IEEE-USA recommends that all individuals, regardless of age, from cradle to grave, have longitudinal digital electronic Personal Health Records (PHRs). IEEE-USA believes efficient use and widespread adoption of electronic Personal Health Records can help address the health care needs of individuals and reduce health care expenditure. The only common denominator in our distributed, diverse, fragmented health care delivery system is the patient to whom care is being rendered. While much emphasis has been placed on provider-based Electronic Health Records (EHRs), that information remains relatively sequestered and unavailable outside the provider’s practice or institution. Because individuals lack universal identifiers, this information cannot follow an individual through a life that often includes changing locales, physicians, insurers, and/or health delivery systems. Many standards and policies created for Electronic Medical Records are applicable to Personal Health Records.

IEEE-USA believes that, while information contained in Electronic Health Records could be dynamic, it remains sequestered behind the walls of the organization that created them, and further, that Personal Health Records need to be in a flexible mode, always available and dynamically active in promoting individual participation in a person’s own health. The strength of a digital (electronic) Personal Health Record is that it contains both patient-reported and provider-based health information. Both are credible, but the source and date of the information need to be identified to support that credibility. The federal government should support public-private enterprises that facilitate the widespread adoption of Personal Health Records, by promoting financial inducements, educational grants and regulatory changes. To this end, IEEE-USA recommends that:

- Information contained in Personal Health Records is private, and only the person to whom the information pertains, or the person’s authorized representative, should control access to this information. Strict guidelines and legislation should be instituted to prevent use of patient information contained in the Personal Health Record without express authorization of the person whom the information is about, or their authorized representative.
• Current HIPAA privacy regulations need to be extended to protect information contained in Personal Health Records with oversight and proper regulatory environment to provide appropriate privacy and security safeguards.

• Individuals should control the portions of their Personal Health Records they choose to divulge on a case-by-case basis.

• Personal Health Records should have communication capabilities to provide electronic notification of health-tracking information to medical providers after user/patient authorization.

• Standards for data fields, terminology, accessibility, authentication, and others developed for electronic medical records should also be adopted for personal health records.

• Interoperability standards should be established to facilitate content mapping and information interchange between Electronic Health Records and Personal Health Records.

• Personal health records have the capability to accept, as well as to share, data from numerous sources and to reference the origin of the data. Sources of data contained in a Personal Health Record should be identified as either being patient-generated, or provider-generated -- such as physician source, lab, or institution.

• Health care provider financial and other incentives are needed to promote data-sharing.

• Public-private partnerships should be created for safe storage of Personal Health Records, with immediate 24/7 availability, and with complete redundancy/backup.

• A consumer medical terminology thesaurus should be available to facilitate transfer of consumer health terminology into appropriate medical terminology.

• Promotion of access and dissemination to individuals and their caregivers, of condition-specific information from credible knowledge sources, based on the individuals Personal Health Record. Examples of condition-specific information include weight management programs, smoking cessation education and programs, hypertension, diabetes, and cardiovascular, to name a few conditions. Individuals should be able to obtain current, relevant and documented information pertinent to improving and maintaining their health.

• Facilitation of adopting of technologies, such as tablet devices and cell phones for Personal Health Records, and recording home health monitoring by removing legislative and administrative barriers to facilitate convergence of these technologies, without undue regulatory burden.
• Electronic Personal Health Records should incorporate assistive technologies to improve their access and usability.

• The federal government should provide long-term financial incentives to private industry for developing and implementing educational and marketing programs to enhance consumer adoption of Personal Health Records.

• As a longitudinal flexible record, the Personal Health Record should facilitate the monitoring of medication usage, immunization records and changing patient demographics, including insurance information, and where appropriate, provide descriptions of functional and physical impairments, as well as descriptions of assistive aides.

This statement was developed by the IEEE-USA Medical Technology Policy Committee and represents the considered judgment of a group of U.S. IEEE members with expertise in the subject field. IEEE-USA advances the public good and promotes the careers and public policy interests of more than 200,000 engineers, scientists, and allied professionals who are U.S. members of IEEE. The positions taken by IEEE-USA do not necessarily reflect the views of IEEE or its other organizational units.