

Personal Health Records

Things to think about

Hurricane Katrina demonstrated the importance for patients to have copies of their Personal Health Records (PHRs) when official records were destroyed. Since then we have discovered that even the best records can miss essential details that only the patient knows. They also have a dark side. In the wrong hands, PHRs can facilitate identity theft and impersonation bringing fraudulent insurance claims and bills to unsuspecting victims. This creates a legal nightmare and lasting damage. Digital records make it easier for everyone except the criminals when appropriate measures are taken to safeguard private information.

Personal Health Records are going digital. Paper records are being merged into databases. It is certainly an efficient way to handle data. One of these days there will probably be a central database that contains everything that anyone could ever want to know about each one of us. There are dangers to this. Information is subject to fraud. Privacy policies notwithstanding, employees can abuse their power and steal. In addition, some organizations likely have hidden agendas and want to use data for their own benefit, not the patient's.

There is no free lunch. It seems as though everyone is getting into the Personal Health Records business. Microsoft, Google, large hospitals and insurance companies are among them. Some are working together. There are websites offering free services. Simply establish an account and start uploading your data. You can print and share reports. Unfortunately, there is no assurance about control and security, and systems are not as complete and flexible as everyone would like. Since companies are in business to make money, we wonder how participation in these programs will affect the privacy of their users. All it takes is one rogue employee to compromise systems. Personally, we feel safer when we control our own information and give it out on a "needs-to-know" basis. We have created an application for personal computers that helps to make this easy. There are other choices, too.

Standardization of records has yet to happen. It requires considerable effort and improvement. We have found that what is collected varies considerably. Some caregivers take copious notes; others fail to do a bare minimum. This is not surprising given time pressures and variations in specialization and performance of individuals. We believe that the contents of Personal Health Records will expand as more and more uses are found for them. Working together to improve the quality and completeness of recordkeeping is important to healthcare outcomes. It has both direct and indirect implications. Data is important to personal care and also medical research.

The best time to start a record is at conception. Collecting information on a pregnancy can be useful later on. It avoids speculation should there be any questions. Start with description of parents, if known. Add information about mother's weight gain, use of pre-natal vitamins, diet, blood pressure readings, ultrasound scans and delivery complications. Continue after birth with growth data, immunization record, dates teeth appear and diet.

Every stage of life has its own special recordkeeping needs and attributes. Knowing details will enable correlation with medical research to help explain the reasons for certain conditions later on. For example:

- **Did obesity begin early in life?**
- **Were immunizations a factor in autism?**
- **Was employment a factor in causing cancer?**
- **Did competitive sports wear out joints?**
- **What will you do if your doctor retires and leaves you without a thorough record?**
- **How do you know that your annual physical exam was thorough?**

There is no right or wrong PHR for everyone. Your Personal Health Record must meet your changing needs to the best of its ability. You must be comfortable and capable of accomplishing what needs to be done. Not everyone wants to record granular detail. Neither do they want to create a record that lacks substance and is useless. Pick a tool with a default configuration, the ability to perform simple customization and ongoing product upgrades.

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