

## Chapter 39

### Addressing the Global Burden of Neurological, Mental, and Substance Use Disorders using Information Technology

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#### Take-home messages:

- Neuropsychiatric disorders impose an enormous medical, economic and personal burden on all populations of the world.
- Western approaches to neuropsychiatric care, which rely on sufficient numbers of highly trained medical professionals, are not viable in many resource-poor settings.
- Cost-effective information technology can enable primary and community health workers to greatly reduce the mental health burden.

#### The Global Burden of MNS Disorders

Mental, neurological, and substance use (MNS) disorders, or simply “mental disorders,” impose the largest burden of all chronic disease classes in the world (Collins et al., 2011; Idro et al., 2010; Prince et al., 2007). Though long overlooked as health care priorities, mental disorders are an enormous economic burden on nations. This is particularly true for low-income nations, where the lack of capacity to deal with the problem leads to anguish for patients, which in turn affects caregivers, families and communities. Yet the burden may still be underestimated because current measures fail to take into account the connection between the mind and body. Many chronic medical conditions have comorbid mental and cognitive conditions, leading to poor outcomes. Similarly, mental conditions can contribute to the burden of acute and chronic physical disorders. As the World Health Organization (WHO) constitution states: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” Thus, there is no health without mental health.

#### *Social and Economic Burden*

Mental disorders not only affect the well-being of individuals, but also their families, communities and societies. Mental disorders do not respect income or social conditions: mental illness accounts for a larger proportion of disability in high-income countries than any other group of illnesses. For example, an estimated 25% of adults in the United States reported having a mental illness in the previous year (Reeves et al., 2011). The economic burden imposed by these disorders, in high-and low-income nations alike, includes loss of gainful employment, with the attendant loss of family income; the

requirement for care giving, with further potential loss of wages; the cost of medicines; and the need for other medical and social services. These costs are particularly devastating for poor populations (WHO, 2008).

A functioning mental health care system also helps to reduce poverty (WHO, 2008). Homelessness and incarceration in prisons are common occurrences for people with mental health conditions, which exacerbate their marginalization and precariousness. Rates of mental illness among the homeless can be greater than 50% (Fazel et al., 2008) and studies reveal that more than one third of the prison population have mental health conditions (Kleinman, 2009). People with mental health conditions often lack educational and employment opportunities. Not surprisingly, severe mental illness is associated with unemployment rates up to 90%, the highest rates of all disabilities (WHO, 2008). Moreover, mental health conditions in a single individual can lead entire families into poverty and thus hinder economic development (Chisholm et al., 2007a).

### *Effects of War and Conflict on Mental Health*

War, armed conflict, and terrorist attacks introduce a significant cause of mental health burden in many parts of the world. A particularly high burden is borne by low-income regions, where indirect effects of conflict greatly exacerbate the damage. Armed conflict causes widespread injury and illness that contribute to a breakdown of health services where they are most needed.

Children may bear the greatest burden from the mental health effect of war. They suffer with disabilities resulting from depression, anxiety symptoms, psychoactive substance use problems, and malnutrition, and experience a failure to thrive as younger children, in addition to other consequences throughout their lifetime. This is especially true in Africa. Consequences of war that may damage young minds include displacement from homes, loss of family, destruction of schools and social structures important for psychosocial development. Higher rates of mental health problems, such as post-traumatic stress disorder (PTSD) and depression, have been documented among child soldiers. These are further influenced by post-conflict risk and protective factors (Betancourt et al., 2010). A strong association between maternal symptoms of depression, anxiety and PTSD and symptoms of PTSD in their children was found in a Middle Eastern region afflicted by conflict (Feldman and Vengrober, 2011).

In addition to the direct effects of war on mental health, recent evidence suggests an epigenetic intergenerational transfer of the effects of mental stress from parents to offspring (Devakumar et al., 2014). Interestingly, stress levels caused by psychological trauma in mothers can affect their unborn babies similar to under-nutrition, possibly mediated by changes in the hypothalamic-pituitary-adrenal (HPA) axis (Holsboer, 2000).

While the ultimate solution to trauma-induced mental disorders is the cessation of conflict, the creation of low-cost approaches to early detection may help to alleviate some of the impact and reduce long-term burdens by enabling early interventions.

*Moral Imperative: A Failure of Humanity*

Mental health care is more than just a public health issue and economic burden—it represents a moral failure. The current state of care for mental health patients in the world, in both rich and poor regions, has been called a *failure of humanity* (Kleinman, 2009). The lives of people with mental disorders, particularly in resource poor societies, are deprived of basic human rights. As Kleinman (2009) eloquently argues, “the widespread stigma of mental illness,” which prevails in countries as disparate as China, India, Kenya, Romania, and Egypt, as well as selectively in the United States, “marks individuals with severe psychiatric disorders as virtually non-human. None of the world’s major religions—no matter how strong is its message of support on behalf of the most marginal and vulnerable sufferers—has been able to break this cycle of misery. Nor have modern anti-stigma campaigns and mental health laws.” Although greater awareness of mental disorders as treatable, medical conditions has led to improvements in care in some countries, widespread stigma and misunderstanding prevail. The conditions under which people with mental disorders live in both rich and poor regions continue to be deplorable. In addition to restrictions on the right to work and to education, they live in unhygienic and inhuman conditions, suffer physical abuse, sexual abuse, and neglect, and are subjected to harmful and degrading treatment practices in health facilities. They are often denied civil and political rights and the right to participate in normal public life (WHO, 2008).

Mental health affects progress towards the achievement of several Millennium Development Goals, such as promotion of gender equality and empowerment of women, reduction of child mortality, improvement of maternal health, and reversal of the spread of HIV/AIDS” (Prince et al., 2007). For this reason, the next iteration of the MDGs will take mental health into more specific consideration.

**Barriers to Treatment: The Need for Innovative Solutions**

Despite growing awareness of the personal, social, and moral burden of mental disorders globally, solutions are not easily found. While effective interventions are known for many of the most prevalent mental disorders, a large proportion of people with such problems do not receive treatment and care (Rebello et al., 2014). A large multi-country survey supported by WHO showed that 35–50% of serious cases in developed countries and 76–85% in less-developed countries had received no treatment in the previous 12 months. A review of the medical literature found treatment gaps to be 32% for schizophrenia, 56% for depression, and as much as 78% for alcohol use disorders. Many population-based studies have shown that more than 95% of people with epilepsy in many resource-poor regions do not receive adequate treatment (WHO, 2008). These numbers are strikingly high, particularly when known interventions exist that could greatly reduce the impact of the disorder.

The gap in mental health services between what is already known about treating these disorders and the number of people who actually receive care is quite large and

cannot be resolved by extending current approaches that have been primarily developed in Western countries. It will be essential to adapt known treatments and therapeutic approaches to local cultures and empirically document their effectiveness (Becker and Kleinman, 2012). Integration of mental health services into existing health care systems, using available health care workers, with a view to provision of holistic health care throughout lives, will be required. Three specific barriers are often identified that must be overcome for this goal to be realized. These are described here, and then the potential for information technology to overcome these barriers is presented.

Perhaps the greatest barrier to development of mental health services has been the lack of attention to mental health as a serious public health issue among national leaders. This impacts financing available for mental health care. Governments have allocated relatively small amounts for mental health within their health budgets, and interest among NGOs and philanthropic organizations is lacking (Saraceno et al., 2007). Epidemiological data to inform policy makers is a first step to motivating governments—and convincing reluctant leaders—to reallocate resources to accomplish the changes needed for improving mental health services. Importantly, epidemiological data, presented publicly and widely, may also be an antidote to the widespread stigma associated with mental disorders. Indeed, it has been found that mental health professionals and family members contribute to continuing stigma as much as anyone in society (Gray, 2002).

Another barrier concerns the organization of mental health services. The Western approach concentrates mental health resources and professionals in large institutions, usually near big cities. These resources are generally inaccessible to rural populations. Those that are able to access these facilities are often isolated from their families and communities, are more expensive than community-based services, and are associated with inhumane conditions and increased stigma (Saraceno et al., 2007). Effective integration of mental health services with primary and community care services is an important goal for overcoming the urban institutional model of mental health care. In many countries, the systems that provide primary health care are overburdened with high patient loads and lack of supplies. Moving mental health services to primary care settings is hindered by the limited training of primary care providers in mental health care (Saraceno et al., 2007).

The lack of specialists with advanced training in behavioral health is often cited as the primary barrier to better mental health care in many regions of the world, including low- and high-income countries. A lack of trained personnel or lack of access to psychiatric and neurological services obfuscates the enormous burden of mental disorders.

Innovative use of information technology can help to build capacity and overcome all of these barriers to expanding high-quality mental health care among underserved populations. Before discussing the technology itself, a brief review of mental disorders as developmental brain disorders is given. This provides a foundation for considering mental disorders in the context of comprehensive, life-course management of general health and well-being in community and primary care settings.

## **Mental Disorders are Developmental Brain Disorders**

Recognizing that mental disorders are brain disorders will go a long way toward removing the stigma associated with these conditions. This perspective also makes the integration of mental health care into primary care settings seem obvious. Most mental disorders follow a predictable developmental trajectory over time. The symptoms that define the disorder emerge over time, exhibiting neurodevelopmental etiologies. Half of all mental and neurological disorders of adulthood may have antecedents in childhood and 75% emerge before age 25 (Insel, 2014). Changes in brain function must necessarily precede observed changes in behavior or the emergence of symptoms of mental disorders. This follows logically from the simple fact that the brain is the seat of all human thought and action. It is becoming increasingly evident that the brain is quite robust at preserving normal function. For example, 50% to 70% of dopaminergic neurons in the substantia nigra, the part of the brain involved in Parkinson's Disease, must be destroyed before symptoms of Parkinson's Disease begin to become observable (Cheng et al., 2010). If this principle holds generally for most or all mental disorders, then clearly the best opportunity to prevent or reduce the severity of these diseases, in terms of both personal suffering and economic impact, is in childhood.

Large amounts of money are spent on high-end brain research with expensive and complex equipment, with the promise of a future breakthrough that may cure specific mental disorders. The “cruel paradox” is that “while we chase the receding holy grail of future basic science breakthrough, we are shamefully neglecting the needs of patients who are suffering right now” (Frances, 2014).

Innovative adaptation of existing technology can enable mental disorders to be managed in a life-course approach to health care in primary care settings. Many mental disorders, if detected early and treated as chronic disorders, can be managed, allowing a reasonably normal quality of life with existing treatments. There is unfortunately a lag in the application and implementation of existing interventions that can improve people's lives today. We do not need to wait for a breakthrough discovery to produce a “magic pill” to realize such a promise.

## **Information Technology for Improving Mental Health care**

Table 39.1 lists the primary barriers to improved mental health care in underserved populations, along with the information technologies that may be particularly useful for overcoming these. Examples of these uses are given and described further in the text below. These examples have either been developed as pilot demonstration projects, if at all, and are presented in part to inspire new translational research projects to scale up these ideas into working clinical implementations.

Barriers	Technology	Examples
Lack of trained health workers	Community screening apps Mobile EEG-based screening	TQQ implemented in Sana mobile app Portable EEG with app connected to OpenMRS
Organization of services	Electronic Health Record (EHR) Electronic and online training materials	Connecting screening surveys to OpenMRS Use of online instructional materials to train community workers.
Lack of information at state and policy making level	SMS survey	MIT/USF Spring 2014 Global Health Informatics Project: Autism in East Africa
Public attitudes, stigma	SMS messaging, social media	MIT/USF Spring 2014 Global Health Informatics Project: Autism in East Africa

**Table 39.1.**

Existing information technology and how each may be used to overcome major barriers to better and more widely available mental health care services. (OpenMRS = electronic open medical record system ([www.openmrs.org](http://www.openmrs.org))).

### *Mobile Apps for Task Shifting*

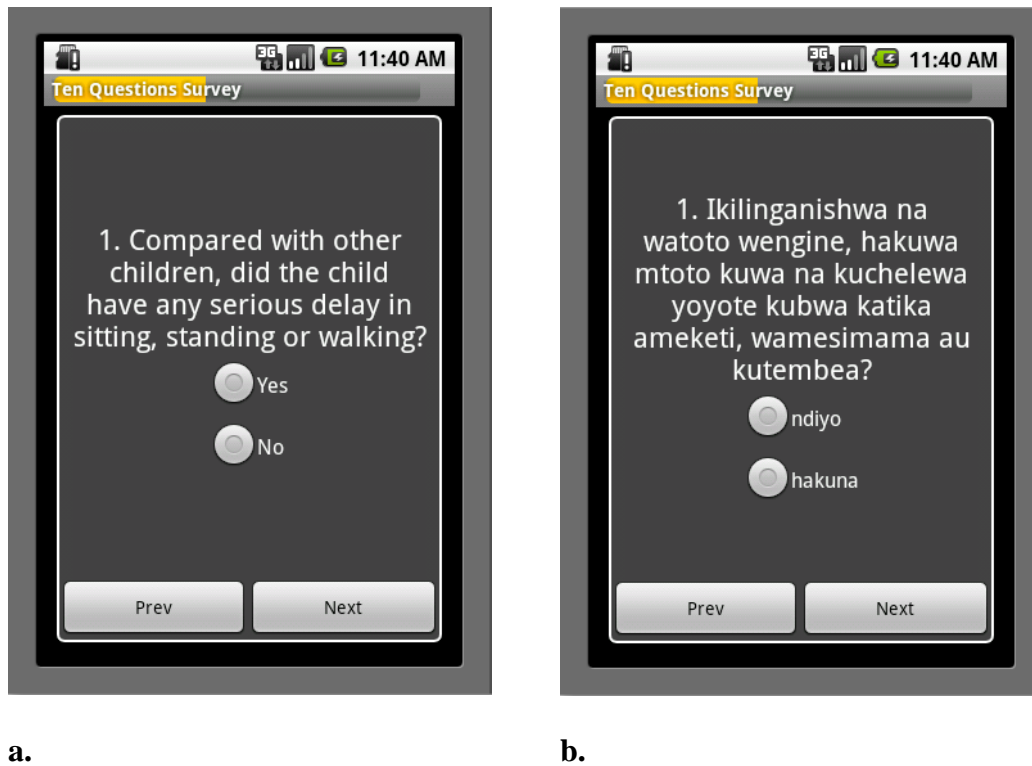
The single largest barrier to scaling efficacious treatments for mental disorders is the enormous scarcity and inequality in the distribution of skilled human resources in low-resource settings. In many countries, the scarcity of human resources and training is simply overwhelming. Delivery of mental health care traditionally requires specialists that are not available to deliver core services in many regions of the world (Kakuma et al., 2011). Three levels of mental health workers are typically identified: specialists, including psychiatrists, neurologists, psychiatric nurses, psychologists, and occupational therapists; non-specialist professionals, which includes physicians, pediatricians, and nurses; and other professionals, which may include teachers, social workers, and community health officers. While many of these professionals, such as teachers and community health officers, may be available, few have the training necessary to assess patients adequately.

One approach to overcoming this shortage involves task shifting, which refers to the strategy of rational redistribution of tasks among available caregivers. The concept involves highly trained health care specialists sharing specific tasks with health workers who have less training and fewer qualifications in order to make more efficient use of the available human resources (Patel, 2012).

Technology can play a critical role in task shifting. “Transferrable technology” is a term that was introduced by (Holtzman et al., 1987) to describe technologies that can be effectively devolved from highly trained professionals to those with a lesser level of training (Nell, 2000). This concept is similar to task shifting, but focuses on the clinical task being performed rather than the persons carrying out the task. An example of how technology might be used for task shifting in mental health care can be illustrated with the Ten Questions Questionnaire (TQQ), a set of questions developed to rapidly screen children living in resource-poor countries, aged 2-9, for the most common moderate to severe neurodevelopmental disorders (Mung'ala-Odera et al., 2004). The TQQ can be used to compare the epidemiology of neurodevelopmental disorders in different parts of the world and to screen for moderately/severely impaired children in resource-poor countries. The low positive predictive values mean that other assessments are required for confirmation. The TQQ was augmented with 13 additional questions for detecting autism spectrum disorders (ASD) in Ugandan children. The 23-question screening tool (23Q) was found to be modestly successful in identifying a subgroup of children at especially high risk for developing autism spectrum disorders (Kakooza-Mwesige et al., 2014).

An example of transferrable technology for mental health screening among pediatric populations is illustrated in Figure 39.1. One of the TQQ questions is shown in the figure in both English and Kiswahili spoken in Kenya. The questions were implemented in the Sana Android framework, which can collect data on a mobile device and upload the data to a medical database. Sana apps are designed to send data to an OpenMRS electronic medical record system ([www.openmrs.org](http://www.openmrs.org)), but others can also be implemented. With a small amount of training time, community workers can be trained to ask questions from an electronic form and type in the answers, which are then saved on the phone and uploaded to the internet when network connectivity becomes available. Remote computers can analyze and score the answers, after which automatic feedback is sent to the health worker. Additionally, epidemiological data becomes available as the population data accumulates. Because the questions in the survey can be controlled and updated remotely, it also becomes possible to adapt questions as needed. For example, additional questions, such as those found in the 23Q, could be added to the TQQ and immediately made available to all community health workers using that app. This enables lightly trained community workers to use the latest tools that are continually evaluated and updated in a central location by more specialized experts. This prototype awaits full implementation and field-testing.





**Figure 39.1:** Mobile apps created with the Sana framework ([www.sanamobile.org](http://www.sanamobile.org)) are illustrated here. One of the questions from the Ten Questions Questionnaire used to screen children for major neurodevelopmental disorders is shown here in both English (a) and Kiswahili (b).

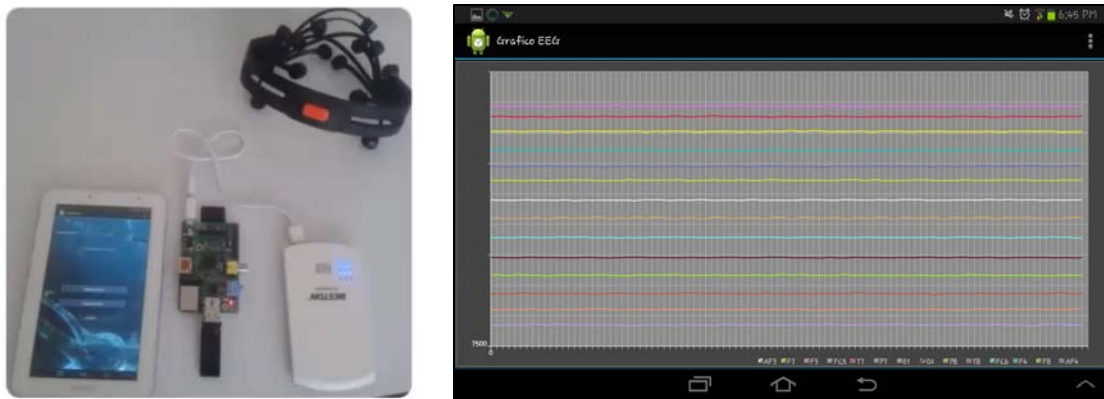
The need for mental health specialists, particularly psychiatrists and neurologists, will continue even if task shifting is implemented extensively. Using mobile technology will enable the expertise of a few specialists to be transferred to many community workers.

#### *Portable EEG Diagnostics*

A mobile system for the collection of clinical and EEG data has been designed to support the initial assessment of neurological problems (Insuasty et al., 2014). The system demonstrates the possibility of collecting data in a community clinic setting and uploading the data to a remote server where it may be reviewed by a specialized health professional (a medical doctor or specialist nurse, for example). Apart from the capacity to complete a standard medical assessment survey such as the TQQ, the system allows the capture of EEG signals by connecting a portable EEG device through Bluetooth. The information collected is stored in the mobile device and automatically sent (if an internet connection is available) to the medical health record (OpenMRS) in order to be assessed by a specialist. The management functionality of the survey and its synchronization with OpenMRS are supported by the Sana platform. For the management of EEG signals, an



Android application called NeuroSana was developed, as shown in Figure 39.2. Three principles guided the development of the system: open source, low cost, and interoperability, which are important attributes for technology deployment in low-income nations. The hardware and software were mainly supported by open source platforms and interoperability standards, e.g., Bluetooth, XML, and the European Data Format (EDF), which is a simple and flexible format for the management of multichannel biological and physical signals such as electroencephalograms or electrocardiograms.



**Figure 39.2:** Shown here are an EEG device, mobile phone with hardware to capture EEG signal, and example signal display using the NeuroSana software developed by the authors (Insuasty et al., 2014).

### *SMS (text) Messaging for Public Education on Autism*

Autism Spectrum Disorder (ASD) is a complex, lifelong, neurodevelopmental disorder, characterized by impaired social communication, impairment of language, and abnormal behaviors. It has profound influence on the social functioning of the affected person and their family. Its impact is quite large due to its growing prevalence: 67 million people, (approx. 1 percent) of the world's population are affected by Autism Spectrum Disorder, a prevalence that is higher than AIDS, cancer, and diabetes combined (Smith, 2011).

Misinformed perceptions of ASD and its causes are aggravated in most African countries by many factors, including all of the barriers previously discussed. In many countries this dearth of knowledge and support is compounded by lack of a specific term to describe ASD. In cultures that are gregarious, there is often little tolerance for people who are unable to engage socially. Such perceptions are hard to shift, especially when children with ASD are frequently seen as blighted or bewitched as a consequence of their parents' wrongdoing.

A pilot project was designed and tested by a student group in the MIT Global Health Informatics program in the Spring of 2014 to evaluate the effectiveness of using SMS (text) messaging as a tool for participatory surveillance to measure public understanding of autism and related disorders in Kenya.

The student project was intended as a pilot study of a larger goal to engage a Kenyan television program, Makutano Junction (MJ), with a viewership of 11 million in East Africa. The goal is to have MJ profile an *autism storyline* within a broadcast series. Questionnaires were embedded in MJ's established SMS and leaflet information service to measure the impact such a storyline has had on knowledge, attitudes, and claimed practices toward those affected by ASD.

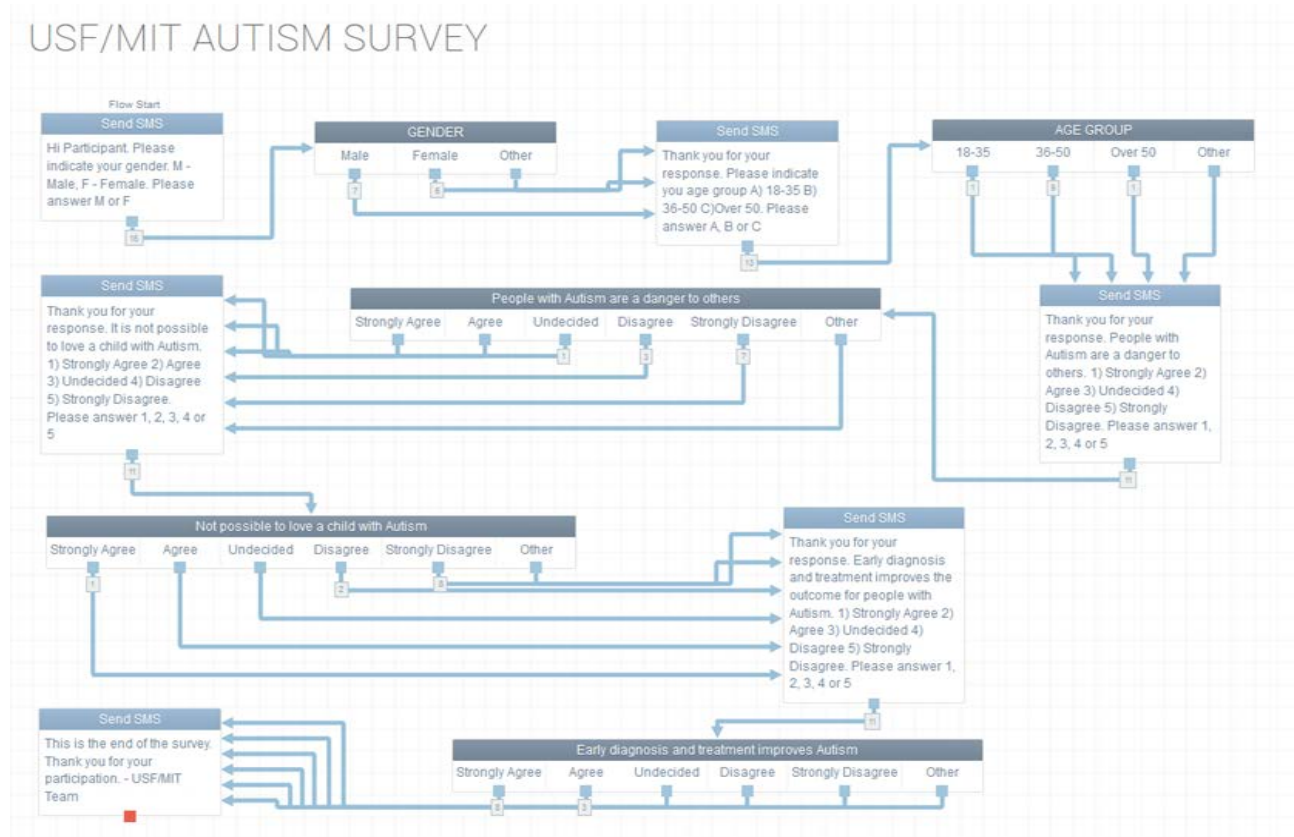
Using a commercially available SMS messaging service called TextIt (<http://textit.in>) and mobile, bidirectional communications, a survey was designed and tested on a small population of students. The survey is designed to evaluate the effectiveness of targeted programming and the use of SMS technology as a methodology for participatory surveillance. SMS messaging is intended to be used to support public information delivered through broadcasts by sending targeted messages to survey respondents.

TextIt is a platform for building SMS applications and sending text messages through a simple Android phone as a small-scale aggregator. For scaling up to very large populations, the TextIt application will be converted to the SMS aggregation facilities of Mediae Company for Education and Development. Figure 39.3 illustrates one of the survey questions that are sent via SMS. Responses are automatically accumulated by the TextIt system and basic statistical analysis results are made available. More involved analytics can be run on large population data after the pilot stage when large data sets are collected.



**Figure 39.3:** SMS messaging used for epidemiological surveys and for broad information campaigns to educate the public and reduce stigma.

The findings from these impact assessments will be useful in planning future MJ shows to address related issues concerning mental health. Given that these findings will be representative of a cross-section of the community from three countries within East Africa, they will provide key insights on how to challenge stigma, reduce the isolation of those affected by ASD, and implement best practices for long-term support. Importantly, successful execution of this project on a large scale will provide mental health information and a means for collecting on-going data that can be used by policy makers for planning and allocating resources for ASD and other mental health services.



**Figure 39.4:** Data flow design used for creating the pilot SMS survey to measure the effectiveness of an autism educational campaign on the public's knowledge of autism.

### *Electronic Health Records (EHRs)*

An important emerging theme in mental health care is the need to incorporate a life-course approach to the treatment of mental disorders, recognizing their developmental course and the need to monitor the course over time (Collins et al., 2011). This life-course approach requires that mental health care be integrated into routine primary care, which also opens up the possibility of early detection and intervention using a community and peer counseling care approach. Because of the need for primary care health workers

to implement such integration, tools for task shifting are needed. Furthermore, some kind of electronic record must be kept for each patient that includes an objective assessment of the relevant associated symptoms, which then enables the effectiveness of treatments to be monitored. One such electronic record is OpenMRS, an open-source, robust EHR platform that is supported by a global network of developers that has been used in over 40 countries in the world (Fraser et al., 2012).

Electronic screening tools are needed in primary care settings to initially identify a behavioral health risk or condition, and are used in behavioral health settings to track patient's progress and outcomes. Integrated care requires the use of standard behavioral health screening and assessment tools, delivery of treatments, and evaluations of progress across care settings. Participants in a roundtable meeting in the U.S. Office for the National Coordinator for Health Information stressed the need for clinical decision support tools related to behavioral health (RTI\_International, 2012). This need is especially acute in low-resource settings for task shifting. However, a survey of the literature found no examples of actual implementation of EHRs in low-resource settings specifically for the screening and monitoring of mental health conditions. This is an area ripe for pilot and demonstration projects.

### **Steps to Adoption in Low Resource Settings**

Several questions must be answered at the level of local or national health ministries when considering the cost of scaling up mental health services in low-income regions. A recent study assessed the resource needs and costs associated with scaling up a package of essential interventions for mental health care over ten years. The core package for this project comprised pharmacological and psychosocial treatments of three mental disorders—schizophrenia, bipolar disorders, and depression—and brief interventions for one risk factor— alcohol use. The results suggested that the extra cost of scaling up mental health services over ten years to provide extensive coverage of the core package should be feasible in absolute terms, although challenging (Chisholm et al., 2007b). Estimates were approximately USD \$2 per person per year in low-income countries and \$3-4 in lower middle-income countries, which were considered to be modest compared to the requirements for the scaling-up of services for other major contributors to the global burden of disease (Chisholm et al., 2007a).

Studies that have attempted to estimate costs have been done, but appear to not yet take into account innovative uses of technology for task shifting, early detection, or life-course monitoring and treatment. While such estimates are difficult to make before the technology has been implemented, we suggest that economic estimates that attempt to incorporate the impact of innovative uses of technology, as described in this paper, might help to spur government investment in new technology development for this task. Integrated mental health care is feasible using emerging health informatics because the innovations needed for such integration into other health care platforms “are consistent with many efforts to strengthen the capacity of primary care systems to address multiple health priorities more broadly” (Patel et al., 2013).

## Summary

Mental disorders impose a significant disease burden on rich and poor nations of the world alike. The burden extends well beyond the suffering of the patients, affecting caregivers, families, and communities. It can be a cause of poverty, and poverty exacerbates mental disease by limiting access to effective therapeutic interventions. Perhaps most compelling of all, the current state of global mental health care has been called a moral failure of humanity due to the atrocious conditions under which many people with mental disorders are forced to endure.

Innovative adaptation of existing technology can enable cost-effective diagnosis and management of mental disorders in primary and community care settings. Many mental disorders, if detected early and treated as chronic disorders, can be managed, allowing a reasonably normal quality of life with existing treatments. The single largest barrier to mental health care in resource-poor settings is the enormous scarcity and inequality of skilled human resources in low-resource settings. Information technology is an important enabler of task shifting. Several examples presented in this chapter show how mobile devices, including phones and EEGs, together with the growing universal accessibility of the internet and cloud-based database resources, are being developed to meet the need for better mental health care globally. It is hoped that this chapter will provide some guidance and inspiration to health technology students and research groups to engage with mental health providers to create new tools to meet this enormous challenge.

## Questions for Discussion

1. What barriers prevent immediate implementation of community mental health programs using the technology presented in this chapter?
2. How much training is needed to implement pilot clinical programs for MNS health care in specific resource-poor settings?

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