Getting your Personal Health Record (PHR) started

This paper is designed to set expectations about Personal Health Records and provide insight and ideas for getting started and creating an effective one. This includes use of specialized software for organizing and managing PHR data. Lifelong, it will bring greater utility and benefits from the time and effort expended.

Personal Health Records can mean different things. In an absolute sense, they literally represent anything that was ever generated about a person's health. At a detailed level, this is every X-ray, blood test report, ultrasound and EKG printout, prescription, doctor's notes, and camera image, to name a few. Over a person's lifetime, this can add up to considerable information. Looking for specific data can be very difficult, especially if information is not centrally located, organized and cataloged. Furthermore, over an extended period of time, it is likely that a lot of information will be lost or discarded. Our experience indicates that health care providers have information retention policies that are in part, governed by state mandates, but typically limit the length of time something is saved. Suffice-it-to-say, no one should expect information that is needed or nice to have will always be available. We believe it is up to the individual to anticipate needs as best as they can, and be prepared.

What are you thinking? At this point, you are probably thinking that collecting vast amounts of data and entering it into a computer database will be a daunting task, likely impossible, and a total waste of time. With that, we agree, but that is not what we are proposing. Our studies have indicated that a great deal of the information that is generated is never reused once it is used a first-time. What usually happens is that detailed information is digested and summarized to present certain facts and conclusions. Essentially details may or may not be retained, but it is the essence that is important. These are the things that support diagnoses and enable informed decisions to improve outcomes. These are the things that should be in the PHR with references that enable details to be found when they are needed.

A PHR is like an insurance policy; you never know when you will need it. Young mothers find them helpful to keep tract of all the vaccinations and childhood illnesses. Children managing the affairs of elderly parents find them especially useful. As medicine becomes more and more targeted and personalized, we expect that a PHR will be increasingly useful and important for everyone to get the greatest value from their healthcare dollars. Those who wait will find it increasingly difficult to reconstruct the past as records are lost and discarded. Those who start now will save effort as they see immediate benefits that will continually grow.

Here is how typical medical data is used. When there is a problem, data is collected, a diagnosis is made, and a course of action is undertaken to treat problems and symptoms. Yes, many people schedule annual physicals to look for problems, but most doctors' visits are reactive, rather than proactive. Once a problem has been solved, the thinking is that any test data will probably never be needed. We on the other hand believe in comparative analysis and recommend retaining test data to continually look for trends from one time to another.

Data that is collected represents pieces of puzzles that can often be used or assembled in different ways. Each puzzle piece can also be compared to similar ones collected at different points in time to look for changing trends. For example, have blood pressure readings been changing? What about cholesterol, those EKG plots, or the internal pictures of a person's eye or the blockages in their blood vessels? Are things getting better or worse? Is it getting to be time to take action? How long has it been since abnormalities started to become evident? We see all of these to represent opportunities to reuse data on a regular basis to improve outcomes. So we recommend saving raw data in case ways are found to reuse it later on. However, our emphasis here is on creating

a high-level health record that is personalized from the patient perspective, one that will help patents manage their care.

Our approach is to use a database tool to create a high-level, summary view of a person's medical history. The result should have sufficient detail to answer most questions and to include references to help find details should they be necessary. The details can be organized and stored separately. Following are examples of what a PHR should be expected to do for the patient that maintains one. There are likely others. Think about other needs that you have as you collect and store your data.

- *Emergency Data* - A PHR should have the capability to format and print a concise summary of facts that will help to jumpstart treatment in the event of a medical emergency. Useful data includes blood type, allergies, chronic conditions and medications being taken.
- *Historical Summary* - Patients need reminders about things that they should communicate to the variety of providers that they encounter over a lifetime. This includes conditions and treatments that they have had and whether or not they have been successful and there have been any lasting implications. Symptoms can have multiple causes. Knowing about immunizations, medications taken, family histories, and past illnesses and injuries provide clues as to causes that can be ruled out. This helps doctors to zero in on what is important. It will help to save time, effort and expense by building upon past experiences and not "reinventing the wheel."
- *Reconciliation of Bills* - Often bills arrive a long time after the fact and fail to detail the circumstances. Sometimes separate bills come from different team members. A PHR can be a big help in auditing bills prior to making payments.
- *Appointment Reminders* - Linked with a calendar program, a PHR can remind the patient when to visit the doctor or get a prescription refilled.
- *Tracking and Analysis* - Patients who use their PHR to record and track vital signs can help spot trends that their doctors need to learn about.

Management voids make it more and more important for patients to participate in managing their healthcare. We believe that successful outcomes depend on having a PHR to assist them. It also aids parents in managing the care of children and family members in helping elderly parents. In the future, as genetic information is associated with specific diseases, we expect PHR's to play increasing roles in proactively anticipating issues and beginning treatments. The sooner an individual starts to collect data and begin building their PHR, the better. Doing so will help them get more involved in a regimen for better health, longevity and quality of life.

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