



Improving Patient Adherence and Health Outcomes

PERSPECTIVES FROM THE IQVIA INSTITUTE ROUNDTABLE FOR RADICAL COLLABORATION

DECEMBER 2021

Introduction

Patient services are evolving as an area of growing interest within the life sciences industry to advance adherence with complex, specialty therapies. At the same time, there is much discussion about moving healthcare services from hospitals and institutions to home healthcare, which is driven by major shifts in the healthcare eco-system.

To discuss how this evolving space is affecting the life sciences industry and other stakeholders, the IQVIA Institute for Human Data Science convened a multidisciplinary Roundtable for Radical Collaboration on June 24, 2021, entitled: **Improving Patient Adherence and Health Outcomes through Patient Services and Home-based Healthcare: Exploring opportunities and challenges for life sciences companies in an changing person-centered healthcare space**.

The virtual roundtable was convened in partnership between IQVIA Patient Support & Nursing Services and the IQVIA Institute and included participation from seven external representatives of large and small life sciences companies, providers, and patient advocacy groups.

The following paper summarizes key the themes from the lively and engaging discussion and includes selected quotes from participants.

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MURRAY AITKEN

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Participants

The opinions shared by participants during this discussion are based on their own experiences and do not necessarily reflect the views of their employers.

EXTERNAL PARTICIPANTS

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PARVATHY KRISHNAN is Foundation Alliance Manager for Global Genes, an organization that provides hope for more than 400 million people around the globe who are affected by rare disease by connecting them to communities, information, and resources. She is also the mother of a child with medically-complex needs.

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IQVIA PARTICIPANTS

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Background

Patient services are a growing business segment for life sciences companies that simultaneously addresses fragmentation in patient care delivery, improves adherence to therapies, and increases patient satisfaction.¹

Simultaneously, there is an elevated focus on the transition of healthcare delivery services from hospitals and institutions to home-based care. This trend is driven by several factors:

- Scientific evidence over the last couple of decades has demonstrated the benefits of treating and caring for people with chronic diseases in their home rather than in the hospital setting.
- *Advances in technology*, such as remote monitoring, personal sensors, telemedicine, and innovative devices at the point of care at home have accelerated the transformation toward home care solutions and services.
- The growing application of advanced analytics, such as artificial intelligence (AI), machine learning (ML) and natural language processing (NLP) have enabled the generation of evidence about the patient experience across the entire care path, including home care.
- *The COVID-19 pandemic* has underscored the benefits of home-based patient care due to the convenience and protection of elderly, frail, and immunocompromised people. It has also accelerated the uptake by providers, healthcare systems, and payors for reimbursement.
- *The Biden Administration's infrastructure plan* has proposed to invest \$400 billion in enhancing the home and community care sector.

Consequently, home-based care is gaining more prominence in the healthcare ecosystem. Recently, the health insurer Humana announced plans to acquire Kindred at Home, thus accelerating the integration of the largest home health provider in the country into Humana's healthcare services platform.

The life sciences industry is expanding its investment and activities in home-based care by focusing on providing patient services and support programs for patients with complex and chronic diseases; these support programs include, among other elements, in-home phlebotomy and per-diem clinical nurse educators.²

Life sciences organizations are investing \$14 billion annually in patient services and the growth of this market segment is outpacing the overall growth of the healthcare sector.³

Home-based care is a potentially promising, expanding field of interest for the life sciences industry that holds opportunities for further growth. However, there are many challenges, including financial, regulatory, legal, compliance, and organizational issues that require further consideration. There are many topics for the life sciences industry to consider in partnership with multiple stakeholders who see the value in the growth of home-based care in improving patient adherence and outcomes as well as reducing unnecessary costs of institutional care.

Key themes in the discussion

Several themes emerged about the evolving space of patient services and home-based care during the discussion, highlighting opportunities for improving adherence and patient outcomes while also pointing to a number of challenges for adoption of home care services at larger scale.

1. THE GROWTH IN SPECIALTY MEDICINES FOR CHRONIC, COMPLEX DISEASES

Specialty medicines have been increasing as a share of spending in higher-income countries, such as the 10 largest developed countries and other high and upper middle-income countries where they have reached 47% and 37%, respectively in 2020, up from 24% and 21% 10 years earlier⁴ (see Figure 1). The growth in specialty therapeutics represents a unique challenge for the healthcare system broadly. While many specialty therapeutics offer advances in the treatment of chronic, complex, and rare diseases, there are complexities for patients and other stakeholders around diagnosis, administration, monitoring, and management of therapies as well as complexities around access, payment, and coverage. There are also challenges regarding the physical management of patients with complex conditions that require additional help and support with their daily living.

These complexities elevate the urgency of providing support to patients and caregivers to improve their experience and to ensure adherence with therapy to generate the desired health outcomes.

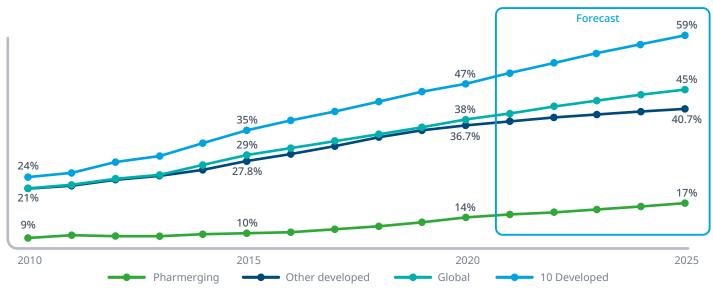
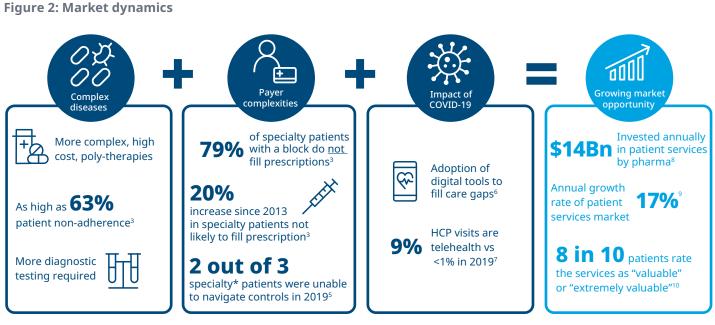


Figure 1: Specialty medicines share of spending

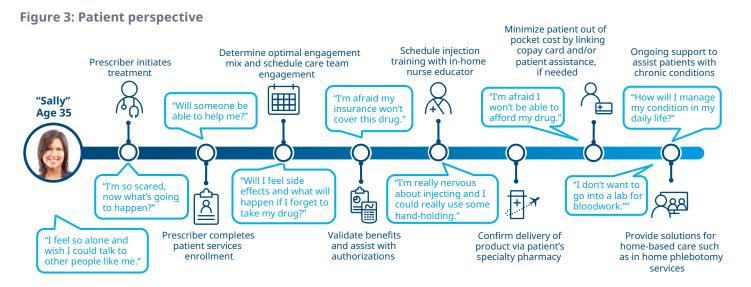
Source: Global Medicine Spending and Usage Trends: Outlook to 2025, IQVIA Institute, Feb 2021



* Specialty markets: HIV, Immunology, Oral Oncology, HEPC, MS, Immuno-suppresants

2. BRIDGING THE GAPS IN THE PATIENT JOURNEY

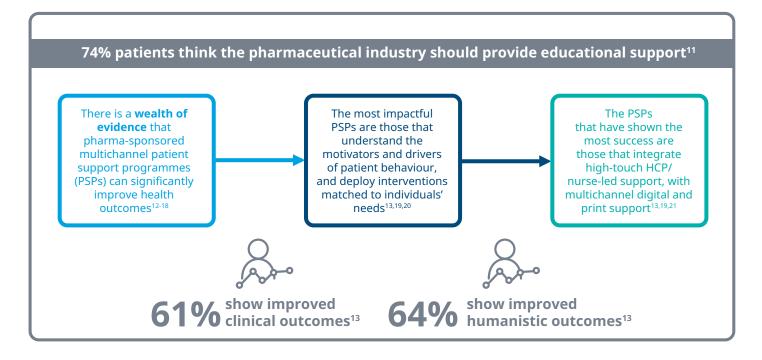
Patient services are evolving as an important effort for life sciences companies to address the complexities around specialty therapies, to support patients and caregivers, and to eliminate or mitigate barriers along the challenging patient journey (see Figure 3). Patient services can also help alleviate the challenges with transportation to and from healthcare services, especially in cases with multiple disease states. Effective patient support programs provide education, address care gaps and can ultimately help improve patient adherence and outcomes (see Figure 4). Due to several factors, including post-pandemic expectations, cost pressures and advances in technology, homebased healthcare is evolving as a major opportunity for delivering patient support services such as in-home phlebotomy and clinical nurse educators.



Note: Illustrative only

Source: IQVIA Patient Support and Nursing Services

Figure 4: Effective patient support programs



"Patients with severe immune deficiency are terrified of leaving their house sometimes, let alone go into either a doctor's office or a hospital to get their medication. Right now, there are issues with payers who are requiring patients to get their infusion or their injection at a doctor's office. We have to do better with these patients who would benefit from getting their infusions or injections in their home, especially if it's a long infusion. Some infusion rates, depending on the product and the disease state, can range from an hour-and-a-half up to six hours. That's a long time for these patients to be in a facility and potentially be at-risk among other patients."

- Erica Stick, Patient Services Director, Rare Disease at Chiesi USA, Inc.

In some cases, patients and caregivers are forced to travel great distances to get to a facility to receive therapy, which puts additional stress on patients with severe and challenging diseases as well as those caring for them.

3. DETERMINING THE RIGHT PATIENTS FOR HOME-BASED PATIENT SERVICES

One of the challenges for patient services in the home is to determine the right services for the right patients.

Many support programs today target patients with rare or ultra-rare diseases; however, there are also unmet needs for elderly, frail individuals with multiple diseases. Furthermore, there are large patient populations even at younger ages with multiple chronic conditions. Therefore, larger patient populations and health systems may have potential benefits from expanded home-based healthcare services.

The management of comorbidities and multimorbidities are particularly challenging due to the high levels of medical complexity. One example is a patient with heart failure who needs treatment with diuretics but also needs infusion therapy for a cancer, which creates challenges with timing of the diuretics because the patient has to travel to the infusion center.

"As a mom of two kids with rare and ultra-rare conditions, we have experienced some significant challenges. We travel to Boston Children's Hospital from North Carolina every three weeks for immunotherapy, and we would love nothing more than to receive treatment at home. But there is hesitancy among physicians to do this at home. There are payers who are refusing to pay, but there is also a lot of doubt among patients and caregivers about the safety of doing this at home when you don't have the medical and nursing team around you."

– Parvathy Krishnan, Foundation Alliance Manager Global Genes "The forgotten voice is that of the caregiver in the patient journey. I've had situations with people who have stopped therapies for chronic, progressive disease that required life-long infusions because the family just couldn't do it anymore. They live too far away, it takes all day to get to the infusion-center, and they have to wait for their turn. I am hoping that the market dynamics have started to change that and we can build on what we have learned during the pandemic."

- Tessy Malone, Vice President, Hospital Transformation Strategy, Grifols "Rare and complex diseases are certainly a challenge, but I would argue that there are actual challenges, especially in the realm of specialty therapeutics, for common chronic conditions as well. I have experienced patients with asthma who needed biologics, but they were afraid of getting sick going to the respirologist's office, so they ended up critically ill." - Niteesh Choudhry, MD, Professor of

Medicine, Harvard Medical School

There are also significant costs from patients being transported to and from infusion-centers by ambulance.

Home-based care services may become a powerful trigger for improving care, enhancing the patient experience, and reducing costs. While there are clear and distinct benefits for patients and caregivers with complex and rare diseases, there are also benefits for broader patient populations with more common conditions who may have challenges either due to the complex nature of their therapy or because of the impact of comorbidities and multidisease.

4. ADDRESSING MENTAL HEALTH ISSUES

When addressing patient needs relating to complex diseases, the focus should be broader than the specific indication that is treated. Mental health issues are important to patients and caregivers with complex chronic diseases. It was mentioned that depression rates in the U.S. have increased to 40%, as corroborated by the National Alliance on Mental Illness.²²

> "Mental health issues are not minor issues. And if you put those on top of chronic diseases, we have a real, major league issue, and problems that need to be addressed both for the patient and the caregiver."

 Welton O'Neal, Vice President, Medical Affairs, Supernus Pharmaceuticals

"I am lucky enough to sit on patient advisory boards and listen to the first-hand experience from these patients. A lot of the parents talk about the emotional stress having children with rare diseases. They may be going through divorce because they can't mentally handle the stress of having a very sick child or a sick spouse, and everything that comes with that."

 Erica Stick, Patient Services Director, Rare Disease at Chiesi USA, Inc. While providing support to the patient and caregiver in their home may appear to be a great benefit, it can also be challenging for the patient and the family. Overall, there is an urgent need for expanding patient support beyond addressing the specific medical issues around the disease to encompass all the aspects around emotional stress and mental health.

"For some patients it is scary to have a stranger – even if it is a healthcare professional – coming into their home, their private sanctuary, even if they are coming to help the patient. It is important to understand this and be able to listen to the customer and their emotional needs and mental health issues when you think about these programs."

 Alexia Burnett Salinas, Group Product Director, Customer Solutions, Neuroscience, Johnson & Johnson "We need to look at a baseline for behavioral health to boost mental health across all therapeutic areas. This was a major learning from the COVID-19 pandemic, and we see it with disparities in healthcare right now. We need to come together to address stress collectively, otherwise we are missing the boat."

– Michelle Santoro, Product Manager, Janssen Oncology

"We have been given support to the medical issues for our two children with medically complex issues. But we did not have any emotional support. We didn't have anybody checking on us saying, How are you feeling doing this? It was just like, chop, chop. This is what you have to do, these are the procedures, and if you don't do any of this, your child can have a bloodstream infection and they can die. There were the best intentions, but a lot of times, the perspective was lost. There are a lot of issues that are not understood by the medical team, such as issues around mental health and caregiver support."

- Parvathy Krishnan, Foundation Alliance Manager, Global Genes

5. OVERCOMING INERTIA AMONG PHYSICIANS

While the benefits of providing patient services in the home may be obvious to patients and families, there may be some hesitation among healthcare professionals to embrace home-based healthcare. This could be due to physician inertia in the practice of medicine.

"The concept of patient-centered care has been in the lexicon for a decade, but medicine is still not really patient-centric. I think a lot of things should be in the patients' control, and we should help support them in that. The medical establishment has long blamed patients for not adhering. Others and I have written a lot about this: Stop blaming the patient. It's not the patient's fault. It is frankly our fault."

 Niteesh Choudhry, MD, Professor of Medicine, Harvard Medical School The point was also made that physicians may fear losing control if care is provided in the home.

The point was made that incorporating services in the home as part of clinical trial protocols may help overcome physician inertia. Once a drug is approved, physicians can then see that the standard of care includes home-based care.

6. COLLECTING AND CURATING THE RIGHT DATA

There are major opportunities for generating information from patients in their home about their health and disease; for example, from wearables that are ambient and unintrusive.

However, it is a challenge for physicians to deal with the constant flow of data if the information is not curated. A constant flow of data on blood pressure and heart rate is not helpful if the data is not collected and provided in a meaningful manner.

The question is how physicians can get access to meaningful information that help them make the right decisions at the right time.

There are two dimensions to collecting and curating the right data; one part is what data is collected at home, while the other part is how that data is delivered to the healthcare provider.

"Some of the more common chronic conditions and treatments are not as glamorous anymore. Maybe that's why they are not being offered in home care services, but I think everybody should be provided the opportunity to get their care delivered at home, and that is not always the case. There is a disconnect here. Maybe it is because doctors want to be in control and they don't feel they can be in control in the home if anything happens."

- Parvathy Krishnan, Foundation Alliance Manager, Global Genes

The data generated at home will need to be specific to the conditions and the treatment being administered, and it may, in some cases, go beyond that to capture sub-clinical assessments that are relevant to safety. This may include mental health and the development of Parkinsonian-like symptoms, which won't be captured through vital signs.

The data needs to flow to the healthcare provider in a manner that is meaningful and enable the right decisionmaking. One of the challenges in data transfer pertains to what computer science terms false alerting, which in medical science is known as alert fatigue. There is the risk getting many data streams from many different sources based on patient-reported information. The question becomes how all the information is curated in a way that is useful for providers so that it can lead to the right actions in the right cases. These are issues that are important in the application of AI and ML.

"How does the right data get across the bridge from the home to the healthcare provider in an intelligent way? That is a big challenge."

 Niteesh Choudhry, MD, Professor of Medicine, Harvard Medical School

7. MEASURING MEANINGFUL OUTCOMES FOR THE PATIENT

The question was also raised as to whether we are measuring the right things. Value is always mentioned as a key metric for measurement, especially for payers. Value tends to be viewed narrowly as an economic dimension, but value also has a personal dimension – satisfaction – which should be measured as well.

Having a standardized quality of life assessment tool may also be a real driver of change.

"As part of the human science effort, we need to have a standardized quality of life assessment tool that can help us measure progress in this area. Today, there is no consistency and no tool available for assessing quality of life across the disease spectrum. If we had a tool that could demonstrate the impact on quality of life before and after a patient receives home care services, it would really move the needle." - Parvathy Krishnan, Foundation Alliance Manager, Global Genes

The critical issue is to determine how to simplify and streamline the data so the most relevant information gets to the right decision-makers at the right time.

It was pointed out that the biggest gap may be the lack of collaboration and the fragmentation in the healthcare ecosystem. There are silos of hospitals and silos of home-care. Even if nurses are contracted to go into people's home to train, help with infusions and monitor reactions, the silos are still not connected seamlessly. If there are gaps in collaboration, data will not connect people across the silos.

The question was raised whether it is possible digitally to bring all the stakeholders together to give them access to the pertinent information at the right time and in the right way – whether it is the doctor, the in-home nurse, the caregiver, the patient advocate, so that they can get just what they need when they need it to better serve the patient. "We had a negative experience with electronic medical records with data being dumped into the EMR system. Having a strategic plan on data and its use is is important when we talk about decision-making for home-based healthcare. What are we trying to accomplish? It is more than making sure patients take the medication. And it's more than just having data because we don't want to end up with analysis paralysis."

– Tessy Malone, Vice President, Hospital Transformation Strategy, Grifols

8. MOVING FROM PATIENT ADHERENCE TO PATIENT-POWERED CARE

The concept of patient adherence was subject to debate during the roundtable.

It was emphasized that the concept of adherence puts the patient in a passive role, i.e., the patient has to adhere to a prescribed regimen, a protocol, or the like. However, unless patients are truly motivated and in the driver's seat themselves, successful outcomes will not be achieved.

"The physician may have the best interest of the patient in mind, but if the patient is scared or if the patient is not confident in their ability to give themselves this infusion or shot, then the best of plans will not work Therefore, the patient will have to be the driver."

- Parvathy Krishnan, Foundation Alliance Manager, Global Genes

"Patients are already in control of most things in the lives but we haven't structured health care for them to have this same control. Patients vote. They drive. They have and raise children. In the case of health care, some patients need more support than others, but ultimately the patient is authorizing me as their physician. There has been a lot of talk about empowering patients, which means giving authority to patients. We should talk about patient-powered care, which is different. "Power" means their choice. If our healthcare system is really going to be patient-centric, we need to begin there and reverseengineer how we can support patients in reaching that goal."

[–] Niteesh Choudhry, MD, Professor of Medicine, Harvard Medical School

9. MAKING PEOPLE AWARE OF SUPPORT PROGRAMS

Despite the proliferation of support programs and services available to patients, families, and caregivers, often provided by life sciences companies, many patients are not getting access to these programs.

Many times patients, caregivers, and physicians are not familiar with these programs, and physicians may have to initiate or change therapies without offering patients the opportunity of taking advantage of these support programs. This can lead to unnecessary costs when patients are not benefitting from the ability of manufacturers or patient advocacy organizations to cover some of the costs of therapies.

"It is unsettling to experience patients being put on costly cancer therapies without knowing that they could have reduced the financial burden by accessing some of these support programs."

– Michelle Santoro, Product Manager, Janssen Oncology

Educating healthcare providers as well as patients about the safety of receiving medications in their home is very important, since it can be hard for patients to stay on top of all the support services that exist across many therapeutic areas; therefore, patients rely on information and recommendations from their healthcare providers.

10. ADVANCING POLICY CHANGES

Opportunities for changes in policies avenues for expanding home-based care were discussed.

There was agreement that coverage and reimbursement is critically-important for expanding of home-based patient care. Today, there are strong limitations on which services can be covered by payers, Medicare, Medicaid, and private insurance.

There are also compliance issues because manufacturers can't offer services that are duplicate of what is offered from specialty pharmacies.

There are also challenges in terms of getting acceptance from the FDA that the home can be a safe setting for care delivery.

All players – providers, payers, patient advocacy groups, policymakers, and regulators – need to work together on breaking down the current barriers to expand opportunities for home-based healthcare.

> "We own a brand, so at the end of the day, we need to be an active participant. If the product is hard to get, it is not going to be prescribed. We have to actively manage that even if customers have high expectations and we have challenges navigating the field."

 Alexia Burnett Salinas, Group Product Director, Customer Solutions, Neuroscience, Johnson & Johnson "There is a reason these produces are developed. It's because it brings value to the patient. So, at the end of the day, if patients don't have a good experience getting the product, if the doctors have issues getting the patient on the product, the patient will not benefit from it. Therefore, it's our responsibility to make sure that patients have access to the products and that they have a good experience. It's not just about the drug. It's about the patient, about the person."

- Erica Stick, Patient Services Director, Rare Disease at Chiesi USA, Inc. "I wonder whether there could be a common ground with pooling of resources, a shared resource that provides true patient care while maintaining brand identity? We can't make this totally brandless, but maybe acknowledge that people may struggle with more than one thing and discoordinated care – even for one condition."

 Niteesh Choudhry, MD, Professor of Medicine, Harvard Medical School

11. THE ROLE OF THE LIFE SCIENCES INDUSTRY

Participants from the life sciences industry acknowledged that industry has to actively embrace home-based healthcare.

There was positive recognition of the pharmaceutical industry for providing broad support to patients being treated with the pharmaceutical brands helping patients get the best possible experience. However, the point was raised that there is a difference between support around the specific brand and whole-person care. In some cases, these two aspects may be slightly at odds with one another. When taking the perspective of a patient with polychronic conditions, there may be more than one therapeutic and more than one patient support system, potentially three, four or more. While everybody is trying to help the patient, the question becomes how to avoid chaos.

Avenues for advancing home-based care

The discussions during the roundtable pointed to several rich areas of opportunity that will help advance patient services and home-based healthcare to generate improved health outcomes.

The IQVIA Institute and IQVIA Patient Support & Nursing Services will explore opportunities for research projects and continued discussions with life sciences companies and other stakeholders to advance understanding and action focused on the following key topics:

- Determining the right patients to benefit from patient services in home-based healthcare: This will likely expand the relevant target patient segments beyond patients and caregivers in rare diseases to more common diseases where patients are affected by complex, specialty therapeutics or may have other barriers to getting access to therapy and achieving positive health outcomes.
- Infusing a strong focus on mental and behavioral health issues in patient services: Mental health and behavioral health dimensions need to be considered and integrated as part of patient services, research, and care beyond the focus on clinical conditions. More research is required to fully understand the role of mental health in the context of complex, chronic diseases and multidisease as well as the burden of families and caregivers.
- Building a connected infrastructure for collecting and curating data: Exploring opportunities for building a connected infrastructure for the collection, curation and dynamic flow of data from the homecare setting to providers will be critically-important to enhance the consistent quality of home-based care and services.

- Incorporating home-care services in clinical trial protocols: This could facilitate subsequent inclusion in the standard of care once a new drug is approved. This may motivate physicians to embrace home-care services more proactively when the plan includes patient therapies.
- Developing a standardized tool for measuring quality of life: A standardized tool for measuring quality of life will help assess the quality and outcomes of patient services and home-based healthcare. It will also enable benchmarking and critical reviews and validation of home-based therapeutic interventions. Furthermore, it will the enable the gradual expansion of the home as a connected care setting as part of a connected health eco-system.
- Moving beyond the brand: Life sciences companies should consider expanding their patient services beyond the brand to incorporate a whole-person approach. This would include sub-clinical dimensions around a condition, mental health and other needs of the patient, family, and caregivers.
- Educating healthcare professionals and other stakeholders about the benefits of home-care solutions: Healthcare professionals and other stakeholders should be provided with information and education about the benefits of home-based care as a driver of improved patient outcomes and more efficient and affordable care delivery.
- **Driving policy changes:** Policy changes should be considered and implemented across a broad range of areas, including improved reimbursement and coverage, legal and compliance barriers.
- Enhancing collaborations: Bringing diverse stakeholders together – across physicians, nurse educators, patient groups, life sciences companies, payers, policymakers, and regulators – in sustained collaborations and partnerships is required in order to advance the field of home-based healthcare in a sustainable manner.

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About the Institute

The IQVIA Institute for Human Data Science contributes to the advancement of human health globally through timely research, insightful analysis and scientific expertise applied to granular non-identified patient-level data.

Fulfilling an essential need within healthcare, the Institute delivers objective, relevant insights and research that accelerate understanding and innovation critical to sound decision making and improved human outcomes. With access to IQVIA's institutional knowledge, advanced analytics, technology and unparalleled data the Institute works in tandem with a broad set of healthcare stakeholders to drive a research agenda focused on Human Data Science including government agencies, academic institutions, the life sciences industry and payers.

Research Agenda

The research agenda for the Institute centers on 5 areas considered vital to contributing to the advancement of human health globally:

- Improving decision-making across health systems through the effective use of advanced analytics and methodologies applied to timely, relevant data.
- Addressing opportunities to improve clinical development productivity focused on innovative treatments that advance healthcare globally.
- Optimizing the performance of health systems by focusing on patient centricity, precision medicine and better understanding disease causes, treatment consequences and measures to improve quality and cost of healthcare delivered to patients.

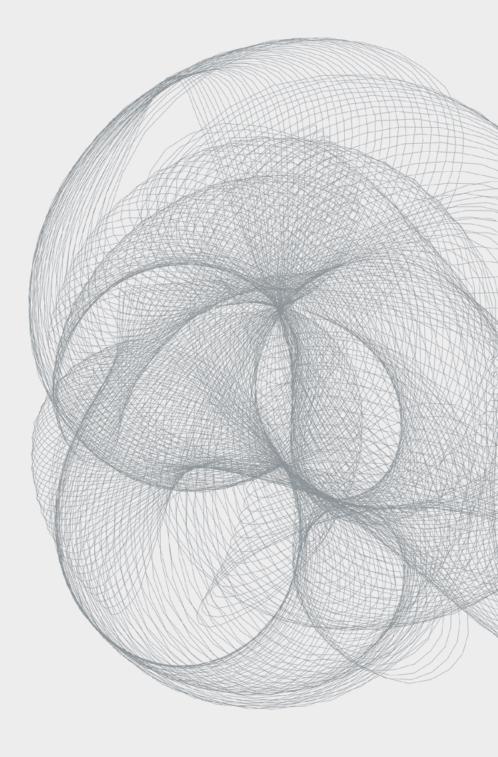
- Understanding the future role for biopharmaceuticals in human health, market dynamics, and implications for manufacturers, public and private payers, providers, patients, pharmacists and distributors.
- Researching the role of technology in health system products, processes and delivery systems and the business and policy systems that drive innovation.

Guiding Principles

The Institute operates from a set of guiding principles:

- Healthcare solutions of the future require fact based scientific evidence, expert analysis of information, technology, ingenuity and a focus on individuals.
- Rigorous analysis must be applied to vast amounts of timely, high quality and relevant data to provide value and move healthcare forward.
- Collaboration across all stakeholders in the public and private sectors is critical to advancing healthcare solutions.
- Insights gained from information and analysis should be made widely available to healthcare stakeholders.
- Protecting individual privacy is essential, so research will be based on the use of non-identified patient information and provider information will be aggregated.
- Information will be used responsibly to advance research, inform discourse, achieve better healthcare and improve the health of all people.

The IQVIA Institute for Human Data Science is committed to using human data science to provide timely, fact-based perspectives on the dynamics of health systems and human health around the world. The cover artwork is a visual representation of this mission.



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