#### Perspective

# Personal medical record: Dominica's low-tech, low-cost solution for a high-tech, high-cost problem

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The advantages of personal medical records in health maintenance and cost reduction have been well studied, and they are recommended as an integral part of health care management. Several Electronic Personal Medical Record (ePMR) systems have been developed, but their popularity and utility falls far short of expectations. Cost, confidentiality, and logistics are all problematic in implementing an acceptable ePMR system. Out of necessity, Dominica, an island nation in the eastern Caribbean, developed a manual Personal Health Record (mPMR), which effectively overcame all of the above problems. Some refinement of its current state will make it the most useful and cost effective system in certain places and an initial step while moving into an electronic phase. Dominica's system may be adopted by smaller nations or small communities (as a unit) in larger countries at a fraction of the high-tech cost and administrative hassle.

**Key words:** ePMR, mPMR, cost, confidentiality, universal adoptability.

#### INTRODUCTION

Recording a patient's medical history and health care issues is the backbone of health care practices. Clinical records provide insight into an individual's health and a disease-stricken individual's progress, remission, or cure and therapeutic interventions. Recorded clinical history from individual patients, from a community, from the larger population of a settlement, or for that matter, from the entire country, can indicate the epidemic or endemic nature of a disease, enabling officials and policy makers to develop policies and programs to cure, detect early, and prevent spread or recurrence of a disease, or death due to the ailment. An individual patient's medical history, therefore, is not only useful to the patient but is the basic foundational tool for a nation's health.

#### HISTORICAL ASPECT

Documenting human activity did not start with medical history taking. Writing was invented as a matter of necessity for documenting production of grain and its distribution, storage, and stocks by Mesopotamians and the ancient Egyptians around 5000 BCE (Ezzamel & Haskin, 2002; Schmandt-Besserat, 1980). Soon

afterward, physicians in the ancient world realized the benefit of recording patients' clinical history. The oldest clinical documentations are written in hieroglyphic, used by the legendary Egyptian physician Imhotep (David, 2010; University of Manchester, 2007). Documentations in Mesopotamia (Webb, 1957), India (Wells, 1999; Patterson, 2001), and China (Hong, 2004; Felt, 2007) all are enlightening., The first known medical documentation in the development of modern medicine was introduced by Hippocrates in the fifth century BCE, the objectives being (a) a record accurately reflecting the course of the disease and (b) an indication of the probable cause of the disease (Van Bemmel & Musen, 1997).

### DEVELOPMENT OF MODERN ELECRTONIC HEALTH RECORD (EHR):

Medical records have been developed for systematic documentation of individual patient medical history and care. This information is compiled by the health care provider and is kept in an institute or doctor's office for retrieval only when it is to be viewed by the doctor affiliated with the institute where it is kept. If the patient

has a family physician or a general practitioner he/she normally consults for health-related issues, the physician maintain а health record clinical documentationand administrative purposes. Medical charts are also maintained by hospitals in case the patient is seen in the hospital. In fact, each health-related contact documented in a clinical record of the patient, by every institute or health care individual, is not normally shared with others. This puts the patient, individual health care worker, and health care institute at a disadvantage, not being a party to the entire clinical picture (Pirtle & Chandra, 2011). In

developed countries like the UK, Canada, and Australia, health care management is centered through one's family physician (FP) or a general practitioner (GP), who is expected to be informed of any health-related encounter with any health care institute or worker. This is not an ideal situation, since the documentation could be incomplete or inadequate. At times inaccessibility of information, when a patient is seen outside this loop, could be hazardous. This would affect correct decision-making, as the doctor then has to rely on the patient's memory and interpretation.

Several clinical facilities with different specialist affiliations are available to an individual who seeks them. The logistics of medical management have become complex. Advances in health care-related information, both for non-professionals and professionals, are easily accessible. The level of public health education and information is improving, through the news media, education, programs sponsored by NGOs (Non-Governmental Organizations), school systems, governmental agencies, and most importantly, the Internet. Medical specialties, sub-specialties, and superspecialties are mushrooming. The complexity of medical technology is advancing so fast that it is difficult to keep up with the speed of its progress. With this widening and multiplying spectrum of clinical and health care systems, it is imperative to maintain a readily accessible, centralized record of one's medical history, with contributions from all caregivers and the individual him- or herself (Scheutzow & Daniels, 1990-1991). With this backdrop of expectations, the ability to utilize electronic health records (EHR) is changing exponentially. In the United States an acceptable EHR should contain: an administrative component, which includes the patient's demography; a laboratory system component; a radiology system component; a pharmacy system component; and clinical documentation. The clinical documentation should contain: physician's notes, nurse's notes, and other relevant clinical notes; flow sheets (of vital signs, input and output, problem lists, medication administration record (MAR)); peri-operative notes; and discharge summaries. An EHR is also expected to contain a system of medical records abstracts, advance directives or living will, durable powers of attorney for health care decisions, consents

(procedural), and release of information, including authorization. Unmitigated application of EHR is expected to be supported by transcription document management, medical record/chart tracking system, staff credentialing/qualification and appointments documentation, chart deficiency tracking, and utilization management (National Institutes of Health, 2006).

For further improvement of EHR's applicability, it is suggested that medical devices be integrated into the flow of clinical information and real- time alerts as the patient's status changes (Haugh, 2006).

## CONCEPT OF PERSONAL HEALTH RECORD (PHR) and PATIENT CONTROLLED PERSONAL HEALTH RECORD (PCPHR)

By self-inspiration, people maintain a diary documenting sporadic symptoms, medical consultations, and hospital admissions with results of treatments offered by their doctors or the health care institute. The impact of this dynamic record on their health and illness is the basis of developing a personal medical record (PMR) or health record (PHR) (Wellcome Library, n.d.; Beveridge, 1998; Cook, 2005; Burns, 2010). As people in the developed world are better and more quickly informed of the availability of and accessibility to health care personnel of various disciplines, training, expertise, belief, faith, and application, a clear and progressive documentation and maintenance of all matters of health and interference to health is a growing requirement.

With conventional treatments, cutting edge therapies, scientific advances, and available alternatives, the need for a personal medical record is becoming essential, if not a human rights issue (Friedman & Gostin, 2012; McGill, 2012).

#### **CURRENT STATUS**

As the complexities of health management increase, it becomes more and more important to keep records of all health-related events in one's lifetime. The modern health-related "information explosion", availability of choices of specialized conventional and unconventional health care and unrestricted mobility of people both inside and outside their home countries, make it nearly impossible to keep track of every event by one's family physicians or local hospitals or, for that matter, health insurers. None of these agents are equipped to summon all health events that take place in one's lifetime and document and preserve the information in the form of a paper file. Digital information technology, with its quickly expanding horizon, scope, and applicability, appears to be the obvious choice for compiling and progressively updating one's health records electronically (electronic health record or EHR). Thus, EHR became a marketable commodity, which has been introduced to society in all forms and shapes, with a broad spectrum of applicability.

Hospitals, family physicians, and pharmacies all jumped onto the bandwagon of going electronic. Since it is not feasible for the EHR providers to record all health-related events experienced by individuals, a natural progression of this concept is to develop a personal health record (PHR), in which patients themselves enter data or events for documentation, which may be used by their physician or a health care provider for future management. A major disadvantage is reliability of data and entry of health events. PHR has proven to be useful in costencounters by several cutting and reducing health institutes, organizations, hospitals, doctors, pharmacies, etc. (EHR Impact, 2009), but it cannot be relied upon on its own (Jha, et al., 2006). Thus, the next conceptual advance is a combination of EHR-PHR or providerconsumer partnership. The institutes maintain an EHR and the patient maintains a PHR or Patient Controlled Personal Health Record (PCPHR). At this stage the logistics of data accumulation, assimilation, and multisource computation become complex and appear not to be cost effective or meet their objective. The deterring factors

are technological deficiencies, physician's lack of conviction of usefulness of the concept, inconsistent data entry and data distribution (EHI, 2007; Gratzel, 2008), unreliable or misconceived event entry in PCPHR, and unavailability of PHR or PCPHR as and when needed (Foreman, 2006). The shortcomings that have so far prevented the universal adoption of EHR and PHR are likely to worsen as medical management gets more and more complex, technological advances allow increasing choices, and data entry becomes complex and requires training and retraining with every change in hardware or software. One can be assured that changes in technology are certain to be a part of reality.

The need for and advantages of adequate, accurate, and appropriate medical records, be they paper-based, electronic, or Internet-based, cannot be overemphasized. Adoption of digitized medical records is a natural progression. The objective of EHR is clear: Digitize all paper records and transmit health records and data electronically, to be updated at regular intervals.

The objective of PHR and PCPHR varies between providers (Gearon, 2007), but the central objective of capturing all health and health care-related events is a constant. Enormous amounts of research have been done and are ongoing to define and create a universally acceptable EHR and PHR/PCPHR, which would be comprehensive and readily accessible, with transferable information and data stored; logistics for regular data gathering, recording, and updating in place; portability and privacy- secured and "hack" proof (Comini, Mazzu' & Scalvini, n.d.; Wootton, 2001; U.S. Dept. of HHS, n.d.; myPHR, 2012).

Millions of US dollars have been spent to develop an ideal system, and the quest continues, with millions more budgeted. So far the national objectives are far from

being met. But in some areas, use of PHR has been shown to be economic, reduce health care cost, improve general status of health, and prevent death (Chen, et al, 2009). But this is not experienced by all regions, services, and providers who have adopted PHR systems for a defined population (Flynn, et al, 2009).

By the year 2007, 167 different types of PHR were available in the US market, targeting different users, i.e., doctors, hospitals, pharmacies, laboratories, imaging and X-ray services, and patients themselves.

Apparently \$19.2 billion of the federal government's total health care reform stimulus packages of \$787 billion have been set aside for digitization and establishment of electronic health records (EHR) (Steinbrook, 2009). This has created a huge "gold rush" for several major companies involved in digitizing health records to assist hospitals, healthcare facilities, doctors, pharmacies, imaging facilities, nursing homes, and other health care providers. Technology titans like IBM, Intel, General Electric, Microsoft, and Wal-Mart (in partnership with Dell) are all competing to provide the "best" system (Gans, Kralewski, Hammons & Dowd, 2005). The result is a lack of uniform objectives, standards, priorities, and focus. Most of these systems are not transportable interinstitute, nationally or internationally, and are not interoperable.

#### ADOPTABILITY OF DIGITIZED HEALTH RECORD

Application and adoption of the first Electronic Health record was carried out 50 years ago, in the 1960s (Tange, Hasman, de Vries Robbe & Schouten, 1997). Even 50 years down the road and two recent American presidents (Bush II and Obama) later, full federal endorsement for digitization of health record is still in a very fluid state in America.

At the core of the usability of Electronic Health Records, be they EHR or PHR or PCPHR, there remain several fundamental prerequisites: access to a computer and a minimum standard of education and health conditions not limiting computer interaction; substantial computer experience; knowledge experience in health care information; medical health concept and terminology and experience in personal record keeping; and ability to search for information needed to create a PHR record. The heath care providers and consumers feel that most useful PHR need to have all lab test results tracked over time; for medication: name of the drug, dosage, prescriber's name, number of the prescription and refill orders; for appointments: appointments with doctors or any other care provider, procedures undergone health recommendations taken, future appointments and preparations needed for the appointment; and the emergency health care provider must have access to the PHR.

Patients were agreeable for their health care worker to



Figure 1. Relative geophysical position of Dominica with its neighboring countries and seas

have access to the PHR but unhappy about the insurance companies or governmental agencies having access to PHR. It is still unclear who should maintain the PHR and the level and type of commitment needed to perpetuate the system. The human resources needed must be available, adequately trained to maintain the system, and the cost involved to maintain the organization must be within budget (Marchionini, Rimer & Wildemuth, 2007).

#### COST OF DIGITIZATION OF HEALTH RECORD

From the US Federal government stimulus incentive it appears 37.5 billion USD has been allocated for theimprovement of health care, of which 19 Billion USD has been set aside for implementation of electronic health records (EHR) (Hollar, 2009). Then one needs to work out the annual operating cost for installation and adoptability of EHR, which should vary from country to country, depending on GDP It has been suggested that it will cost 75 to 100 billion USD over the next 10 years for the transition from paper to electronic health records in the USA (David, 2010). So far the experience from the western countries, i.e., USA, Canada, United Kingdom, France, Germany, Australia, and Denmark that have introduced EHR and PHR has been out the annual operating cost for installation and adoptability of EHR, which should vary from country to country, depending on GDP It has been suggested that in spite of its perceived benefit, it has not come cheaply. The jury is still out in assessing its cost benefit advantage. Some private corporations are quoting a cost of 20,000 USD annually to maintain EHR on the top end and others quote a figure of 895 USD per person per year. When some of

the resource-poor countries' annual per capita income is 800 USD or less, introduction of EHR in its current form will remain nothing but a fantasy to these nations, in spite of increasing access to computer usage (David, 2010). As we appreciate, computer hardware plays a minor but important role in the EHR equation.

#### THE SUCCESS STORY

After 50 years of intensive trial and error in digitization of health records in the United States, we are nowhere near developing a national consensus for adaptation or standardization of EHR-PHR/PCPHR in the USA. There are excellent pockets of successful implementation of EHR, i.e., Kaiser Permanente system, Veterans Health Information Systems and Technology Architecture, and many others have been successful in supporting a group, an institute, a hospital, a group of hospitals or insurance companies--at a price. In spite of these successes and commitment of federal funds, a national consensus for standardization and adaptation is still in progress (Brewin, 2009; Anderson, Frogner, Johns & Reinhardt, 2006).

#### THE ECONOMICS OF EHR-PHR/PCPHR

What we are experiencing is that in the last 50-60 years, there have been significant changes in the way we document our medical records, especially digitization and incorporation of electronic health records in the health care system. These developments have taken place mostly in the USA and to some extent in Western Europe--in other words, in the developing countries. The total population of the world is 6,706,992,932, of

which 978,186,023, or 14.6% of the world's population lives in 35 highly developed countries; the remaining 5,727,771,694 or 85.4% lives in developing countries (Mandl & Kohane, 2008). There is a "big time divergence" of GDP between developed and developing countries. which includes per capita income (Pritchett, 1997). A huge gap exists between the "resource rich" and "resource poor" countries, so it is questionable whether the policies, procedures, and technologies developed in resource rich countries for their citizens can be transported to developing countries. Unless economically viable system is developed that is suitable for resource poor countries, it is futile to adopt EHR-PHR/PCPHR suitable for rich countries. Poor countries can learn the principles and develop technology and systems to suit their national and public coffers. There is also a need to focus on the essential bases of EHR, i.e., governmental funding, statutes implementing EHR programs, public and professional education, computer competence. literacy. availability of

computers at home or within easy reach. These complex socio-economic and political issues are not insurmountable, yet for the last 60 years or so of the program's inception, there has not been an ideal solution or a role model to follow, or any real leadership from the developed world that is suitable for 85% of the world's resource poor nations (AARP International, 2007; Barr, 2010).

#### **HEALTH CARE IN DOMINICA**

Dominica is one of the Leeward Islands of the Lesser Antilles in the Eastern Caribbean region (Figure 1) (Government of the Commonwealth of Dominica, 2010). The majority of its 73,000 inhabitants live in the coastal villages and towns.

A former British colony, Dominica retained a disciplined governmental bureaucracy and an effective health care system. At present the health administration has divided the country into seven health care districts and 10 Parishes. Primary health care is provided through two District hospitals and a network of 52 health centers throughout the country (Government of the Commonwealth of Dominica, 2010).

However, from 1960 onward, the health care system in Dominica deteriorated. The health care situation got worse by 1970 in spite of many well-qualified Dominican doctors trained abroad returning home to serve the country, and improvements in treatment facilities in major cities, i.e., Roseau, the capital, and Portsmouth. The primary health care system in the country was progressively worsening (Andre, 2006).

Adding to the country's woes, Dominica is not free from natural calamities, i.e., hurricanes, landslides, flash floods, epidemics, etc. (Lawrence, 1979). Dominica is used to tropical storms, cyclones, and hurricanes during

hurricane season.The last severe hurricanes that devastated Dominica were in 1806, when 131 people died, and again on 10<sup>th</sup> September 1834, when nearly 200 people died. Dominica has experienced several storms, cyclones, and hurricanes over the years. Citizens were well organized and well drilled to withstand natural disasters like these, but were ill prepared for and unaware of the severity of the one yet to come.

### LEGACY OF HURRICANE DAVID ON HEALTH CARE SYSTEM IN DOMINICA

On 29<sup>th</sup> August 1979 around 11 am, Hurricane David deviated from its anticipated course toward Barbados, struck the shores of Dominica, pounded the island for six hours, and razed almost everything that stood higher than ground level. The wind speed was 150mph (Pan-American Health Organization, 1982). Thirty-seven people were killed, 80% of homes were destroyed, 75% of the nation's population was homeless, and the rest were temporarily displaced (Fontaine, 2003). Severe rain soon after the disaster washed anything and everything out to sea (Lawrence, 1971). With the total razing of all structures, David demolished almost all government offices, major health care centers, and health centers where patients' health documents were stored. By the end of the storm, the country was almost completely without any health records of Dominican citizens. The loss of health documents was almost complete and there was no mechanism to retrieve them (Pan-American Health Organization, 1982; De Bruycker & Coles, 1981).

While the country was being rebuilt from scratch, some form of health and clinical documents needed to be established. In desperation, many prominent Dominican physicians, such as Dr. D.O.N. McIntyre, Dr. Dorian Shillingford, and Dr. Edward Witty, made a consensual decision to create clinical documents in exercise books which were given to patients, who were expected to be the custodians themselves due to lack of storage space, and produce the book at each health-related encounter with any health professionals. Doctors, nurses, health visitors, and pharmacists were all expected to record the dates of their encounters and a very short summary of the visit, so that every clinical visit was recorded for future reference to present a general state of health of the individual holding the "book". This was inadvertently the beginning of Manual Personal Medical Records (mPMR) for Dominicans.

Restoration of health and clinical records after the complete destruction of the system was a colossal task. Dr. Desmond McIntyre took the helm and initiated the rebuilding process by a "Proposal for organizational structure in support of the effective delivery of primary health care" in March 1981 to the government of Dominica (De Bruycker and Coles, 1981). Later he was joined by young and vibrant Dominican Dr. Carissa



Figure 2. Example of some manual personal medical records, i.e., "medical book", in Dominica.



Figure 3. Faithful custodian of Dominica's personal medical record book.

Etienne for its implementation. Participation and support from Mr. Charles Maynard, Mr. Ossie Semmes, Nurse Jean Jacobs, Dr. Dorian Shillingford, and Dr. Griffin Benjamin eventually not only restored Dominica's health care records but also excelled beyond imagination and broke all expectation to be one of the world's best primary health care systems, according to Dr. Mervin Henry, PAHO Caribbean Program Coordinator (Andre, 2006).

I started practicing in Dominica in February 2008. I found almost 100% of patients carried with them their "personal medical book". Some of the books are actually 25 or more years old. They not only produced their "book" (Figure 2), they insisted that I document something about the visit in the book, if I forgot. This is patient-motivated, as opposed to the "carte" and "santé" in the French

territories of Martinique, Guadeloupe, and St. Martin, which had been mandated by the government. All healthrelated encounters are précised till the age of 16. For adults, the Dossier Medical Personnel, popularly known as DMP, had been planned since 2005, but just started to be implemented after 2010, so it is still in the making (Andre, 2006; EHI Europe, n.d.). The Dominica personal medical books are "Cradle to Grave" medical and health care documents voluntarily adopted by the people of Dominica, although initially instituted by the Dominican government. After restoration of official clinical documents in hospitals and health and nursing centers, the personal medical "book" has set the people up as its own custodian, and they are doing it with diligence (Figure 3). I was quite amazed at the amount of health information I could get from these "books". Aside from

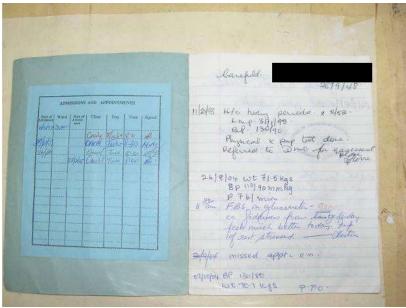


Figure 4. Handwritten medical and personal documents in Dominican medical book.

health care workers' notes, patients document their personal observations, which includes symptoms, monitoring of blood pressure, blood glucose levels, temperature, weight, urinary symptoms, bowel habits, last menstrual period (LMP), medications, physiotherapists, and many more (Figure 4).

### DOMINICA MANUAL PERSONAL MEDICAL RECORD (mPMR)

The mPMR that Dominicans carry has a great impact on the way health care is conducted in Dominica. Being the custodians of their own health records has made people more health conscious. They can flip backward and forward to keep abreast of their own health dynamics. People feel responsible for its maintenance, upkeep, and regular updating with times and events. Compared to EMRs, the cost is practically nil. Since no other agent, program, or place secures it, the chance of it being stolen or abused is less. Confidentiality of documented materials is well guarded by the individual. Since its presence and utility is personally driven, motivation for its continued use is almost guaranteed, without any governmental legislation. Since its impact in the health care system is noteworthy, without the vast expenses incurred by EMR users, Dominica's mPMRs can be significantly and further improved by educating (through workshops) all health care personnel to make useful and essential documentations during patient contact. If necessary, use the government's legislative power to make it mandatory for all health care workers. Use the government's public health education program to enhance public awareness of its usefulness and immense value in their health care. The government may take the role of educating both the public and caregivers to maximize the benefits of a "practical and useful voluntary mPMR system", which is a byproduct of a catastrophe that has become a social and economic triumph. The impact on health care and health care cost is significant. If we nurture this "habit" and beat all the odds, not going "electronic" while the rest of the world is running for electronic PMRs at a significantly higher cost and logistical nightmare, the winning card will be for Dominicans.

Issues in "electronification" of developing countries are several: One needs a basic education, discipline, and sense of organization for meaningful use of ePMR (Electronic Personal Medical Records). In most cases at this point, these qualifications are sadly missing. The availability of computers to the general population to use as a tool for PMR is yet to be a reality, but is improving by the day. Concepts of being educated and educational contents vary vastly from country to country, nation to nation, and culture to culture. The western concept of one's health status exposed to and controlled by others may be a hard sell across the national and cultural divide. Incorporating a PMR undisputedly affects health maintenance and health care cost in a very positive way (Chen, et al., 2009; Flynn, et al., 2009). The question of creating a system for universal and optimal use is yet to be solved.

It appears that "electronification", in the name of progress, of every aspect of human life is inevitable, whether in developed or developing communities, due to the juggernaut of corporate pressure, ill-conceived perceptions of utility and keeping up with the "Joneses". If and when it comes to Dominica, with a well-informed, compliant, and motivated population, changing from

manual to automatic or electronic will be just a matter of "resetting" the button, which will require little effort and persuasion. Everyone is a winner. It is important to understand that to take a leap into the future, we need to excel in our present and improve on our already existing mPMR. There is a strong lesson to be learned from Dominica's experience for all developing countries, be they on an island or a continent.

### DISCUSSION: LESSON FROM DOMINICA'S EXPERIENCE

The mPMR originated in Dominica as a result of a devastating calamity, Hurricane David, in 1979. In response to the total destruction of the country's health documents, a makeshift medical record "book", maintained by the people themselves, was created. After 30 years of its existence, it has grown beyond its "makeshift" status. It has been elevated to an essential and vital link between all medical practitioners, health care workers, and sick or healthy people--a de facto manual Personal Medical Record (mPMR). Establishment of these medical documents, prior to the implementation of a Primary Health System, may have been a pivotal factor in transcending Dominica's primary health care from a destitute "rag-tag" to a "role model" for the world. To maintain Dominica's mPMR, investments are miniscule compared to what is being quoted in the West for similar digitized records.

It is understandable that without a backup system, the possibility of being lost or damaged may mean a serious reliability issue. However, in my last five years of practice, not a single patient reported loss of or serious damage to their cherished medical "book". Few reported without a book; either they were never told or did not go through the conventional medical system. In those cases we initiated a medical book for those patients and made them aware of its importance and their responsibility for its safekeeping. I have no doubt all other health care workers must be doing the same.

As far as backup is concerned, since 1983, after Dr. McIntyre's team rebuilt the health care system and facilities, formal institutional records are kept by the institutes, health visitors, or district nurses.

The problem of security and stealing of personal data for fraudulent usage and monetary gain is not an issue here yet. This is a problem of the so-called automation, mechanization, and blind love affair with technology in the resource-rich world. In Dominica no one even can perceive what he or she can do with his fellow citizen's medical book except to find the person and return it to the rightful owner. But wait a bit--corporate greed, an individual's aspiration to "make a quick buck" at any cost, and blackmailing are all blessings of economic plenty. Until we are blessed with the advanced world's woes, Dominicans can count their own blessings in being protected from these ills, perhaps being a content

society.

#### CONCLUSION

Admittedly, Dominica's low-cost, low-tech mPMR system needs further overhauling and fine-tuning, but its existence and experience in Dominica can be transported anywhere in the world, especially in remote communities, whether in the developed or developing world, island or inland.

The world is watching. Chancellor Imhotep in Egypt is smiling and Reverend Hippocrates in Greece is wondering, why is it taking so long?

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