

## Policy Brief: Health Information Technology

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Much of the dialogue around personalized medicine focuses on the scientific and biotechnology breakthroughs we have witnessed in recent years, as well as the ethical, regulatory and reimbursement challenges facing organizations commercializing these breakthroughs. We have seen great strides in the molecular understanding of disease, resulting in many new diagnostics, therapeutics and treatment regimens impacting quality of life for thousands.

However, achieving the promise of personalized medicine is about fundamentally transforming healthcare, which must include the redesign of healthcare delivery systems and the acceleration of discoveries from "bench to bedside". The Personalized Medicine Coalition (PMC) believes that this transformation is only possible through the synergy of healthcare information technology (HIT) with scientific breakthroughs in the molecular understanding of disease, novel therapeutics and diagnostics, as well as a fundamental redesign of healthcare delivery.

Therefore, the Personalized Medicine Coalition proactively supports and endorses the creation of a National Health Information Network (NHIN). This health information network must be a robust, standards-based information infrastructure across the entire spectrum of healthcare participants and take into account the unique needs of the basic, clinical and translational research community. This network must safeguard patient privacy while enabling information to be shared between the clinical and research domains seamlessly.

The creation of a National Health Information Network offers an incredible opportunity to begin breaking down the silos that currently exist not only between various healthcare providers but also between the clinical and research infrastructures. For example, very little information that is captured throughout the course of clinical care is currently able to be used in the study of disease or mined to understand correlations between treatment and outcomes. A NHIN provides the opportunity to have an interoperable information infrastructure in place that enables information about patient outcomes to be integrated and correlated with molecular information being generated in the research enterprise. This not only promises to accelerate personalized medicine, but may be a pre-requisite for achieving it.

Additional benefits of a National Health Information Network to personalized medicine include, but are not limited to:

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1. Faster identification of clinical trial candidates for targeted clinical studies as well as improved trial administration.
2. Acceleration of translational research initiatives resulting from better understanding of treatment and clinical outcomes.
3. More effective post market surveillance of approved therapeutics.
4. Improved communication between the research community (both academic and commercial) and physicians.
5. Enablement of disease management programs, leading to more efficient use of healthcare resources and ultimately better outcomes at reduced costs.
6. Acceleration of new personalized medicine breakthroughs by providing a mechanism to “push” these new treatments to the front line of patient care.
7. Requisite foundation for clinical decision support that correlates molecular information with the specifics of a particular patient.
8. Empowerment of consumers through personal health records ultimately leading to the creation of personalized, web-based health management initiatives.

To date, much of the focus of the value of the NHIN has been on its need to reduce healthcare costs and reduce medical errors. The PMC also believes that the NHIN is an imperative enabler to catalyze and accelerate the adoption and dissemination of personalized medicine. Ultimately, the value of an NHIN will be measured in lives saved as a result of more personalized medicines and treatments reaching more patients faster.