THE JOHNS HOPKINS
INDIVIDUALIZED
HEALTH INITIATIVE

Transforming Health for
People and Populations
THE JOHNS HOPKINS INDIVIDUALIZED HEALTH INITIATIVE

BETTER INFORMED DECISIONS MEAN BETTER HEALTH

In our current health care system, the specific factors and interventions that shape a person’s health are poorly understood. Relevant data, if collected, is spread throughout disjointed information systems. Unless a new approach is taken to capture key health information and use it wisely, a coming tsunami of new biomedical data—DNA sequences, RNA expression levels, protein structures, epigenetic markers, standardized clinical data, structural and functional images of the brain—may, rather than improve health care, only make matters worse. More data does not necessarily mean more knowledge and better decisions.

What might such a new approach entail? Imagine a world in which you and your physician can use careful, individualized analyses of all relevant medical information, coupled with data from the latest bioscience discoveries, to unravel the many factors that define your health, and change your behaviors and treatment accordingly. For example, using technology that can detect the whisper of the abnormal gene that signals cancer, you could begin treatment before tumors have a chance to grow. You would never need to undergo surgery or the hardships of radiation or chemotherapy, and your health plan—and your fellow taxpayers—would not have to pay the higher costs of those treatments.

Through the Johns Hopkins Individualized Health Initiative—Johns Hopkins inHealth—this approach is within our grasp. As our scientists continue to discover the causes of disease, and develop earlier detection strategies and more targeted therapies, we will couple their discoveries to clinical care in ways never before possible. Using not only the health information we have now, but also new data from genetics, biomarkers, advanced imaging technologies, and innovative analytic methods, we will improve management not only of the individual patient but also, one day, the management of entire groups of people. It’s an exciting prospect—but one we can realize only with your help. We invite you to learn more about Johns Hopkins inHealth, and how you can join in our mission.
WHY JOHNS HOPKINS SHOULD LEAD THIS INITIATIVE

The crucial addition to our enormous research capability is the Johns Hopkins Health System, a $5-billion-per-year integrated global health enterprise and one of the leading health systems in the United States. The system comprises four academic and community hospitals, four suburban health care and surgery centers, and 35 primary health care outpatient sites serving a total of more than 1 million patients per year. Johns Hopkins Health Care LLC manages care for 275,000 members in three health plans. Our Home Care Group treats 82,000 adults per year. The Johns Hopkins Health System provides Johns Hopkins inHealth the opportunity to demonstrate its new approaches for patients and doctors in a successful health care system.

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“LEADING A PARADIGM SHIFT”

The United States spends nearly twice as much on health care as our peer nations, translating to an additional $1 trillion per year. Yet according to the Organisation for Economic Co-operation and Development (OECD), we rank 26th in life expectancy, 31st in infant mortality, and first in the incidence of adult obesity out of the 34 OECD countries. “We don’t have more illness to treat, but we spend more to treat those diseases and conditions prevalent in our society, often without better results” says Scott Zeger. “In a society that has rejected top-down organization of health care, poor quality health information, resulting in poor decisions about prevention, diagnosis, and treatment, has become a major contributor to this excess health spending. Johns Hopkins inHealth is leading a paradigm shift in the way we deliver health care in America that will improve health for millions and directly address this spending crisis.”

SCOTT L. ZEGER, PHD
Director, Johns Hopkins inHealth, Vice Provost for Research, Professor of Biostatistics, Bloomberg School of Public Health

“A UNIQUELY JOHNS HOPKINS STRATEGY”

“Johns Hopkins inHealth will allow us to implement a uniquely Johns Hopkins strategy for tailoring cancer screening protocols to the needs of each individual. Each person has unique risks of cancer based upon age, family history, and other individual factors. By designing a protocol specifically for a person’s risk, we will improve our capacity to detect cancers early and reduce the fraction of false-positive tests that frighten the patient and sometimes lead to unhelpful, invasive procedures with non-trivial medical risks. The strategy includes an on-line system with patient and clinician modules. With patients and doctors working together, relying on more careful analysis of health information, we will save lives, reduce fear, and reduce the costs of population health. The project is a chance to change medical screening practice around the country and the world.”

H. BALLENTINE CARTER, MD
Director, Division of Adult Urology, Brady Urological Institute; Professor of Urology and Oncology, Johns Hopkins School of Medicine
Now is the perfect time to integrate health information from multiple sources to individualize patient care. With your philanthropic support, we will harness the combined assets of the many Johns Hopkins University academic divisions, the Applied Physics Laboratory, and the Johns Hopkins Health System. Together, we will improve people’s health through the interface of emerging bioscience discovery and big data science, demonstrating how customized health decisions can make world-class affordable health care a 21st-century reality. With your help, we will create a new model of health care that will:

**Accelerate those bioscience and data science discoveries that advance patient and population health**

Exploiting remarkable advances in basic biomedical and data sciences can significantly improve decisions made by physicians and patients, for example in screening for cancer. Using genomic and epigenomic technologies, Johns Hopkins researchers have discovered, and are actively pursuing, methods to identify and classify cancer tissue. The key next step is to engineer non-invasive methods that use the small numbers of cells available in urine or serum samples. These methods can be much more accurate and sensitive than prostate-specific antigen test (PSA). In prostate cancer, watchful waiting and surgery are the options that most patients face. It is often said that most men may die with prostate cancer, but not because of it. Clinical trials have suggested that the PSA for prostate cancer can save lives for a specific group, for others it provides more risk than benefit. The cost and degree of imprecision of this tool are well documented. Its advantages for a population subset are offset by overuse among people who can derive little benefit, and by overtreatment of non-life-threatening cancers that the test reveals. Biostatisticians estimate that, to save a single life from prostate cancer, more than 1,400 men over age 50 would need to have PSA tests. These tests, in turn, would lead to 47 unnecessary radical prostatectomies, many with severe side effects such as impotence and incontinence—at a cost of millions of dollars.

In our new model, the patient’s complete health record—showing the genetic and epigenetic profile, medical history, and much more—will follow the patient, precluding the need for new diagnostic tests every time the patient moves or changes doctors. Then, using comparative data from thousands of other patients with similar health profiles, Johns Hopkins physicians will be able to communicate clearly the benefits and risks of treatment options tailored to a particular patient, manage the risks more ably to improve health outcomes, and manage costs at the same time.

**Empower individuals with greater understanding of how to promote their own health and well-being**

Given proper advice and emotional support, a person with a family history of diabetes who becomes obese at an early age can improve his or her diet and begin exercise instead of waiting for the onset of diabetes. A serious medical condition with significant health and cost implications. Someone with mild hypertension, once diagnosed and educated, can begin to take preventive steps, including the use of blood pressure medication, decades before the age at which heart attacks commonly occur. Because cancer is fundamentally a genetic disease, it is most likely susceptible to prevention and control-based strategies developed through the use of genomic data. In all these cases, the challenge is to learn which preventive and therapeutic interventions work well enough to justify their costs, and to implement them in collaboration with the patient.

By collecting and analyzing relevant health information, we can set intelligent standards for investing in health interventions. Key information will come from clinical trials, and a vast amount more could come from new research-oriented patient care records. By creating tools that combine both sources of evidence about treatment efficacy and safety, we will improve health at more affordable costs.

**Move beyond healing the sickest to also preserving and enhancing health**

According to the Centers for Disease Control, most of the top 10 causes of death for Americans begin decades before symptoms appear: cancer, heart disease, respiratory diseases, and diabetes, among others. Instead of waiting for these diseases to manifest themselves, we will discover how best to define, measure, and communicate each person’s health state and the trajectory along which it is changing, and use these measurements in tools that help individuals guide their trajectories in the most healthful direction.
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MAKING JOHNS HOPKINS inHealth A REALITY

Transforming the use of information in medicine and public health is a significant challenge. It will entail a new kind of partnership—bringing together Johns Hopkins basic and clinical researchers, engineers, sociologists, bioethicists, computational and data scientists, policy experts, and ordinary citizens. We are ready to take on the challenge—to create an epochal transformation in human health—with your visionary leadership and generosity.

Johns Hopkins inHealth will span more than a decade and require an investment of $1.6 billion. We will dedicate $600 million of our own resources to build the health information backbone essential to our success. The 2,000 members of our faculty working on human health will support Johns Hopkins inHealth programs by competing for additional $500 million of new federal and sponsored projects. We must be able to rely on private philanthropy to complete funding for the initiative.

Private philanthropy will allow us to invest in the components of the project that are not readily fundable by competitive federal grants or health system revenues. These initial investments fit into four cores:

- Information for Health will create new information tools, such as inHealth mobile apps, to decipher big sets of health information for clinicians, their patients, and population health managers.
- Learning Communities for Health will allow each Johns Hopkins patient or study participant to benefit from knowledge gained and cataloged from previous patients and participants.
- Bioscience Discoveries to Advance Health will leverage the power of discovery to create solutions to fundamental and applied problems in medicine and health care, just as the discovery of radio waves enabled radar.
- Organizational Models for Affordable Health Care will apply the learning from the first three cores to improve a population’s health at a more affordable cost.

The initial projects, spanning all four cores, are focused on:

- cancer screening
- autoimmune disease
- cystic fibrosis
- brain imaging
- obesity/diabetes

Additional funding will be directed to projects identified as necessary to advance affordable health care.

"TRANSLATE FINDINGS TO THE CLINIC"

The Nobel Prize-winning discovery of telomeres and telomerase by Carol Greider, Johns Hopkins Professor and Director of Molecular Biology and Genetics, explained how genetic material is passed from one cell generation to the next. Her colleagues are building on this discovery, as Mary Armanios explains. “There is a need and an opportunity to exploit our Johns Hopkins basic science and clinical resources to advance patient care in this challenging area in medicine. This endeavor will require a deliberate, concerted effort across several fundamental research areas, and the ability to quickly and effectively translate findings to the clinic. The collaborative teams that are already in place make envisioning paradigm-shifting basic science research and its translation to the care of patients a tangible reality of huge potential impact on modern medicine.”

"IMAGES IN A ‘BRAIN CLOUD’"

“When a radiation oncologist reviews images of a patient’s tumor to decide upon the proper radiation dose, she relies upon past experience with other patients with similar tumors. But experience has its limits, especially as the amount of information that must be processed grows. Until now, the images of those tumors were stored mainly in clinicians’ minds. Thanks to work at Johns Hopkins Radiology, we can now store images in a ‘brain cloud,’ or shared electronic repository, so that any oncologist can reference thousands of such images in making medical decisions for the individual patient. But the utility of thousands of images for an individual patient requires careful analysis using the methods of Johns Hopkins inHealth. Your data will be a part of the evidence base that informs decisions about other patients in similar situations. What is wonderful about Johns Hopkins inHealth is that you benefit from all the patients who came before you, and you contribute to all who come after.”

JONATHAN S. LEWIN, MD
Martin W. Donner Professor of Radiology; Director, Department of Radiology, Johns Hopkins School of Medicine

MARY Y. ARMANIOS
Associate Professor of Oncology, Johns Hopkins School of Medicine
HOW YOU CAN TAKE THE NEXT STEP

By obtaining the full benefit of the many forms of health information available now and in the future, Johns Hopkins inHealth can improve the health of individuals and populations and in the process increase the efficacy and lower the costs of our health care system. For the initiative to succeed, your involvement is critical. There are several ways to get started.

LEARN AND SHARE

Visit rising.jhu.edu to learn more about Johns Hopkins inHealth, hear directly from faculty and clinicians connecting discovery to patient care, and engage with others who are passionate about finding solutions. Share your thoughts with us and help spread the word through your professional and personal networks.

MAKE A GIFT

Please contact us to explore gift opportunities and to plan a gift that answers your goals and ours.

CONTACT US TODAY

To pursue any of the options listed above, please contact:

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