Creating a New Home for Informatics

The Institute for Informatics (I2) is a comprehensive home for biomedical informatics and data science research, education, and services spanning Washington University, BJC HealthCare, and affiliated entities. It was created in response to changes taking place across modern healthcare and life sciences environments. There has been a fundamental shift toward transdisciplinary, integrative, and data-intensive approaches to basic, clinical, translational, and population-level research. These developments have been coupled with the widespread use of information technology platforms to re-engineer healthcare delivery and achieve greater value alongside improved outcomes and safety. The complex data, information, and knowledge needs associated with these trends require a comprehensive and systems-level approach to biomedical informatics and data science research, education, and practice.

In response to these trends, Washington University created I2 in 2016 to serve as an academic and professional hub for biomedical informatics and data science research, training, and practice. I2 engages faculty, staff, and trainees, as well as external partners recruited from the School of Medicine, the McKelvey School of Engineering, the Institute for Public Health, the Brown School of Social Work, the Olin Business School, the Healthcare Innovation Lab at BJC HealthCare, the Center for Clinical Excellence at BJC HealthCare, and the Cortex Innovation Community. The institute engages in innovative research, workforce development, and dissemination activities targeting a variety of critical areas of need, including:

1. The integration and dissemination of heterogeneous data, information, and knowledge resources
2. Computational approaches to the interpretation of biomolecular, image, and clinical phenotypes to inform precision medicine
3. The acceleration of clinical and translational research through the systematic management of study protocols, data resources, and analytical pipelines
4. The creation of learning healthcare systems in which cyclical evidence generation and application become integral to care delivery
5. The use of ubiquitous computing and sensing technologies capable of facilitating population health monitoring and intervention strategies
6. Methodological and technical approaches to enable and enhance research reproducibility and rigor

This strategic plan provides a road map for the institute’s priorities and areas of continued growth as we continue to build a leading program that will improve the quality of healthcare across the globe.

Sincerely,

Philip R.O. Payne, PhD, FACMI

Strategic Overview

The Institute for Informatics (I2) focuses the informatics landscape at Washington University School of Medicine in order to transform research, education, and patient care — emphasizing precision medicine and efforts to improve the quality of healthcare and public health initiatives locally, nationally, and worldwide.

VISION

I2 serves as the academic and professional home for a preeminent interdisciplinary program of research, education, and service in informatics at Washington University, enabling advances in biomedical research and improvements in the quality of healthcare.

I2 coordinates informatics efforts across the Medical and Danforth Campuses, while developing partnerships with the Healthcare Innovation Lab at BJC HealthCare, the Cortex Innovation Community, and other regional partners.

Defining Informatics

As a relatively young and highly interdisciplinary field, biomedical informatics (BMI) has struggled to agree on and communicate a succinct self-definition by which it can be compared and contrasted to other domains. In part, efforts to establish such a common definition are complicated by the existence of a number of similar or complementary scientific domains such as computer science, information science, statistics, mathematics, cognitive science, social science, and any number of engineering disciplines with application in the biomedical domain. Here, we present four key definitions for terms used within this plan:

1. Biomedical Informatics
2. Big Data
3. Data Science

1. Biomedical Informatics

“Biomedical informatics is the science of information applied to, or studied in the context of medicine wherein information can be described as data with meaning.”

2. Big Data

“Big data are data whose scale, diversity, and complexity require new architecture, techniques, and analytics to manage and extract value and hidden knowledge from it.”

3. Data Science

“Data science is the study of the generalizable extraction of knowledge from data.”

References:

The following strategic framework guides the institute’s future research, positioning and growth

Learning Healthcare Delivery Systems

"Every day, physicians and other clinicians around the country record millions of observations and treatment decisions in electronic medical records — creating a vast repository of information that is increasingly being used by clinical researchers to answer practical questions about the safety, effectiveness, and value of healthcare services. As these researchers turn data from routine clinical care into knowledge and knowledge into guidance for physicians at the point of care, they help create what the Institute of Medicine has called "learning healthcare systems."10"

Clinical Research Informatics

"The subdomain of biomedical informatics concerned with the development, applications, and evaluation of theories, methods, and systems to optimize the design and conduct of clinical research and the analysis, interpretation, and dissemination of the information generated.11"

Applied Clinical Informatics

"The clinical information systems, administrative and management systems, eHealth systems, information technology development, deployment, and the evaluation, sociotechnical aspects of information technology, as well as health IT training.11"

Population Health Informatics

"Integrating aspects of public health, clinical informatics, and healthcare delivery with the target of improving healthcare system effectiveness and the well-being of communities and populations.12"

Mobile Health

"The use of real-time, continuous biological, behavioral, and environmental data collected by wireless and mobile technologies to improve our understanding of the etiology of health and disease, particularly when integrated with data collected by wireless and mobile technologies.12"

Translational Bioinformatics

"The development of storage, analytic, and interpretive methods to optimize the transformation of increasingly voluminous biomedical data into proactive, predictive, preventive, and participatory health.12"

Key Foci

Research Highlights

Personalizing Medication with New Technology

Fuhai Li, PhD, Assistant Professor of Pediatrics, School of Medicine

"Diverse genetic variations in individual patients are believed to be responsible for heterogeneous drug response. However, it’s challenging to identify precision drugs or combination therapies for individual patients because of the complicated, mystery disease signaling networks. We have proposed systems biology models to reposition drugs and combination therapies by integrating diverse pharmacogenomics data and disease signaling networks constructed by integrating protein interaction with genomics data of patients.14"

Using Synthetic Data to Develop New Cardiovascular Drugs

Randi Foraker, PhD, Director, Center for Population Health Informatics

"Reducing the cost of developing new cardiovascular therapies will require fundamental changes to the way in which we conduct preclinical and clinical trials in order to make them faster, cheaper, and more adaptable. Here, we suggest that the use of synthetic data derivatives may help with the development of new and novel cardiovascular drugs.15"

Automating Cancer Genomic Learning Approach

S. Joshua Steudelidas, MD, PhD, Associate Professor, Pathology and Immunology

"Persistent weaknesses in variant calling pipelines remain, especially in an era of constantly changing and variable sequencing data quality. Sophisticated context-specific pattern matching abilities of humans are still needed to refine and confirm somatic variant calls, which is expensive and laborious. We show that with a relatively small amount of project-specific review for model retraining that most manual review can be replaced with an automated classifier approach, providing more reproducible and refined calls for clinically relevant variants.17"

Pain care for patients is often suboptimal and negatively affects patients' quality of life, causes disability, and increases the potential for dependencies on opioids. Representing pain scores as graphical trajectories provides opportunities for understanding and treatment of pain. We developed a context-dependent statistical approach to characterize the dynamic properties of pain trajectories for improved pain management and treatment. We are currently extending the pain trajectory approach in post-surgical patients for more efficient pain care.20"

Finding Innovative Solutions for Pediatric Patients

Margaret LovatoVsky, MD, Chief Medical Information Officer for St. Louis Children’s Hospital and Child Health at BJC

"Children are not little adults; their healthcare needs are unique and must be carefully considered. Finding innovative solutions to enhance the workflow of physicians while improving the quality of care for our pediatric patients allows us to utilize technology to its full potential. Using genomic and phenotypic data to provide personalized care to our most vulnerable patients has the potential to change the landscape of medicine."

Improving Pain Management Through Context-Dependent Statistics

Thomas Kannanupallil, PhD, Associate Chief Research Information Officer, School of Medicine

"Pain care for patients is often suboptimal and negatively affects patients' quality of life, causes
Priorities & Guiding Principles

These 10 strategies and associated tactics serve as the Institute for Informatics’ road map over our first four years.

Strategy 1
Develop and execute an external faculty recruitment plan, emphasizing the following informatics subdisciplines:

- Translational bioinformatics
- Clinical research informatics
- Applied clinical informatics
- Population health informatics

TACTICS
In an effort to continue the growth of research programs with relevance to the delivery of personalized medicine, and further, to increase collaboration across departments, I2 recruits a diverse pool of faculty, including joint recruitment efforts with a variety of units including the departments of medicine, pathology and immunology, radiology, radiation oncology, and cellular biology.

Top faculty hiring priorities are to recruit 1-2 additional faculty members with expertise in computational biology, translational bioinformatics, and/or population health informatics before the end of year 4.

Year 1: Clinical research informatics, population health, translational bioinformatics (3)

Year 2: Precision medicine (deputy director), applied clinical informatics, mobile health, translational bioinformatics (4)

Year 3: Clinical research informatics, applied clinical informatics, translational bioinformatics (5)

Year 4: Population health, clinical research informatics, translational bioinformatics (2)

Strategy 2
Develop and execute an internal faculty recruitment plan, creating a trans-institutional community of practice that builds on existing strengths and expertise.

TACTICS
Create a faculty community of practice for the engagement of current informatics expertise in conjunction with new faculty hires, including the following components:

- Multitiered membership model (e.g., full member, associate member, early career member)
- An internal stakeholder advisory board to meet on a regular basis and provide input regarding I2 activities and programs
- Convening activities, including regular seminars, symposiums and workshops, as well as an annual informatics-focused scientific retreat
- Mentoring programs targeting the career development of early-stage faculty (both internal and external recruits)

Strategy 3
Establish a robust operational support team that enhances and accelerates the scholarly activity of I2-affiliated faculty.

TACTICS
- Hire and support an operations team that can cultivate an efficient and impactful I2 program, as well as related activities
- Implement a dynamic matrix model of operational responsibilities
- Implement and report on all activities to enable continuous process improvement
- Emphasize customer service and efficient resource utilization in all aspects of operations
Strategy 4
Support and enable strategic research initiatives in the following emergent areas:
- Genomic medicine (including translation from “lab to laptop”)
- Learning healthcare system(s)
- Population health and ubiquitous computing (e.g., mobile, sensors)

**TACTICS**
Provide internal grant opportunities for collaborative clinical, operational, and research teams to develop innovations in informatics and healthcare delivery, emphasizing the following areas:
- Transforming research, education, and patient care
- Utilize personalized health data to optimally inform care
- Move care delivery closer to where patients live, work, and play
- Harness community data for community health
- Engage patients in shared decision-making and longitudinal health behaviors

Strategy 5
Create a multifaceted educational and workforce development portfolio that targets both informatics practitioners as well as future informatics investigators. This includes a K-12 and undergraduate pipeline program to assist in recruiting such individuals.

**TACTICS**
Establish a comprehensive program of educational offerings, emphasizing the following areas:
- Pipeline activities focused on K-12 and undergraduate coursework and research opportunities
- Continue to grow in-career and professional learning via certificate, master’s degree, and accredited fellowship mechanisms
- Ongoing development and execution of international programming to create a global workforce
- Align all curricular offerings with prevailing AMIA/CAHIIM competency models and personalization for individual learners therein
- Pursue NIH and NSF training grants to support and enable the aforementioned portfolio offerings
- Support educational offerings through regular and active engagement with the AMIA Academic Forum

Strategy 6
Realign mission-critical informatics service lines and consultative units in order to provide a single point of entry and economies of scale as relates to:
- Standardized bioinformatics pipelines (stratified by instrumentation and organism)
- Clinical research data collection, storage, and access/dissemination
- Secondary use of EHR-derived data sets
- Advanced data analytics and visualization

**TACTICS**
Identify synergies and/or redundancies between major informatics and biomedical computing service lines, and implement new organizational structures and/or business models to achieve economies of scale therein. Key emphasis areas for such economies of scale will be:
- Standardized bioinformatics pipelines (stratified by instrumentation and organism)
- Clinical research data collection, storage, and access/dissemination
- Secondary use of EHR-derived data sets
- Advanced data analytics and visualization

Establish a virtual and physical single point of access with appropriate request and project/task management mechanisms, so as to enable one-stop shopping for informatics services by the WU research and clinical communities

Identify and engage with WU and BJC IT organizations, as well as external technology service providers, to reduce infrastructure and operational costs and increase the scalability and elasticity of core computational facilities and expertise supporting informatics service lines

Working with a faculty stakeholder advisory group, identify opportunities to phase out services that are not able to demonstrate substantial value/impact, while also enumerating and prioritizing new services to be created so as to enhance organization research and clinical capacities

**GUIDE:**
- Plan
- Execute
- Plan and Execute
Strategy 7
Pursue internal and external outreach and engagement activities in order to educate stakeholders about I² activities and to create strategic partnerships, funding, and advancement opportunities.

TACTICS
Establish and regularly consult with an external advisory board with representation from:
• Analogous academic informatics units
• Local and national private sector leaders with interests in the informatics domain
• Community representatives and leaders with interests in biomedical research, healthcare transformation, and population health

Similarly constitute and regularly consult with an internal advisory board, consisting of engaged and senior leaders drawn from throughout the WU organization

Design, implement, execute, and continuously evaluate an advancement campaign with the intention of engaging additional external corporate development capital for the institute. This effort will also include the establishment of a formal industry-affiliated program

Identify and pursue opportunities to serve as a statewide and/or regional convener for informatics-focused scientific and workforce development networking activities

Identify philanthropic partners, yielding investment and knowledge exchange, and pursue global engagement that can enhance and extend I² scientific and educational leadership at the worldwide level, in alignment with WU’s strategic international outreach and engagement efforts.

Strategy 8
Systematically brand and communicate all I² programs both internally and externally through the creation, execution, and maintenance of a comprehensive digital media strategy.

TACTICS
Design, implement, execute, and continuously evaluate a comprehensive branding, marketing, and communications campaign, so as to project information concerning the mission, vision, and activities of I² to both internal and external audiences

Strategy 9
Ensure access to adequate and appropriate technology resources for all I² affiliates through collaborative efforts with both WU and BJC IT leadership and operational entities.

TACTICS
Coordinate with WU and BJC IT to identify and engage in efforts to obtain and commoditize core technology infrastructure in support of all I² activities, with an emphasis on:
• Elastic, cost-effective, and scalable technology deployment
• Reductions in redundancy of infrastructure
• Increases in support and security of infrastructure

Strategy 10
Continuously coordinate, evaluate, and report on all I² programs through the use of best-in-class management, portfolio, and project management, as well as use of tracking/evaluation tools and methods.

TACTICS
Establish a process and outcomes-focused tracking and evaluation program for I², emphasizing the following areas:
• Faculty recruitment, engagement, and productivity
• Extramural funding
• Knowledge dissemination
• Workforce development
• Advancement
• Operational efficiency and resource utilization

Report on the aforementioned evaluation program using balanced scorecards tailored for senior leadership, internal advisers, external advisers, and institute members

Generate an annual institute report, commensurate with the preceding measures and highlighting critical and high-impact accomplishments
Big Data: Putting Information-Based Tools in Doctors’ Hands

BY DEB PARKER
Reprinted from Outlook Magazine, Summer 2014

Big data is coming at medical professionals from all directions. Many have no idea how to effectively leverage it for patient care.

Philip R.O. Payne, PhD, is an internationally recognized leader in informatics, a field that translates big data into actionable knowledge.

As inaugural director of the university’s Institute for Informatics, he leads the way he speaks — at double speed. In 20 months of existence, the institute has made significant inroads at this large, decentralized university.

For Payne, the path forward is clear. “If you ask physicians what they want, it’s the equivalent of a ‘patients like mine’ button on their electronic device,” he said.

“They tell us, ‘Given the patient that’s in front of me right now, show me similar patients who have been seen in the past six months, one year or 10 years. What treatment decisions were made? Who had the best outcomes? Who didn’t?’

“Physicians want to know, based on their wisdom and the wisdom of colleagues, how to optimize outcomes for the patient in front of them.”

Information Overload

Provider burnout nationally is at an all-time high, with doctors citing factors as job complexity and having too few hours in the day. By some estimates, EHR upkeep requires 31 percent of physicians’ time.

A few decades ago, doctors could stay abreast of medical advances by reading scholarly journals. Now, it’s virtually impossible to keep up with the constant flow of information.

“Human short-term memory is optimized to remember seven pieces of information at a time, plus or minus two,” said Payne, also the Robert J. Terry Endowed Professor. “Informatics is essential to figuring out how we connect the dots between the millions of data points, contextualize them and deliver them back to clinicians who may have only 10 minutes with a patient to interpret and act on that information.”

Payne envisions a new landscape — where doctors and researchers have the necessary tools and expertise to extract meaningful information within vast data sets.

When many people hear the word informatics, Payne said, they associate it with interpreting the human genome, but that’s just one aspect of the institute’s work.

A top priority is improving EHR efficiency. The EHR requires a mental shift for some physicians who are used to free-form documentation of patient encounters on paper versus a more rigid, checkbox system that perhaps even influences medical thinking. Many clinicians find it clunky, burdensome and disruptive. Institute team members are shadowing clinicians at the point of care to design technologies that adapt to workflow.

Efficiently designed systems can close the gap between digesting the data and making clinical decisions, Payne said. “The real challenge is not getting more data. It’s figuring out what to do with what we already have.”

Recently, Payne and David H. Gutmann, MD, PhD, the Donald O. Schnuck Professor and director of the Neurofibromatosis (NF) Center at Washington University, employed informatics to predict symptom severity in children with NF1, a genetic disorder that causes brain and nerve tumors, as well as autism spectrum disorder (ASD). NF1 varies widely in severity and symptoms — from harmless brown spots on the skin and benign bumps to optic gliomas and malignant cancers. Parents don’t know which symptoms might manifest in their child.

In a matter of hours, using computer analytics and existing NF1 patient data, Gutmann and Payne improved risk models that others had created following months of painstaking deliberation in conference rooms. With even greater specificity, they outlined various NF1 subtypes, their trajectories and associations with optic gliomas and malignant cancers. Parents don’t know which symptoms might manifest in their child.

Andrew Michelson, MD, left, a pulmonary and critical care fellow, and Sean Yu, a biomedical informatics doctoral student in the Payne-Lai lab, discuss analytical methods to predict septic shock.

Big Data: Putting Information-Based Tools in Doctors’ Hands

G enomic medicine. Personalized medicine. Precision medicine.

When it comes to interpreting and applying big data in health care, people may not agree on the best terminology. Most agree on one thing: Big data is an abstract, intimidating concept. DNA sequencing generates millions of data points for a single individual. Clinical trials yield massive amounts of treatment information.

The electronic health record (EHR) expands with every patient encounter. And wearable fitness trackers and apps — which measure steps taken, food consumed, heart rate, blood pressure and sleep patterns — open up a whole new area of possibility.

Big data is coming at medical professionals from all directions. Many have no idea how to effectively leverage it for patient care.

Philip R.O. Payne, PhD, is an internationally recognized leader in informatics, a field that translates big data into actionable knowledge.

As inaugural director of the university’s Institute for Informatics, he leads the way he speaks — at double speed. In 20 months of existence, the institute has made significant inroads at this large, decentralized university.

For Payne, the path forward is clear. “If you ask physicians what they want, it’s the equivalent of a ‘patients like mine’ button on their electronic device,” he said.

“They tell us, ‘Given the patient that’s in front of me right now, show me similar patients who have been seen in the past six months, one year or 10 years. What treatment decisions were made? Who had the best outcomes? Who didn’t?’

“Physicians want to know, based on their wisdom and the wisdom of colleagues, how to optimize outcomes for the patient in front of them.”

Information Overload

Provider burnout nationally is at an all-time high, with doctors citing factors as job complexity and having too few hours in the day. By some estimates, EHR upkeep requires 31 percent of physicians’ time.

A few decades ago, doctors could stay abreast of medical advances by reading scholarly journals. Now, it’s virtually impossible to keep up with the constant flow of information.

“Human short-term memory is optimized to remember seven pieces of information at a time, plus or minus two,” said Payne, also the Robert J. Terry Endowed Professor. “Informatics is essential to figuring out how we connect the dots between the millions of data points, contextualize them and deliver them back to clinicians who may have only 10 minutes with a patient to interpret and act on that information.”

Payne envisions a new landscape — where doctors and researchers have the necessary tools and expertise to extract meaningful information within vast data sets.

When many people hear the word informatics, Payne said, they associate it with interpreting the human genome, but that’s just one aspect of the institute’s work.

A top priority is improving EHR efficiency. The EHR requires a mental shift for some physicians who are used to free-form documentation of patient encounters on paper versus a more rigid, checkbox system that perhaps even influences medical thinking. Many clinicians find it clunky, burdensome and disruptive. Institute team members are shadowing clinicians at the point of care to design technologies that adapt to workflow.

Efficiently designed systems can close the gap between digesting the data and making clinical decisions, Payne said. “The real challenge is not getting more data. It’s figuring out what to do with what we already have.”

Recently, Payne and David H. Gutmann, MD, PhD, the Donald O. Schnuck Professor and director of the Neurofibromatosis (NF) Center at Washington University, employed informatics to predict symptom severity in children with NF1, a genetic disorder that causes brain and nerve tumors, as well as autism spectrum disorder (ASD). NF1 varies widely in severity and symptoms — from harmless brown spots on the skin and benign bumps to optic gliomas and malignant cancers. Parents don’t know which symptoms might manifest in their child.

In a matter of hours, using computer analytics and existing NF1 patient data, Gutmann and Payne improved risk models that others had created following months of painstaking deliberation in conference rooms. With even greater specificity, they outlined various NF1 subtypes, their trajectories and associations with optic gliomas and ASD.

This information allows families to plan ahead, and alerts clinicians as to whether additional imaging or other interventions are warranted.
"We want to create a system where what we learn from each patient informs how we treat other patients and what questions we ask in the lab."

PHILIP R.O. PAYNE, PHD

"Precision medicine isn’t always about curing," Payne said. "We can improve quality of life by illuminating the unknown. It’s also helpful for the clinician in the exam room, who is facing imaging reports, EHR data, gene sequencing results, maybe a social/behavioral evaluation report — and an anxious child and an anxious parent. We are relying on physicians to integrate on demand and make the best possible decision. That’s a source of stress for providers, who have limited time and an EHR that isn’t designed very well.

"But if we can integrate that data and say to those providers, ‘This patient has an 80 percent probability of developing an optic glioma and here are the outcomes for the last 10 children you saw similar to this,’ then we’ve allowed them to get down to the really important information, have a conversation with the family and not just sit there clicking and pointing and typing. “That’s the real promise if we do all the things we’re talking about.”

A data-driven approach, Payne said, is going to be a key differentiator as institutions compete to provide exceptional care in an information-rich era. Within its storehouses, big data holds the answers to pressing medical questions of our time; it has the power to develop drugs faster at lower cost, speed diagnosis, deliver on the promise of personalized, or precision, medicine, and improve quality of life.

A Home Advantage

Harnessing this power requires an environment that’s built to rapidly translate discovery out of the lab and into the clinic.

Washington University, in partnership with BJC HealthCare, stands uniquely poised to lead on the informatics frontier, with key strengths in medicine, basic science, cancer, genomics, radiology, public health, social work, business and engineering, among others. Nearby sits the 200-acre Cortex Innovation Community, a thriving hub for bioscience research, development and commercialization.

“We have one of the best genome institutes and one of the most productive and most impactful basic science research enterprises in the world,” Payne said. “We have some of the smartest care providers that you will meet. We have a unique living laboratory between Washington University Physicians and BJC HealthCare, where we have a large academic referral center, plus regional hospitals and primary care practice sites in urban and rural environments.

“We have all the pieces we need to study what the future of health care looks like. Very few U.S. academic health centers are truly primed to take advantage of the health-care information age.”

Until the institute’s launch, the university had all the raw pieces, except one. Although pockets of informatics strength existed — including leadership in the Human Genome Project, the Connectome Project and efforts to understand the microbiome — there was no central academic and professional home for informatics science and practice.

Every School of Medicine department chair contributed funding from department reserves to establish the Institute for Informatics, also known as I².

One Patient, One Record

After putting critical team members in place, institute leaders turned their attention to their first, most fundamental task: Getting everyone within this expansive, 15-hospital system and medical school on the same page.

This June, with the institute’s active participation, the medical school and BJC HealthCare will roll out the Epic electronic health record system on the academic campus. It already has been launched in many of BJC HealthCare’s community hospitals.

Once fully implemented, Epic will replace more than 50 standalone EHR systems that had been used by individual physician groups, specialty clinics, hospitals and even departments within the hospitals. Previously, outpatient data generated through Washington University Physicians (faculty practice plan) was not connected to hospital inpatient data. And some records were still paper-based.

As Sam Bhayani, MD, chief medical officer of Washington University Physicians, explains, the medical center draws patients who live hours away and who have complex problems and see multiple specialists.

Bringing data into one centralized location eliminates the need for patients to recall their entire medical history, such as the date of their last tetanus shot or prescription dosages, and will reduce treatment redundancies, potentially saving money, and help eliminate harmful drug interactions. It also allows clinicians to view patients holistically and consider all factors across the continuum of care. What should emerge is a more comprehensive picture of a person’s health care, including total cost of care.

This, however, is only half of the vision. Patient information must be returned back to investigators as they consider new ways to solve complex health-care problems. Data mining within a decentralized system has been an arduous, inefficient task.

“We have some patients, we had very little data. All we knew is what happened during their hospital visit,” said Chief Research Information Officer Albert M. Lai, PhD. “If you’re a researcher trying to understand optimal care delivery, it’s basically impossible given this fragmented view.”

A New Research Paradigm

A centralized EHR has revolutionary research implications for Washington University — joining together and unlocking access to more than 6 million records of inpatient and outpatient care.

“We want to translate data into knowledge,” Payne said. “We want to create a system where what we learn from each patient informs how we treat other patients and what questions we ask in the lab. In turn, what we learn in the lab can benefit patients more quickly.

“Right now, we have clinical investigators seeing patients. But they go back to their labs and they don’t have access to data generated by their own patients, at least not to the degree necessary to test basic hypotheses. We need to make that data more accessible.”

The real forward leaps in innovation will come as the institute builds out a large, integrated database — known as the Research Data Core (RDC) — that links all data. The RDC powerhouse will include the common EHR, which feeds a continuously updated stream of patient data, plus data from any remaining legacy or departmental clinical systems. Plans call for the addition of genomic and biospecimen information.
WHEN DATA BECOMES TREATMENT

**Sources**
Data is generated through the EHR, clinical studies, genome sequencing and patient-reported outcomes, among other sources.

**Methods**
Data is integrated in the Research Data Core, a centralized warehouse managed by statistical data analysts. Here, various approaches can be used to analyze data — from machine learning to visualization.

**Output**
From this analysis, decision-support tools can be designed to assist physicians at the point of care. These tools — such as reminders for preventive care or alerts about potentially dangerous situations — can be deployed through laptops, tablets and mobile phones.

**Impact**
Precise, knowledge-based interventions benefit doctors, researchers, patients, communities and policymakers.

Statistical data analysts within the institute will manage the RDC. These informatics professionals will help researchers pull data from the central system, design studies and maintain patient confidentiality. They and other team members are available to educate, answer questions and analyze and visualize data in meaningful ways.

Through self-service tools, researchers will be able to access the RDC and do some analysis on their own computers. Informatics leaders say a new partnership with a company called MDClone also has the potential to fast-track research. Washington University is the first U.S. academic institution to have this technology.

Under current federal regulations, investigators must wait weeks or months to begin research projects involving real patients. For each project, researchers must file paperwork and wait for approval from an institutional review board (IRB), an administrative body that protects the rights and welfare of human research subjects. Following approval, researchers then must wait for the data analyst to pull the necessary data before research can get underway.

MDClone’s unique niche is its ability to create synthetic data — data that looks like an actual patient population, but isn’t. Data engines yield synthetic data that is statistically identical to original protected health information, but without privacy concerns.

“With MDClone, you could effectively have no time delay,” Lai said. “If you think of an idea, you can pull up the data and analyze it, right then and there, from the computer in your office, potentially make discoveries on the data, with zero risk to patient privacy.”

If the data looks promising, researchers can follow the standard IRB steps to confirm the result with real data. If not, Lai said, they can just move on to the next question.

The institute is testing MDClone’s performance via pilot research projects. Pending a successful evaluation, MDClone will become part of the RDC infrastructure.

Creating efficiencies in research saves time and allows grant dollars to stretch further, Payne said, which, in turn, will attract top U.S. researchers.

**Speeding Discovery**
Payne hopes to speed up the process of taking discoveries into clinical trials. Currently, it can take 15 to 20 years and more than $1 billion to develop therapeutic agents for disease.

Treatment solutions, however, are waiting to be found in big data. Repurposing or using new combinations of approved drugs, which already have passed toxicity tests, could save valuable time.

Using an informatics concept known as “machine learning,” computers can be programmed to comb through clinical and drug data, going back through decades of medical literature, analyzing billions of variables, to discover meaningful patterns and new uses for existing medicines.

Payne, also a cancer researcher, points to malignant melanoma as one example. Frontline therapies are effective at causing tumors to disappear, but patients often become resistant within 12 months of the first treatment. By using public data and computational methods, researchers have found drugs — developed for other diseases — that could be combined with melanoma frontline therapies to prevent or delay resistance onset. So far, Payne’s research team has taken this combination therapy all the way to animal models, and they did it in about a year.

Once a therapeutic agent is ready to move to clinical trials, the RDC also should make it quicker and more efficient to identify test subjects.

**Enhancing Human Health**
The dream, Payne said, is to use big data not only to help the sick, but also to keep people well, to intervene in the communities where they live, work and play, and not just inside our hospitals.

An evolving EHR likely will include more data about patients’ daily activity levels, gathered through smartphones and fitness trackers, and other health influencers, such as water quality in the home, proximity to grocery stores and family support networks.

Big data has the power to promote wellness by generating a picture of the whole patient — connecting genes and environmental factors to social factors and outcomes.

“The institutions that figure out how to bring all these pieces together will be the first to begin delivering personalized, precision medicine,” Payne said. “Rather than treating people as a function of averages, personalized health care that is powered by big data is about enabling physicians to provide the right care at the right time, based on the unique characteristics of the patient in front of them.”

**Impact**

"We have all the pieces we need to study what the future of health care looks like. Very few U.S. academic health centers are truly primed to take advantage of the health-care information age.”

PHILIP R.O. PAYNE, PHD

Get the latest IP news at informatics.wustl.edu.
Creating Healthier Communities Through Informatics

The newly launched Center for Population Health Informatics (CPHI), a center within the Institute for Informatics (I²) at Washington University in St. Louis, is developing and studying innovative uses for data and technology at the point of care and beyond to improve population health outcomes. "I want to make sure that we are conducting projects and gaining insights into how to improve the well-being of our clinic populations, but also the broader populations in the St. Louis region and beyond," says CPHI Director Randi Foraker, PhD, an associate professor of medicine in general medical sciences at Washington University School of Medicine.

Using Data to Increase Awareness of Cardiovascular Disease Risk in Cancer Patients

The CPHI’s latest research project is the development and testing of AH-HA, or Automated Heart Health Assessment, a clinical decision support tool designed for use in cancer survivorship settings. The web application builds upon an earlier CPHI-developed tool known as SPHERE, or Stroke Prevention in Healthcare Delivery Environments. Like SPHERE, AH-HA is embedded in patients’ electronic health records and automatically populates with their personal medical data to create an interactive infographic of their risk for heart disease.

While SPHERE was primarily focused on modifiable cardiovascular disease risks — physical activity, diet, smoking status, blood pressure and body mass index, among others — AH-HA takes it one step further by also factoring in cancer survivorship risks, specifically the cardiotoxic treatments received by some cancer patients.

"Cancer survivors are at an elevated risk for cardiovascular disease compared to the general population," Foraker says. "They tend to be in adverse cardiovascular health coming into their diagnosis. And some cancer patients receive cardiotoxic treatments that damage the heart."

With AH-HA, Foraker and her fellow researchers are hoping to increase awareness and dialogue at the point of care. "Oftentimes, cancer patients are laser focused on their cancer and getting well following their diagnosis but aren’t necessarily thinking about the effects on the cardiovascular system," Foraker says. "Using the app positions the oncologist to talk to the patient about their cardiovascular health. It’s a very personalized and dialogic approach to delivering information at the point of care."

In the same vein, the CPHI is also developing an algorithm that predicts cardiovascular disease risk among breast cancer survivors. "This is an important gap because traditional cardiovascular risk algorithms underestimate risk among cancer patients," Foraker says.

OUTREACH

Creating Partnerships Across Disciplines

To accomplish its mission, the CPHI is actively engaged in cross-disciplinary collaborations. Foraker maintains a multidisciplinary lab of students and trainees from the Mckelvey School of Engineering and the Brown School with whom she meets regularly to facilitate new research opportunities and ongoing projects. "There are some very natural connections between the research that those faculty and students are doing and our expertise in the CPHI," she says.

On the faculty side, she’s currently assisting Sean Joe, a Benjamin E. Youngdahl professor of social development in the Brown School, with a grant application to investigate using wearable clinical data sources to gain insights into the journey of patients with mental health diagnoses through the healthcare system. The objective is to learn how that path is linked to important outcomes, such as hospital readmissions and community-service referrals.

Academic Programs

The Institute for Informatics (I²), provides a variety of opportunities for students to pursue an education in informatics — from graduate-level coursework to fellowships and internships.
Institute for Informatics (I²)
INFORMATICS.WUSTL.EDU

FASTER RESEARCH, MORE CURES, HEALTHIER COMMUNITIES