Reports

August 2020

Genomic Data in Health Systems

Survey results on the importance of an enterprise-wide strategy

Center for Connected Medicine

HIMSS

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Introduction

Genomic data management strategy and the future of precision medicine

This report about genomic data management at health systems outlines findings from a survey of health system professionals in clinical, operations, and information technology (IT) roles. Throughout its pages, you will find data from the online survey and qualitative analysis from Center for Connected Medicine (CCM) expert advisors; these individuals lent their thinking to the survey findings to bring you insights from the frontlines.

'Genomic data management' is intended to pertain to the capture, storage, analysis, utilization, and communication of data rendered from precision medicine programs. Three examples of precision medicine programs are pharmacogenomics, wherein DNA test results are used to guide prescribing; newborn genetic screening, wherein testing can diagnose disorders that impact normal development; and next generation tumor sequencing, which is when oncologists turn to tumor DNA for insight on how to treat cancer more effectively.

CCM research released in fall 2019 found optimism around precision medicine's ability to improve patient care, but showed precision medicine programs at most health systems in a low maturity stage or not yet deployed. This CCM survey, conducted in partnership with HIMSS Media, indicates precision medicine programs are becoming widespread at health systems, and the prominence of genomic data management strategy suggest its importance is well-known.

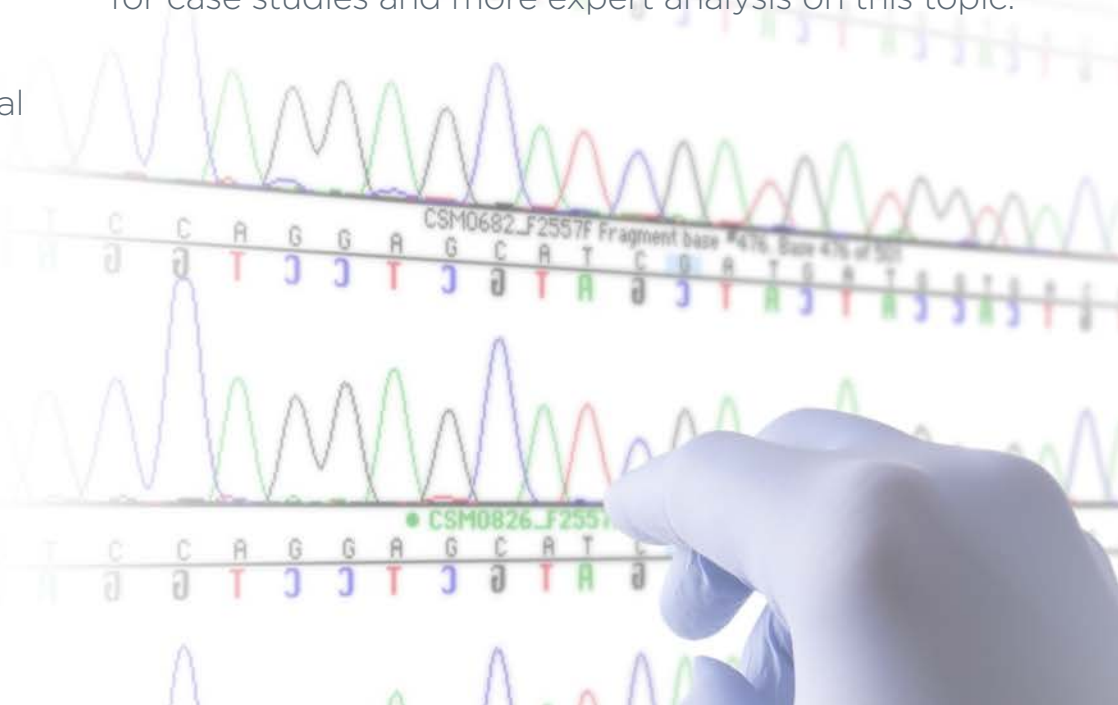
Without infrastructure to recall genomic data, genomics is unable accompany a patient across his/her care journey or prevent duplicative diagnostic costs. Without a platform that can apply reinterpretation and current clinical guidelines to existing genomic and genetic data, opportunity for positive health outcomes will be lost. Without an enterprise-wide approach, research is limited.

Yet, CCM expert advisors suggest there is likely a great deal of variance in what genomic data management strategies look like. A health system in pursuit of an integrated, enterprise-wide strategy could be talking about PDFs attached to medical records, purchasing and implementing an electronic health record's (EHR) genomics solution, constructing a cloud-based enterprise-wide warehouse — or some combination of these and more.

Variance aside, the CCM views near unanimous respondent efforts on genomic data management strategy as foreshadowing of the growth and significance of precision medicine at hospitals and health systems. The survey shows academic medical centers (AMCs) lead the way in currently providing precision medicine programs; this, coupled with 'industry research' as top source for best practices, suggest non-AMCs are watching to see how AMCs stand up genomics IT infrastructure.

The resources and attention required to make choices, bring on partners, and build infrastructure are substantial. But those investing in precision medicine infrastructure today are positioning to maximize a competitive advantage, as they ready for an inflection point and swelling adoption curve; to some, this investment may be analogous to investment in telehealth by health systems seeking to innovate, even before consumer appetite and reimbursement caught up.

Thank you for reading on for more about genomic data management strategy at health systems. Find CCM Resources at www.connectedmed.com/resources for case studies and more expert analysis on this topic.



About the Expert Advisors Who Contributed to this Report

Thank you to the expert advisors who informed the creation of this survey and to those who provided feedback on its findings.

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Go to **CCM Resources** for case studies and expert analysis on this topic and view our **Contributors page** to learn more about the executives we work with and ways to get involved.

Key Findings

1. Precision medicine and genomic data management strategy are gaining traction

Nine out of 10 survey respondents report their organizations are currently providing or planning to provide genetic/genomic testing; academic medical centers are more likely to currently provide precision medicine programs than integrated delivery network (IDN)/multi-hospital systems. One third of organizations already have a genomic data management strategy in place and another 64% have a strategy in progress.

2. Majority of health systems are focused on an enterprise-wide strategy

Two thirds of respondents say their genomic data management strategy is, or will be, at the enterprise level.

3. Informatics personnel and clinicians are at the helm of setting strategy

Informatics personnel and clinicians who use genomics in the daily care of patients are leading the way in setting genomic data management strategy; IT/technology and business/administration/operations executives are frequently involved.

Key Findings

4. Re-interpretation of genomic data and clinician notification are top platform criteria

The ability to facilitate re-interpretation of genomic data and support clinician notification, consume test results from a wide variety of molecular labs, and offer in-workflow integration with multiple EHRs are the most valuable criteria for an enterprise platform.

5. Health system execs anticipate the number of precision medicine vendors their organizations partner with will grow

Health systems have an average of two or more vendors in each of these areas: production of genomic/genetic information, genomic/genetic data storage, and genomic/genetic analysis. Approximately 60% of respondents anticipate the number of vendors will increase across the board by 2023.

6. Clinical and cost effectiveness most likely to lead to launch or further development of precision medicine

Evidence of clinical and cost effectiveness and reimbursement are the top three factors likely to expand genetic/genomic testing and precision medicine programs, with executives most commonly turning to industry research, case studies from other health systems, and conferences for information.

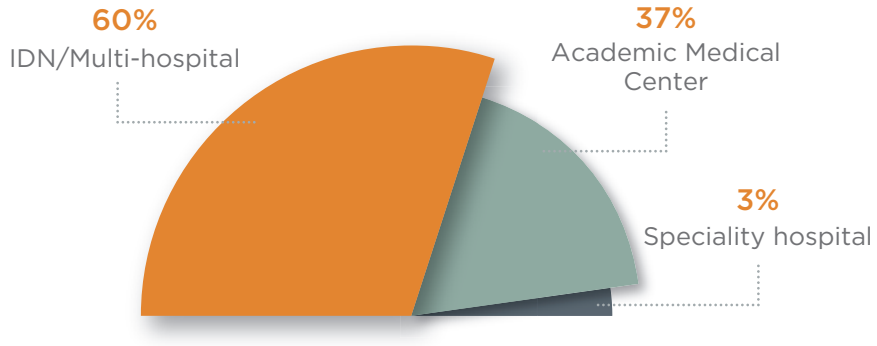
Research Overview

The CCM partnered with HIMSS Media to conduct a survey of professionals at U.S. hospitals and health systems in March 2020. The goal of the research was to better understand how health systems and hospitals are approaching genomic data management.

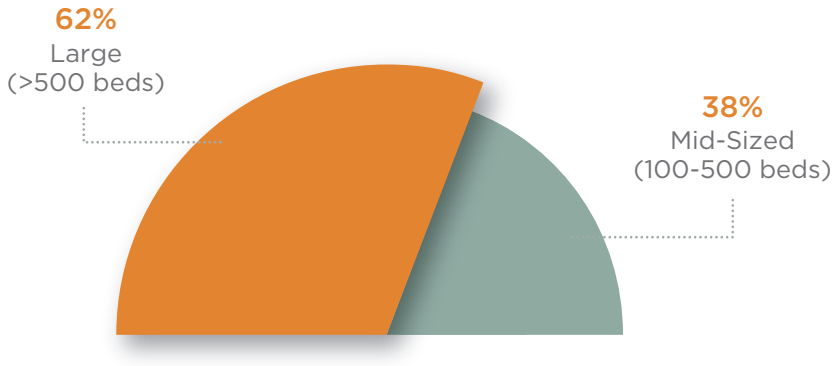
A total of 101 qualified respondents were surveyed and they represented a mix of information technology, informatics, business, and clinical roles who use genomics in daily care of patients at U.S. hospitals and health systems. Respondents were asked questions about their organization's genomic data management approach.

HIMSS Media conducted the online survey and the CCM was not identified as a sponsor of the research. Qualified respondents were sent an email from HIMSS Media inviting them to participate and were offered an incentive for completing the survey.

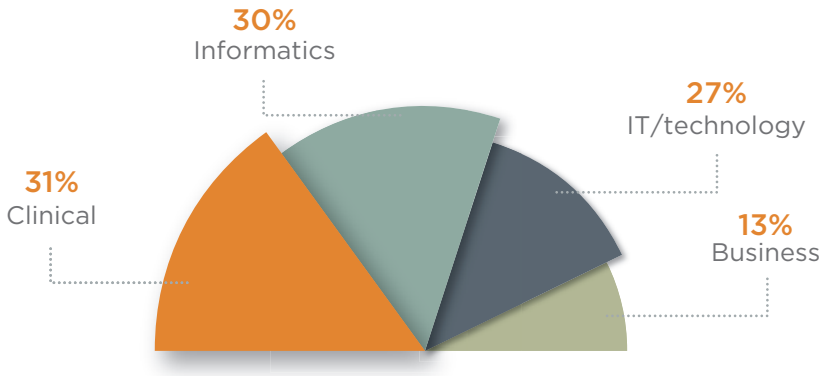
Respondent Profile



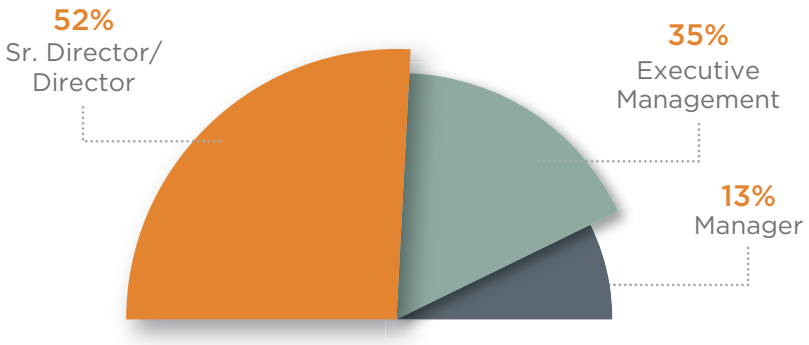
Worksite



Organization Size



Job Role

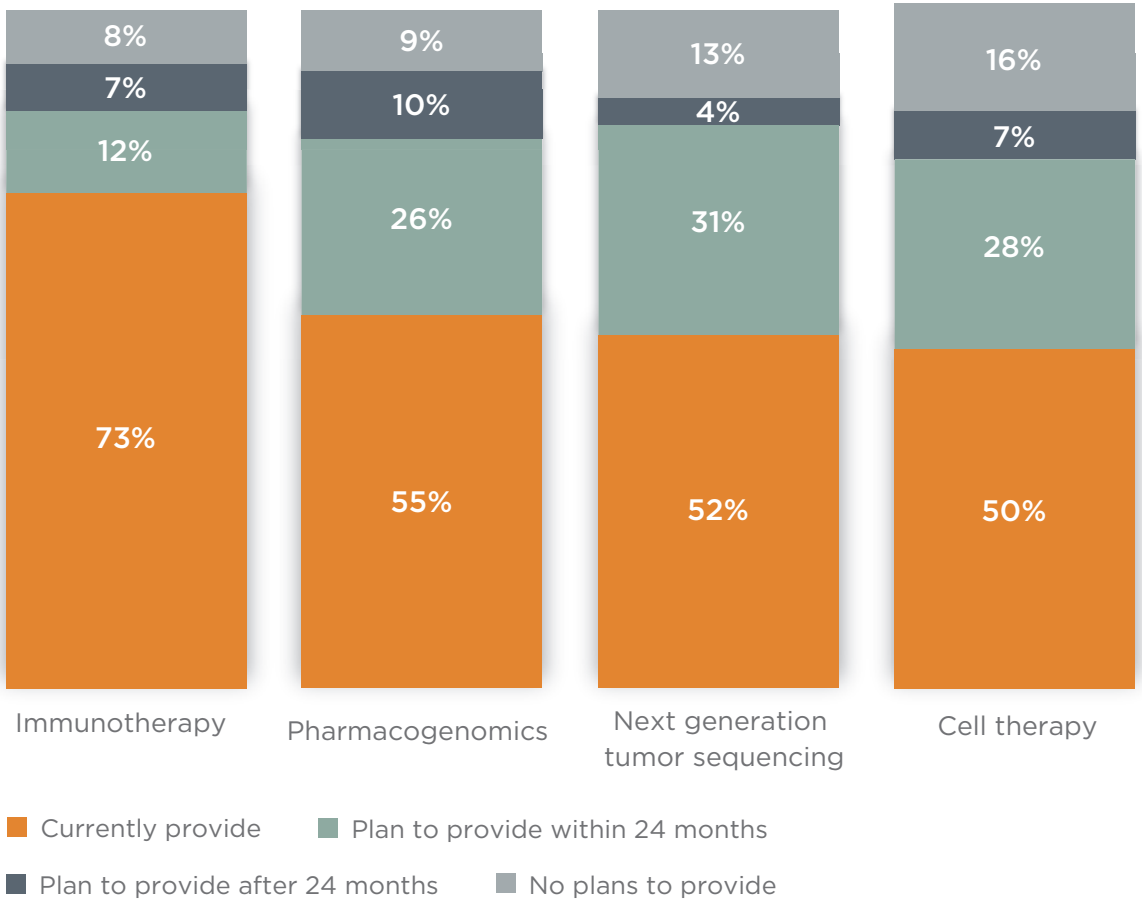


Job Level

Detailed Findings

Precision medicine is picking up speed

Nine out of 10 respondents say their health system currently provides or plans to provide genetic/genomic testing as part of precision medicine programs. Academic medical centers are more likely than multi-hospital systems or integrated delivery networks to currently offer all of the precision medicine programs listed below, and the gap is wider for more complex, technical programs such as next generation sequencing and cell therapy.



Currently provide

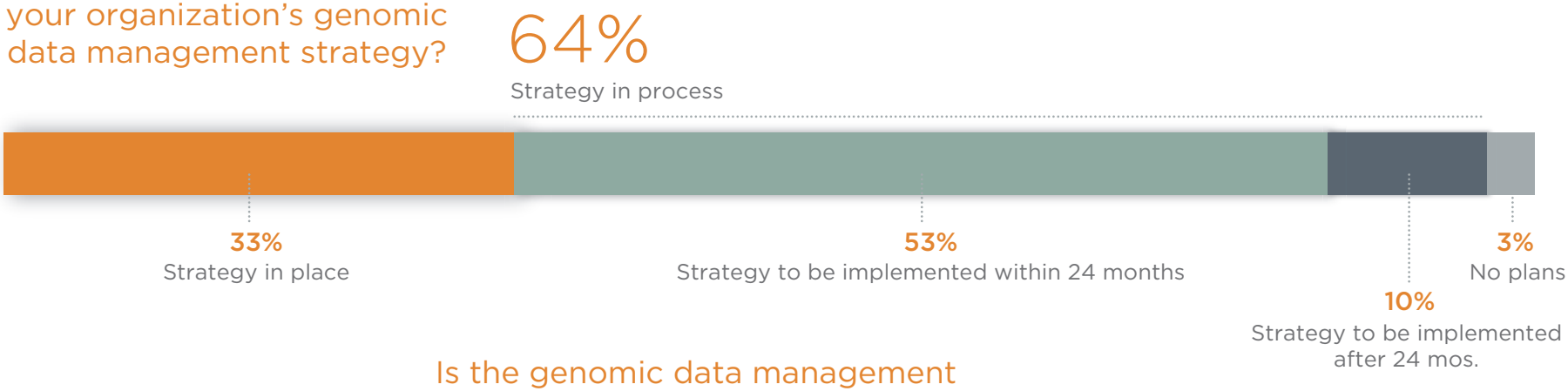
	Next generation tumor sequencing	Cell therapy
Academic Medical Centers	68%	65%
Multi hospital systems/IDNs	43%	38%

Detailed Findings

Implementing a genomic data management strategy is a common, often enterprise-wide endeavor

One third of organizations already have a genomic data management strategy in place and another 63% have a strategy in progress. Two-thirds of respondents say their genomic data management strategy is, or will be, at the enterprise-wide level.

What is the current status of your organization's genomic data management strategy?



Is the genomic data management strategy enterprise-wide or at the department level?

Expert Insight

Health systems may take different strategies when implementing because of expectations for the long-term re-use of genetic data. For a tumor board, a PDF report is common and may be acceptable given the targeted, short term use. But in other applications such as pharmacogenomics, germline data are re-usable over a patient's lifetime. Each new prescription may need to trigger clinical decision support leveraging genetic data and updated knowledge perpetually. Increasingly, health systems are pursuing an integrated, enterprise-wide genomic data management and cloud-based enterprise warehouses used for analytics, research, and clinical care — which is how we're looking at this."

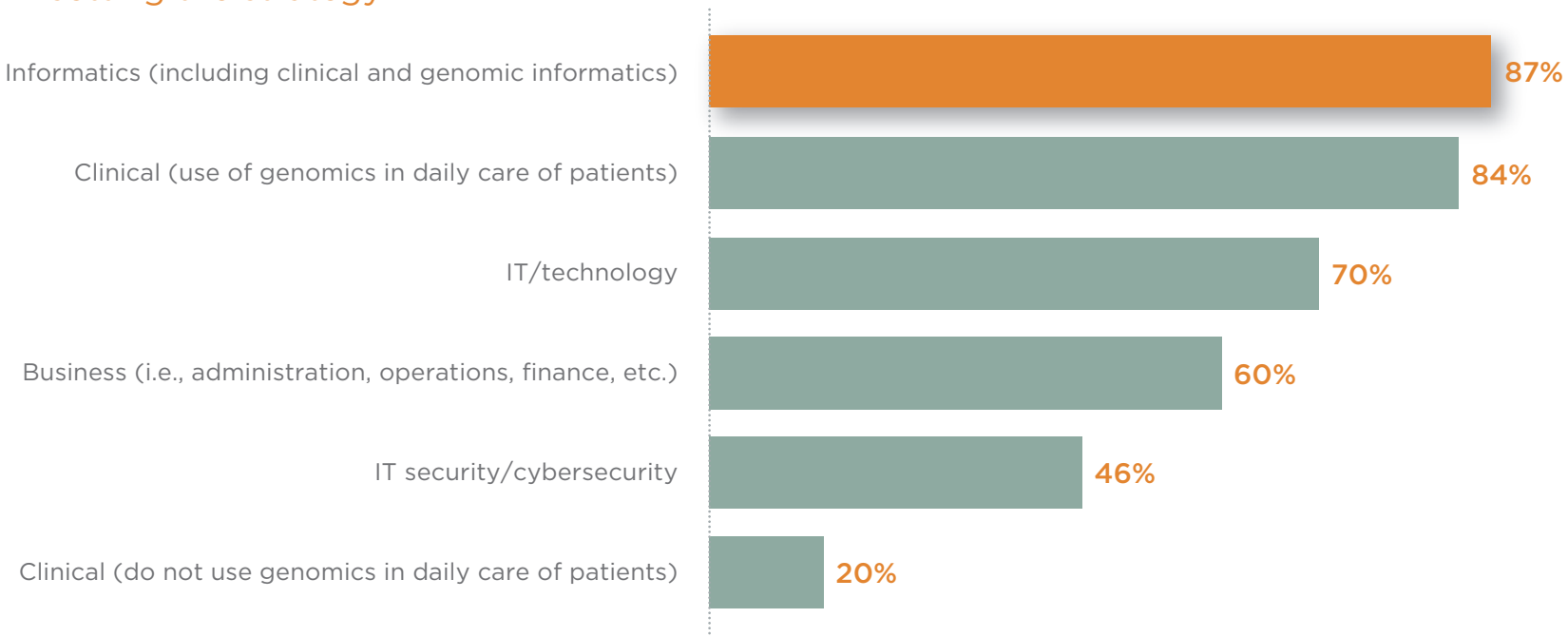
Philip Empey, PharmD, PhD, *Associate Director for Pharmacogenomics, The University of Pittsburgh/UPMC Institute for Precision Medicine and Associate Professor, Department of Pharmacy and Therapeutics, The University of Pittsburgh*

Detailed Findings

Informatics personnel and clinicians setting strategy

Informatics personnel and clinicians who use genomics daily in the care of patients are leading the way in setting strategy. IT and business leaders are also integral, as there are financial and technical needs involved in implementing genomic data management strategy.

Who has been involved in setting the strategy?



Expert Insight

Business operations and finance are important stakeholders, because precision medicine and genomic data management require investment. Precision medicine can be compared to telemedicine before COVID-19: more expense than direct clinical value. We see this as a strategic investment and the buy-in is there. Forward-thinking strategists and business leaders can help health systems position themselves on the leading edge. This will become more and more important as consumer demand for these services grow."

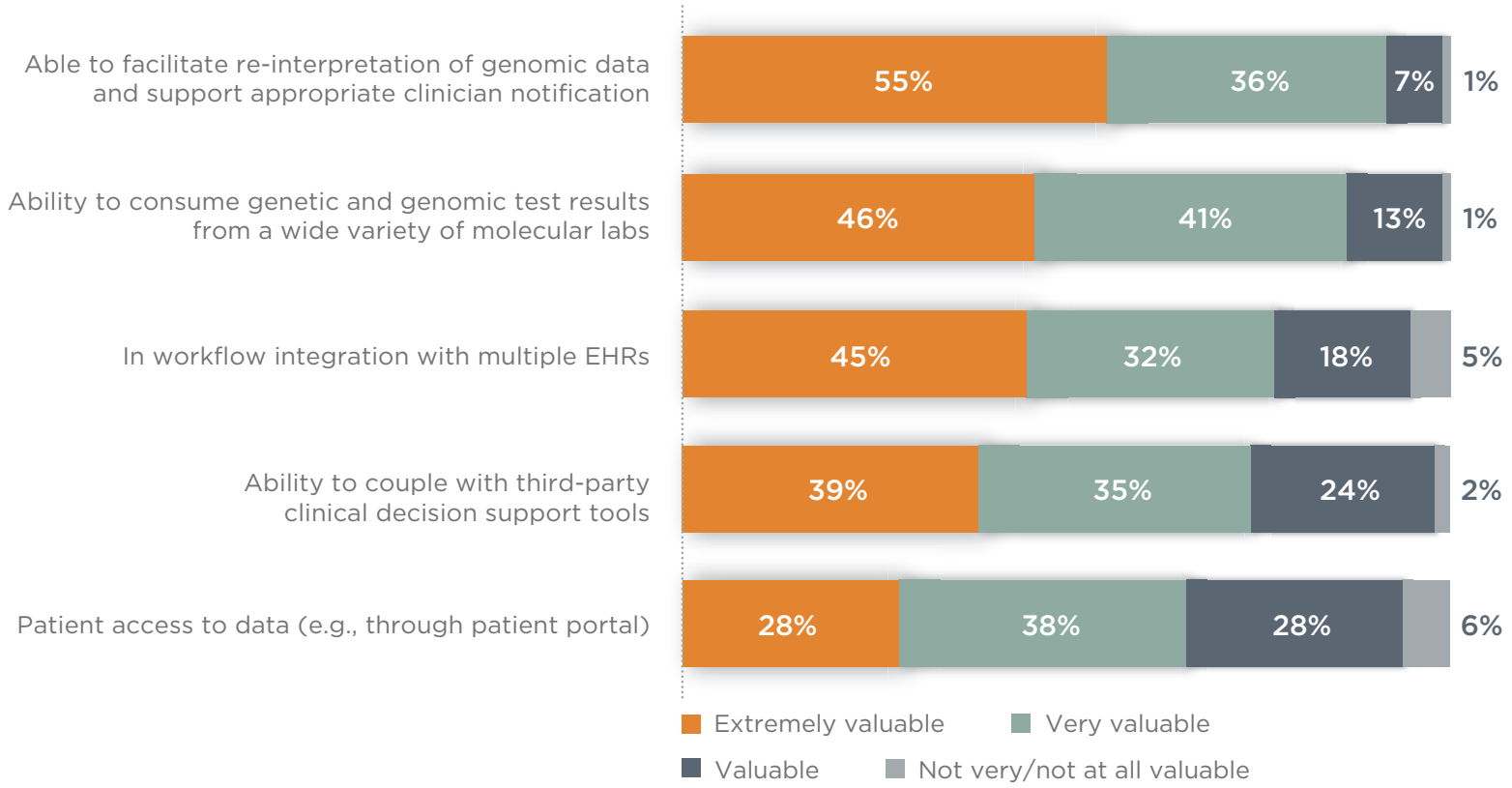
Rob Bart, MD, *Chief Medical Information Officer, UPMC*

Detailed Findings

Re-interpretation and clinician notification are the most valuable platform features

The ability to facilitate re-interpretation of genomic data and support clinician notification, consume test results from a wide variety of molecular labs, and offer in-workflow integration with multiple electronic health records (EHRs) are the most valuable criteria for an enterprise platform.

When thinking about an enterprise-wide platform to support genomic data management, how valuable is each of the following criteria?



Expert Insight

> Patients want access to information in a way they can understand. This holds true for physicians, too. Consumability of genetic and genomic data is a real challenge. Patient access to data falls toward the bottom of this list, but consumability for providers and patients is something our team spends a great deal of time thinking about."

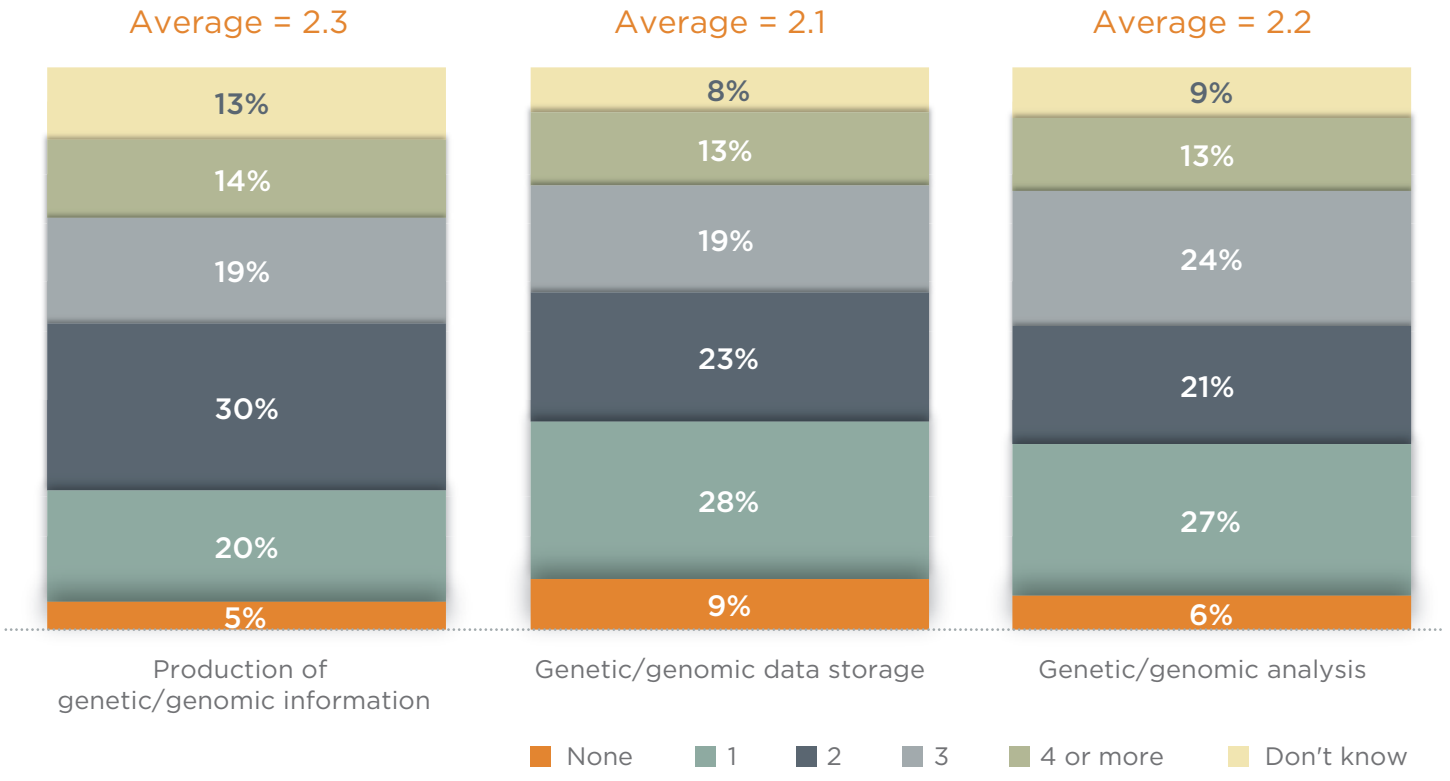
Rob Bart, MD, *Chief Medical Information Officer, UPMC*

Detailed Findings

An end-to-end solution is not on the horizon

Health systems have an average of two or more vendor partners in each of these areas: production of genomic/genetic information, genomic/genetic data storage, and genomic/genetic analysis. One can envision how a single end-to-end vendor could simplify genomic data management, but health system executives do not see this as feasible in the near-future.

How many partner organizations/vendors are currently involved in the following areas?



Expert Insight

An end-to-end solution is unlikely. The reality is that health systems are building solutions using discreet evidence, pulling best in class capabilities and partners in along the workflow. We need to ensure systems and data are interoperable to meet clinical and business needs, and that's where the strategy comes in. Data science and clinical science have a strong partnership in precision medicine."

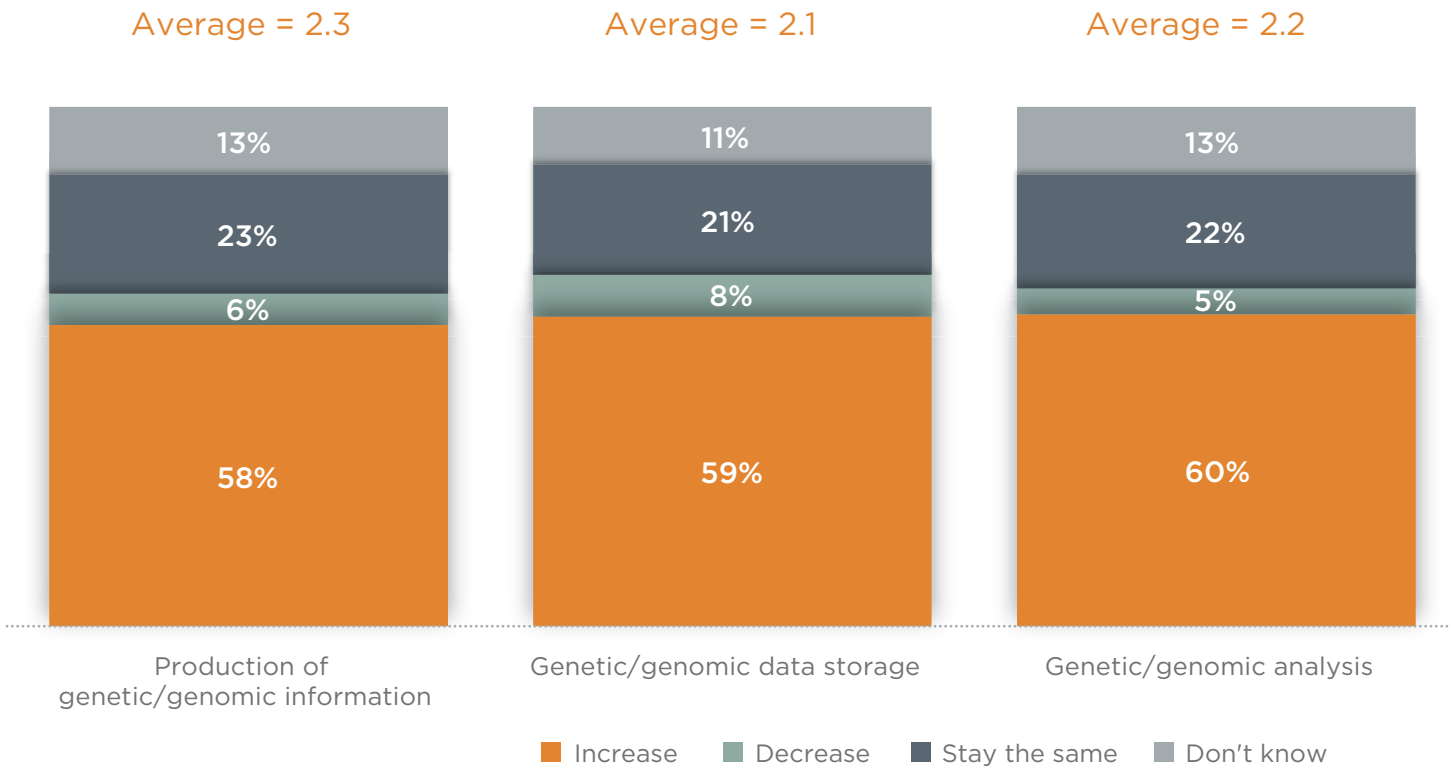
Matthias Kleinz, PhD, *Vice President, Translational Programs, UPMC Enterprises*

Detailed Findings

Health system execs anticipate increasing number of precision medicine vendors

Approximately 60% of respondents anticipate the number of vendors their organizations work with in all areas below will increase by 2023.

How many partner organizations/vendors are currently involved in the following areas? And do you anticipate that number will increase, decrease or stay the same in 3 years?



Expert Insight

From a scientific standpoint, COVID-19 opened the floodgates for demand for immediate access to data. It grew our aspirations to have data immediately at our fingertips. I believe this will impact the future of genomic data management strategy and vendor models. We're pursuing a holistic, integrated data system able to deliver real-time insights. Historically, data transfer between health system and vendor has been timely and technically challenging. I think models that can eliminate this will be attractive."

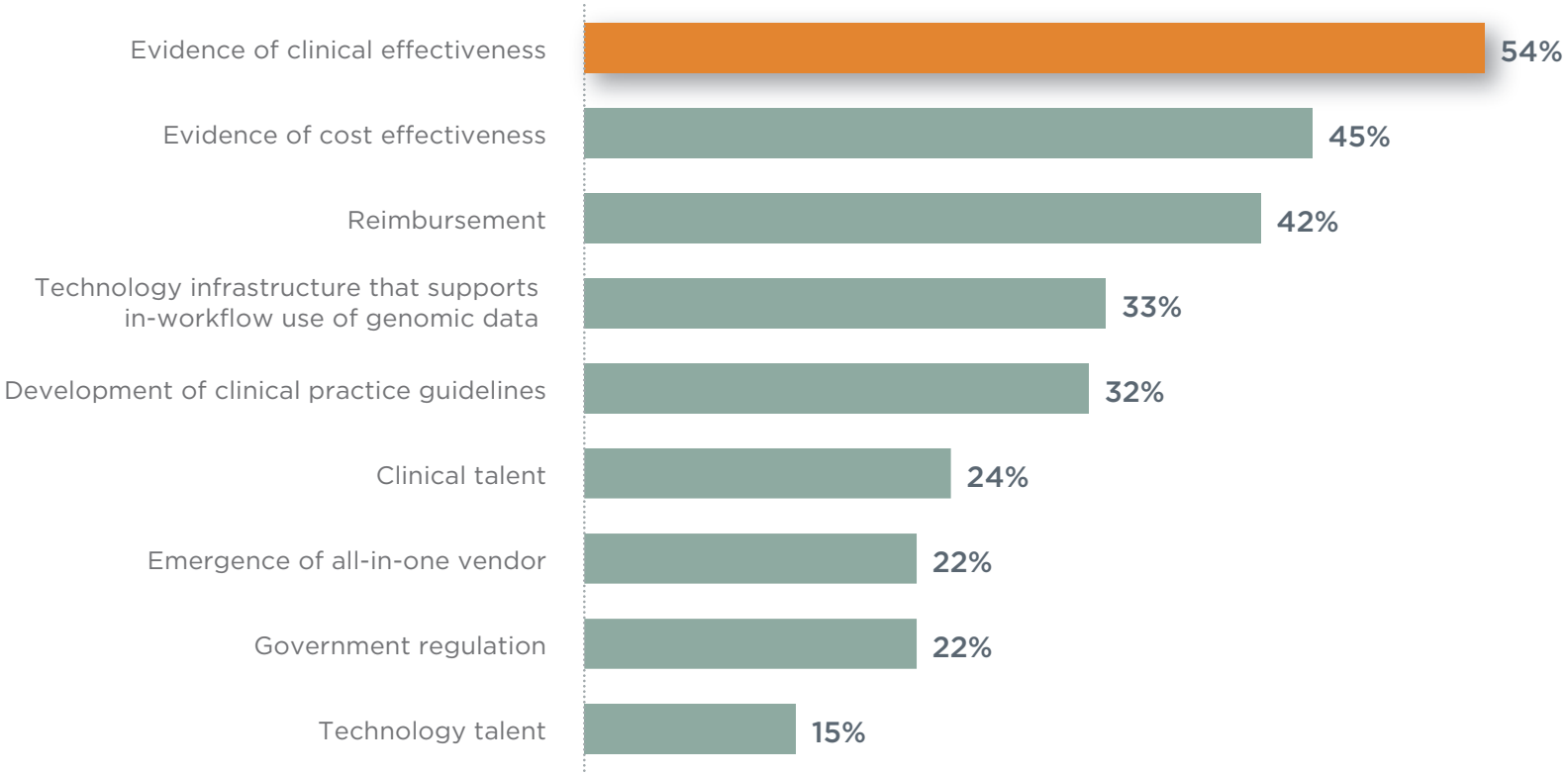
Adrian Lee, PhD, *Director, The University of Pittsburgh/UPMC Institute for Precision Medicine and Professor of Pharmacology & Chemical Biology, and Professor of Human Genetics, The University of Pittsburgh*

Detailed Findings

Clinical and cost effectiveness most important to growing precision medicine

Evidence of clinical and cost effectiveness and reimbursement are the top three things likely to expand genetic/genomic testing and precision medicine programs.

What are the top three things most likely to lead to the launch or further development of genetic/genomic testing and precision medicine programs at your organization?



Expert Insight

Patients are another force driving precision medicine. For example, we are seeing informed patients who are asking to have their tumor sequenced. This suggests to me that precision medicine program strength will be a competitive advantage and add value to the organization."

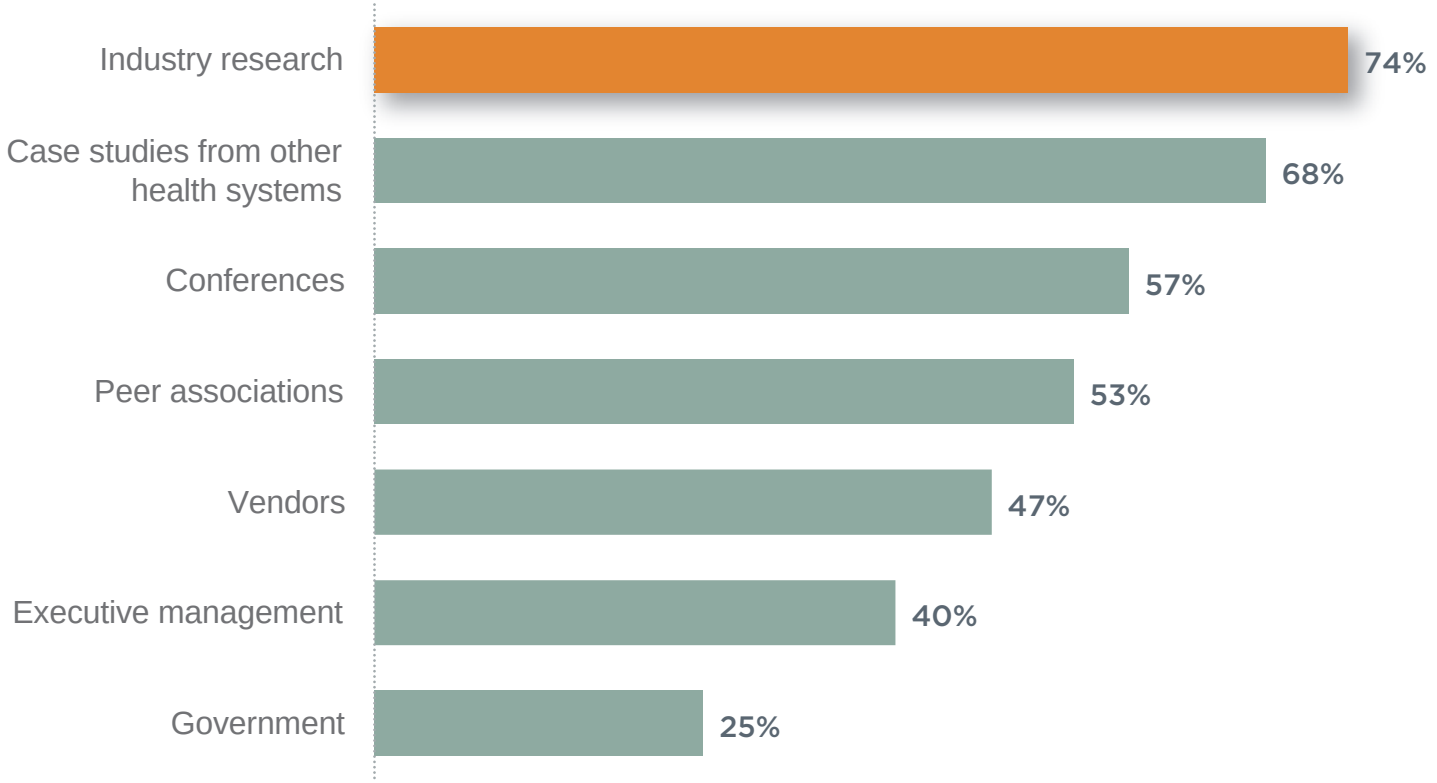
Adrian Lee, PhD, *Director, The University of Pittsburgh/UPMC Institute for Precision Medicine and Professor of Pharmacology & Chemical Biology, and Professor of Human Genetics, The University of Pittsburgh*

Detailed Findings

Industry research and health system case studies inform genomic data management

Executives most commonly turn to industry research, case studies from other health systems, and conferences for information and best practices related to genomic data management.

Where does your organization turn for best practices related to genomic data management?



Expert Insight

Right now, with the industry watching one another, as seems to be the case in this space, it will be interesting to see whether COVID-19 leads to tighter budgets and less investment in innovation, or if systems pursue key differentiators like precision medicine to try to gain market share."

Matthias Kleinz, PhD, *Vice President, Translational Programs, UPMC Enterprises*

About the CCM

The CCM connects and inspires leaders and innovators who want to advance health care. Collaborating with a network of experts, we serve as a resource for information and events focused on the future of digital health. Join us at **connectedmed.com**.

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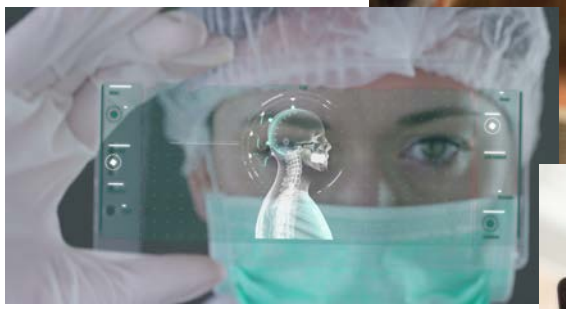

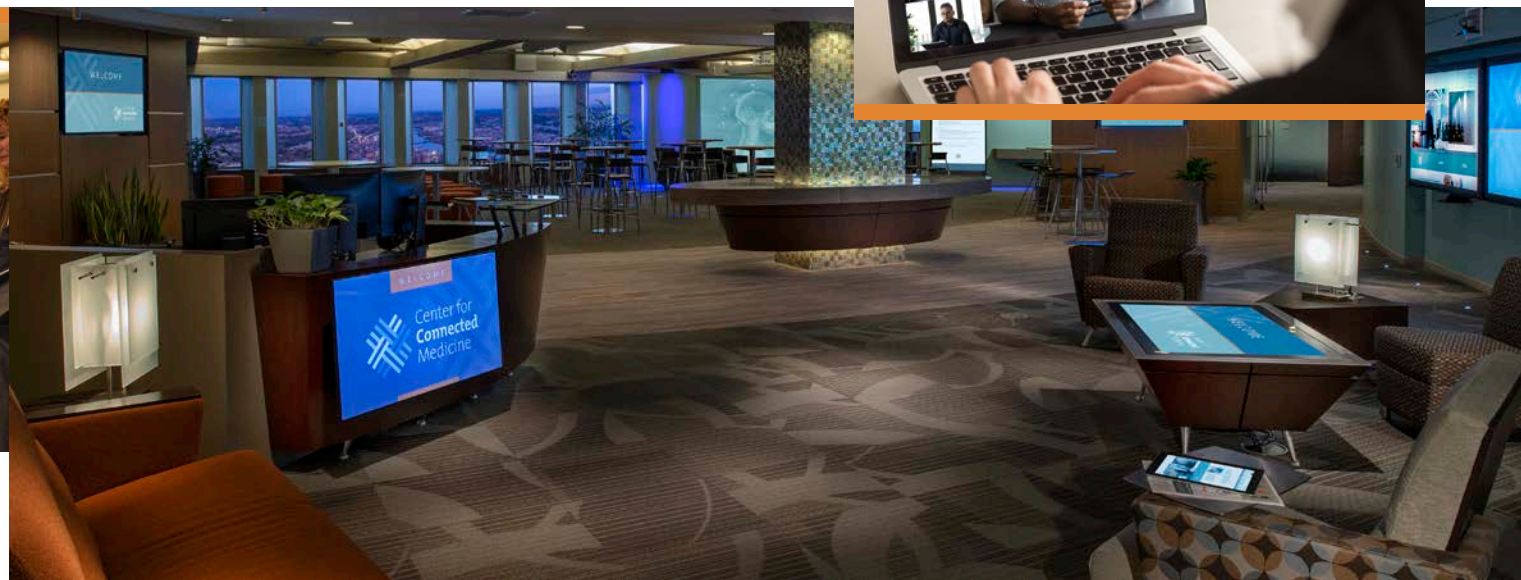

View more about precision medicine and genomic data management strategy in health care from the CCM and its partners at **connectedmed.com**

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