Using Participatory Sensing to Monitor and Self-Manage Chronic Illnesses

Drake D. Arvidson
University of Minnesota, Morris
arvi0039@morris.umn.edu

ABSTRACT

This paper looks at participatory sensing and how it can be used to help monitor or self-manage a chronic illness. It will look into how the device being used is able to gather data with the use of sensor networks. The paper also includes discussion on the goals and challenges of using participatory sensing, including how various approaches impact usability, accuracy, and patient privacy.

Categories and Subject Descriptors

C.2.1 [**Computer Systems Organization**]: Computer-Communication Networks—*Network Architecture and Design*; D.4.6 [**Software**]: Operating Systems—*Security and Protection*

General Terms

Algorithms, Experimentation, Security

Keywords

Participatory Sensing, Sensor Network, Health Self-Management, Chronic Illness

1. INTRODUCTION

Chronic illnesses are an area of health care that lead to many complications for both the patient and the doctor treating the patient. Instead of looking to cure a chronic illness, the doctor has to work with the patient to ease their symptoms and make it so they can live as normal of a life as possible with the chronic illness. It is an ongoing task for both sides and they will encounter challenges along the way. Of course the symptoms are a challenge for the patient, but dealing with the symptoms is not the only challenge. Patients need to keep track of what symptoms are occurring and then they need to get that information to the doctor. Doing both of these accurately will provide the best care for the patient.

UMM CSci Senior Seminar Conference, April 2012 Morris, MN.

For many chronic illnesses a doctor needs to know the patient's exact symptoms in order to provide the best treatment. Along with the symptoms, the doctor needs to know how severe the symptoms were and how often they occurred. This is something that is very difficult for the patient to track. There are obvious ways, like taking down notes of symptoms on a piece of paper. This is something that is not always easy to do if an individual is suffering from a chronic illness that may have more extreme symptoms. There is a concern that soon the number of chronically ill patients will exceed the maximum number that healthcare sector can provide for, which means self-management is going to become even more important as the number of chronically ill patients grows larger [4]. This means patients need to be able to help themselves and not have to visit a doctor every time their illness begins to flare up. The focus of this paper is to look into using participatory sensing to help monitor patients with chronic illnesses and help keep track of their symptoms. Participatory sensing is when an individual uses a sensor or a network of sensors to collect data that is meaningful to the individual. Using a personal device, along with participatory sensing, to keep track of symptoms as they occur is something that can help a patient suffering from a chronic illness. Using participatory sensing provides the patient with an automated way to record their symptoms. This will result in an easier way to keep track of their symptoms without much effort on their part. It could also provide them with information that tells them how to treat their symptoms, giving them the ability to self-manage their chronic illness with less need to see a doctor all of the time.

A few examples of chronic illnesses where participatory sensing could help are diabetes, cystic fibrosis, and irritable bowel syndrome. Diabetes really depends on the person suffering from it, the diabetic, to self manage the disease in order to ensure they do not develop more health problems [2]. A patient suffering from cystic fibrosis will cough many times throughout a given day. It is important for the patient to know how many times they are coughing and also know the severity of their coughs. This can help the doctor know what will be the best treatment, and what other health problems might be prevalent [3]. Irritable bowel syndrome is something that is never the same from one patient to the next. There are so many symptoms that can exist as a result of irritable bowel syndrome. Participatory sensing could provide a great way to keep track of all these symptoms that occur before a patient is able to see their doctor again. This would help make sure the patient did not forget a symptom. It is very difficult for a doctor to treat the

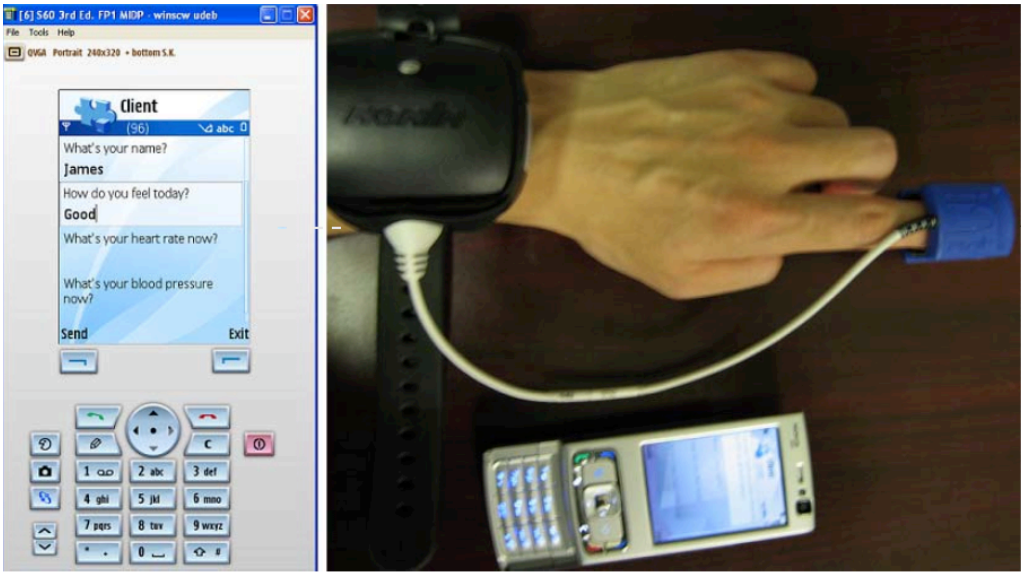

Figure 1: A smart phone being used with participatory sensing [6].

patient without awareness of all of the symptoms.

2. GOALS AND CHALLENGES

Being able to use a personal device to assist with tracking and managing a chronic illness is something that will greatly improve the field of healthcare. Tracking symptoms will help patients and doctors both when it comes to providing better relief and treatment for these symptoms [4]. There are goals for trying to incorporate personal devices, such as making the device user-friendly, and meeting these goals will provide more momentum for the idea of having personal devices assist in caring for chronically ill patients. These goals are not always met with ease and they often lead to new challenges. As the devices and what illnesses they can be used with are expanded, there will be an increase in the challenges with using them as well [3]. After describing the goal of providing accessible and usable devices, the challenges related to gathering relevant and accurate data will be visited. One challenge that stands out is maintaining the patient's privacy.

2.1 Accessibility/Usability

A chronically ill patient is going to be fighting nonstop in order to live a healthy lifestyle that will help combat their illness and make symptoms manageable. The purpose of using participatory sensing is to provide chronically ill patients with a device that will help make the process easier. These devices are designed to help patients both monitor and evaluate their symptoms in order to help them know the best lifestyle decisions for their illness and symptoms [4]. One goal is to work towards having the participatory sensing work with devices that the average patient either has access to or can afford to purchase. Tracking symptoms is something that most chronically ill patients have done without the aid of a device. In order for the patient to learn how much a device can help them they really just need to try it out. This will only happen if the goal is met, of providing patients with an inexpensive or free way to obtain and use these devices.

The next goal is to provide the patient with a device that is easy to use [3]. A device that is any tougher to use than the common mobile phone will likely scare away some potential users. The device should not require the user to be technologically advanced. Providing devices that have user-friendly software and hardware will be that much more appealing to a wider range of patients. This would help include middle-aged and elderly patients as possible users. Along with the device being easy to use, it should also be something that is compact, mobile, and unobtrusive [3].

2.2 Relevant/Accurate Data

The next difficult goal to address is having these devices provide both relevant and accurate data. Something that really puts a strain on providing relevant data is the fact that chronic illnesses can have many symptoms and the symptoms that are present can vary greatly from one patient to the next. Therefore, what these devices are able to sense needs to cover many things in order to provide the most helpful care. The devices and programs need to have a way to be tailored to the specific needs of a given patient and the symptoms that they suffer from [4].

If the devices are going to be used to help patients self-manage their illness and also provide a doctor with the symptoms that occurred, then the data needs to be accurate. If the doctor is going to prescribe the patient medication based on the symptoms and the frequency of the symptoms, these devices need to reliably provide accurate data. More accurate data lessens the risk of a patient overdosing on medication accidentally. The more accurate the data is, the more it will help the patients to make decisions that are going to help them cope with their illness [4].

2.3 Privacy

With the goal of having the data being as accurate and relevant as possible comes the challenge of preserving the patient's privacy. In order for the data to be both relevant and accurate, certain illnesses would need to have sensing occur more frequently. In respiratory diseases where coughing

and frequency of coughing are very important in determining what should be used for treatment, microphones that record the patient's coughs are used [3]. This brings an issue of having various noises being recorded, as well as all the private conversations of the patient. There are going to be different ways the privacy of the patient becomes vulnerable depending on what illness they are suffering from. The progress being made on preserving a patient's privacy while also tracking their coughs will be presented in an upcoming section.

Other privacy issues surface when the security of the sensor network itself is being discussed. Because the networks that are going to be used are wireless, as a result of the goal to have usable devices, patients will worry about the safety and security of their data. The biggest concern is for patients that will be using devices that do the sensing and send the results over the network to the doctor at a remote location [2]. Although this is a big concern for many people, there is useful wireless security in place today and because of this it will not be addressed again in this paper.

3. BACKGROUND

An introduction to both participatory sensing and sensor networks is necessary in order to see how they can be used to monitor and self-manage chronic illnesses. A better understanding of the two will show both the benefits and challenges that come along with using participatory sensing to monitor a patient with a chronic illness.

3.1 Participatory Sensing

Participatory sensing uses sensors to gather information. Then this information is brought together to form a new set of knowledge. Handheld devices, such as mobile phones, are very beneficial to participatory sensing. These mobile devices have a number of sensors and provide knowledge based on the information gathered by the sensors. There are difficulties when it comes to using participatory sensing. This paper has already described a few of the challenges when using participatory sensing. Because of these challenges, it is necessary for participatory sensing to provide a clear benefit. Without the benefit, the risks would turn individuals away from participatory sensing [9].

With participatory sensing the individual makes the decisions about the sensors. They decide when the sensor should sense, what the sensor should sense, and where the sensor should sense. These sensors are part of a system that use sensor networks to relay the information from the sensors to somewhere the data can be used and saved [5]. A simple example of participatory sensing is an individual using a heart rate monitor. The sensors are collecting data based on how rapidly the individual's heart is beating. The sensors are then relaying the data to a device for it to be displayed. Most commonly with heart rate monitors, the device is similar to a wristwatch. The watch-like device is where the data from the sensors is displayed in a meaningful way for the user.

3.2 Sensor Networks

A sensor network is made up of many sensors that are used to monitor the environment. Many things can be monitored, and in the field of health the most helpful things are temperature and sound. Most sensor networks that are used are now wireless, and are referred to as a wireless sensor network

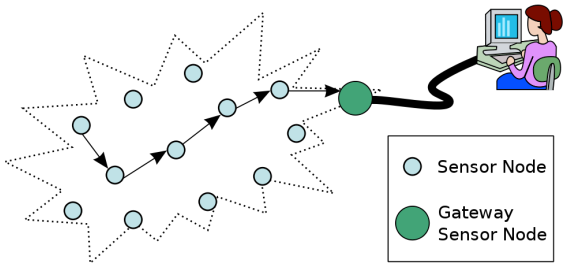

Figure 2: A wireless sensor network [10].

(WSN). A WSN can be thought of as a number of nodes, and each of these nodes are all connected to a sensor. It is common for a WSN to contain a large number of nodes, anywhere from the hundreds and up into the thousands. Figure 2 is an example of a WSN.

These sensor networks have different architectures and a common one for a WSN is a distributed sensor network. Centralized architecture is used in sensor networks, but this architecture does not work well in a WSN. With the centralized architecture the sensor network is dependent on the central node. If that central node fails, then the whole network would be lost. The distributed architecture provides the sensor network the ability to have nodes that fail, but do not cause the entire network to break [10]. This is important, because when using a wireless network nodes can frequently be lost. This gives the central node a greater chance of failing in a centralized architecture, which shows why a distributed architecture is the optimal choice for a WSN.

An example of a sensor network being used in a personal device is described in, *A Smart Phone Assisted Chronic Illness Self-Management System with Participatory Sensing* [6]. The device is a smart phone connected to a sensor network. The researchers here used the sensor network to collect biomedical and environmental data. The sensor network is made up of biosensors, environment sensors, and a global position system (GPS) sensor. The biosensor is a sensor similar to the sensors used in glucometers that patients with diabetes would use. In a glucometer, the biosensor is able to measure the blood sugar level for the patient by placing a drop of blood on the sensor [8]. The biosensors in this case are used for tracking pulse, blood pressure, and rest-versus-activity cycles of the individual who is using the sensors. The environmental sensors in the phone are used to pick up the sound, temperature, humidity, and light of the environment. The GPS sensor is simply to provide the location of the individual using the device. The smart phone uses Bluetooth to communicate with the sensors that are being used in the sensor network. The phone itself is similar to the Gateway sensor node in Figure 2. The biosensor, environmental sensor, and GPS sensor would all be sensor nodes. The phone receives the data from the sensors in the network and has the ability to temporarily store the data from the sensors. With the smart phone, it actually takes the sensor data from the entire sensor network and sends it out to a remote server. The remote server then stores all the data it receives where a doctor can then access all of the stored sensor data. This allows the patient to use the sensors for any extended period of time. Whenever they choose they will be

monitored and they will not have to record anything that is happening. Because this device is actually using a remote server, it is the job of the doctor to look through the data that is coming from the sensor network and being stored on the remote server. The doctor will look through the data to find anything that stands out and seems unusual, which would allow the doctor to help treat the patient's symptoms.

4. MEETING THE GOALS/ADDRESSING THE CHALLENGES

Participatory sensing can only be helpful if patients are willing to use it. The difficulty of ensuring the devices are both accessible and usable, track relevant and accurate data, and overcome the challenge of maintaining the patient's privacy are all things that might shy a patient away from using participatory sensing. The following sections will highlight some solutions to specific situations where participatory sensing is being used to help patients with chronic illnesses.

4.1 Providing Accessible and Usable Devices to Patients

Patients who suffer from chronic illnesses have to pay attention to their health and self-manage their symptoms as much as they can. One example of a disease that really needs to be self-managed is diabetes. Diabetes can result in a patient developing even more health problems. The risk of developing more health concerns can be reduced through monitoring and maintaining a healthy blood glucose level. There are many factors that can lead to a great change in the patient's blood sugar levels. Research has been done that shows a patient using a self-management system for diabetes can lead to them having greater control over their blood sugar levels. A glucometer is a small device that can be used to measure the patient's blood sugar level. Glucometers are an example of a device that is usable for patients and should largely help diabetics control their diabetes. The patient decides when they want to use the glucometer and where they want to use it. The meters are small enough for the patient to bring them wherever they go. With the increasing capabilities of the smart phones available in the world today, the glucometer technology is also being integrated with cell phones. This is simply because in a world where it is common to carry a cell phone the patient will not need to carry around another separate device [2]. If a patient with diabetes already owns a phone capable of running the glucometer software they no longer have to consider whether or not using participatory sensing is going to be affordable.

4.2 Gathering Relevant and Accurate Data

In order to provide the patient with the most relevant data and assist them with managing their illness, frequent sensing is better. The reason it is helpful to monitor the patient as much as possible is because then any of the symptoms that occur throughout a day will be recorded. This will eliminate the chance of the patient forgetting some symptoms that occurred on a given day.

Respiratory diseases are an example of illnesses, that when monitored at all times can be reduced and cause less severe symptoms when they are treated early. These diseases cause an individual to cough numerous times every day. Patients who suffer from asthma or cystic fibrosis will benefit from being monitored at all times [3]. The frequency of the coughs and the severity of the coughs both provide helpful information when it comes to treating a patient that is suffering from coughing. At first patients would just self report their coughs to a doctor and they would try to treat the patient from there. A study was done on patients that were doing self-reporting on the frequency of their coughs. The study was to see how accurate patients were when they were reporting how frequently they were coughing. When coughs were self reported by patients, they counted an average of 22.8 few coughs per hour when compared to the number of coughs the audio recording had picked up. Coughs per hour ranged between 10 and 178, with an average of 33 coughs per hour [3]. This shows how difficult it is for a patient to accurately self report the number of coughs they have throughout the day. The simple solution here seems to be using the microphones and just recording every sound of the patient for any number of days. This would be very helpful with providing both relevant and accurate data, because the doctor could go through the recordings to find every cough the patient experienced. The relevant data would simply be providing the doctor with the audio of the coughs. Otherwise the doctor would have to sort through hours of audio recordings to find the relevant data amongst all of the irrelevant noise. This is simply not feasible, even if the doctor only had one patient to deal. Although meeting the goal of providing relevant and accurate data, in the case of the microphone and recordings it brings with it many challenges that have to do with ensuring the preservation of the patient's personal life [3].

4.3 Preserving the Patient's Privacy

As it was stated before, privacy becomes more difficult to preserve as the amount of relevant and accurate data gathered increases. Consider the case of patients wearing a microphone to record all of their coughs throughout the day. It is difficult to design a microphone that has the ability to record every cough that a patient has in a given day and not record anything else. One of the big things patients worry about with these microphones is the recording of their private conversations. If the microphone is setup to record coughs all day, then how can it manage to record the coughs accurately and not take away from the privacy of the patients by recording their private conversations?

In order for this to be possible there has to be a way to quantify the difference of the audio of normal conversation and the audio of a cough. Using a spectrogram, like the one in Figure 3, the difference of a cough from other audio sounds can be seen when noticing the decibel levels. The cough audio has a much greater decibel level than any other noise that was recorded. The intensity of the cough also ranges a much larger frequency, both high and low, than the frequency of any other noises recorded. A program from a mobile device, or any sort of handheld device, can then use this knowledge of the characteristics of a cough to take audio recordings of a patient and reconstruct the audio with only the audio of the cough and every other sound and noise will be eliminated [3].

4.3.1 How Does the Software Recognize Coughs?

The method mentioned above, that provides a way to quantify cough sounds, contains two important parts that help recognize and classify coughs. The algorithm uses prin-

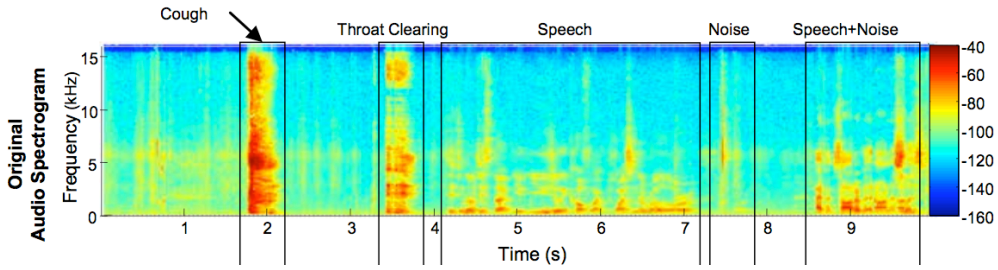

Figure 3: An example spectrogram of cough and non-cough audio sounds [3].

cipal component analysis and random forests as the classifier [3].

Principal component analysis is what is used along with the spectrogram of cough sounds. In this algorithm, 10 components proved to provide enough distinction by resulting in considerably accurate classification of the coughs. The spectrogram of cough sounds is examined and then in this case 10 components of the analysis of the spectrogram were created. These 10 components allow other cough sounds to be classified based on the similarity between one cough's spectrogram and principal component analysis and the next. Each of the components also carry a weight, because some components of a cough mean more when determining what kind of cough it is [3].

The random forest then has the job of taking the principal component analysis of a cough and classifying that cough. A random forest is constructed of many decision trees [1]. The random forest takes in input that will lead to the construction of the trees that make up the given forest. In the method used in detecting coughs, the audio goes through an event extraction phase [3]. This is where possible events of a cough are taken and then passed to the random forest classifier to generate its trees. Once the forest has been constructed it is able to take in input vectors and use the trees to determine how to classify the input vectors [1]. This is where the principal component analysis of the cough audio spectrogram comes in. These components are passed to the random forest as vectors and then each tree within the random forest assigns a value to the input to determine where it fits best [1].

4.3.2 Results of the New Method

Principal component analysis and random forests were not the only techniques used in the method above for recognizing and classifying coughs. However, these were two important steps inside the algorithm that has proven to be effective [3].

The researchers that developed this new method for recognizing coughs ran tests and compared their results to five other methods. Two features that the researchers pointed out were that their algorithm resulted in unintelligible speech and the reviewer of the recordings has the ability to remove false positives [3]. When looking at the results the thing that stands out most about this algorithm is that it requires no calibration. All of the previous five methods used required an initial calibration. This meant that for these previous methods to be successful the individual that was being recorded also had to wear a special sensor on their chest. No matter what the sensor was specifically being used for it still increased the expenses for every other method. This method also ranked second overall when looking at the algorithms mean true positive rate. The algorithm ranked first overall when considering the mean false positive rate [3]. This algorithm provides great results with limited expenses.

5. CONCLUSION

In the field of health, chronic illnesses are going to continue become an even greater problem. With a growing number of chronically ill patients it will be very difficult to provide care and treatment for all of them using current methods [4]. Participatory sensing can make things easier for both the doctor and the patient. With sensor networks that send data to a server for storage, a doctor will not even need to see a patient face-to-face to know what symptoms they are suffering from. Patients will be able to a have record of all of their symptoms for their doctor visits without having to worry about forgetting to record one of their symptoms.

The challenges that come along with using participatory sensing can be overcome. The technology is going to continue to improve with the patients and doctors in mind. The privacy will always be important and technologies will be improved to better protect a patient's privacy while using participatory sensing. As the technology gets better, it will also be adapted to be even more user friendly. The devices involved will only get simpler and easier to use. There will be even more participatory sensing on smart phones, which provides patients with an affordable solution to self-managing their chronic illness.

Ultimately the use of participatory sensing with chronically ill patients will increase their wellbeing. This provides patients with an attitude that they are fighting their illness and working towards living a healthier life. Participatory sensing can provide these patients with the necessary assistance to self-manage their chronic illness and giving them more control over their health [7].

6. ACKNOWLEDGMENTS

I would like to thank my professors Kristin Lamberty and Elena Machkasova for their advising and editing help during the process of writing this paper. I would also like to thank Justin Mullin for reviewing my paper and providing helpful feedback.

7. REFERENCES

[1] L. Breiman. Random forests. *Machine Learning*, 45:5–32, 2001. 10.1023/A:1010933404324.

[2] A. J. Jara, M. A. Zamora, and A. F. Skarmeta. An internet of things—based personal device for diabetes therapy management in ambient assisted living (aal). *Personal Ubiquitous Comput.*, 15:431–440, April 2011.

[3] E. C. Larson, T. Lee, S. Liu, M. Rosenfeld, and S. N. Patel. Accurate and privacy preserving cough sensing using a low-cost microphone. In *Proceedings of the 13th international conference on Ubiquitous computing*, UbiComp '11, pages 375–384, New York, NY, USA, 2011. ACM.

[4] M. Laverman, J. H. M. Schonk, P. J. M. van der Boog, and M. A. Neerincx. Personalized and contextualized information in self-management systems for chronically ill patients (periscope). In *Proceedings of the 28th Annual European Conference on Cognitive Ergonomics*, ECCE '10, pages 327–330, New York, NY, USA, 2010. ACM.

[5] M. Mun, S. Reddy, K. Shilton, N. Yau, J. Burke, D. Estrin, M. Hansen, E. Howard, R. West, and P. Boda. Peir, the personal environmental impact report, as a platform for participatory sensing systems research. In *Proceedings of the 7th international conference on Mobile systems, applications, and services*, MobiSys '09, pages 55–68, New York, NY, USA, 2009. ACM.

[6] K. Sha, G. Zhan, W. Shi, M. Lumley, C. Wiholm, and B. Arnetz. Spa: a smart phone assisted chronic illness self-management system with participatory sensing. In *Proceedings of the 2nd International Workshop on Systems and Networking Support for Health Care and Assisted Living Environments*, HealthNet '08, pages 5:1–5:3, New York, NY, USA, 2008. ACM.

[7] S. Torsi, N. Nasr, P. C. Wright, S. J. Mawson, and G. A. Mountain. User-centered design for supporting the self-management of chronic illnesses: an interdisciplinary approach. In *Proceedings of the 2nd International Conference on PErvasive Technologies Related to Assistive Environments*, PETRA '09, pages 43:1–43:4, New York, NY, USA, 2009. ACM.

[8] Wikipedia. Biosensor — wikipedia, the free encyclopedia. `http://en.wikipedia.org/w/index.php?title=Biosensor&oldid=478798034`, 2012. [Online; accessed 9-March-2012].

[9] Wikipedia. Participatory sensing — wikipedia, the free encyclopedia. `http://en.wikipedia.org/w/index.php?title=Participatory_sensing&oldid=472772525`, 2012. [Online; accessed 6-March-2012].

[10] Wikipedia. Wireless sensor network — wikipedia, the free encyclopedia. `http://en.wikipedia.org/w/index.php?title=Wireless_sensor_network&oldid=479985024`, 2012. [Online; accessed 6-March-2012].