Practice Article

Internet-based approach to population screening for common hemoglobinopathies in United Arab Emirates

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Abstract

This article reports on efforts to overcome common hurdles that were faced during population-based screening for common hemoglobinopathies in the United Arab Emirates. An Internet-based approach was designed and implemented to increase the acceptance of the screening program. The process involved: an awareness campaign, a simple bilingual (Arabic/English) online consent form and registration process, the use of a barcode for sample labeling, an equipment upgrade, electronic communication of a successful registration process, test results, and a counseling process. Before the implementation of the Internet-based system, great concern was noted among the clients in terms of the availability of accurate and timely test results, the need for pretest and post-test counseling, and the way that their personal health information was handled. Lapses in information exchange between the clients who participated in the screening program for the carrier state of inherited disorders and the screening laboratory posed significant challenges. The emphasis on confidentiality and the ease of access to services was instrumental in increasing the level of acceptance of these services in our community. Based on an analysis of > 10,000 samples, we conclude that Internet–based reporting holds much promise for improving the quality of care that clients receive.

Key words

hemoglobinopathies, Internet-based, population screening.

INTRODUCTION

The Internet has emerged as a potential vehicle for distributing health communication to millions of individuals because it is interactive, user-controlled, and offers breadth and depth of information (Gawande & Bates, 2000). In recent times, health information technology has emerged as a tool that holds much promise for improving the quality of care that clients receive by preventing medical errors, providing clinicians with better clinical decision-making tools, allowing the sharing of information about patients with other clinicians, tracking health outcomes, and coordinating public health activities. Information technology is now used extensively as a connectivity and reference tool for commercial, personal, and educational purposes (Glowniak, 1995). Many government organizations have been using the Internet to publish vast amounts of health-related information (Hubbard et al., 1995; Kim et al., 2005; Dorfman et al., 2010). To the best of our knowledge, we have not come across a population-based genetic screening program, where an Internet-based approach has been used in its entirety to cover all phases of the screening process.

Genetic blood disorders represent a major public health problem in the Arab world, including in the United Arab Emirates (UAE). Several factors contribute to this situation, including the lack of public measures that are directed towards the early recognition and prevention of inherited diseases (Al-Gazali et al., 2006).

Background

UAE Genetic Diseases Association (UAEGDA) is a non-profit organization that was established under the patronage of H. H. Sheikh Nahyan Mubarak Al Nahyan, the Minister of Higher Education and Scientific Research, UAE, with the main aim being to control and prevent population-specific genetic disorders that are prevalent in the UAE. This organization first initiated a massive public awareness campaign under its first project, “Emirates free from new births of children with thalassemia disease by the year 2012.” This effort resulted in the inclusion of sickle cell and beta-thalassemia screening as mandatory under the UAE Federal Pre-marital Legislation Program that has been active since 2005. In 2007, following generous support from its chief patron and strategic partners, UAEGDA started offering free
genetic counseling and free laboratory services to the entire student population of the UAE. Through this project, UAEGDA aims to identify the carriers of various hereditary blood disorders, including sickle cell and beta-thalassemia, particularly in the premarital age group and student communities in various universities and colleges across the country.

In the Middle East, there are an estimated 57,425,046 Internet users; between 2000 and 2009, this region witnessed an impressive Internet usage growth rate of 1648.2%. The “most wired” country in the Middle East is the UAE (Internet World Stat, 2009). As a measure to address the problems that are faced in the initial screening process, UAEGDA decided to implement a paperless reporting system. We present here our experiences in initiating an Internet-based laboratory testing and counseling process that helped us to address the many problems that are encountered in the practical implementation of the National Hemoglobinopathies Program (Matar et al., 2010) in the multi-ethnic population of the UAE. So far, we have tested this system in a target population that comprised > 10,000 students who were studying in various colleges and universities across the seven states (referred to locally as “emirates”) of the UAE. Below, we report on the methods that were adopted in designing the Internet-based laboratory information system, subsequently providing a discussion and our conclusions about this process.

**DESCRIPTION OF THE PROCESS**

As mentioned, our project aimed to overcome the common hurdles that were faced during population-based screening for common hemoglobinopathies in the UAE. Prior to the project’s commencement, we obtained research approval from the Scientific and Ethical Committee of UAEGDA.

**Analysis of the problem**

The first step in the process was to understand the problem and the uncertainties that were involved in the entire screening process. We conducted a screening program using conventional paper-based reporting in one of the colleges, which involved the screening of 1114 students. Following this, we conducted group meetings and a survey in order to understand the reasons for the low client turnover during these sample-collection events. The survey covered the students, the teachers, and the medical team that was involved in the screening program.

**Equipment upgrade**

The second step was to upgrade the existing equipment to include an auto sampler and barcode modules. Where such upgrading was not feasible, the process was initiated through the purchase of new equipment, with older equipment acting as a back-up unit in times of crisis or maintenance. In the screening program, an automated hematology analyzer (Cell-Dyn 3700; Abbott Laboratories, Santa Clara, CA, USA) for complete blood count (CBC) testing was used, ion-exchange high performance liquid chromatography (HPLC), using a fully automated variant-II beta-thalassemia testing system (Bio-Rad Laboratories, Munich, Germany), was carried out for the screening of abnormal hemoglobin, and an automated analyzer (UDILIPSE; United Diagnostic Industry, Dammam, Kingdom of Saudi Arabia) was used for the glucose-6-phosphate dehydrogenase (G6PD) quantitative analysis.

**Implementation and customization of the laboratory information management system**

Our laboratory received a generous donation of a laboratory information management system (LIMS) from Microsmart Systems – Australia (Melbourne, Australia). Our clinical geneticist, Dr Mohammed Naveed, was involved in the design of all the modules, testing, and subsequent implementation of the system.

**Equipment interfacing and testing**

Over 3 months, the system was tested with frequent surveys on the ease of the electronic communication that included a bilingual Arabic/English registration process, user identification (ID) and password access, ease of reading the bilingual test results, and attending the genetic counseling clinic for those who tested positive. Based on all this feedback, the system was customized to meet our needs regarding online registration, testing, and counseling. We did realize that the younger student community from the northern states of the UAE had difficulty in understanding the online process, as their medium of communication was Arabic in their pre-university curriculum. This group was given additional face-to-face education in order to understand the process during the pretest awareness sessions.

**Creating the demand for services**

For the cost-effectiveness of the program and to decrease the overheads, it was necessary to increase the volume of the analyzed samples. Several public awareness programs were initiated through the press, TV media, and mobile phone network (SMS messages). Along with information on the organization and its activities on the webpage portal, educational offerings for healthcare providers and patient education materials were distributed through various public events and health awareness days at the colleges and universities.

**Refining the process**

Further customization was necessary in order to include an online consent form (English/Arabic), registration module, communication of a successful registration process, and data security, fix possible gaps in the data entry from clients, as well as deal with the ease of access in retrieving the bilingual test results, the communication process in arranging a counseling session, and documentation of the entire counseling process. Special attention was given to confidentiality, privacy, and security issues. Other important measures
included regulations and policies concerning the storage, transmission, retention period of electronic health information, handling of database servers, and database back-up, as well as defining the administrator and user security matrix.

RESULTS

Over 8000 individual samples were processed on this novel Internet-based reporting system. The various sections that were addressed on the LIMS and the work flow at the National Screening Laboratory are illustrated in Table 1 and Figure 1. Specific descriptions of some of the salient areas are described here.

Client registration

A client can register for the screening process through UAE-GDA’s website (http://www.uaegda.ae) and this can be done from anywhere and from any computer with Internet access. This registration process can be done in English or Arabic. Before accessing the registration page, the client has to agree to the terms and conditions that represent an online consent form (Fig. 2). After a successful registration process, a unique number and profile is created for each client automatically. The client receives an email communication on the successful completion of the registration process (Fig. 3). This also informs the client about the laboratory’s acceptance of the collected blood sample for testing.

Blood sample collection

The process of blood sample collection is the first step in the management and operations process in the laboratory, where the sample collection is planned at a remote laboratory, a collection center, or main laboratory. The sample then is transported in an appropriate state and time. In all cases, the registration process is online and a barcode that is generated from the system is used on the sample collection tubes. The phlebotomists are trained in the client identification process, generation of a unique barcode, sample labelling, and collection process. Once the sample arrives in the laboratory, the receiving desk will check the sample according to a specific checklist (see Table 2) that also needs online documentation. This sample checklist is an important quality assurance step to determine the fitness of the collected sample for the next process in the testing area. If the sample does not meet the checklist criteria, it is rejected with automated feedback to the client about a repeat collection. Once the sample is accepted and registered online, the client gets an email confirming this event. This email also gives instructions to the client on checking the result online through a unique username and password that are generated soon after the successful blood-collection process.

Blood sample analysis

The blood sample is processed through various test process automated equipment (for CBC, HPLC, ferritin, and G6PD assay) and also through other manual tests, depending on the initial screening results. All the automated equipment that is used in our laboratory has both an auto-sampler and a barcode-reading facility. The remaining sample is stored for further needed investigations, including DNA extraction and DNA analysis.

Exporting of the test results to the laboratory information management system and reporting

The result for each client and each test is verified and exported to the database area, to which only the laboratory director has access. Here, the laboratory director can approve or disapprove the generated results or advise the laboratory technologist on a further testing process. Once approved, the results are generated as a test report (bilingual) and can be viewed in the client profile section.

Release of the test results

A certificate of analysis is made available in the client profile as a PDF file after the approval process. Here, the client checks the result online through the unique username and password that were generated soon after the successful blood-collection process (Fig. 4). If the results are negative, there is no need for further action. All the reports are released to the clients within 48–72 h of a working day (Fig. 5). There is an online feedback form on customer satisfaction that all clients can complete at the time of accessing their result. We also conduct independent audits on these services.

Counseling process

If the results are positive at the time of reporting, the laboratory director electronically communicates a scheduled counseling session to the client. Again, the entire process is controlled online. Automated bidirectional email communication between the LIMS and the client confirms the counseling session (Fig. 6). Every counseling session that is conducted is documented. The clinic nurse coordinates this counseling process and the counseling is provided by the clinical geneticist or genetic counselor. In most cases, only the client who tested positive attends the counselling session. On some occasions, when the client is a minor and/or when family studies are required, other members of the family attend the counseling session. All clinic visits and counseling sessions are free. The clinic visit for counseling also concentrates on extended family screening. Most of the time, one counseling session is sufficient as all those who participate in the counseling program have prior knowledge of what to expect through the pretest awareness programs and lectures that have been conducted in the schools and colleges.

DISCUSSION

During the earlier phase of the program’s implementation, individual and group surveys were undertaken. Lapses in information exchange between the clients who participated in the screening program for a carrier state of inherited
### Table 1. Description of the various menus (headers and their descriptors as a submenu)

<table>
<thead>
<tr>
<th>Header</th>
<th>Description headers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client profile</td>
<td>Certificate of analysis, Clinic appointment</td>
</tr>
<tr>
<td>Testing</td>
<td>Test progress, Test reporting</td>
</tr>
<tr>
<td>Counseling</td>
<td>Confirmed, Completed, Re-appointment</td>
</tr>
<tr>
<td>Table and parameters</td>
<td>Units, Minimum value, Maximum value, Remarks</td>
</tr>
<tr>
<td>ISO compliance</td>
<td>Certificate, Vendor details, Daily maintenance, Preventive maintenance</td>
</tr>
<tr>
<td>Equipment maintenance</td>
<td>Value, SD, CV</td>
</tr>
<tr>
<td>Internal QC/QA</td>
<td>Appearance, Toxicology, Risk phase, Safety code</td>
</tr>
<tr>
<td>MSDs</td>
<td>Type, Nature, Origin, Cost, Quantity, Remarks</td>
</tr>
<tr>
<td>Stores</td>
<td>Description, Result, Demographics, Volunteer</td>
</tr>
<tr>
<td>Advanced search</td>
<td>Client, Payroll, Forms, Leaves, Job description</td>
</tr>
<tr>
<td>Security control</td>
<td>Employee, Contract, BPQ, Competency matrix, Performance appraisal</td>
</tr>
<tr>
<td>Employee profile</td>
<td>Staff, Administrator, Payroll, Action</td>
</tr>
<tr>
<td>Document control</td>
<td>HR policies, SOPs, Test methods, Processes, Diagrams, Others</td>
</tr>
<tr>
<td>Client feedback</td>
<td>Suggestions, Improvement, Workflow, Diagrams, Others</td>
</tr>
<tr>
<td>Non-conformance</td>
<td>Minor, Major, Action, Action, Action</td>
</tr>
</tbody>
</table>

CV, coefficient of variation; HR, human resources; ISO, International Organization for Standardization; MSDSs, material safety data sheets; QC/QA, quality control/quality assurance; SD, standard deviation; SOPs, standard operating procedures.
disorders and the screening laboratory posed significant challenges. Great concern was expressed by the clients in terms of the availability of accurate and timely test results, the need for pretest and post-test counseling, and the way in which their personal health information was handled. The students who participated in the conventional testing process expressed resentment regarding the communication mode of the test results.
All screening programs that target a population or a high-risk group need to be cost-effective. We were challenged to make the screening program as cost-effective as possible. When we started the student testing, we were faced with many challenges regarding organizing the events (without disturbing the students’ academic curriculum) and the quick delivery of the blood samples to our main laboratory. The conventional approach did not yield good results, as many of the students were apprehensive about going through the testing process because it was a group activity, with possible peer pressure and curiosity regarding each other’s test results. In order to provide our services in the most ethical and confidential way, we organized small batches of blood collection and tried to call the students a second time to release the individual test results in a sealed envelope. The paper-based reporting system resulted in delayed reporting, poor communication of the results, and poor customer satisfaction. It also demanded the services of additional staff members to collect information through regular student and faculty surveys and constant monitoring. This mode of service still stigmatized the clients and dissuaded them from participating in large numbers. Additionally, arranging a counseling session for those who tested positive on screening was laborious and not always timely. All these issues were faced by us in the early stage of service delivery and had an impact on the quality of the care that was delivered. Therefore, we temporarily suspended the program until we started the Web-based reporting system.

An Internet-based laboratory facility involves real laboratory equipment being controlled remotely over the Internet, enabling access to laboratory equipment processes and test reports at any time from any location. In spite of several advantages, there was very little effort or interest within the academic community of this region (Arab world) in implementing the Internet-based laboratory reporting system. The possible reasons that were noted included the relatively complex operation, complicated design, extensive maintenance effort, higher implementation cost, and lack of human interaction.

The scenario that has been presented here focused on a client’s ability to use the available computerized technologies to communicate with the laboratory and the counseling clinic by using secure messaging capabilities. However, as indicated in prior research, we did face resistance from some students from the northern states of the UAE in accepting this communication process and Internet usage (Straub et al., 2001). Acceptance of the LIMS-based data communication improved over a period of time, with the clients being reassured along the way that their personal health information would be handled and stored appropriately. The dissemination of the process of screening through a corporate video film did make a significant impact. The clients also realized...
the benefit of an easy communication process from receiving their results early, the quality of care, and the efficiency of the genetic counseling process. This also resulted in the efficient use of the staff members’ time, a fewer number of staff members, less technical errors, less recurring costs, and maximized efficiency. The technical staff and clients both were satisfied and benefited from this electronic communication.

At the end of the communication exchange, the client, the laboratory support staff, and the clinician completed information about the communication event and documented the event, as required.

With the implementation of the above processes, the laboratory is able to handle a large number of samples with a minimal staff, comprising one phlebotomist, one assistant technician, one senior laboratory technician, one event coordinator, and one laboratory director. With the provision of Web-based services, the laboratory director not only is able to monitor activities remotely, but also is able to report test results from anywhere with Internet access. The other modules that are included in the LIMS help to effortlessly handle various other sections, including human resources management and purchasing and stores, without the need to recruit skilled staff for these areas. The system has been adopted and customized to meet local needs. Therefore, our clients are able to send secure emails and gain access to appointments with the laboratory and clinician in a timely and efficient manner, instead of a conventional office visit. The laboratory staff and clinician also benefit from this secure communication process and online document control, thereby promoting evidence-based, personalized, better health care. Additionally, the system helps to securely send reminders to clients regarding their follow-up visit and to encourage family members to participate in the testing process, thereby promoting preventive health care more effectively (Matar et al., 2010).

One of the limitations of the application of such Internet-based screening programs is the literacy level of the population that is tested. Our screening program mainly targets the literate student community in various colleges and universities. All of these colleges and universities have good information technology support and every student has an email ID through which the student and faculty communicate. With this level of computer literacy, the implementation of our screening program was relatively easy. However, it will be

Figure 5. Example of a screening test result. CBC, complete blood count; HPLC, high performance liquid chromatography.
challenging to educate the general population. When the colleges and universities are closed for academic vacations, we start screening the corporate sector.

This work that has been carried out in our laboratory has demonstrated significant potential for the further expansion and development of Internet-based laboratory systems in other projects. This project is progressively developing towards improved access and data security. Following a successful attempt to screen > 10,000 clients, we are now planning to target the women who attend antenatal clinics and extended family screening.

CONCLUSION

The approach that we adopted can be considered to be a hybrid of the efficient introduction of a population-based genetic screening program and community research, intended to enhance the quality of the services that are provided in a cost-effective manner. We realized that the end result should be not only a better Web-delivered intervention, but also insights that can contribute to more understanding and increased acceptance of the services that are provided to the community. We capitalized on the public awareness campaigns, higher dissemination of information technology, and active, information-seeking student community in turning to a Web-based screening program. Our results suggest that clients’ educational level might not be a barrier to appreciating Web-based access to information, provided that they can feel that they have sufficient choice and that they can gain access quickly to the specific information that they value. These principles may well apply to all users who have limited knowledge of information technology and Internet use. Where possible, we highly recommend the use of an Internet-based laboratory testing and counseling process to the premarital group as it addresses many problems and improves the level of client enrolment and customer satisfaction.

ACKNOWLEDGMENTS

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