any professional guidelines or industry standard". Overall it has been found that gamification in health and fitness apps is on the rise and the overarching issue is a "lack of integrating important elements of behavioral theory" in the apps industry.

Paper [9] looked into user embodiment within a 3D virtual world to alter users' health behaviour for better self-efficacy with weight loss management. It was found through qualitative analysis that avatar-based virtual interventions can improve "motivation and efficacy to try new physical activities" however users who have little interest in video games are likely not to benefit from this form of intervention.

4. Characterisation Framework

To formulate an understanding of the Computer Games for Health Behaviour Change landscape as revealed in this review, we propose a framework of 3 dimensions to describe candidate games, as follows.

4.1. Game Intention

Each game, whether it be a health related game or a recreational game, has an intention as part of its design. Often for a typical game the intention is player enjoyment and satisfaction. However when it comes to heath games, the intention is dependent upon the intended outcome as a result of playing the game. A health game may have an intention of competition in which one is either competing against oneself in order to better oneself e.g. a step counter type game that encourages a user to complete more steps each week than in the previous weeks, or than the step count of another participant. Another form of intention in a health game is to challenge the user. This may be a set of tasks or goals to achieve that escalate in difficulty with the intention of helping the user help themselves through self-improvement. Yet another health game intention can be an informational experience to the user. By playing the health game the user learns about relevant information specific to their type of condition. This would allow them to be better informed and it is speculated that as a result they will better manage their condition.

4.2. Behaviour Change Principle

A game focused on health behaviour change targets a particular behaviour and aims to modify it within the user. Adjusting a users' health behaviour can be done in several different ways and three of them which were identified in the papers reviewed will be used as exemplars: modifying habits, reminders, and encouragement.

- Modifying habits: altering the way in which a user currently manages a task related to their condition to manage it in a way that allows the user greater self-efficacy.

- Reminders: notifications for the user regarding schedule based tasks or goals for managing their condition. E.g. a diabetic is reminded to check their glucose levels at regular intervals.
- Encouragement: reinforcing positive behavior of a user to allow for good habits to continue rather than trend downwards.

It should be noted that many other behaviour change principles could be included in this list, if a wider range of publications on such games was available for consideration.

4.3. Health Purpose

The health purpose refers to the way in which using the health game will help the user manage their condition not only in the short term, but in the long term also. This is the ultimate purpose of the game to have long lasting positive effects on the user. For example, health purpose may include increasing the amount of physical activity through the use of a weight management game, or adopting new activities to help manage a health condition, or varying the users' activities to ensure a more balanced lifestyle. It was difficult to find a natural grouping for this aspect into a few categories, so it will be treated as an annotation rather than a categorical dimension. The work considered here was mostly aimed at health lifestyle maintenance through physical activity and nutrition management, with two papers targeting diabetes [4],[7] and two targeting obesity [4],[9].

Table 3 shows how this framework could be applied for characterising the papers in this review in the first two dimensions, using a 'best-fit' protocol. Papers [2] and [9] fit in two categories as equal best-fit. Paper [6] is not included as it covers too many areas for a narrow best-fit. The predominant Game Intention category was Informational, with Challenging being the next highest. The predominant Behaviour Change Principle category was Modifying Habits, with Encouragement next. Competitive and Reminder categories were the least popular. The framework is extendable as needed, to cater for a broader range of studies.

Table 3. Characterising the reviewed papers into the Characterisation Framework.

		Game Intention		
		Competitive	Challenging	Informational
Behaviour Change Principle	Modifying Habits	[5]	[1],[9]	[2],[3],[4]
	Reminder			[7]
	Encouragement		[5],[9]	[2],[8]

Conclusion

The recent growth of interest in the use of serious games for health generally, has led to widespread generation of ideas and experimentation with computing artifacts, but little conclusive evidence about "what works". Attempts thus far to understand this space

have relied more on mapping of behaviour change principles [10] than on attempting to link the types of gamification elements with specific behaviour change aspiration. The characterisation framework suggested in this paper provides an improved approach which factors in some of the additional environmental variables. Doubtless higher dimensionality extensions could be developed, but the proposed framework is considered to be sufficient for the purposes of undertaking trials and other validation processes for evaluating future exemplars of games of this type.

For a game to be effective in achieving the particular health behaviour change objectives, it must be "serious" enough to reflect on the users' condition and provide a guiding environment that directly works towards a health goal for the user at a personal level. It is also equally important that a game has a certain degree of "fun" to allow an amount of enjoyment for the user and generate an on-going interest for the user in the game. Finding the fundamental balance between "serious" and "fun" [4] game elements will allow for the greatest chance of health behaviour change success. This aspect has not been addressed in depth in any of the work reviewed here.

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The Same Language Speak We Do – Consensus Terminology for Telehealth

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Abstract. e-Health has grown to become interjurisdictional in scope and in practice. Central to successful implementation and scaling of e-heath solutions is clear and concise communication of ideas and principles, and instructions during construction. This paper addresses the need for an agreed taxonomy and terminology and focuses on explaining, proposing, and recommending terms and action for an international consensus-based terminology for telehealth. *Methods* Two structured database literature searches were performed to identify literature relevant to telehealth / telemedicine taxonomy or terminology. *Results* The terminology search identified 162 resources of which 4 met the inclusion criteria, while the taxonomy search identified 447 resources of which 5 met the inclusion criteria. Using these literature sources, a telehealth terminology was developed. *Discussion* The literature shows clear lack of and need for a common telehealth taxonomy and terminology. Of those proposed in the literature none has been universally adopted or applied. *Conclusions* Proponents of telehealth and those working in or aligned with the field, must develop, agree upon, adopt, and use clear and accurate telehealth terminology to ensure concise and accurate communication in the application of telehealth globally.

Keywords. Telehealth, terminology, taxonomy, definitions

Introduction

The myth of the Tower of Babel is commonly known – once different languages were imposed on workers, they could no longer understand one another and building of the Tower became impossible. *Bâbel* – the name of the Tower - means 'a confused noise'. This concept can be transferred to the context of e-health (the use of Information and Communication Technologies (ICT) for health [1]), where there has been substantial confusion generated due to a lack of a common taxonomy and terminology. Proponents of e-health have been largely responsible for this circumstance, as evidenced by the volume of definitions of both e-health and telemedicine/telehealth [2, 3]. Fatehi and Wootton identified that the terms 'telemedicine', 'telehealth' and 'e-health' are often used interchangeably, and concluded that the variation in the level of adoption for these terms suggested ambiguity in their definition and a lack of clarity in the concepts they refer to. These differences can exist within a country [4] or a profession [5].

When casually debating, when describing indicators and measures, or when striving to develop telehealth implementations, it is essential that a common understanding exist of what is meant by any particular term. There may be confidence about Integrated

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Services for Digital Network (ISDN), Internet Protocol (IP), and 4G, but whilst technology is an essential component of telehealth, it is not the core. Rather, the heart of telehealth lies in the skills, experience, and enthusiasm of the people involved which is conveyed in less technical terms. Further, the networked nature of telehealth (e-Health) requires that it cross many barriers or boundaries, making uniformity in understanding of the words exchanged central to building a strong foundation for each project, intervention, or policy. Consistent taxonomy and terminology is crucial to effective communication intra- and inter-jurisdictionally. At this time there is no single or universally accepted source available that describes or defines common terms applied within the telehealth environment.

A further complication exists. How do you create a stable taxonomy and terminology for something that is 'incomplete'? e-Health and its component parts (telehealth; health informatics; technology enabled and enhanced learning; e-commerce) are not fundamental 'laws' or 'constants'. The field is in a constant state of flux, with new ideas and technologies - and evolving capabilities - sprouting. Recently, social media have begun transforming e-health, a decade ago m-health was not common practice, and ten years before that neither was teleradiology. Just how many pieces are there to this e-health puzzle? Can e-health and its myriad components be accurately and concisely categorised, and defined or described at this time?

But without this, gaps in understanding arise creating inconsistencies, adversely impacting the quality of evidence, and damaging effective communication, interaction, and consultation amongst and between stakeholders - the public, healthcare providers, health system managers, researchers, and policy makers - in regard to e-health. This paper addresses the need for an agreed taxonomy and terminology within the telehealth setting. It provides insight regarding the terms taxonomy and terminology, and other closely related terms, discusses the current literature regarding taxonomy and terminology in relation to telehealth (telemedicine), and then provides a preliminary listing of recommended terms and their definition or description. Adoption and consistent use of these terms would ease precise data acquisition and meaningful comparison of initiatives, and facilitate more rapid and insightful knowledge growth.

A variety of words have been used when speaking of consistency in language for telehealth. These include:

- ***Glossary.*** A list of technical terms in some specialised field of knowledge
- ***Lexicon.*** A stock of terms used in a particular profession, subject, or style
- ***Ontology.*** An explicit formal specification of how to represent the objects, concepts and other entities that are assumed to exist in some area of interest and the relationships that hold among them
- ***Taxonomy.*** Classifying according to presumed relationships; division into ordered (hierarchical or networked) groups or categories
- ***Terminology.*** The vocabulary of technical terms used in a particular field, subject, science, or art
- ***Vocabulary.*** The sum of words used by, understood by, or at the command of a particular person or group.

These are not one in the same, and serve two types of purpose. One group refers to categorising or classifying terms (taxonomy, ontology), while the second group are more explanatory in nature, describing and / or defining terms (terminology, vocabulary, or lexicon). A 'glossary' is simply a list of the terms, whether categorical or defining. Here, the intent is not to develop an 'ontology', which is a far more philosophical debate than

a practical tool. Lexicon and vocabulary inter-relate and can be subsumed under 'terminology'. This leaves 'terminology' and 'taxonomy'?

Taxonomy is the practice and science of classification; ordering things into a hierarchical structure. The process creates a catalogue able to provide a conceptual framework for discussion, analysis, or information retrieval. A good taxonomy is simple, easy to remember, and easy to use. Within a taxonomy there is a need to be clear about what is meant by any word or phrase. For this a terminology is required, that is, a vocabulary of specialised terms that focus on clearly transmitting meaning and conveying concepts. More specifically, the International Standards Organization (ISO) indicates terminology is a "set of designations belonging to one special language" [ISO 1087-1], the main goal of which is to eliminate ambiguity by means of standardisation.

Since they are closely related and interdependent there is a need to concomitantly develop a common terminology whilst at the same time developing some taxonomic structure. These tasks are related but distinct goals, and must be clearly differentiated. Whilst a categorisation scheme is needed to form a common frame of reference, you cannot categorise until you know the full scope and clarity around the number and type of terms required. Thus, a terminology may have more entries than a taxonomy, but each entry from a taxonomy must also have a description or definition within a terminology!

1. Methods

To understand available literature, two searches of PubMed were completed. Searches of PubMed used the following strings: Telehealth AND (Terminology OR Vocabulary OR Lexicon OR Nomenclature), and Telehealth AND (taxonomy OR ontology). Inclusion criteria were: abstract available and direct reference to telehealth / telemedicine and a search term; no date restriction. Titles and abstracts were reviewed to determine inclusion or exclusion. These searches were supplemented by hand searching.

2. Results

The first search identified 162 resources of which 4 met the inclusion criteria, while the second search identified 447 resources of which 5 met the inclusion criteria. Despite the fundamental importance of the issue presented, the literature shows limited work on either telehealth taxonomy or terminology [4, 6-13].

The taxonomy related search identified 5 papers. Vincent and colleagues created a taxonomy by identifying four characteristics against which a telehealth encounter could be matched [12]. These were: the type of telehealth interaction, the location of the controlling medical authority, the urgency of care required, and the timing of the communication (real-time or synchronous, versus store-and-forward or asynchronous). Using these parameters a matrix was created which the authors considered was comprehensive in categorising telehealth activities, and had distinct advantages over previous taxonomies. In the same year, Tulu et al. created a taxonomy they intended to help categorise and compare existing programmes and help in planning for future programmes [13]. The authors used five dimensions to classify telemedicine activities: application purpose, application area, environmental setting, communication infrastructure, and delivery options. Each dimension had multiple sub-dimensions. This

model was then used in an analysis of data from the Telemedicine Information Exchange (TIE) to identify trends while comparing and categorising 211 active telehealth programmes. The authors anticipated that application of telemedicine in different application areas would use different combinations of options available in the delivery dimension for different purposes. Their analysis validated the model and provided interesting insight into active telehealth programmes.

In 2011 Bashshur et al. presented a comprehensive discussion, analysis, and ultimately a taxonomy of telemedicine [11]. Certain debatable positions were taken regarding various terms in the analysis, highlighted and discussed by the authors (e.g., differentiation of telehealth and telemedicine), but were secondary to the task of creating a taxonomy. The final taxonomy presented had functionality, applications, and technology as the first level dimensions, each of which was then split into additional sub-dimensions, and each of those then had further sub-divisions. The authors concluded by noting that confusion around nomenclature and taxonomy hinders research and implementation by impeding research focussed on the true benefits and costs, and by interfering with informed decision-making by stakeholders. The authors urged clarity and consensus regarding what constitutes the content of telemedicine, telehealth, e-health, and m-health. This is something that would be significantly aided by establishment of a common taxonomy.

More recently Santana et al. presented the Telehealth Ontology (TEON) for the delivery of telehealth services in an attempt to differentiate telehealth service from telehealth practice [9]. Interestingly they promoted the use of both ontologies and/or terminologies but chose to address ontology to create domain-specific, controlled terms. Colucci took a more reflective approach, and highlighted that the issue is not just theoretical, but has practical ramifications in preventing useful comparison between initiatives, impeding repeatable research, and hindering identification of lessons thereby interfering with proper applicat7777ion of ICT in healthcare [10]. He then performed an etymological analysis using the terms ‘telehealth’ and ‘telemedicine’ as the starting point. A classification scheme with domains, subdomains, and actions was presented, but its general applicability is unclear.

The terminology related search identified 4 papers. Doarn et al. surveyed members of the Federal Telemedicine Working Group representing 26 US Government agencies [4]. They found that the terminologies and definitions in the lexicon of those agencies varied. They also found that although similar, the individual definitions used were nuanced to reflect each organisation's legislative intent and the population they served; that is, they were stipulative definitions. Although they concluded that a common nomenclature for defining telemedicine would be of benefit, they did not proffer such. However, they did highlight important aspects by acknowledging the term e-health broadly encompasses all aspects of telehealth as well as other uses of digital technology related to healthcare, that telemedicine is subsumed under telehealth, and that a common misperception is that e-health is restricted to use of the Internet.

Reynolds et al. addressed the tele-intensive care unit, and developed a comprehensive lexicon (terminology) for activities and technology solutions applied to the tele-intensive care setting [6]. These authors created a set of general, structural, and care model ‘Descriptors’ for the tele-Intensive Care Unit (ICU). Some of the approaches may have value in looking towards a broader terminology for telehealth.

In 2010, Ludwig and colleagues performed a systematic literature review to examine and develop a nomenclature for sensor enhanced trans-institutional health information system architectures for home telehealth services for elderly people [8]. These authors

proposed six important descriptor groups that influence design of home telehealth architectures; users, services, operating organisations, information flow, geographic reach, and architectural paradigm. Specific terms were identified for each of the six descriptor groups, and then each of these discussed in some depth. Specific definitions were not provided. Ingenerf, in 1999, focussed on terminology servers (servers for supporting the semantic interoperability between software systems) as a means for improving the interpretability of medical language data by machines, but did not address a specific terminology for telehealth or telemedicine [7].

Handsearching of the literature provided additional insight. Canada Health Infoway produced in 2006 its first Benefits Evaluation (BE) Indicators Technical Report [14], and later in 2012 version 2 [15]. Intended to provide guidance to those planning evaluations of the benefits of e-health, they contained clear definitions or descriptions of various indicators, which is a rich source of potential terms to be considered. The first version also contained a listing of telehealth related terminology (Appendix A4), much of which has been used below, some with slight modification. Also, in the late 1990's, the Australia New Zealand Telehealth Committee (ANZTC) did excellent work in preparing a document entitled the ANZTC Telehealth Data Definitions Summary. The document is no longer available but was reported on elsewhere [16]. Within that document the Committee listed 30 'items' (within 5 'entities'; telehealth facility, telehealth session, client, healthcare worker, and telehealth service). Each item was defined, and additional insight was provided including context, guide for use, source, and comment. This work did not receive widespread publication, acknowledgement, or application.

Other literature referred to the task of defining fundamental terms such as e-health, telehealth, and telemedicine. For example, in 2007 Sood et al. identified 104 definitions of telemedicine from 1974 to 2003 [2], discussed their theoretical basis, and proffered a revised definition of telemedicine: "a subset of telehealth, (telemedicine) uses communications networks for delivery of healthcare services and medical education from one geographical location to another, primarily to address challenges like uneven distribution and shortage of infrastructural and human resources." These authors noted that definitions do not reflect the evolution of technology and perspective that is an inherent property of such a dynamic field as telemedicine. To this point, none of the proposed taxonomies, terminologies, or definitions identified above have prevailed.

3. Discussion

There has been a substantial amount of miscommunication generated within the telehealth (e-health) field due largely to a lack of common taxonomy and terminology. This may have derailed effective interaction and consultation amongst and between stakeholders, including healthcare providers and policy makers, in regard to telehealth. Such feelings have been voiced for at least two decades, reported by Shannon conveying discussion from the Atlantic Rim Telemedicine Summit in 1997 [17]. That report stated "belief was expressed that, rather than being merely an issue of semantics, revised terminology could very well lead to an improved environment for cooperation and collaboration among all players in the healthcare system, including consumers / patients".

A critical process in developing common terminology is the process of creating definitions. A *definition* can be considered a statement of the meaning of a word, phrase, or term. Over decades a world of varied and variable terminologies, taxonomies, and glossaries have been created within telehealth. Much of the process has been *ad hoc* and

strongly influenced by the prevailing organisational culture and practice of those who created the terms and defined them. Little heed has been paid to either basic pragmatic or linguistic principles, or what occurs globally. Since definitions are tools upon which all should depend, it is incumbent on those who would create definitions to use specified principles to develop them. Solli et al. promoted an approach that shunned logical principles in favour of *pragmatic principles* (based primarily on practical concerns rather than ideological notions) and *linguistic principles* (abstract rules and grammar applicable to a language) [18]. This approach has been adopted here in selecting and recommending the terminology in Appendix 1.

Linguistically, the type of definition considered here has two parts, the *definiendum* (the word or phrase to be defined) and the *definiens* (word or group of words that defines it). For example, in; 'e-Health is the use of Information and Communication Technologies (ICT) for health' the word e-Health is the *definiendum*, and everything after the word "is" is the *definiens*. Pragmatically, a good definition would be one that is simple, succinct, sufficient, and specific. Simple in using language that is easy to understand, succinct in being focussed (neither too wide nor too narrow in context and content), sufficient in providing the essential attributes of the *definiendum*, and specific in being suitably precise and focussed that it is impossible for the definition to refer to any other entity than the *definiendum*. It is also preferable that definitions not be circular (e.g., stating 'Calgary is in Canada' may be a true statement, but offers no evidence that is distinct from the conclusion) or negative (e.g., defining health as 'not sick').

Even differentiating between 'describing' and 'defining' is important at this early stage of development of a cohesive taxonomy and terminology. A *description* is a textual representation of the nature and characteristics of something. In contrast, a *definition* is a statement of the meaning of a word, phrase, or term that serves to differentiate it from related concepts. The former is looser. Without consensus and common application it might be premature to suggest some terms can be adequately defined.

A final consideration is recognising and differentiating *stipulative* definitions (those that provide a meaning the writer intends to impose upon it) from *descriptive* definitions (those that provide the meaning that a term bears in general use). Most literature definitions are stipulative. It is instructive to consider some published e-Health examples.

After almost 20 years in use, the term e-Health is still debated. Pagliari et al. performed extensive work examining the term e-Health, grounding their work in potential e-Health areas and issues, an opportunistic and iterative search of the literature, and 36 definitions of e-Health garnered from the literature (Table 4 in their paper) [19]. Their work was heavily influenced by the perspective of medical informatics, and they concluded by supporting the definitions of Eng and a slightly modified version of one offered by Eysenbach [20, 21].

Eysenbach suggested in 2001 that e-Health be defined as: "e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology" [21]. A simpler definition was provided by Eng also in 2001, e-Health is "the use of emerging information and communications technology, especially the Internet, to improve or enable health and healthcare" [20]. However, neither of these references are satisfactory, failing to meet the desirable pragmatic characteristics of simple, succinct, sufficient, and specific. Furthermore, the

use of terms such as 'the Internet' or 'emerging' immediately stale-date a definition and render it of little lasting value - the implication would be that all alternate or preceding use of ICT for health would no longer fit the definition and be excluded.

Often overlooked is the definition of e-health first applied by the WHO in 2005: "e-Health is the use of Information and Communication Technologies (ICT) for health" [1]. This remains the simplest and most accurate definition of e-health available, meeting both pragmatic and linguistic principles. Although itself debated [22] the common definition of 'health' (formulated in 1948 and supported in the Alma-Ata Declaration of 1978) is that of the WHO: health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [23]. With the advent of 'e' (electronic means provided through use of ICT), the above WHO definition for e-Health follows naturally. However, this definition remains very underutilised. Indeed, Showell and Nøhr [24] suggested "There is no useful definition for eHealth; …" and Moghaddasi et al. [25] stated "developing a clear definition of e-Health is needed", both as recently as 2012.

Another group involved in establishing or embedding terminology, often indirectly, are 'standards' organisations, of which many exist both nationally and internationally. International organisations include the International Standards Organisation (ISO), the International Telecommunications Union (ITU), and the European Committee for Standardization (CEN). These and other standards organisations, often led by health informaticians, began their consideration of telehealth under the rubric of Health Informatics. This reveals historical bias; towards subsuming telehealth and telemedicine under health informatics or medical informatics (rather than telehealth and health informatics being independent branches under e-health), and a focus on data exchange and data manipulation (i.e., computing). Given this focus, an intent of many of these standards organisations is to achieve semantic interoperability for unambiguous data exchange between computer systems. However, evidence shows standards organisations either accept the discordant and *ad hoc* situation, add to the confusion by providing other stipulative definitions or descriptions of a term, or - most commonly - by using prior, flawed definitions. For example, the ITU [26] applies the definitions for e-Health of Mitchel [27] and Eysenbach [21], and not the definition provided by the WHO [1].

4. Towards a Telehealth Terminology

Terminology is considered a discipline, and is context specific; thus there can be military terminology, policy terminology, scientific terminology, technical terminology, and certainly telehealth terminology. To this point in time, *ad hoc* terminology has been prevalent within telehealth; a more systematic telehealth terminology is needed. According to Wikipedia, terminology as a discipline is based on its own theoretical principles and the following aspects [28]:

- analysing the concepts and concept structures used in a field or domain
- identifying the terms assigned to the concepts
- in the case of bilingual or multilingual terminology, establishing correspondences between terms in the various languages
- compiling the terminology, on paper or in databases
- managing these terminology databases
- creating new terms, as required.

This understanding (together with pragmatic (simple, succinct, sufficient, specific) and linguistic principles) provides important guidance in terms of how to move forward. These principles were used as touchstones when selecting or developing the proposed terminology listed in Appendix 1.

Conclusion

The literature is clear that taxonomy and terminology in the broader field of e-health (including telehealth and telemedicine) is largely *ad hoc* at this time, and that this lack of clarity causes issues for all stakeholders related to basic understanding, research, implementation, and strategy and policy development. Proponents working in or aligned with telehealth must develop and agree upon a clear and accurate telehealth terminology to stop this abuse of terms, and ensure clear, concise, and precise communication in the concept, design, and application of telehealth globally.

A clear and standard terminology is needed that uses natural language to define or describe concepts. Creating any standard requires unanimous agreement of all partners involved which, given differing legal, cultural, and practice settings, is a tall order. However, the value to the telehealth domain would be immense.

This paper proffers pragmatic definitions or descriptions for common elements within the field of telehealth (Appendix 1). Their widespread adoption, active use, and citation is encouraged. With the support of the telehealth community - that is, with ***your*** support - these could form the basis for a globally accepted standard terminology for telehealth.

Appendix 1. Definitions / Descriptors for Proposed Common Telehealth Terminology

i) Fundamental Descriptors and Definitions

e-Health (Definition): The use of Information and Communication Technologies (ICT) for health [1].

Health (Definition): A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [23].

Telehealth (Definition and Descriptor): A component of e-Health that uses Information and Communication Technologies (ICT) to deliver health and health related services (*Definition*). These services can be clinical, educational, administrative, or research based. Telehealth is different from telemedicine because it refers to a broader scope of ICT facilitated health and health related services than telemedicine (*Descriptor*).

Telemedicine (Definition): A component of Telehealth that uses ICT to deliver clinical services.

ii) Telehealth Infrastructure Descriptors

Telehealth Unit (Descriptor): The related group of elements (hardware and software, including peripheral devices) that comprises a distinct and functioning apparatus that can be used to perform a specific *Telehealth Activity, Application, or Service* [see definitions below]. A *Telehealth Unit* may be static, mobile, or handheld, and includes units for off-site and personal use.

Telehealth Facility (Descriptor): A discrete and identifiable physical location (e.g. dedicated room, or dedicated space within a room) from which telehealth related pursuits are

provided or received. A *Telehealth Site* (see below) may have more than one *Telehealth Facility*.

Telehealth Site (Descriptor): A discrete and identifiable geographic location (e.g. healthcare facility, clinic, campus) from which one or more *Telehealth Activities, Applications, or Services* are provided or received. This will include 'client' homes and other more mobile locations as home and personal telehealth activities expand.

iii) Telehealth Service Provision Definitions and Descriptors

Telehealth Session (Definition): A period of time set aside or used for a telehealth-related activity.

Audioconference (Definition): A telephone meeting conducted between two or more separate callers in which participants can only hear one another.

Videoconference (Definition): A meeting conducted between two or more separate callers in which the participants can hear and see still or motion video images of each other or recorded material.

Teleconference (Definition): A generic term for a meeting held virtually or 'at a distance'. The term would include both audio- and video-conferences.

Consultation (Definition): A meeting with an expert in order to seek advice. In the clinical setting the expert would be a healthcare provider.

Teleconsultation (Definition): A consultation provided remotely using some form of ICT to facilitate the process.

Telehealth usage (Definition): The rate at which telehealth services are accessed; measured as 'consultations per site per week (c/s/w) [29].

Telehealth uptake (Definition): For a given user population, the percentage change in usage of telehealth services month over month.

User satisfaction (Descriptor): The degree to which the user's needs were met through the telehealth experience. "User" is relative and may refer to any consumer of telehealth (i.e., provider, patient, citizen etc.).

iv) Descriptors of Functional and Maturing Telehealth Implementations

Telehealth Activity (Descriptor): A telehealth mediated pursuit, at the *experimental, pilot, or formative evaluation* stage.

Telehealth Application (Descriptor): A traditional or novel healthcare related pursuit (clinical, administrative, research, or educational) at the *summative evaluation* stage or demonstrated through sustained application (> 1 year) to be *effectively facilitated* through the use of telehealth.

Telehealth Service (Descriptor): A specific and proven *Telehealth Application* offered routinely between *Telehealth Sites*, ideally within a *Telehealth Programme* [e.g.; Forensic Telemental Health Assessment; Pre-catheterisation Teleassessment; Home Telemonitoring].

Telehealth Programme (Descriptor): A distinct, appropriately conceived, designed, staffed, managed, and funded set of *Telehealth Services* orchestrated under a common theme and common administrative structure [e.g.; Telemental Health Programme; Telecardiology Programme; Home Telehealth Programme]. Ideally a telehealth programme will be accredited.

Telehealth Network (Descriptor): An aggregation of *Telehealth Programmes* and / or *Applications* linked to one another through some form of common communications and administrative structure [e.g.; the Ontario Telemedicine Network (OTN), Veterans Administration (VA) Telehealth Services].

Telehealth Setting (Descriptor): A distinct type of facility at which a *telehealth session* is performed (e.g.: hospital, community health centre, community health facility (Long Term Care facility / residential care facility), general practice, specialist practice, home, or other).

Telehealth Integration (Definition): The degree to which telehealth is seamlessly integrated within the existing healthcare system.

v) Administration and Scheduling Related Descriptors

Differentiating sending and receiving sites:

- For clinical telehealth activities (Definitions).
  Note: In practice, a clinician will 'refer' or 'send' a patient to another more experienced or specialised clinician who 'receives' the request; therefore:
  - Receiving site is that site at which the specialist or clinician who 'receives' the request is located (to whom the request is referred).
  - Sending site is that site at which the clinician who refers (and / or the patient) is located (from whom the request is sent).
- For administrative meetings facilitated via telehealth (Descriptor).
  - No distinction is made between any sites as delivering or receiving. Each site is considered to be participating on an equal footing.
- For educational telehealth activities (Technology Enabled / Enhanced Learning) (Definitions and Descriptor):
  - Sending site is that site at which the primary presenter is located.
  - Receiving site(s) is that/are those site(s) at which the learners are located.
  - Hybrid sessions may occur, where sessions are delivered from 2 or more sites.

vi) Governance Related Definitions and Descriptors

Telehealth Policy (*Definition*): A set of statements, directives, regulations, laws, and judicial interpretations that direct and manage the life cycle of telehealth [30].

e-Health Strategy (Descriptor): An evidence- and needs-based document that describes where and why an entity (healthcare facility, region, country) requires specific e-health options to address identified health needs [31]. Designed and prepared correctly, the e-health strategy aligns with related strategies (e.g., Health Strategy, Education Strategy, Communications Strategy) and is agnostic to technology, invoking e-health only when other solutions to the health need(s) are shown to be inappropriate.

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Interactive Games for Home Delivery of Exercise and Rehabilitation Interventions for Older Adults: An Australian Perspective

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Abstract. Over the past few decades there has been a wealth of published scientific evidence for the physical, cognitive and social health-related benefits of increased physical activity, especially in older adults and people living with chronic disease. Despite the clear evidence base demonstrating the health-related benefits of physical activity, uptake and adherence is often disappointing. Therefore, methods for remote delivery of guided exercise programs are required, both to maximise the reach of physical activity promotion initiatives and programs across the older community and to minimise attrition once people begin to be physically active. One method by which we can increase understanding of the importance of, and compliance with, exercise programs involves the use of fun and engaging videogames. In the following we outline two ways in which we are using games technology in an Australian context.

Keywords. Serious games, videogames, fall prevention, stroke rehabilitation, regional health service delivery

Introduction

The majority of the world's increasingly older adult population requires some form of care due to loss of function following failing health or increasing frailty. The costs associated with this care are steadily increasing. In Australia, more than a quarter of Australian government spending is currently directed to health, age-related pensions and aged care. Without an intervention to curtail the increasing financial impact of aged healthcare, the Australian government spending on these areas is projected to increase significantly, pushing total spending to almost half by 2049-50 [1].

Declines in physical or cognitive function are associated with age-related degeneration of, or injury to, the brain and nervous system. Neurodegeneration and neural injury contribute to parallel declines in self-confidence, social interactions and community involvement. A cycle is set up, where social isolation leads to further loss of confidence, leading to further isolation. The social circle contracts as friends age or pass away, and a greater emphasis on family is often a result. Fear of a major incident

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such as a stroke or a bone-breaking fall [2] can lead to the decision to move into a supported environment. Moving from an individual's private home into an aged care setting is then viewed as a major step in the loss of independence and quality of life.

Continued successful independent living is a high priority for older people and those who work with and for them [3]. Therefore monitoring the physical, cognitive and social markers of health, and comparing them to clinical models, enables us to draw conclusions about the current physical, cognitive and social health of the individual and their capacity to remain living independently. However, assessment of these variables usually depends on labour intensive and obtrusive manual assessment by clinical professionals that require the individual to travel to a central clinic or hospital facility. In remote and rural communities, especially in a country like Australia, the distance, inconvenience and expense of travel often make routine assessment of health very difficult. There is therefore a pressing need to develop automated or semi-automated measures of health status that can be gathered from peoples' home environments, especially for those living in regional, rural or remote Australia.

Daily, weekly or monthly home-based monitoring of health provides the ability to detect and act upon changes in these markers of health should they deviate significantly from an individual's history or accepted clinical models of good health [4]. Telehealth (or telemedicine) technology, which combines digital data acquisition, information and communication technologies and the internet to monitor health status in the home, has proven successful for acquiring accurate, reliable and time critical health marker data [5], reducing healthcare costs [6], empowering patients and promoting disease self-management with resultant improved health care outcomes [7]. Furthermore, a systematic review of studies on telemonitoring of patients with congestive heart failure concluded, "patients were living longer without increasing their use of health-care facilities" [8]. For individuals who may be isolated, either by distance in regional, rural or remote Australia, or functional impairment following neurological damage or disease, broadband-enabled telehealth technologies will also be critical for researchers to fully understand the progression of disease course, or the effectiveness of intervention strategies, over the long term [9].

While telehealth technologies can provide opportunities to significantly alleviate the burden of healthcare and facilitate continued independence of the elderly, implementation of technology also faces barriers related to acceptance and use by older adults, their family and clinical support networks. Barriers may include lack of awareness of available technologies, problems in use of technology amongst older adults, lack of financial incentive/capacity to use or invest in technology, lack of adequate training or support, lack of consensus on the value of the technology, cultural obstacles and absence of adequate technology infrastructure [10]. To overcome these barriers it is important for designers of telehealth technologies to work closely with older adults throughout the design and development process in order to learn how their preferences, attitudes and capabilities relate to technology adoption and how products and services can be designed to promote their widespread and long-term use [11, 12].

The dominant information and communication technology already adopted widely by older adults is the ubiquitous home television set. With the advent of digital television, apart from delivering news, information and entertainment, the television will soon also become the technology platform for delivery of health services to the homes of older adults [13]. In the work presented in this paper we extend this concept and consider ways in which devices that connect to the television, namely interactive videogame technologies, can be leveraged as a telehealth technology. Consumer driven

forces for new ways to interact with videogames have led to development of sophisticated video capture and inertial sensing devices for measuring movement of the human body. Until recently, such technology could only be found in expensive and dedicated laboratory facilities. For example, devices such as the Microsoft Xbox Kinect are now at a price point (ca. AUD$200) that it is possible to deploy relatively inexpensively motion capture and feedback technologies directly into the homes of people for use in exercise interventions. In the following we describe ways in which videogames have been used to address two health issues that significantly impact upon the continued independence of older adults: injury and disability resulting from falls and stroke, the risk for both of which are known to be significantly ameliorated by engaging older adults in sufficient levels of physical activity (PA).

The work we describe in the following describes how we have developed videogame technologies to deliver exercise and rehabilitation interventions into the home.

1. Fall risk reduction and monitoring by step training "dance" games

Falls are very common in older people [14] and can have a major impact on their continued independence. Declines in physical and cognitive functioning, that have also been identified as intrinsic fall risk factors [15, 16], may lead to reduced capabilities for taking proactive and reactive steps in order to maintain balance [17, 18]. Fortunately, falls are a public health problem that is largely preventable through implementation of targeted exercise programs. Over 50 randomised controlled trials have provided robust evidence to support interventions for preventing falls in older people. Exercise has been shown the most effective single intervention strategy with a fall reduction of up to 47% [19]. However, despite clear evidence demonstrating benefits of exercise for reducing fall risk, uptake and adherence to exercise programs in fall prevention is often disappointing [20,21]. Efforts to improve exercise adherence are needed to increase the impact of falls prevention programs at a population level.

One method by which compliance with exercise programs that target fall risk could be improved involves the use of games that promote high doses of weight transfer and stepping. Interactive, exercise-based videogames (exergames) that combine player movement, engaging recreation, performance feedback and social connectivity via competition have been shown to promote motivation for, and increase adherence to, physical exercise amongst children and young adults [22, 23]. Providing exergame technology to older people for home-based training could increase compliance to effective programs, potentially benefiting more people. Through funding from the Australian National Health and Medical Research Council (grants 510385, 568724) author Smith and colleagues modified and evaluated an open source version of a popular step-based exergame (StepMania; www.stepmania.com) and developed an internet connected PC system for delivering an in-home fall prevention exercise intervention [24]. Parameters of game play (speed, colour, drift rate etc of game elements) were informed by an iterative process of design and testing involving collaboration between research staff, technologists and older adults themselves such that the final exercise game delivered was appropriate for the physical, sensory and cognitive abilities of an older population [25].

The system (Figure 1) was designed to measure fall risk as well as deliver exercise-based intervention into the homes of older adults. Several stepping tests exist that discriminate between fallers and non-fallers with limited evidence that cognitive load is needed [26]. The choice stepping reaction time (CSRT) task has shown to be a better discriminator between fallers and non-fallers than other sensorimotor and balance measures and to predict falls in older people, mediated via physiological and cognitive pathways. We therefore developed and validated dance mat-based applications for measuring the physical and cognitive abilities involved in stepping performance [27, 28]. Parameters of physical and cognitive function measured by these applications in the home can then be tracked over time by a remote clinician and decisions made about the ongoing fall risk of the older adult.

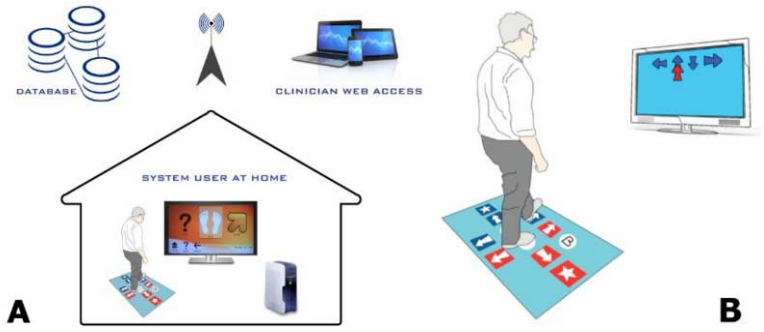

Figure 1. Schematic of main components of the telehealth step training system including sensor mat paired with low-cost PC connected to TV (A). Representation of the modified step training game (B).

The system has been successfully deployed across a number of randomized controlled trials for delivery of a fall risk reduction program into the home. Schone and colleagues [29] installed the system in the homes of 18 older adults residing in independent-living units of a retirement village in Sydney. The intervention recommended that participants engage in 2-3 sessions of dance game activity per week for 10-15 minutes per session for eight weeks. In addition participants were asked to complete a test of stepping reaction time once each week. Usual care control group participants received education material about fall risk reduction and engage in normal activities for the eight weeks. Participants in the intervention group played a median of 2.75 sessions/week and compared to the control group, significantly improved on their stepping reaction times, a standardized physiological measure of fall risk as well as performance improvements in a timed up and go test involving cognitive demand. In a larger randomized controlled trial (N=90, 47 in intervention group) conducted in community-dwelling older adults we extended the range of exercise-based games that could be delivered through the system. These games (Figure 2) include more complex cognitive challenges where tasks required participants to divide their attention, inhibit responses to irrelevant stimuli, switch between tasks, rotate objects and make speeded decisions [30]. Compared to the CG, the IG improved significantly in measures of processing speed, visuo-spatial ability and concern about falling.

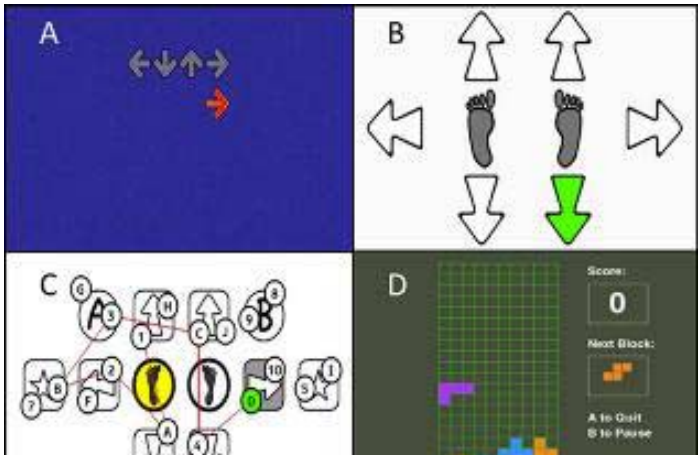

Figure 2. Screen shots of game screens, A. Step training game, B stepping reaction time, cognitive trail making task, D modified version of Tetris. Image from [30] is licensed under Creative Commons.

2. Game-based system for neurological and musculoskeletal rehabilitation

In addition to fall risk reduction, our group is exploring the application of game-based systems for rehabilitation of motor function in older adults. Every year more than 60,000 Australians have a stroke, making it the second largest cause of disability in Australia. More than half of those who survive a stroke require help with normal daily activities. The cost of strokes to the Australian economy is in excess of $2 billion per annum. More than eighty percent of individuals who have suffered a stroke have an initial deficit in limb function and while there is as yet no cure for stroke, there is clear evidence that early rehabilitation after stroke is highly effective. However, delivery of rehabilitation comes with challenges; many patients, particularly those living in regional, rural and remote Australia, find it difficult to access rehabilitation services and those who do don't always comply with treatment. Observational studies in different countries have found that rehabilitation unit inpatients are surprisingly inactive for the vast majority of the waking day. For example, Bernhardt and colleagues have found that 13% of stroke unit patients' day was spent in activities related to functional outcome such as active therapy or walking practice [31].

It is unlikely that rehabilitation units can substantially increase the dose of repetitive exercise within current staffing levels and treatment approaches. Health care resources are limited and as rehabilitation staff costs are already over $700,000,000 annually in NSW alone it is unlikely that substantially more resources (i.e., therapy staff) could be allocated to rehabilitation services. As with fall prevention training in older adults, two factors limiting rehabilitation outcomes are: a) poor patient compliance [32] exacerbated by the repetitive and unstimulating nature of most rehabilitation exercises; and b) restricted access to services due to either a lack of local facilities and staff, or a lack of transportation [33]. To address these challenges we are currently exploring the use of a tailored rehabilitation solution (Jintronix^{TM}) that makes use of the motion capture capabilities of the Microsoft Kinect camera to 'gamify' rehabilitation exercise [34].

Figure 3. Screen shots of game screen in the Jintronix rehabilitation system. In this case a weight transfer game involving a right kick of a virtual soccer ball Note elements of gamification such as stars representing feedback for the task as well as progress bar (top left).

Jintronix, a Montreal-based company, has recently launched a Kinect-based rehabilitation system, Jintronix Rehabilitation System (JRS), which provides an easy-to-use software solution for patients to use. The software solution has been designed in collaboration with physical and occupational therapists and draws upon the motor relearning recommendations by Carr and Shepard [36]. As such, upper limb, sitting balance, standing balance and stepping rehabilitation tasks have been programmed in the JRS as fun and engaging video games that can be played at a number of different levels of complexity and speed (Figure 3). The system is also capable of automatically measuring changes in the range, speed and quality of motion to give patients instant feedback on their progress. A second feature of the JRS is a cloud-based client management telehealth system for clinicians to recommend rehabilitation tasks and track and record performance of those tasks (JRS Portal). The Portal allows clinicians to provide patients regular updates and information on what has happened to them with daily, weekly or monthly progress reports on their rehabilitation, either face-to-face or remotely (Figure 4).

Figure 4. Screen shots of patient summary data for use of Jintronix system. Enables clinicians to get a quick snapshot of patient engagement in activities and current level of function

3. Serious Games for (tele)Health.

Despite the widespread, possibly skeptical, perspective that games can only ever be an indulgent leisure time activity, games are considered ”serious” when they are developed and used in sectors such as education, defense, emergency planning, politics, engineering, urban planning, manufacturing and service delivery. Games also offer the potential to disrupt healthcare delivery. For example, current rehabilitation practice (e.g. following stroke) involves a period of intense, guided rehabilitation during the early stages of recovery, often in an acute hospital setting. Patients are then gradually discharged back into the community, with limited funded ongoing support through transition care programs, to lead the remainder of their lives functionally impaired to various degrees. Often patients are discharged from rehabilitation with sheets of printed instructions for the kinds of exercises they should engage in to aid their recovery of physical, psychological, emotional and social function. For patients returning to regional, rural or remote Australia, the paucity of access to rehabilitation services is particularly distressing.

Imagine instead a world where the person recovering from a stroke is sent home from hospital with a videogame console, pre-loaded with a suite of engaging, informative games to engage them in their rehabilitation program. As they engage in rehab gameplay, their centrally located rehabilitation specialist can monitor performance and adjust challenge posed by the games, ensuring that progress of rehabilitation is guided, informed and encouraging. Furthermore, for the patient who may have formed close social bonds with others on the rehabilitation ward in hospital, they now have the opportunity to “play” against each other irrespective of the physical and functional distance that may separate them. The possibilities for games in telehealth are enormous.

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An Integrated Patient Information and In-Home Health Monitoring System Using Smartphones and Web Services

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Abstract. Modern healthcare systems are undergoing a paradigm shift from in-hospital care to in-home monitoring, leveraging the emerging technologies in the area of bio-sensing, wireless communication, mobile computing, and artificial intelligence. In-home monitoring promises to significantly reduce healthcare spending by preventing unnecessary hospital admissions and visits to healthcare professionals. Most of the in-home monitoring systems, proposed in the literature, focus on monitoring a set of specific vital signs. However, from the perspective of caregivers it is infeasible to maintain a collection of specialized monitoring systems. In this paper, we view the problem of in-home monitoring from the perspective of caregivers and present a framework that supports various monitoring capabilities while making the complexity transparent to the end users. The essential idea of the framework is to define a 'general purpose architecture' where the system specifies a particular protocol for communication and makes it public. Then any bio-sensing system can communicate with the system as long as it conforms to the protocol. We then argue that as the system grows in terms of number of patients and bio-sensing systems, artificial intelligence technologies need to be employed for patients' risk assessment, prioritization, and recommendation. Finally, we present an initial prototype of the system designed according to the proposed framework.

Keywords. Aged care, in-home monitoring, health information system, bio-sensing

Introduction

With the advancement of medical science, life expectancy of population has increased steadily over the last decades, especially in the developed countries. With the growth of the ageing population, prevalence of chronic conditions, such as, cancer, diabetics, hypertension, and heart diseases, have also increased significantly. The ageing population and the prevalence of chronic conditions, thus demand for growing health care services [1]. In 2012, OECD countries, on average, spent 9.3% of their GDP in health care [2]. Health care expenditures are projected to increase significantly as a percentage of GDP both in developed and developing countries [3].

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Information and communication technology are expected to play a pivotal role in alleviating the pressure on health care services. Various Information Systems (IS), such as, Hospital Information Systems, Laboratory Information Systems, and Human Resource Management Systems, have greatly facilitated efficient management of health care activities and resources. Now, with the advancement in bio-sensing, wireless communication, mobile computing, and artificial intelligence technologies, in-home patient monitoring promises to significantly reduce the healthcare spending.

In this paper, we propose an integrated framework for in-home health monitoring system. The framework aims at leveraging the ubiquitous smartphones and the Internet for a cost effective solution. We view the problem of in-home monitoring from the perspective of a caregiver which may be a hospital, a clinic, or a geriatric center. The rationale for this perspective is that caregivers are the one who will monitor the patients' conditions and act accordingly. Certainly, while deploying a monitoring system, a caregiver must ensure that the system is comfortable to use for the patients. Many ad hoc monitoring systems have been proposed in the literature those differ in their modalities, interfaces, and functionalities. However, for a caregiver, it is extremely difficult to maintain a diverse collection of monitoring systems. Thus, an effective in-home monitoring system must support various monitoring capabilities while hiding the complexity from the end users, i.e., healthcare professionals and the patients. More specifically, it must provide coherent and consistent interfaces to respective users irrespective of the sensing systems and the underlying information and communication technology framework.

The organization of the rest of the paper is as follows. We briefly review the relevant literature in Section 1. In Section 2, we state the requirements that a remote health monitoring system should ensure. We also present our proposed framework in Section 2. In Section 3, we describe the implementation of an initial prototype designed according to the proposed framework. Finally we conclude the paper in the Conclusion and Future Works section.

1. Related Works

A web-based remote pulse monitoring system has been proposed in [4]. An essential component of the system is a single-on-chip embedded system that senses the pulse signal and wirelessly transmits it to a web-server. This system is costly since it requires the web-server to be hosted in the patient's home. From the caregiver perspective, the system is too specialized and it is difficult to scale the system for multiple patients.

The health monitoring system proposed in [5] uses easy-to-wear sensors to continuously measure the patient's blood pressure, pulse, oxygen level, and ECG signal. The system essentially uses a PDA as a platform for a 'health assistance' that collects these measurements via Bluetooth and informs the patients about their current status. Although the system has the provision for transferring the measurements to a healthcare center using the Internet, it requires a healthcare professional manually assessing the situation.

Remote health monitoring systems using mobile phones and web-services have been proposed in [6]. The central component of these systems is a web-service that provides the medium of communication among the patients, the database (storing medical data), and the doctors. These systems implement a web-client running on the patient's mobile phone to transmit relevant measurements using the Internet to a

database. Another web-client provides the platform for doctors to access the patients' database. The major difficulty with the systems proposed in [6] is that they do not specify how the measurements will be acquired in the first place. While the scheme proposed in [7] uses Bluetooth technology for wireless acquisition of ECG data, all these systems lack a smart component at the web-server that will efficiently manage the data coming from different patients and of different modalities.

Indeed, most of the systems proposed in the literature assumed that a remote health monitoring system consists of two phases: acquisition of the data from the patients and transmission of the data to a remote location. Thus, these systems are specially designed for a specific application scenario. Hence, implementation of a specific system requires an ad hoc information and communication infrastructure. Without an integrating framework, it is technically and economically infeasible for the caregivers to maintain a collection of heterogeneous special purpose monitoring systems. Besides, each of the systems comes with its own user interface. This hinders the acceptance of monitoring systems to healthcare professionals as it is extremely difficult for a person to be familiar with a diverse collection of interfaces.

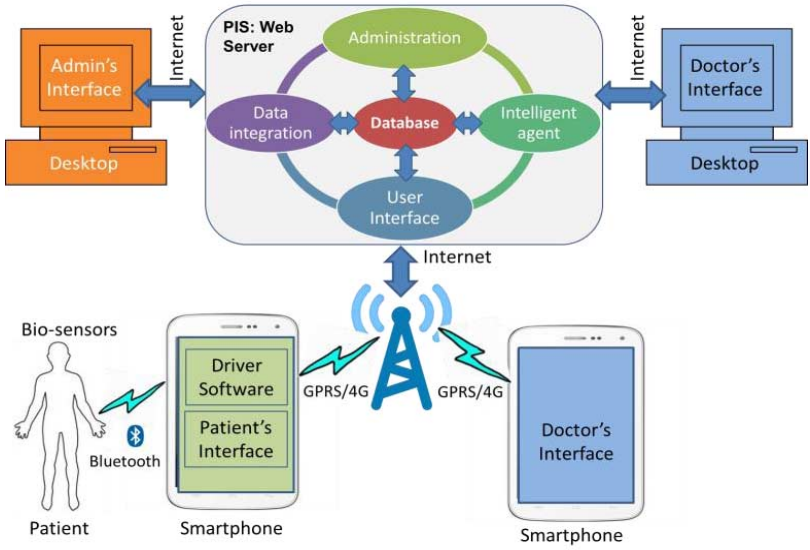

Figure 1. The proposed framework.

2. The Framework

The proposed framework is based on the following principles.

- It must support acquisition of various physiological signals using portable/wearable bio-sensors which are comfortable to use for a patient.
- The system must provide a coherent and consistent interface to the healthcare professionals about patients' information while hiding the complexity arising from the deployment of different physiological sensors.
- The system must have an intelligent agent to detect critical conditions and generate alert for appropriate actions.

2.1. Acquisition of Bio-Signals

The first step in the monitoring system is the acquisition of physiological signals from a patient's body using portable/wearable bio-sensors. Clearly, the bio-sensors should be comfortable to use to be acceptable to the patients. Advanced electronic technologies have made possible miniaturized bio-sensors that are light-weight, low-powered, and low-cost. Now wearable sensors exist to measure various physical parameters, such as, blood pressure, oxygen level, ECG signal, heart rate, blood sugar, body temperature, respiration rate, skin hydration, body motion, and brain activity. For comprehensive reviews of wearable sensors see [9], [10], 11].

Emergence of fabric based bio-sensors has enabled measuring various bio-signals without compromising the comfort of patients [11][12]. Besides, portable devices exist for non-conscious monitoring of patients using sensors attached to doors, wheel chairs, refrigerator to gather contextual and behavioral information [13].

2.2. Wireless Transmission of Bio-Signals

After acquisition of the bio-signal, the measured data needs to be transmitted to a central database that can be accessed by healthcare professionals. Wired transmission of the data is infeasible as this impedes the patient's mobility and comfort. Therefore, wireless transmission of the data is preferable. Thus, the portable/wearable bio-sensors usually come with wireless connectivity to provide access to the acquired signals from a short distance.

Various wireless communication technologies of varying range and transmission rate are available. For example, the ZigBee standard can transmit data at a rate up to 250 kbps and has an operating range of 0 – 10 m. Bluetooth standard has both an increased transmission rate (721 kbps) and an increased transmission range (0 – 100 m), however at the cost of increased power requirements. WLAN technology has even a larger transmission rate (20 Mbps) and thus consumes even more energy. Thus, depending on the data transmission requirement, appropriate wireless communication technologies are used by the bio-sensors. For example, transmission of ECG signal requires higher data transfer rate than that required for the transmission of blood pressure data.

Since the wireless communication technologies used by the bio-sensors have short operating ranges, the measurements need to be received and transferred to a central database to make them available to the caregivers. Indeed, the ubiquitous smartphones with processor, memory, operating system, and transmission capability, can be used to receive and pre-process the data and then transfer them to a central database. The smartphone can use GPRS/4G technology or the Internet to transfer the data to the databased hosted in a web-server. A bio-sensing system is thus completely defined by the physical sensing system along with the software running on the smartphone that coordinates the transmission of the measurements from the sensors to the web-server.

2.3. Patient Information System

Central to the proposed system is a Patient Information System (PIS) running on a web-server. It defines an abstract interface to receive the measurements about the patients from varying sources. The interface specifies only the format of information exchange leaving the implementation details to the monitoring systems. A bio-sensing

system is compatible with PIS if its driver software, running on the smartphone, transmits the data according to this interface. It is this abstract interface that enables the PIS to receive data from heterogeneous systems.

The PIS is driven by the database storing all the patient information. The database stores patients' information coming from all possible sources such as laboratory test, imaging test, and those acquired by the remote bio-sensors. Finally, the PIS provides consistent and coherent web-based Interfaces to healthcare professionals as well as to the patients. It is the consistent interface that hides the underlying complexity, arising from heterogeneous systems, from the end users.

2.4. Intelligent Agent

One of the major issues to be addressed for successful adaptation of an in-home monitoring system is scalability. As the system grows in terms of number of patients and systems, automation of patients' risk assessment, prioritization, and recommendation becomes essential. Therefore, advanced artificial intelligence techniques should be employed to prioritize the patients based on the expert knowledge in the relevant domain.

Since most artificial intelligent algorithms are computationally intensive, they are expected to run on the web-server. However, the smartphones are general purpose computing devices with processors, memory, communication ports, and wireless connectivity managed by an operating system. Their main limitation is that they are low-powered devices. Therefore, low-complexity intelligent algorithms can also run on the smartphones that can detect critical conditions and alert relevant personnel using text messages.

The overall framework is depicted in Fig.1. One of the salient features of this framework is that it is *scalable* and it supports *heterogeneous* bio-sensors. The smart phone is a general purpose computing device that can support various software and connectivity. Similarly, the PIS is also a general purpose system defined by its abstract interface and driven by the underlying database. This general purpose setting enables easy integration of a new monitoring device. The new monitoring systems only need to provide 'driver software' that will run on the smartphones. The drivers will access the signals from the bio-sensors and transmit them to the database hosted in the web-server.

3. Initial Prototype

We implemented an initial prototype of the framework, presented in the previous section, using off-the-shelf bio-sensors and open source technologies.

A MySQL database, hosted in the web-server, maintains a collection of tables to record various types of measurements for each patient. The PIS defines the following protocol to receive measurements. Any bio-sensing system that implements the protocol is compatible with PIS irrespective of its type, implementation, and complexity.

1. A patient must be registered to the PIS. An API running on the web-server will assign a unique ID to a patient upon registration.
2. The driver software running on the mobile device can start uploading measurements for a particular ID using an API. The uploading of the

measurements must use the following JavaScript Object Notation (JSON) format: <*ID*, *TYPE*, *DATA*>, where *TYPE* refers to the type of the measurements, such as, temperature, and *DATA* refers to actual measurements.

The PIS, driven by the database, provides interfaces for registration of patients, healthcare professionals and centers.

Initial implementation of the prototype focuses on heart related problems because of their prevalence as a chronic disease. For continuous acquisition of ECG signal from a patient, we used the commercially available Alive Bluetooth Heart & Activity Monitor [14]. This single channel bio-sensor uses wireless Bluetooth technology for real-time transmission of ECG and accelerometer data. The driver software for receiving the data from the sensors and transmitting to the web-server was implemented in a Samsung Galaxy S5 mobile phone running on Android platform. The driver software also provides interfaces to doctors and patients for visualization of ECG signal. Fig. 2 (a) is a snapshot of the dashboard of a doctor showing his/her patient list and brief information about them.

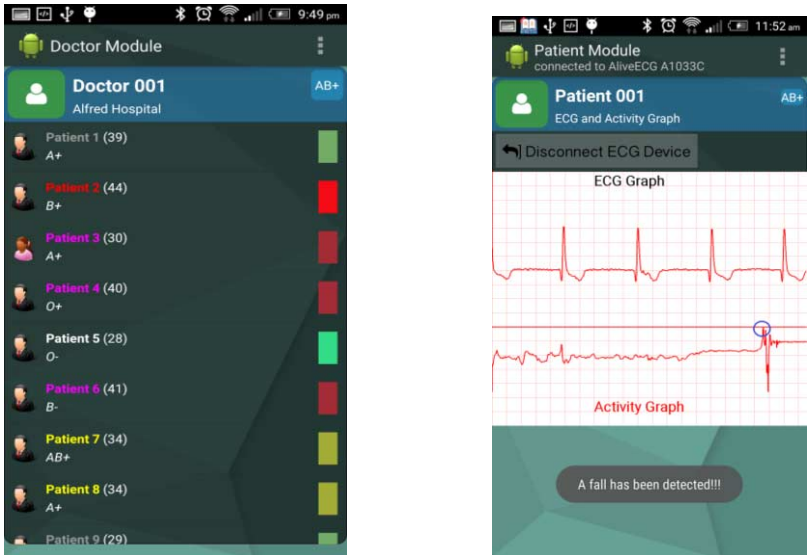

Figure 2. (a) Doctor's portal showing a list of patients; and (b) Patient's portal showing the ECG graph and the magnitude of three-dimensional acceleration. It follows from the graph that the magnitude of acceleration crosses the threshold τ during the fall.

3.1. Fall Detection

The driver software at the mobile phone implements an algorithm to detect falls from the accelerometer data. Since a fall is a critical condition, it needs to be detected at the mobile phone. This will enable alerting the relevant personnel directly without relying on the Internet connectivity to reduce the communication latency and uncertainty. Thus, we implemented the threshold based fall detection algorithm proposed in [15]. The essential idea of scheme stems from the observation that the magnitude of acceleration during fall is greater than those during normal activities. Therefore, the algorithm continuously computes the magnitude of acceleration in three-dimensional space from

the acceleration values along three axes. If at any point the magnitude of acceleration exceeds a threshold τ then it assumes that a fall has been occurred.

An important parameter for the above fall detection algorithm is the value for the threshold τ. To empirically determine its value, intentional falls were performed by a healthy volunteer while the Alive Bluetooth Heart & Activity Monitor bio-sensor was mounted on his waist. Our experimental results demonstrated that τ=4.3G is quiet effective in distinguishing between normal activities and a fall. Fig.2(b) shows that at the time of the fall, the magnitude of acceleration exceeds the threshold.

Conclusion and Future Works

In this paper, we have proposed an integrated framework for in-home patient monitoring. The framework, designed from the perspective of caregivers, enables integration of heterogeneous bio-sensing systems. We have argued that for the system to be scalable, it must incorporate an intelligent agent for automatic prioritization of patients and recommendation for appropriate action based on the information stored in the database. However, our current prototype partially implements the full functionalities of PIS. In future, we plan to implement those functionalities and implement various artificial intelligent algorithms to support automatic decision making from various qualitative information and quantitative data.

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Cost and Time Effectiveness Analysis of a Telemedicine Service in Bangladesh

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Abstract. Telemedicine has great potential to overcome geographical barriers to providing access to equal health care services, particularly for people living in remote and rural areas in developing countries like Bangladesh. A number of telemedicine systems have been implemented in Bangladesh. However, no significant studies have been conducted to determine either their cost effectiveness or efficiency in reducing travel time required by patients. In addition, very few studies have analyzed the attitude and level of satisfaction of telemedicine service recipients in Bangladesh. The aim of this study was to analyze the cost and time effectiveness of a telemedicine service, implemented through locally developed PC based diagnostic equipment and software in Bangladesh, compared to conventional means of providing those services. The study revealed that the introduced telemedicine service reduced cost and travel time on average by 56% and 94% respectively compared to its counterpart conventional approach. The study also revealed that majority of users were highly satisfied with the newly introduced telemedicine service. Therefore, the introduced telemedicine service can be considered as a low cost and time efficient health service solution to improve health care facilities in the remote rural areas in Bangladesh.

Keywords. Telemedicine, health care, information and communication technology

Introduction

Telemedicine service is a value added service taking advantage of the developments in telecommunication and growing internet facilities. It can play a significant role in providing medical facilities in remote areas where modern health facilities are very limited. This service paradigm is especially critical for developing countries like Bangladesh where access to medical facilities and necessary equipment are limited in rural areas. Telemedicine can be a cheaper and easier way to disseminate medical facilities among large group of people in the remote areas by using limited resources [1].

The total population in Bangladesh is over 150 million. Among them, 77% people live in rural areas. A substantial improvement in health care sector in Bangladesh has reduced child mortality rate and maternal death, and increased immunization coverage and life expectancy of citizens [2]. However, due to having huge disparity in health care distribution between rural and urban areas, large portion of people living in rural

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areas are deprived from these modern health care facilities. They are required to travel long distance to access health care services which are costly and time consuming [3]. There are 663 Government hospitals in District head-quarters and Thana (sub-town) areas. Total number of beds available in both public and private hospitals and clinics are 51,648. Nevertheless, the ratio of hospital bed to citizen is around 1:2571 [4] with doctor to citizen ratio 1:43660 [5] in Bangladesh. However, most doctors in Bangladesh are located in urban areas due to a poor infrastructure in rural health care centers and villages.

Due to ill-equipment, insufficient numbers of doctors and health care professionals, and poor healthcare infrastructure, most rural people are required to travel long distance to access modern healthcare facilities mostly located in urban areas. To overcome this disparity in healthcare access, Telemedicine can play a critical role. It has great potential to improve both the quality and the access to health care service delivery with reduced costs even in the scarcity of resources [4]. Telemedicine could potentially reduce waiting times for patients and cost of health system's operations; it can improve interdepartmental and inter-hospital communication and collaboration; it can provide opportunity for sharing best practices among physicians within Bangladesh and international hospitals, and can enhance better resource allocation [6].

Leveraging the potentiality with Telemedicine services, recent years there has been an increasing concern about telemedicine services in Bangladesh. As a consequence, a number of Telemedicine initiatives have been taken in place [4]. However, none of them have been successful due to a number of reasons. For example, Mostafa et.al [7] in a study stated as 'Even though enthusiasm has been observed in deploying telemedicine in Bangladesh from different quarters, however, lack of sustainability and long-term deployments are major issues. Unfortunately, many pilot projects are not followed up to turn into stable and fully functional healthcare systems. The primary reason is that the projects started with a narrow scope and did not address a proper framework for telemedicine application in Bangladesh.' Another study by Nessa, et.al [4] indicated that technical issue was one of the major reasons for deployment of a telemedicine service in Bangladesh.

Previous research has also identified some other challenges in successful implementation of Telemedicine in Bangladesh including unavailability of initial huge startup costs, poor Information and Communication Technology (ICT) culture of healthcare professionals, poor power supply and people embedding political meanings into the system [7]. The weak state of information infrastructure at the hospital is another problem in the implementation of Telemedicine. The success of Telemedicine largely depends on effective communication in spite of differences in location, time, equipment, levels of expertise, and health care organizations involved in the exchange [8].

To introduce a new program, resource limitation is one of the major problems in developing countries. Although Telemedicine is started with high desire, it cannot reach its destination due to high costs, underdevelopment infrastructure, and lack of technical expertise [9]. The Interagency Working Group (IWG) ASIA Task Force on Telemedicine [10] discussed in a report that the implementation of Telemedicine is hampered by several challenges such as insufficient human and capital deficiencies.

The above review indicates that there are some studies investigating barriers and challenges in Telemedicine application, however, little or no significant systematic studies have been conducted from the beneficiary perspective in Bangladesh. The aim of this study was to evaluate the effectiveness, in terms of time and cost savings, of a

locally developed PC based diagnostic equipment and software based telemedicine services, which will be described in the next section, introduced in two districts (Faridpur and Madaripur) in Bangladesh. This study also attempted to analysis the service recipients' attitude towards this services.

1. Introduced Telemedicine System

To overcome the disparity in healthcare access, a locally developed PC based low cost diagnostic equipment and software telemedicine service has been introduced in various districts in Bangladesh. These services have been provided through local pharmacies as rural healthcare center considering the fact that most people see these places as a first place of contact for an initial medical advice if they have any health issues, especially rural people. Service feedbacks are collected by volunteers following the schedule. These services have become popular particularly to women, senior and disabled citizens, since they are unable to travel other places due to distance and cost. In addition, patients can receive health care services from a particular mobile telemedicine service point at a nearest place. The center provides one day free consultancy for poor, vulnerable, and disadvantaged people. A trained operator collects primary information of a patient such as name, age, weight, blood pressure, check diabetes, any previous report or prescription, etc. Through online Telemedicine application, patient can even consult with urban doctors through video conferencing. Remote doctor provides prescription, if necessary, of a patient to the local operator through the Internet. A remote doctor can access the physical condition of a patient using stethoscope over the Internet with the help of a local operator if necessary. This service also provides the ECG health monitoring facilities to the local patients. All patients' data are reserved in web server for further follow up services.

2. Methodology

The study was both qualitative and quantitative in nature. The study was conducted at Nagarkanda Upazilla in Faridpur District and Shibchar Upazilla in Madaripur District as a pilot project. Therefore, the citizens from those areas, who receiving Telemedicine service, were recruited as the study population. Informed consent was sought before conducting an interview. Data were collected through structured and semi-structured interviews shown details in Table 1.

Table 1. Data collection methods

Methods of data collection	Number of Respondents
Over phone interview with structure questionnaire	69
Interview with semi-structured questionnaire in person	66

Data entry was done concurrently with data collection. Data analyzed in SPSS software were reviewed, edited and cleaned by performing a series of frequency and data checks.

3. Findings of the Study

3.1. Demographics Details

About 56% service recipients were female and 44% male in this study. The findings of this study indicates (Table 2) that about 28% respondents accessed necessary health services from nearest general doctor's practices, whereas 22% respondents from district level medical college hospitals. On the other hand, about 20% service recipients opined they had necessary health services from private clinic or hospital, while 13% service recipients from district health center.

Table 2. Location of usual health services used

Location	Percentage (%)
Nearest doctor practice	28
Faridpur medical college hospital	22
Private clinic/ hospital	20
District health center	13
Government hospital/ medical center	6
Upazilla health center	6
Nearest dispensary/ rural doctor	5

3.2. Comparison of Time Consumption in Telemedicine and Conventional Health Service

Figure 1 shows the time spent by the participants in accessing health care services through Telemedicine and the conventional healthcare system. According to the figure, about 23% service recipients received health service in 30 minutes via Telemedicine service, whereas only 1% had access the similar service spending the same amount of time in conventional means of health service. Figure also shows that 48% respondents indicated that they had access health services by an hour whereas only 8% in conventional health service. In contrast, 27% Telemedicine service recipients and 65% conventional health service recipients were to spend about 5 hours in accessing health services. In Telemedicine service, only 2% service recipients were to spend more than 5 hours compared to 25% in conventional health services.

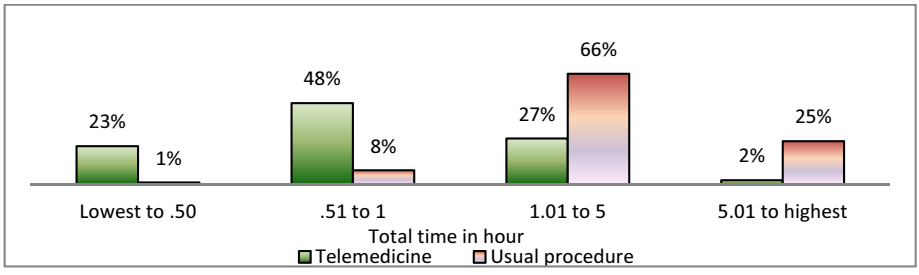

Figure 1. Time required by service recipients in Telemedicine and Conventional health service systems

3.2.1. Testing the Significance Level for the Time Requirement

Null Hypothesis

Ho: average time required by those who had access telemedicine service= average time required by those who did not have access telemedicine service.

Alternative (Research) Hypothesis

Ha: average time required by those who had access telemedicine service≠ average time required by those who did not have access telemedicine service.

Table 3. Test of significance for time requirement

	Test for equality of Variances		Test for equality of Mean		
	F-value	Significance Level	t-value	Degree of Freedom	Significance Level
Equal Variances assumed	.797	.373	-2.424	242	.016
Equal Variances not assumed			-2.629	177.746	.009

As per the Table 3, significance level (0.373) is greater than .05. Therefore, the variances are assumed to be equal. Thus, the null hypothesis can be rejected with the p-value for this t-test with 0.009. Therefore, this can support that average time required for those who received telemedicine service is not equal to the average time spent by those who did not access this service.

3.3. Cost Comparison between Telemedicine and Conventional Health Service

Figure 2 shows the total cost required in both approaches. According to the figure, 10% respondents receiving Telemedicine service cited that they were required to spend ≤ 50TK (US $1= 78TK) whereas this was the cost with 9% in conventional health service. In contrast, a much higher percentage of participants (87% compared to 19%) accessed health care service with the same cost (i.e., 150TK) via telemedicine service. About 4% and 28% respondents accessed health services via Telemedicine service and conventional health service respectively with the cost of 400TK. The figure clearly shows that about 43% informants were to spend 11,200TK to access required health services though the conventional health care system.

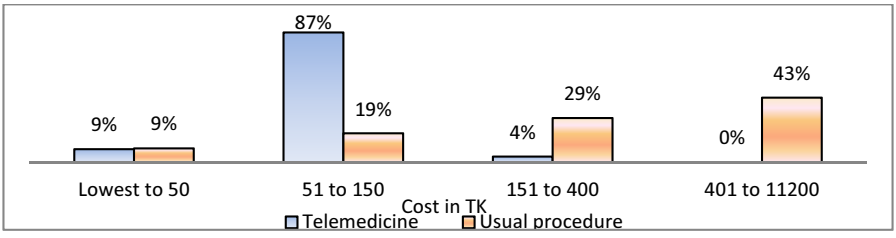

Figure 2: Total cost in both service processes

3.3.1. Testing the Significance Level for Cost

Null Hypothesis

Ho: average cost of those who received telemedicine service = average cost of those who did not receive telemedicine service**.**

Alternative (Research) Hypothesis

Ha: average cost of those who received telemedicine service ≠ average cost of those who did not received telemedicine service.

Table 4. Test of significance for cost

	Test for equality of Variances		Test for equality of Mean		
	F-value	Significance Level	t-value	Degree of Freedom	Significance Level
Equal Variances assumed	30.224	.000	-5.061	242	.000
Equal Variances not assumed			-4.546	108.093	.000

As per the Table 4, Significance Level (0.000) less than 0.05 indicates that the variances are not assumed to be equal; the null hypothesis can be rejected with the p-value for this t-test with 0.000. Therefore, it can be concluded that there is a significant evidence to support that average cost incurred to those who received telemedicine service is not equal to the average cost incurred to those who did not have access this service.

3.4. Comparative Analysis of Time and Cost

From the Table 5, it can be seen that the time spent by a patient to access healthcare services via introduced Telemedicine service was reduced by 56% (226 min to 99 min) compared to the tradition way of accessing the similar service. Similarly, average cost reduced by 94% (710TK to 45TK) in Telemedicine service. From the above discussion, it can be concluded that Telemedicine service appears a more cost effective and time efficient to the rural people in accessing their health care service requirements.

Table 5. Average time and cost in both service systems

Indicators	Required in manual system	Required in telemedicine	Saved (%)
Time (in minutes)	226	99	56
Cost (in TK.)	719	45	94

From the Table 5, it can be seen that the time spent by a patient to access healthcare services via introduced Telemedicine service was reduced by 56% (226 min to 99 min) compared to the tradition way of accessing the similar service. Similarly, average cost reduced by 94% (710TK to 45TK) in Telemedicine service. From the above discussion, it can be concluded that Telemedicine service appears a more cost effective and time efficient to the rural people in accessing their health care service requirements.

3.5. Advantages of Telemedicine Service

Study revealed that the introduced telemedicine service offers various advantages shown in Figure 3. In addition to a substantial reduction in time and cost, it provides other advantages including easy access to service (68%), less frequency of visit (67%), easy access to specialized doctor (65%), less harassment (59%), better service quality (54%), less travel (49%), and 24/7 service availability (46%).

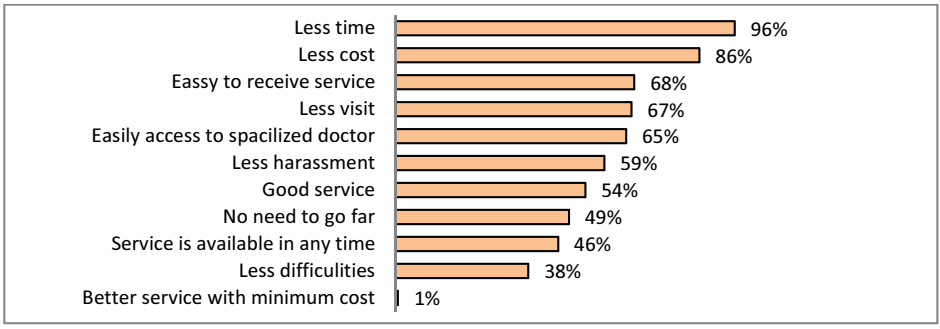

Figure 3. Advantages of Telemedicine service (multiple responses)

Table 6. Level of satisfaction of the respondents about Telemedicine service

Satisfaction Level	Percentage (%)
Satisfied	51
Moderately Satisfied	11
Very Satisfied	38

3.5.1. Level of Satisfaction

Table 6 shows the level of participant satisfaction in accessing health care services through proposed telemedicine system. About 51% informants opined that they were satisfied with Telemedicine service, whereas 11% were moderately satisfied. In contrast, 38% service recipients indicated that they were very satisfied with the introduced Telemedicine service.

Conclusion and Discussion

The findings of this study show that telemedicine service reduces significant amount of time and cost for the user to access the required health services. Majority of participants indicated that they had access their required health services within an hour. The significance test also supports the finding in that the telemedicine service consumes less time to provide health care access compared to the conventional procedure. In terms of cost, the study revealed that the telemedicine service reduces the health care cost of patient to a great extent. Users had to spend even less than 50TK on an average whereas they had to spend about 1000TK to access the same service in a conventional means of the service. In addition, the telemedicine service offers other

advantages resulting a higher satisfaction in the service recipients. Therefore, the Telemedicine service seems very cost and time effective health service method for the rural population of Bangladesh. It ensures easy accessibility to the health services for a large portion of citizens. This service decentralizes the modern health facilities offering rural population easy access to specialist doctors or hospitals from remotely. A Telemedicine system can, therefore, be considered as a potential and effective health service access means for the people especially living in remote and rural areas.

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Improving the Quality of Informed Consent in Clinical Research with Information Technology

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Abstract. The clinical research industry has yet to fully embrace information technology (IT) for informed consent purposes, even though it is used indispensably in our everyday lives and in other areas of clinical research and healthcare. This paper presents findings of a meta-narrative literature review to discuss the potential for IT to improve the quality of clinical research informed consent. The review reveals three main rationales for including IT in research consent. First, in the *current context* consent documents frequently fail to be effective decision aids for patients, and the lack of patient centricity in the process. Second, *social media* provides opportunities for patients to consult with a broader community during research consent to seek broader support, and potential to participate in creating a more patient centric process. Third, *multimedia tools* provide opportunities for improved patient education, engagement and decision making during research consent. IT offers opportunities to achieve more meaningful research consent, but more research is needed to create an evidence base, policies and economic analyses on the return on investment of using IT in the process.

Keywords. Clinical research, human subject research, informed consent, information technology, multimedia, social media

Introduction

People find it rewarding to contribute to clinical research; it is a way to give back and also an opportunity to access early forms of treatments. Potential participants are required to give informed consent before contributing to research. This is a legal and ethical requirement. Informed consent in human subject research is defined in the US Code of Federal Regulations (CFR) as a

> *"...person's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic, or preventive procedure. In giving informed consent, subjects may not waive or appear to waive any of their legal rights, or release or appear to release the investigator, the sponsor, the institution or agents thereof from liability for negligence [Federal*

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Policy §116; 21 CFR 50.20 and 50.25]" (http://www.hhs.gov/ohrp/archiven /irb/irb_glossary.htm).

Informed consent in clinical research should provide a potential participant with adequate knowledge, understanding, support, and time to consider participation in a study. In reality, the practice of research consent is variable and its theoretical ideal is hard to achieve.

The absence of an extensive body of literature focusing on the use of information technology (IT) in research consent, means our collective understanding of how IT may improve the quality of the process remains fragmented. Our research question was, 'How can the inclusion of information technology in clinical research informed consent enhance the consenting process?' In this paper we describe the metanarrative literature review method we used, and the results of that review.

1. Method

Greenhalgh et al.'s meta-narrative mapping method [1] was used for the review as per Table 1. This qualitative, iterative and interpretative method was suited to the research question and allowed data from the heterogeneous, interdisciplinary body of literature (traditional and non-traditional references) to be gathered, synthesized into meta-narratives and discussed with a transparent systematic process. The review process can be broken down into six phases (planning, search, mapping, appraisal, synthesis and recommendations) which overlap and each feed into the next.

Table 1. Phases of the meta-narrative review and results

Metanarrative literature review phase	Activities and results
Planning – scoping literature search	• Hand search, browsing in journals. • Electronic search in Google Scholar. • Talking with experts and industry representatives. • Search terms ascertained for use in the formal search phase.
Searching	• Focused database search in PubMed → snowballing. • Focused database search in Scopus → snowballing. • Hand search in clinical research industry magazines → snowballing.
Mapping	• Draft set of meta-narratives. • Additional searches using intuition, informal networking (with supervisors and industry representatives), serendipity (discovering a useful article during the process of searching for something else) and browsing electronic sources such as industry websites.
Appraising	• Appraisal of traditional literature (empirical studies). • Appraisal of non-traditional literature (narratives, opinions, policy documents, reviews, commentaries websites).
Synthesizing	• Iterative refinement of 3 meta-narratives (Current Context, Social Media, Multimedia Tools).
Number of sources used for final report	• Final report (Masters Dissertation (2)) 134 sources: 73 articles, 36 empirical articles, 17 websites, 4 books, 4 policies/reports.

Table 1 illustrates the six phases and how they were used in the review. In total, 134 sources were included in the review – see the full report [2] for complete treatment of methods, results and discussion. For the purposes of this article, a selection of 25 representative sources [3-27] forms the core of our results.

2. Results

Patterns emerged from the literature that resulted from the search. There was very little literature on multimedia tools used for research consent but there was a significant amount of literature on the use of multimedia tools for education associated with clinical research, and social media show promise in the healthcare context. There was a paucity of literature on the use of electronic consent (e-consent). We found three main rationales for including IT in research consent.

2.1. Current context

Many challenges exist in the face-to-face interview and paper based (traditional consent) process. Education and support are often compromised by the health status and education and/or literacy level of the patient, communication skills of the person obtaining consent. Lack of time for patients to ask questions is often an issue. Adding to the complexity, researchers need to ascertain patient comprehension of lengthy documents, which include medical and legal jargon [3-6]. Brehaut et al. [4] conducted a study that looked at the extent of 139 informed consent documents from trials registered with ClinicalTrials.gov and how they conformed to patient decision aid standards. The study concluded that most standards were not achieved by the consent forms and most emphasized information provision over support. The challenges inherent in traditional consent often result in patients making poorly informed choices when it comes to trial participation. In turn, this can lead to complications during a study such as increases in recruitment time, withdrawals, adverse events, law suits, and cost increases.

Meaningful research consent is often not attained in traditional consent processes due to the numerous challenges it presents. Meaningful informed consent can be explained as patient education and engagement in the informed/shared decision making process. It should inform patients about their options and the significance of their choice and ensure that the process is aligned with laws, codes and regulations relating to informed consent, confidentiality and individual choice [7]. A seminal paper by Beecher [8] points out that there is a general assumption that the principles incorporated in codes and regulations will be practiced during traditional consent. A basis is thereby provided for informed consent that is meaningful and available when required, but this is often not the case as is evident from several highly unethical incidents in research consent that resulted in harm to participants.

Traditional consent lacks patient centricity. The aim of patient centric care is to allow patients to become more involved in their health care and decisions by improving patient engagement with improved access to information and shared decision making. Patient needs in clinical research have traditionally not been met. The industry has come to the realization that by addressing patient needs, sponsors of clinical trials may also benefit by creating more efficient processes which can decrease burden during a study and trial costs [9]. The 2011 Salzburg statement on shared decision making

supports the shift to patient centricity in healthcare practices [10]. The statement points out that for decision making between patient and clinician to become increasingly shared, policy makers, patients, and clinicians need to change expectations and practices and create pressure to change laws. In 2010, the US President's Council of Advisors on Science and Technology recognized that patient needs and specific characteristics are important in clinical research, and that processes should be organized around these needs and characteristics [11].

IT has not been brought to bear in research consent. The results of pilot studies by those producing software for research consent purposes, electronic consent (e-consent) and consent applications (apps) may need to be approached with caution as the impartiality of the literature cannot be assumed [12]. It is important then to look at empirical research and examples from the literature, of the use of multimedia tools (which can be incorporated in e-consent and apps) and social media in other areas of healthcare, as they hold significant insights into how IT may be incorporated in research consent to enhance the quality of the process.

2.2. Multimedia Tools

Multimedia tools and features incorporated in e-consent and consent apps may enhance information provision and support during research consent. Studies focusing on e-consent and apps are scarce [13]. Studies that focus on multimedia tools and their features to improve the quality of patient education and comprehension in various other areas of health care generally show positive results. Examples of these features and tools include: interactive education [14]; simplification of documents and language to improve readability and comprehension [15]; audio tools to improve education and reduce anxiety preoperatively [16]; video tools for pre-operative consent [17]; and tools for verification of understanding [18]. The literature shows increases in comprehension, likelihood to read a whole consent document, and patient satisfaction, and improvements in preferences to take up treatment. There are mixed results regarding knowledge recall and increases in knowledge. The literature shows that anxiety decreases.

2.3 Social Media

Social media may provide benefits for information provision and support during research consent. Examples of social media used to improve the quality of patient education and comprehension in various other health care settings include: blogs and microblogs; social networking; professional and thematic networking sites; collaborative filtering, e.g. HLWIKI Canada; media sharing sites, e.g. American Heart Association; and Multi User Online Environments (MUVE) [19-21].

The inclusion of various forms of social media in research consent may improve the quality of the process by opening up various communication channels. Its incorporation during research consent may mean that information provision and support are enhanced as interaction is not restricted to patient and clinician. Instead, patients can open up online dialogue and interaction with peers and professionals and exchange information, opinions and experiences during the process from anywhere and at any time [22]. There is value in having up to date information and support readily available through social media for this iterative process [4].

The use of social media in research consent may improve the quality of the consent process by overcoming comprehension issues associated with medical and legal jargon. It has been noted though that the simplification of language in documents may result in a lack of precise information [23]. The use of reference systems via social media may create opportunities to retain precise information while simultaneously offering support and enhanced comprehension. Clauson et al. [24] looked at Wikipedia's accuracy by comparing it to the Medscape Drug reference. They concluded that Wikipedia includes 76% of the information in Medscape with few factual errors, but that the scope was narrow and contained errors of omission. Nevertheless Wikipedia is a good starting point for those seeking health information. An additional source of information available through the Internet is Medline Plus (https://www.nlm.nih.gov/medlineplus/), a patient focused source of information specifically developed for people not clinically trained. The purpose of SemLink is to make the text in discharge summaries more comprehensible to consumers [25]. Infobuttons collects online context specific health information [26].

Patient powered research networks, can form quickly and easily on social media and are often comprised of participants who have rejected sponsor-led research studies, sometimes due to the lack of patient centricity. They have started their own studies, sometimes by unblinding themselves, pooling data, scouring and dissecting literature, conducting statistical analyses, and posting their findings online [27].

3. Discussion

We conducted a literature review to examine how IT can enhance the informed consent process for clinical research. Three themes emerged: examination of how traditional research consent fails to achieve informed consent goals; the potential of multi-media tools to improve knowledge acquisition and recall; and the promise of social media in offering interactivity between participant, research teams, and other participants. The role of IT in research consent is potentially far reaching. E-consent tools and apps create opportunities to broaden access to consent information to a wide variety of patients and support people at any time and from anywhere. Social media creates opportunities for patients to consult with a broader community during research consent. IT stimulates innovations to improve consent processes and enhance patient centricity. IT signals a new direction for regulatory-compliant meaningful informed consent in clinical research.

While e-consent and consent apps may standardize informed consent procedures and provide an audit trail, new regulatory concerns emerge, such as issues pertaining to privacy and confidentiality [28]. While social media may increase information exchange, there is the risk of deviations occurring from ethical standards, and of misrepresentation and lack of validity of information. As a consequence of these concerns, e-consent tools and apps go through rigorous legal and licensing processes before market release [29]. The tools are included in the Institutional Review Board (IRB) process, and access can be encrypted to ensure only authorised access.

New regulatory concerns arise from patient powered research networks formed on patient thematic networking sites such as PatientsLikeMe [22, 30]. Current ethical guidelines assume that in research a participant and researcher exist. Informed consent is carried out between the two, and documented before any research procedures are carried out. Social media changes this: it is not clear who the patient is and who the

researcher is, or one person plays both roles (Wicks, 2014). Applying current regulations in this type of situation may not be possible if the regulations are designed to protect the patients from researchers. Regulations may need to focus on the risks of peer-to-peer research rather than the traditional model of patient-researcher [22].

Fear of the unknown and lack of understanding of the true risks, and lack of empirical research, may be major barriers against the development of new codes and regulations [31]. Questions are now being raised as to how laws and guidance for the use of technology in research consent should be developed while providing adequate protection. According to the theory of cultural lag [32], when social guideline development for the use of material technology is slower than development of the technology it can result in conflict leading to liability accusations and product stigmatization. The principles of cultural lag provide a means to avoid controversies that may result from new technologies by viewing and anticipating problems before they occur. Public education should be coupled with market demands for the new technology. This can be achieved by lay and professional discussions to aid establishment of guidelines, which in turn develop social consensus around the appropriate way to use these new technologies [33, 34].

In response to the need for new guidelines, the US Food and Drug Administration (FDA) released draft guidance for the use of social media [35] in June 2014. In 2015, the FDA released revised guidelines on the use of mobile medical applications, "Mobile Medical Applications-Guidance for Industry and Food and Drug Administration Staff," limiting the use of mobile technologies to those that have been established to be safe. This was followed by a new draft guidance document offering specific guidance on the use of IT in research consent [36].

This research has limitations. The scope was limited by the constraints of a dissertation. Since the inclusion of IT in clinical research consents is relatively new, there was a broad range of research, and limited empirical research on the use of social media and multi-media in informed consent processes. This was mitigated by the use of the meta-narrative approach to literature review, which embraces many narratives and diverse forms of empirical research methods.

Conclusion

The role of IT in research consent is potentially far reaching but the uptake of it has been slow. The traditional consent process remains the mainstream practice even when difficulties are well documented and the benefits of IT are applied in other areas of health care. The development of codes and regulations for the use of IT in research consent lag behind the available technology – a situation that may be compounded by the lack of available research. IT in the form of multimedia tools and social media in e-consent may offer the potential to improve the quality of research consent, attain a meaningful and patient centric process, overcome the challenges with the suboptimal traditional consent process, and may allow for an alternative to this process.

Further considerations and questions which may encourage future research and development of regulations and codes to allow for the widespread, lawful, ethical and secure use of IT in research consent include:

- Can IT become a substitute for the traditional informed consent process in research consent, or is it better used in conjunction with the traditional informed consent process?

- Is it appropriate to delegate discretion to the clinician obtaining research consent to decide if the use of direct patient-to-clinician interaction on social media is appropriate in the process?
- What are the economic effects of the introduction of IT in research consent?

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The Promise of New Technologies in an Age of New Health Challenges
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A Review and Critique of Teledermatology in the South African Public Health Sector

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Abstract. Nearly 80% of the world's population live in developing countries in Asia, Africa, and Latin America. Many of these countries must face a triple or quadruple burden of disease with severely limited resources and health systems. South Africa (SA) is one such country, and recognises the potential for e-health to moderate these limitations. Dermatological issues remain a concern in SA and globally. Indeed, the World Health Organisation (WHO) has recognised that a number of diseases are most likely to manifest themselves through a dermatological problem before becoming full-blown. However, there is an acute shortage of dermatologists in SA. Teledermatology has promise as a service delivery intervention. This study reports on the current status of teledermatology services in the public health sector of SA. Methods: The study adopted a qualitative, inductive research approach based on a structured literature review of teledermatology in SA. A modified Momentum-Treat tool was used to critique identified teledermatology services. Results: 159 resources were identified, of which 68 were excluded. The remaining 91 resources revealed a history of ad hoc teledermatology services, of which few remained active. Requests for teledermatology service confirmations provided some feedback, together with follow-up meetings and interviews. Discussion: No evidence of scaling of teledermatology services and integration into routine healthcare was found. Of eight services, 4 remain active. Review and modified Momentum-Treat critique showed opportunities for improved readiness assessment, programme governance, and alignment to government policy direction, in order to improve scaling and sustainability. Conclusions Full-scale teledermatology integration is possible, but stronger programme development is needed. Findings will inform development of a teledermatology scale-up framework to assist with future integration of teledermatology into routine healthcare.

Keywords. South Africa, teledermatology, scaling, Momentum-Treat

Introduction

About four-fifths of the global population live in developing countries, most of which are said to face a triple burden of disease: communicable disease, non-communicable disease, and socio-behavioural illness [1]. Often they do so with limited resources, insufficient skilled healthcare providers, and inadequate healthcare systems. e-Health, the use of information and communication technologies (ICT) for health, is being promoted as one means to address some of these challenges [2].

South Africa (SA) suffers from a quadruple burden of disease: HIV/AIDS and tuberculosis, high maternal and child mortality, non-communicable diseases, and violence and injuries [3, 4]. The leading cause of death is HIV/AIDS with morbidity

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and mortality in relation to skin diseases including HIV/AIDS, skin cancer, and burn wounds [5, 6]. Indeed, the World Health Organization (WHO) has recognised that a number of diseases are most likely to manifest themselves through a dermatological problem before becoming full-blown [7]. But there is an acute shortage of dermatologists in South Africa, with the majority (65%) of the 167 registered dermatologists in private practice and concentrated in major urban hospitals [8]. The dermatologist to population ratio is 1:310,000 vs the ideal estimate of 1:50,000 [9, 10].

In SA, health related policy development, legislation and programme leadership lies at the National level with the Minister of Health, with responsibility for planning and delivery of services at the level of the 9 Provinces, and with local government responsible for municipal health services relating to environmental health [11]. SA spends 8.5% of GDP on healthcare, higher than the WHO recommended 5.3%, yet health outcomes are not comparable with other developing nations [12]. There is also maldistribution of resources, with SAs health system being comprised a two-tiered public and private system, with the under resourced public sector serving 84% of the 52 million population.

The country requires innovative interventions to address the burden of disease [13], the inequitable access to health services [12], and the appropriate use of ICT through telemedicine [14-16]. Dermatology, partly due to its visual nature and the shortage of dermatologists, is one of the most common uses of telemedicine after teleradiology and telecardiology [17, 18] and is uniquely positioned to enhance the effectiveness and efficiency of the referral process [19]. The SA government has identified the use of telemedicine as a service delivery intervention to support appropriate access to healthcare through the National eHealth Strategy and mHealth Strategy [14, 20].

The government's support for telemedicine's value proposition (enhanced service delivery interventions that improve patient care in rural areas and improve referral decision-making [14, 21]) is demonstrated through formulation of various strategies. These include the formalisation of eHealth [14] and mHealth [20] strategies, together with an ICT Research Development and Innovation Roadmap [22], National Health Normative Standards Framework for systems interoperability [23], National Health Strategy (2014 to 2019) [13, 24], and the development of an Electronic Health Patient Registration System [25]. Attempts to formalise ethical guidelines since 2008 and a telemedicine strategy since 2012 have not yet been realised [26, 27].

The initial national telemedicine programme, the National Telemedicine System, (NTS) launched in 1999 did not include teledermatology. The NTS failed for various reasons ranging from low system utilisation and cost effectiveness concerns, to technical and organisational challenges [28, 29]. The province of KwaZulu-Natal (KZN) took advantage of the videoconferencing infrastructure installed for the NTS, and synchronous teledermatology was initiated in 2003.

While teledermatology has been practised, no teledermatology service has yet been scaled-up to meet the needs of a Province or SA as a whole [30, 31]. An opportunity exists to address this scale-up gap by developing a teledermatology scale-up framework (TD-SF) that would enable the widespread operationalisation of teledermatology in the public health sector. The aim of this study is to gain an understanding of the history and current status of teledermatology programmes in South Africa's public health sector to inform the development of a TD-SF.

1. Methods

The study adopted a qualitative, inductive research approach [32, 33] based on a structured search of databases of peer-reviewed journals, Scopus, PubMed, and Science Direct, and grey literature.

Search strings included the following terms: teledermatology, telemedicine, or telehealth, linked to South Africa and SA's nine Provinces (Eastern Cape, Free State, Gauteng, KwaZulu-Natal, Limpopo, Mpumalanga, Northern Cape, North West, Western Cape). Only papers in English, and published to the end of 2015 were sought. In addition, hand searching of electronic grey literature was performed by doing backward and forward secondary reference checking [34]. eMail requests were sent to authors to confirm the status of identified teledermatology services. Inclusion criteria were reference to teledermatology or teledermatology related telemedicine programmes or services in any of the country's nine provinces. All abstracts were screened for inclusion criteria and full texts of included records were read and analysed.

The services were categorised into three groups according to the communication mode: asynchronous, synchronous, or hybrid. In addition a high-level critique of the identified services was performed using a modification of the 2015 MOMENTUM-TREAT-Toolkit (Momentum-Toolkit) [35], intended to support the scaling-up of telemedicine programmes. The toolkit comprises a core requirement, four domains, five elements, 18 critical success factors (CSF), and supporting indicators (Table 1) [35]. The core requirement is based on the Model for Assessment of Telemedicine (MAST) [36], and must be met prior to considering scale-up . The developers of the toolkit recommended the tool be adapted to specific contexts, and indicated that some CSFs overlapped. Taking this into consideration, the Momentum-Toolkit was modified, and only CSFs 1, 2, 3, 4, 9 and 17 were selected (Table 1). This selection was representative across the four domains and enabled a high-level critique: CSF1 relates to context; CSF 2 relates to context and core requirements; CSFs 3 and 4 relate to people; CSF 9 relates to plan; and CSF 17 relates to run. Additional criteria such as financial plan to support CSF 9 (business plan) and technological readiness to support CSF 1 (cultural readiness) were included (Table 2). A Likert scale was used to evaluate how well the service met a selected CSF (1 = "Not Met", 2 = "Unsure", and 3 = "Met").

Ethical clearance for this study was granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal.

2. Results

A total of 159 unique records were identified of which, 68 did not meet the inclusion criteria. The remaining 91 records were from journal articles (44), conference papers (14), web pages (11), theses and dissertations (9), books (4), and reports (9). There was a steady increase in the number of peer-reviewed teledermatology and related service literature over the past 21 years: 21 (1995–2005), 24 (2006–2010) and 46 (2011–2015).

Table 1. Adaptation of the MOMENTUM-TREAT-Toolkit with selected CSFs in bold and shaded.

Elements	Core requirements	Domains			
		Context	People	Plan	Run
Strategy and management (strategic elements necessary for the initiation of the services)	**Need for evidenced based intervention** **IT system design**	**CSF 1: Cultural readiness**	**CSF 3: Leadership**	CSF 7: Resource aggregation	
		CSF 2: Compelling need			
Organisation and management (management challenges for successful implementation)			**CSF 4: Stakeholder involvement**	CSF 8: Primary Client	
			CSF 5: Patient centeredness	**CSF 9: Business plan**	
				CSF 10: Change management	
Legal and security (important legal and security issues)				CSF 11: Legal and security conditions	CSF 13: Legal and security guidelines
					CSF 14: Legal and security experts
					CSF 15: Privacy awareness
Technology and market (technical infrastructure and market relations)			CSF 6: User friendliness	CSF 12: Potential to scale-up	CSF 16: IT and eHealth infrastructure
					CSF 17: Service monitoring
					CSF 18: Market procurement

Fourteen requests for teledermatology service confirmations were sent and feedback from seven (50%) received (Western Cape, Eastern Cape, KwaZulu-Natal (KZN), and Limpopo). five interviews conducted. Sufficient literature was available to critique services in only three provinces, Eastern Cape, Western Cape, and KZN. Currently, there are only four active services, two in KwaZulu-Natal (Dlova N and Mosam A, 2016, interviews) and, two in Western Cape (Todd G, 2015, email).

Two projects were reported in the Eastern Cape, neither of which is active. In 1999 a store and forward service was reported between a general practitioner in rural Port St Johns, and the University of Walter Sisulu, the Medical University of South Africa, Armed Forces Institute of Pathology (USA) and the Lemuel Shattuck Hospital (USA) [37]. In 2002 the project was migrated to an Internet based, asynchronous modality using iPath, and was last reported in 2004 [38].

In KZN a store and forward email based service started in 2001 between UKZN and doctors at the most rural hospitals. Due to lack of connectivity in the hospitals doctors had to use their own computers from home after hours using dialup modems to provide the service. This was too labour intensive and the service ended in 2002 (Mars M, 2016, interview). A synchronous service started in 2003, which a proof of concept at one site with the aim of scaling up across the province with three sites active to date [39-41]. This service reduced the referral rate by 75%, enhanced the University's out-reach programmes, and supplemented the continuing medical education programmes

for doctors and nurses [41]. In a few exceptional instances further contact was made by telephone to confirm availability of drugs or the treatment plan. In 2013, a spontaneous, unplanned teledermatology service began, which used smartphones to take, send and receive images and data between residents/registrars undergoing dermatology training and subsequently doctors at rural hospitals, with dermatologists at UKZN. This service continues to grow [6, 42, 43].

In the Western Cape an asynchronous service originated at the University of Cape Town's Department of Dermatology in collaboration with the University of Washington, with referral sites in three provinces [44]. A nurse-led cellular phone based service from a mobile clinic has been reported in the Overberg District [45], and spontaneous use of mobile devices for teledermatology has been reported, similar to that in KZN (Todd G, 2015, email). The results of the high-level critique, based on the adapted MOMENTUM-TREAT Toolkit, are shown in Table 2.

Table 2. Results of high-level critique.

Requirement Type	Description	Eastern Cape	KwaZulu-Natal	Western Cape
Core	Compelling need (CSF 2)	3	3	3
Domain				
1. Context	Cultural Readiness (CSF 1)	2	2	2
	Technological readiness	2	3	2
2. People	Leadership (CSF 3)	3	3	3
	Stakeholder involvement (CSF 4)	2	3	2
3. Plan	Business plan (CSF 9)	2	2	2
	Financial Plan	2	3	2
4. Run	Service monitoring (CSF 17)	3	3	3

All the services achieved a 'met' rating (score of 3) for meeting the core requirements of being based on a defined need. In terms of the context domain, all services received an 'unsure' rating (score of 2) for uncertainty of conducting assessments for cultural readiness. In terms of technological readiness only KZN provided anecdotal evidence that an assessment was performed prior to expanding the videoconference infrastructure from 9 to 37 (Mars M, 2016, interview). In the people domain for KZN literature supports leadership and stakeholder involvement and received a 'met' rating [21, 40]. Although the Eastern Cape [46, 47] and Western Cape [48] provided evidence of service leadership there was insufficient information on stakeholder involvement. In the plan domain, the literature was unclear on the existence of a business and or supporting financial plan for both Eastern and Western Cape. In comparison KZN received an 'unsure' rating based on unclear evidence to support the existence of a business plan, but there was anecdotal evidence of initial supporting financial plans [21]. Finally, all the provincial services performed initial service monitoring and evaluation [37, 41, 48]. The total number of 'met' ratings for the various services across the core requirement and the four domains are 6 for KZN, of which three (50%) are based on anecdotal evidence, and a rating of three each for both Eastern and Western Cape services.

3. Discussion

Various attempts have been made to implement teledermatology in South Africa since 1999. There are currently four active services, with no evidence of a national or

provincial scale-up. There is no evidence of Provincial leadership or budgeting for teledermatology, with the KZN and University of Cape Town services being driven by the medical schools. An unexpected finding was the existence and growth of spontaneous adoption of mobile devices for teledermatology from 2013 onwards. Migration to an Internet based platform was not successful. The literature although increasing, provided scarce programmatic evidence, with the exception of KZN where access to initial leadership was possible.

Despite the intention to scale up in KZN, this has not been realised. While the National Department of Health (DOH) supports the concept of telemedicine it is noteworthy that the reported teledermatology services originated at University Medical Schools, the Medical Research Council (MRC) of South Africa and the Council for Scientific and Industrial Research. There is little or no evidence of support from the respective Provincial Departments of Health, with the exception of the Eastern Cape, which provided digital cameras to 50 clinics for asynchronous teledermatology [31]. In Limpopo province the Provincial DOH entered into a public private partnership for the implementation of telemedicine services, including teledermatology. No data have been reported for either of these services. A recent survey found little evidence of Provincial DOHs taking ownership of telemedicine or budgeting for it.

Other constraints exist. The Health Professions Council of South Africa, the statutory body regulating medical practise has hampered telemedicine uptake through press releases stating that "telemedicine is unethical" [49] and tardiness in releasing guidelines for the ethical practice of telemedicine, which have been in development since 2007 [50].

The pervasiveness and utility of mobile technology is evident in the spontaneous uptake of mobile devices to provide healthcare services at the point of care. The cost of ownership and cost of connectivity for such services are borne by healthcare providers to the benefit of the healthcare system [43]. Although there is no reported resistance by patients or clinicians to the use of mobile devices in this fashion, concerns have been raised about data security and clinicians bearing the costs. Supporting this is evidence from Botswana that patients find mobile teledermatology acceptable [51], and from a Korean study that the process was found to be simple and the diagnostic accuracy "superior" to non-dermatologist diagnosis [52].

There is evidence of telemedicine devices having been installed in all provinces by the MRC but no data on their subsequent use are available. The continued reality of box dropping in the provinces, whereby equipment is procured and installed without a holistic systems implementation approach, is seen as an end in itself, which contributed to a premature termination of the NTS [40, 53, 54]. The exception to this is Limpopo Province where the public private partnership aided implementation of telemedicine services, but no data on its use have been reported. The critique reflected this overall trend of informal planning with 'unsure' ratings.

The WHO's Expandnet network confirms that scale-up needs to be planned for from the outset to ensure success [55]. Furthermore there is no compromise for adopting a holistic approach to context sensitive, technological, financial, and human resource planning for an intervention. In addition there is a need for alignment with national strategies, definition of measurable objectives, performing readiness assessments, rigorous implementation management, and feedback loops to enable the realisation of intended impact. Van Gemert-Pijnen et al. and Van Dyk provide support for the adoption of an holistic approach [56, 57].

The Momentum programme [35] provides one of the more recent attempts to incorporate a holistic approach, but further refinement is required to ensure it meets the unique South African context. Mars and Dlova [41] and a related study by Colven et al and O'Mahony et al. [37, 48] provide evidence of evaluating the outcome of the intervention against defined objectives including educational benefit. Colven found up to 60% enhancement of diagnostic acumen of primary care providers, and Mars and Dlova found that referring doctors highly rated the educational benefit of case discussion with the dermatologist during and after synchronous consultation [41, 48].

The critique was limited by the paucity of peer-reviewed teledermatology specific literature for all the Provinces, resulting in only three Provinces being considered. Furthermore the requests for confirmation and additional information from authors of reported services were largely unsuccessful with the exception of KZN, Western Cape, and Limpopo. In addition the available literature lacked detailed project conception, planning, implementation and operational information. Of importance is that the reviewed papers reflect on the state of the services at the publication date and not their current state. The state of services in the Western Cape, KZN and Limpopo were confirmed through emails, and interviews.

Conclusion

Although limited, the understanding gained of teledermatology's history and current state in SA will inform the development of a holistic conceptual teledermatology scale-up framework of potential value domestically and elsewhere. Scale-up will contribute towards equitable dermatologist access through an efficient, effective, and sustainable referral service delivery intervention. The framework should embrace the bottom-up progress and ensure alignment with the Provincial and National Government's top-down strategic and policy direction. In particular, the results from the high-level critique and literature (showing a requirement for an evidenced based health need; cultural and technological readiness; leadership and stakeholder buy-in; business and financial planning; and service monitoring) will provide the initial minimum requirements for the development of the teledermatology scale-up framework.

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The Promise of New Technologies in an Age of New Health Challenges
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A Population-Level Data Analytics Portal for Self-Administered Lifestyle and Mental Health Screening

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Abstract. This paper describes development of a prototype data analytics portal for analysis of accumulated screening results from eCHAT (electronic Case-finding and Help Assessment Tool). eCHAT allows individuals to conduct a self-administered lifestyle and mental health screening assessment, with usage to date chiefly in the context of primary care waiting rooms. The intention is for wide roll-out to primary care clinics, including secondary school based clinics, resulting in the accumulation of population-level data. Data from a field trial of eCHAT with sexual health questions tailored to youth were used to support design of a data analytics portal for population-level data. The design process included user personas and scenarios, screen prototyping and a simulator for generating large-scale data sets. The prototype demonstrates the promise of wide-scale self-administered screening data to support a range of users including practice managers, clinical directors and health policy analysts.

Keywords. Data analytics, mental health, population health, primary care, screening

Introduction

Increasing computerisation in healthcare delivery provides a wealth of 'Big Data' for analysis. In the US context, Bates et al. [1] characterise the opportunity primarily in terms of reducing costs, with key use cases for Big Data in high-cost patients, readmissions, triage, patients with worsening conditions, adverse events, and diseases affecting multiple organ systems. In primary care, there is potential for substantial long-term health gains by moderating risky behaviours (such as smoking, alcohol misuse, problem gambling and physical inactivity) and treating mental health issues including anxiety and depression, as well as anger and abuse. To gain these benefits requires detection in the first instance, and longer-term tracking for assessing needs and trends at the population level.

The electronic Case-finding and Help Assessment Tool (eCHAT) has been developed to provide systematic screening for risk behaviours and mental health issues [2]. eCHAT is designed to be operated directly by the health consumer. Screening questions assess potential issues and are followed up by validated assessment tools if

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necessary (e.g. the 9-item Patient Health Questionnaire–Depression, PHQ-9 [3]). Further, eCHAT asks a 'help' question in each identified problem area, directly asking the health consumer if they want help with the issue (not at all, at the present time, or later). In the present deployment context, eCHAT is completed prior to visiting a primary care physician (often in the waiting room using a tablet computer provided by the practice) and a summary report is transmitted directly to the doctor's electronic medical record (EMR) system for discussion in the consultation.

The intention is to roll-out eCHAT widely (in its home country of development, New Zealand, in the first instance). This would result in the potential for screening results being available in aggregate at many levels, including the individual practice, as well as to wider networks, regions and nationally. In this paper, we describe the design of a prototype data analytics portal to support use of population-level eCHAT data.

1. Determining Requirements for the Portal

Requirements for the data analytics portal were formulated by analysis of the data collection tool (eCHAT), its data (screening results) and of the intended use of the data.

As mentioned, eCHAT asks the health consumer a series of questions around lifestyle and mental health issues. To keep this computerised interview relevant and as short as practical, the questions on each topic (module) follow a general sequence:

- Screening questions. If these are answered in the negative then the rest of the module is skipped (e.g. if you say you do not drink, then no further questions on the effect of alcohol on your life are asked).
- Discovery questions. Questions where the answers are part of the characterisation of any potential problem in this area.
- Assessment questions. Questions that combine to form a score from a validated instrument (e.g., PHQ-9; Alcohol, Smoking and Substance Involvement Screening Test, ASSIST [4]).
- Help questions. To reduce false-positive assessments and give an indication of patient preference, a module that had a positive screen/assessment finishes by asking if the health consumer wants help with this issue: "no"; "yes, but not today"; or "yes".

There are some overlaps among these types of questions. Taking the depression module as an example, the first two questions of the PHQ-9 serve as the screening questions; and the 9 questions of the PHQ-9 are the totality of the discovery questions (with the last PHQ-9 question, regarding potential self-harm, having specific significance), as well as constituting a set of assessment questions. Furthermore, not all modules have assessment tools, and some screening questions (e.g. regarding concern about sexual orientation in youth) may of themselves constitute the discovery.

At the time of the portal design (2015), eCHAT had recently been expanded with a set of sexual health questions intended for youth. This modification of eCHAT had been field tested at a secondary school in a low-income area of Auckland metro, resulting in 107 interview records collected over four days, from 45 male students and 62 female students (median age 16 years). These records were analysed in concert with

eCHAT technical specifications to develop a full understanding of data domains and dependencies. Additionally, possible research questions specific to these data were discussed between the technical (first two authors) and psychology/clinical (latter two authors) researchers. Note that development, field testing and analysis with respect to expansion of eCHAT for youth sexual health was undertaken in accordance with a protocol approved by New Zealand's 'Northern A' Health and Disability Ethics Committee (NTY/11/10/102).

To further elicit the data analytics requirements and envision the usage of the portal, we followed the interaction design practices of developing personas ("hypothetical archetypes of actual users" [5], p. 123) and scenarios (presentations of "possible ways to use a system to accomplish some desired function" [6], p. 34). We developed a set of personas representative of intended future users of population-level data at various levels of aggregation from an individual practice to nationwide. We then created scenarios for the personas using the portal in ways typical of their roles and responsibilities as they might if eCHAT data were available on a large scale. These personas are summarised in Table 1; Figure 1 shows an example scenario.

Table 1. Data analytics portal user persona summary

Persona Role	Relevant Aspects of Their Job	Example Specific Interest
Practice Manager	Oversees resource allocation in her practice of 3,000 enrolled patients and 3 full-time equivalent primary care physicians	Assessing need for providing specialised sexual health support to patients
Primary Health Organisation (PHO) Clinical Director	Keeping the doctors in his network abreast of evidence based healthcare and clinical variation	Tracking preventable cardiovascular risk factors in Māori patients, including smoking
Ministry of Health Public Health Policy Analyst	Researching and monitoring issues to provide evidence-based policy advice relating to mental health	Following trends in youth depression to address media prompted by a high-profile youth suicide

Review of the personas and scenarios revealed that future users would be interested in far larger data collections than the 107 records that were to hand. For instance, if eCHAT were successfully rolled out to all decile 1 (lowest income) schools in New Zealand and used routinely we would expect approximately 50,000 interview records per year; this would be the data set of interest for our Ministry of Health Policy Analyst persona investigating a question about youth depression. To address this, we opted to create a data simulator. This software generates cases using probability distributions. These were initially programmed with two profiles: one modelled on the distribution in the youth data set; and another with expert (latter two authors) estimates for a general population. The simulator follows the 'rules' of an eCHAT interview in that if a randomly-generated case is negative for the screening questions, then discovery, assessment and help questions for that module are left null.

With the above information to hand, design and implementation of a prototype portal was undertaken (principally by the first author) with periodic feedback from the research team (all authors). Many of the output graphs were initially prototyped in Microsoft Excel prior to being programmed for fully-automated production.

It is nearing the end of the year and Amy is reflecting on the operational aspects of the clinic as she begins to plan for the next year. The three GPs who work at the practice have commented that the number of young people who want help with their sexual health and sexual orientation is increasing, but they lack the expertise and time to offer them long-term support. She wonders if demand is high enough to warrant hiring a sexual health specialist as a part-time or full-time staff member.

The eCHAT tool has been in regular use with her clinic for the last year, so Amy opens the data analytics portal and loads the dataset for her clinic. She decides to focus on youth so she filters by age, selecting 13 as the lower boundary and 18 as the top boundary. Then she navigates to the sexual health domain and begins by looking at how many of the teenagers at the clinic are sexually active. Around 30% admitted to being sexually active and she finds that of those, nearly all admit to feeling at risk of a sexually transmitted disease or pregnancy. "How many patients does that equate to?" she wonders. She changes the labels on the display from percentages to number of patients and discovers that 50 patients have indicated willingness to receive immediate help. She repeats this process to find out the number of teenagers who want help with their sexual orientation concerns or unwanted sex and is surprised by the large number of teenagers struggling with these issues. Amy uses the figures obtained from the data analytics portal to estimate how many hours per week a sexual health specialist/counsellor is required and how much it will cost the practice so she can incorporate it into the clinic's budget.

Figure 1. Data analytics portal usage scenario with Practice Manager persona Amy Simpson.

2. Results

The data analytics portal prototype was built using Shiny, an R package used to build interactive Web applications [7]. A Shiny application is comprised of two components that work in conjunction with each other: a server file that provides instructions for the server, allowing it to create output that responds to user inputs; and a user interface file that acts as an HTML interpreter. The prototype required customised features so additional HTML, CSS and JavaScript code was created to work alongside the R code.

With this architecture, the data analytics capability presents to users as a Web portal operating in their browser, and thus is easily scalable for wide delivery to a range of user types as per our personas. Within the scope of the present study, we did not prototype the security model. However, the personas provide guidance for development of role-based access levels.

The data simulator was developed using Python (Python Software Foundation) with a community-contributed module XlsxWriter [8] to output directly to a Microsoft Excel file format. The examples below use a simulated cohort of 5,000 interviewees generated following frequency distributions derived from the 107 real youth eCHAT field study participants.

Figure 2 shows an example screen from the data analytics prototype. The left-hand side controls data access filtering including the domain of analysis (i.e. which eCHAT module), the range of interview dates, and case demographics (age range, gender and ethnicity). The main section of the screen has a tabbed control. Tabs vary by the domain of interest. For a module with an assessment, such as the depression results shown, a first tab shows frequencies of positive and negative screening. The second tab, as per the figure, shows the frequency distribution for the help question result (using a traffic light colour model) joint with the major ranges of the assessment (level of

depression by PHQ-9 in this case). In this case, a distribution on about 500 cases is shown as the simulator was set to have around a 10% rate of interviewees screening positively and following the branch to complete the full PHQ-9. An additional control on the prototype allows shifting between percentage frequencies and frequency counts. Further tabs give additional data including tabular summaries. As can be seen from this data, youth often did not want help with their depression. Note that while the frequency of asking for help with depression for cases with a positive screen is based on the real data, the correlation between asking for help and severity of depression is *not* modelled in the simulator (see more on this limitation in the Discussion section).

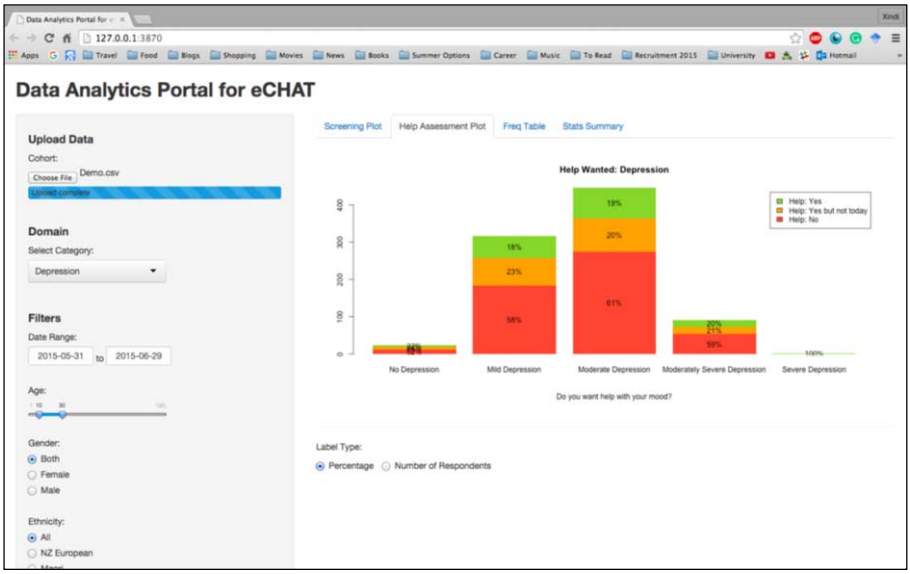

Figure 2. Data analytics prototype screen showing help wanted by depression level

Figure 3 shows a portal screen with the sexual health domain selected. With this domain selected, the left-hand controls adapt to allow selection of sub-domains (sexual orientation, sexual activity or unwanted sexual contact). The main portal provides options within the tabs appropriate to the selected subdomain. The results shown indicate a surprisingly low number of respondents indicating that they are sexually active. As this frequency was derived from the real data, the result served to reveal a problem in the wording of the screening question. The sexual activity screening question explicitly mentions sex involving “your mouth, vagina or bottom” but it does not mention “penis” and thus may have been misinterpreted by many male respondents. Although the wording of the question had been vetted and found clear by a mixed-gender youth focus group, it was flawed in the actual flow of the questionnaire. This shows the value of data analysis to the ongoing refinement of any data collection instrument.

Lifestyle and mental health problems are known to sometimes be correlated [9] or to occur in related clusters [10]. A further area to extend the data analytics platform would be toward analysis of associations between (and among) eCHAT assessments per individual. Some basic design concepts for this, such as use of scatterplot, were prototyped with Excel but not implemented into the R/Shiny prototype.

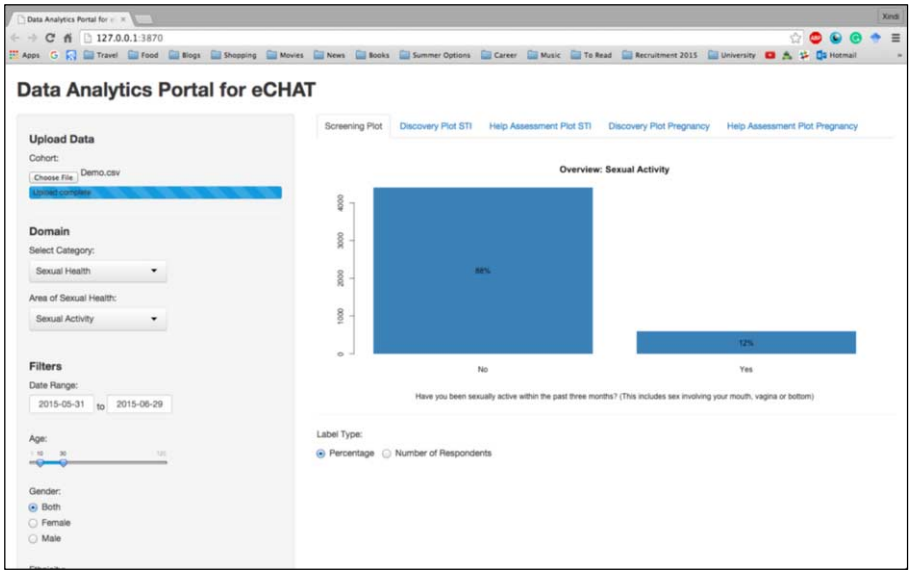

Figure 3. Prototype screen showing screening results for sexual activity.

3. Discussion

This paper reports on the development of a prototype data analytics portal to support use of population-level screening data as applied to eCHAT. This systematic screening tool is a self-administered computer-based instrument measuring lifestyle and mental health issues and has potential for wide-scale deployment in primary care, including settings tailored for youth (e.g., secondary schools). For youth cohorts, a module of sexual health questions was developed and field tested. The data analytics portal prototype demonstrates easy-to-use data filtering and summary displays that would suit a range of future user personas envisioned as having an interest in the aggregate screening results of eCHAT.

There are specific architectures for management of large-scale health data that are relevant to consider as the data analytics capability moves from prototype to production use. Notably, the 'integrated biology and the bedside' (i2b2) [11] is proven as a software framework to create 'data marts' for analysis and could map to the eCHAT case. Moreover, we should not limit our vision to eCHAT used in isolation, given the excellent potential for extensive data linkage through the Statistics New Zealand Integrated Data Infrastructure (IDI) [12] for combination with social determinants of health, health outcomes and other variables. Nonetheless, we feel that the prototyping exercise presented herein is useful for understanding minimal requirements for a system built on these more extended infrastructures. Moreover, it appears there are many useful questions held by typical users that could be answered with relatively simple capabilities, particularly if they are available with the ease-of-use of a customised tool such as we have demonstrated with the present prototype design.

One area in need of considerable functional expansion is the ability to examine associations among screening variables. In visual terms, simple scatterplots of two variables are a starting point. To address multivariate associations, and to cope with the

larger end of our anticipated scale of data (e.g. for national level users), visual representations such as data cubes with interactive pan-and-zoom manipulation of the range of display [13, 14] are promising and increasingly mature. It is unclear whether ease of use can be maintained while providing support for the range of questions (and related visualisation and analysis needs) likely to arise from users of the data collection. At some point an 'export' to a traditional statistical package would be needed to address more advanced analytical goals; however, some easily accessed in-built functionality for analysis of associations seems warranted to address cases in keeping with our personas and scenarios. Further, some of the easy-to-use filtering features may be a convenient starting point for selecting a data subset for export to another package.

Related to the display of association in the data, further research is needed to create a data simulator that can generate test data with the expected associations among variables. The present simulator generates values independently. Therefore as an example, a problem gambler is no more likely to be depressed than a non-gambler, which is contrary to existing findings [10]. Modelling this will require a more sophisticated case generation module with an explicit representation of problem correlations and clusters.

There are moves to employ eCHAT in a number of different vulnerable populations including youth in secondary school and primary care settings, and ethnic minorities in New Zealand such as Chinese and Korean. It is also planned to adapt the tool for non-clinical settings, especially for young people, who can self-administer the test and receive tailored self-management interventions including psychoeducation and links to e-therapy. Analyses of population-level data can assist in estimating the prevalence of mental health and lifestyle issues, gain an understanding of their inter-relatedness and assess unmet service need.

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