

**MOTOROLA****iDEN Mobile Devices – Advanced Technology
Seamless Health Center of Excellence****IEEE-SA Health IT Standards Study Group**

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Summary

This paper compiles a list of proposed next steps to develop standards for Personalized Health Informatics (“PHI”) systems.

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..students of medical economics have long realized that what consumers demand when they purchase medical services are not these services per se but rather better health.¹

NOTICE: This document complements the following documents:

- http://grouper.ieee.org/groups/hit/files/IEEE_Study_Group_Health_IT_2.07.pdf
- http://grouper.ieee.org/groups/hit/files/Lacal_Proposal_IEEE-SA_Health_IT_Standards_Study_Group_032006_06.ppt
- http://grouper.ieee.org/groups/hit/files/Lacal_Proposal_IEEE-SA_Health_IT_Standards_Study_Group_032006_Scope_03.ppt
- http://grouper.ieee.org/groups/hit/PHI/IEEE_SA_PHI_FAQ_09.pdf
- http://lacal.net/files/hs/HealthSmart_M.pdf

Please read these files first and only then this one. Thanks.

Executive Summary

This document outlines specific next steps and working sub-groups that need to be formed to advance the PHI project. Interested volunteers can find herein the specific work areas they can contribute their knowledge and leadership to.

¹ Grossman M, “The Human Capital Model.” In *Handbook of Health Economics*. Volume 1A; Culyer, AJ; Newhouse, JP (Eds.). North-Holland - Elsevier Science, B.V. (2000).

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Acronyms and Definitions

This section defines the acronyms and terms used throughout this document.

Term	Meaning
CDC	{US} Centers for Disease Control and Prevention
EHR	Electronic Health Records
F/OSS	Free and Open Source Software
HMO	{US} Health Maintenance Organization
ICT	Information and Communication Technologies
LDCs	Less Developed Countries
NCDs	Non-Communicable Diseases
NHS ²	UK's National Health Service or NHS as it is more commonly known, was set up on the 5th July 1948 to provide healthcare for all citizens, based on need, not the ability to pay. The NHS is funded by the taxpayer and managed by the Department of Health, which sets overall policy on health issues. It is the responsibility of the Department of Health to provide health services to the general public through the NHS. It was launched as a single organisation based around 14 regional hospital boards. This new NHS was originally split into three parts: <ul style="list-style-type: none"> • hospital services • family doctors, dentists, opticians and pharmacists • local authority health services, including community nursing and health visiting
PAHO	Pan-American Health Organization
PHI	Personalized Health Informatics. A comprehensive set of Internet-based tools that place the individual (and his/her dependents) at the center of an encompassing architecture of services that promote and enhance health. Focused on the family as the unit of care (each person is truly embedded into a larger family unit).
PHR	Personal Health Records
RHIOs	Regional Health Information Organization(s)
SDO	Standard Development Organizations
WHO	World Health Organization

Table 1: Acronyms and Definitions.

² Source: <http://www.nhs.uk/england/aboutTheNHS/history/default.cmsx>

Version History

Throughout the document I readily acknowledge all the comments, criticisms, and suggestions for improvement that I have received. Any and all remaining errors are solely my fault.

01: José C. Lacal 05/31/2006

02: José C. Lacal 05/31/2006

03: José C. Lacal 06/04/2006

04: José C. Lacal 06/13/2006 (First public release for comments).

Proposed Sub-groups

This section presents an attempt to define how to distribute the work to accomplish PHI's goals.

- Sub-group's title:
This is the initial name for the sub-group.
- Area of focus:
Detailed explanation of the specific topic this sub-group will conduct research and submit proposals on.
- Rationale, value to PHI:
Why is this area of focus chosen, and what value will this sub-group bring to the overall project.
- Expected output:
What is the expected product coming out of this sub-group.
- Initial sub-group leader:
Based on volunteers' availability, an individual will be appointed as interim sub-group lead (please refer to the [Selection of Leaders](#) section below for more details).
- Notes:
Additional material relevant to this sub-group.

Requirements for Sub-Group Leadership

These are my thoughts on what it takes to be a sub-group leader:

- Ability to clearly define the goal to achieve
- Willingness to make everybody a star
- Wisdom to let people grow
- Recognize and reward team members

Responsibilities

Each Sub-Group Leader will be responsible for:

- Voice of the User: capturing and representing the needs and desires of the end users of PHI-based systems. For example: what are the needs of a disabled person living in India? How can PHI-based standards help that person?
- Voice of the Expert: capturing and representing the needs and operational limitations of those experts currently involved in delivering health services. For example: what are the needs of nurses in Peru, and how to use PHI-based standards to provide them with better tools to treat their patients?
- Implementation: define, manage, and deliver working prototypes of F/OSS-based software implementations of the PHI standards within the scope of the Sub-group.
- Recruit, motivate, and nurture volunteers in the sub-group to achieve all of these goals.³
- Manage and be responsible for the sub-group's schedule of deliverables.
- Manage Public Relations and media promotion in local area.
- Grow the team.

Selection of Leaders

This is a very important section. Please read this carefully if you would like to become a Sub-Group Leader:

- All sub-group leads will be "Acting sub-group heads" until December 2006.
- Every 06 months there will be elections within each sub-group to name the next leader. The premise behind this concept is that all volunteers working on the PHI project are equal, and your own individual contributions to the project will define your place in the hierarchy.
- We will maintain historical records for long-term recognition.
- Leadership will not be defined by formal titles, location, institution or education. Rather, anybody who contributes a lot, builds the community, and demonstrates an ability to influence people can be elected as Sub-Group Lead.

You might want to read "Quality Improvement in Volunteer Free Software Projects: Exploring the Impact of Release Management"⁴ as a good primer on managing volunteers.

Project Manager

The project requires a dedicated Project Manager.

Documentation Manager

The project also requires a dedicated Documentation Manager. This person will also manage the translation of relevant documents from English (the project's official language) to other languages as possible (subject to the availability of volunteers that contribute their time to translating such documents).

³ Read "Three top tips for surviving open source projects" at <http://builder.com.com/5100-6315-5031709.html>

⁴ Available at http://www.cyrius.com/publications/michlmayr-quality_improvement_release.pdf

Benefits to Volunteers

Why would anybody contribute to this project? Some thoughts:

- Show your leadership potential.
- Global visibility, display expertise.
- Use affiliation with PHI (a global effort supported by the IEEE) to increase your credibility in your community.
- This could be your chance to have a global impact from your own hometown.
- Make contacts on a global basis.
- Growth opportunity: increase your level of expertise
- Become a seller of PHI-based Health Engineering goods and services.

Proposed Sub-Groups

Given the magnitude of the proposed scope for the PHI project, the following sections outline each of the proposed sub-groups.

Call for Volunteers

If you are interested in joining the PHI standardization effort, please send an e-mail to Jose.Lacal@Motorola.com with the following information:

- Indicate what sub-group(s) would you like to lead (see list below) and why.
- Provide URL(s) with documentary evidence of your experience, CV (resume), and other relevant material
- Indicate your understanding of and agreement with the responsibilities outlined in the [Requirements for Sub-Group Leadership](#) section above.
- Indicate that you are willing to take the responsibility to lead the sub-group(s) on an “acting leader” capacity for 06 months until December 2006. Thereafter, the role will be subject to elections every 06 months.

Certified Health Engineers

Sub-group's title	Certified Health Engineers
Area of focus	Develop a mechanism (in collaboration with WHO, PAHO, etc.) to "certify" interested individuals that have demonstrated the ability to contribute to other individuals' or communities' health and well-being.
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	Please refer to the "Certified Health Engineers" section in the FAQ document. ⁵

⁵ Source: http://grouper.ieee.org/groups/hit/PHI/IEEE_SA_PHI_FAQ_07.pdf

Content Management

Sub-group's title	Content Management
Area of focus	There are massive amounts of data available on topics of interest to PHI (nutrition; prevention; sanitation. Etc.). Most of the data is available for free through the Internet. How to catalog, organize, and distribute such data is a significant challenge.
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	

Decision Support Systems

Sub-group's title	Decision Support Systems (DSS)
Area of focus	There are technologies available today to assist professionals (physicians), para-professionals (nurses), as well as individual users to analyze their health condition / illness and suggest a course of action. The challenge here is how to develop a DSS that is open, accurate, and yet freely implemented using F/OSS.
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	

Design for Six Sigma / TQM for Health

Sub-group's title	Design for Six Sigma / TQM for Health
Area of focus	
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	Six Sigma for health

Exercise and Rehabilitation

Sub-group's title	Exercise and Rehabilitation
Area of focus	
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	

Financial Industry Linkages

Sub-group's title	Financial Industry Linkages
Area of focus	
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	Financial institutions have all the underlying requisites to host Even in poor LDCs there is usually some semblance of a financial / banking system where locals have some level of trust in the system.

Food Safety

Sub-group's title	Food Safety
Area of focus	
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	

Gaming for Health

Sub-group's title	Gaming for Health
Area of focus	Exploring the use of on-line gaming to cause health behavior changes. Also, using on-line gaming to distribute health information.
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	

Global Regulatory Issues

Sub-group's title	Global Regulatory Issues
Area of focus	
Rationale, value to PHI	
Expected output	
Initial sub-group leader	
Notes	Even though PHI standards will not deal with regulated activities (such as medicine and prescription drugs), all PHI project members should at all times have a good and respectful working relationship with their local government regulatory agencies.

Health Education and Health Behavior

Sub-group's title	Health Education and Health Behavior
Area of focus	
Rationale, value to PHI	
Expected output	
Ideal leader profile	Passion for leveraging ICTs to develop new Health Education and Health Behavior interventions.
Initial sub-group leader	
Notes	

Mental Health

Sub-group's title	Mental Health
Area of focus	
Rationale, value to PHI	
Expected output	
Ideal leader profile	Expertise in the delivery of mental health services via non-traditional means (that is, everything else beyond face-to-face counseling sessions).
Initial sub-group leader	
Notes	

Nutrition

Sub-group's title	Nutrition
Area of focus	
Rationale, value to PHI	
Expected output	
Ideal leader profile	Passion for human nutrition and the development of dietary guidelines.
Initial sub-group leader	
Notes	

Off-network Distribution

Sub-group's title	Off-network Distribution
Area of focus	
Rationale, value to PHI	
Expected output	
Ideal leader profile	Performing artist or radio-production expertise.
Initial sub-group leader	
Notes	Performing arts (music, theater); print media (magazines, newspapers); radio; television.

Open Source Clinical Trials

Sub-group's title	Open Source Clinical Trials
Area of focus	
Rationale, value to PHI	
Expected output	
Ideal leader profile	Some experience conducting clinical trials.
Initial sub-group leader	
Notes	<p>Many un-tested, yet promising non-chemical treatments. Pharma companies have absolutely no interest.</p> <p>Open Source Clinical Trials: contribute your time, your body, your IT resources. Leverage well-established framework, training, reporting mechanisms</p> <p>Open Medicine, PLoS, BioMed Central http://www.ctnbestpractices.org http://www.clinicalresearchnetworks.org</p> <p>Extend ePCRn globally (URL to Kevin Peterson's ePCRn⁶)</p> <p>Duke: a Sourceforge.net for open clinical trials?</p>

⁶ Source: <http://www.epcrn.org/index.php>

Security and Privacy

Sub-group's title	Security and Privacy
Area of focus	
Rationale, value to PHI	
Expected output	
Ideal leader profile	Demonstrated expertise (and industry credibility) in these issues. Must have a libertarian, "individual freedoms first" philosophy.
Initial sub-group leader	
Notes	

Sponsorships

Sub-group's title	Sponsorships
Area of focus	
Rationale, value to PHI	Research agencies in developed countries (such as the US's NHI) spend billions of US\$ for healthcare and pharmaceutical research. This sub-group must articulate a message to secure support from those agencies for PHI's activities in the health improvement arena.
Expected output	Grant proposals
Ideal leader profile	Demonstrated grant-writing and –winning skills.
Initial sub-group leader	
Notes	Insurance companies could benefit from the work of PHI: free content. Best practices: you follow them, lower premium. If not, pay the standard premium.

Tools

Sub-group's title	Tools
Area of focus	This sub-group will have a dual focus: a.) responsible to deploy, manage, and maintain the necessary tools for the entire project (and all sub-groups) to operate efficiently and effectively; and b.) responsible to develop a reference implementation of the PHI standards using 100% F/OSS tools
Rationale, value to PHI	
Expected output	
Ideal leader profile	Extremely heavy, demonstrated software development and project management skills working with distributed development teams.
Initial sub-group leader	
Notes	