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working world

Harnessing the power of data: can reality catch up with ambition?

Insights and learnings from the use of data and
analytics to re-imagine the health and wellbeing of
citizens across the globe



The better the question.
The better the answer.
The better the world works.

Imperial College
London

INSTITUTE OF GLOBAL
HEALTH INNOVATION

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Key enablers for harnessing the
power of data and analytics

Foreword

Data and analytics have transformed every aspect of our lives. As users, we expect efficiency and effectiveness from the services we receive. As staff, we demand solutions to the pain points of our day-to-day jobs. And as leaders, we are finding that unlocking the power of data can lead to improved quality and cost-efficiency. The health and human services (HHS) sector is no exception to this. Arguably, it is the sector in which these changes matter the most.

While there is widespread acknowledgment that HHS have lagged other industries, the COVID-19 pandemic has put the use of data and analytics in the sector's spotlight. Out of necessity, organizations have leapfrogged in the use of data and analytics for service provision, as we show in our report [Embracing digital: is COVID-19 the catalyst for lasting change?](#)

Never has it been more important for HHS organizations to share their experiences and learnings in this area. This is key to ensuring that data and analytics can support service provision during this time of crisis, and that we build infrastructure and capabilities for the future.

Over the past year, a team from Imperial College London's Institute of Global Health Innovation (IGHI) has been investigating the benefits, challenges, risks and enablers that HHS organizations encounter in implementing analytics and data solutions. This report includes insights drawn from secondary research, expert interviews and in-depth case studies across the world.

We find inspiring examples of success at different levels of digital maturity, highlighting that there are gains to be obtained from leveraging data and analytics at every stage:

- Staff who can see a holistic picture of the communities they serve and can intervene earlier to keep families together.
- Cancer patients who are empowered to report their symptoms to their clinicians in a structured and validated way, leading to improved ownership of their care pathway and better relationships with their doctors.
- A local authority that can identify those that are most vulnerable to COVID-19 in the community and reach out to them proactively to offer support.

These are just some examples of the benefits that HHS organizations are deriving from harnessing the power of data and analytics. The value that these solutions bring to the citizens they serve are immeasurable.

Our findings provide actionable recommendations for HHS organizations across the world on how to ultimately leverage the power of data and analytics to improve the lives of the communities they serve. It is our hope that HHS organizations will be inspired by those who are further along in the journey, learn from the challenges they have faced and use these valuable insights to harness the power of data.



George Atalla
**Global Government and
Infrastructure Leader**

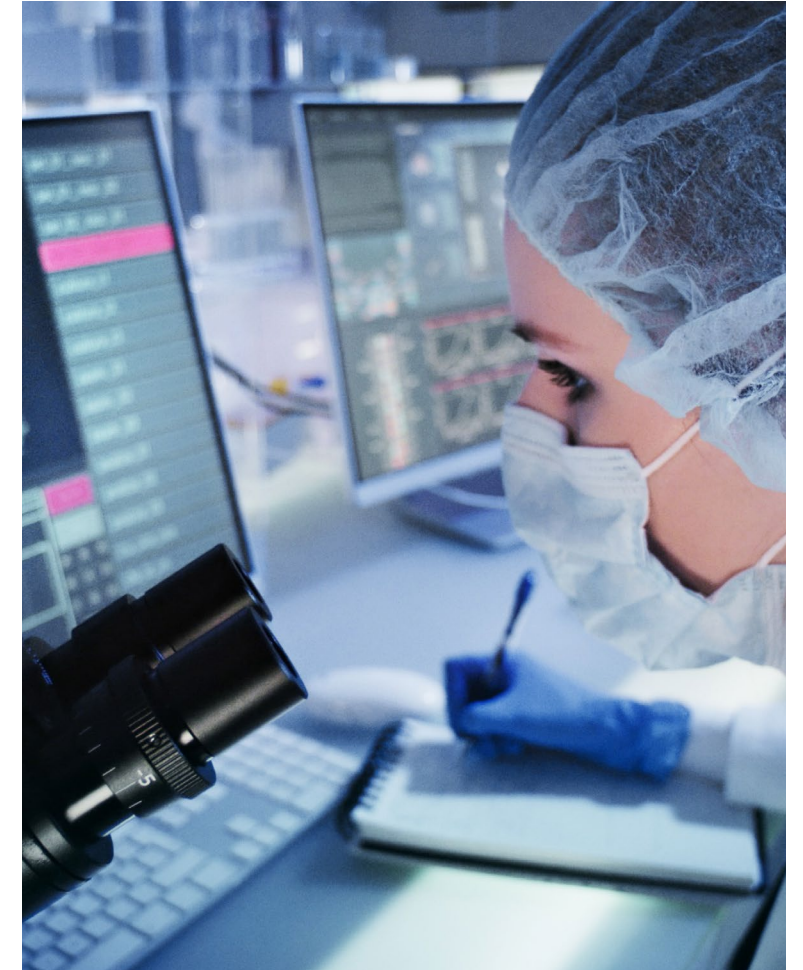
Definitions

Health and human services

This report looks at organizations that provide health or human services, or both, across the world. In this report, health and human services (HHS) refers to social assistance programs that contribute to the welfare and well-being of communities. This includes “everything from health care and counseling services to food and shelter, offered through government and nonprofit agencies, and designed to contribute to the welfare and happiness of communities by delivering a broad range of help and support to individuals and families.”¹

Data and analytics

This report looks at the use of data and analytics in HHS organizations for the specific purpose of improving the health and well-being of citizens. This includes data that is gathered through the direct provision of services, as well as third-party data that may be relevant to the well-being of individuals or families. In this report, “analytics” refers to the analysis of this data for the purposes of informing decision-making and improving service provision.

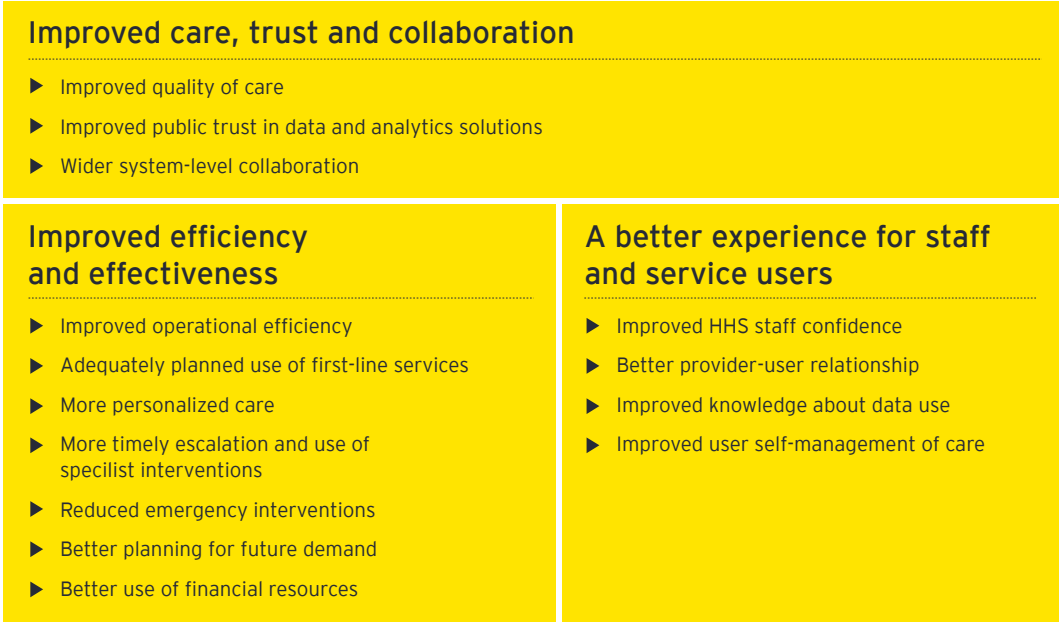


Executive summary

HHS organizations across the world are harnessing the power of data to improve the health and well-being of citizens. Nevertheless, there is a general sense that organizations can, and should, be doing more. Using findings from secondary research, 39 expert interviews and 5 organization case studies, this report identifies actionable opportunities to support organizations in their move from ambition to reality.

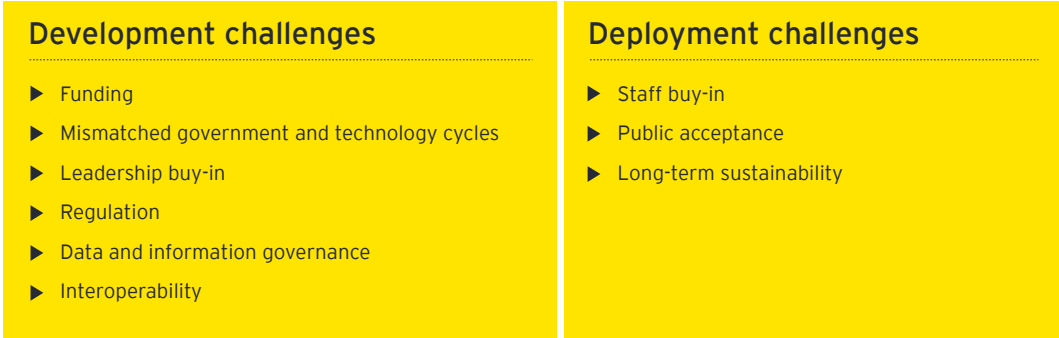
We find that the successful development and deployment of analytics solutions in HHS organizations can lead to **benefits**, including improved efficiency and effectiveness; improved user and staff experience; and, ultimately, improved care, trust and collaboration.

Figure 1: Benefits of data and analytics solutions in HHS



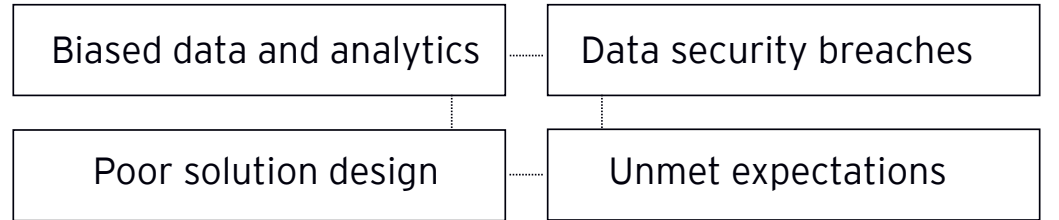
In the journey to realizing these benefits, HHS organizations face multiple **challenges**. They may be most acutely felt in the development or deployment phases, but it is important to note that they can all affect data and analytics projects at any stage.

Figure 2: Challenges faced by HHS in leveraging data and analytics



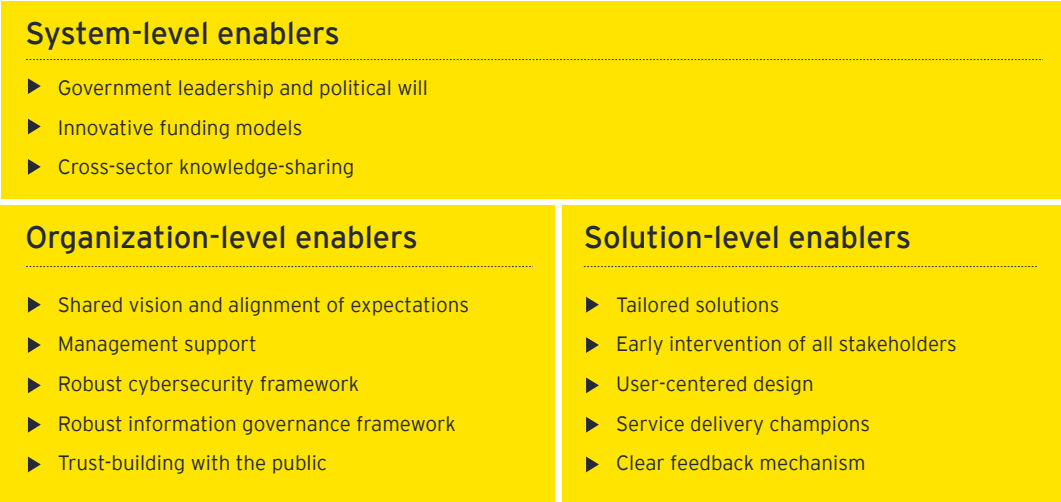
There are also important **risks** in using data and analytics in the provision of HHS services. The impact of these risks, if left unaddressed, can go as far as harming organizations and citizens.

Figure 3: Risks of using analytics solutions in HHS



HHS organizations that have already successfully implemented data and analytics solutions are an invaluable source of guidance on how to overcome challenges and minimize risks. Through interviews, case studies and secondary research, we have identified multiple demonstrated **enablers** for success. These can be classified as system-level, organization-level and solution-level enablers.

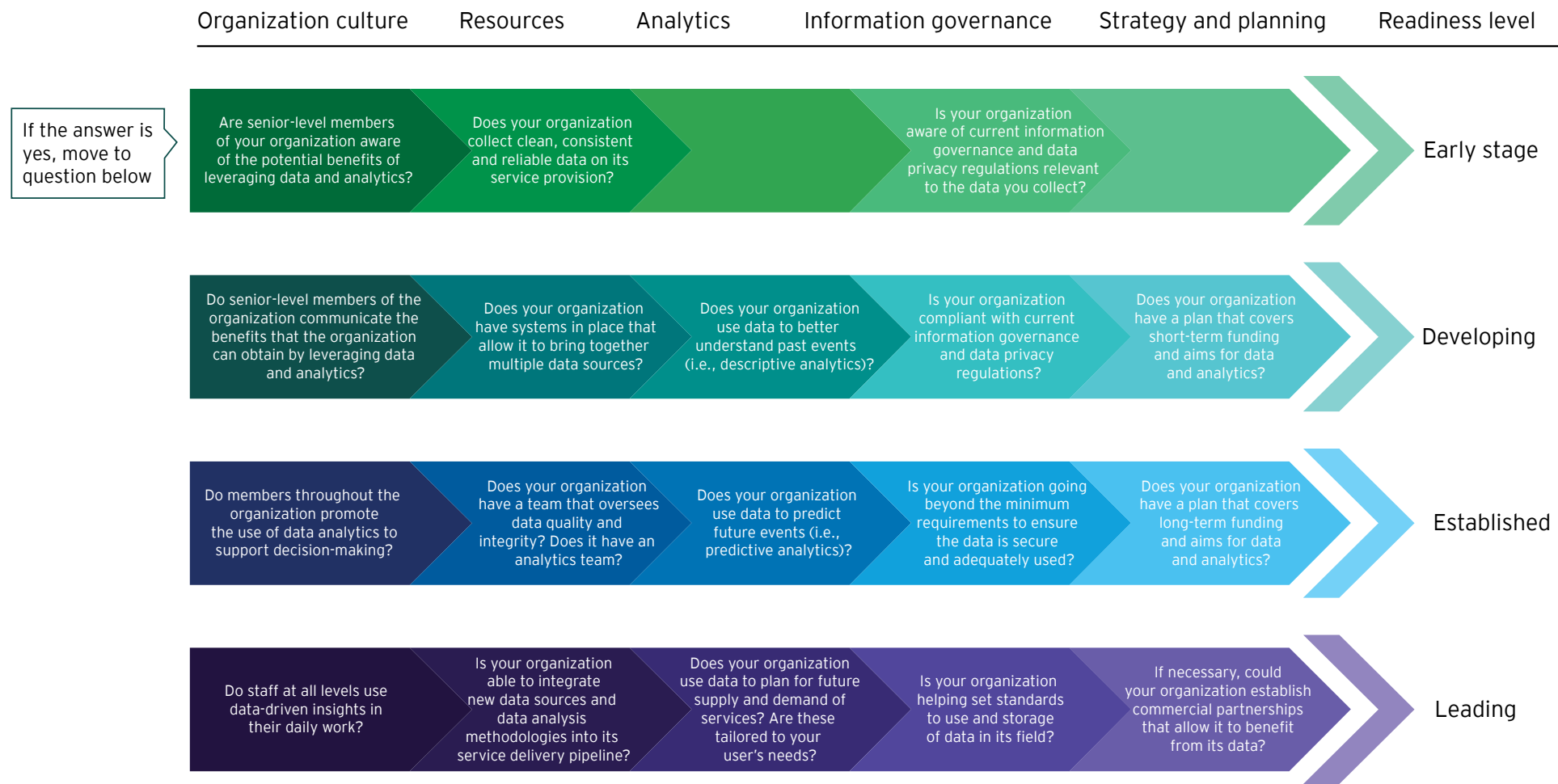
Figure 4: Key enablers of success in the use of analytics in HHS



Each HHS organization is unique in its needs, capabilities and readiness to harness the power of data and analytics. We propose a **diagnostic** that includes a list of questions that organizations can discuss internally and with potential analytics partners to assess their level of readiness for data and analytics (Figure 5) overleaf. These relate to organizational culture, resource availability, analytics capabilities, information governance, strategy and planning. Answers to these questions can help organizations determine their readiness level (early stage, developing, established or leading) and can support the development of a road map for success.



Figure 5: Diagnostic for assessing HHS readiness for data and analytics solutions



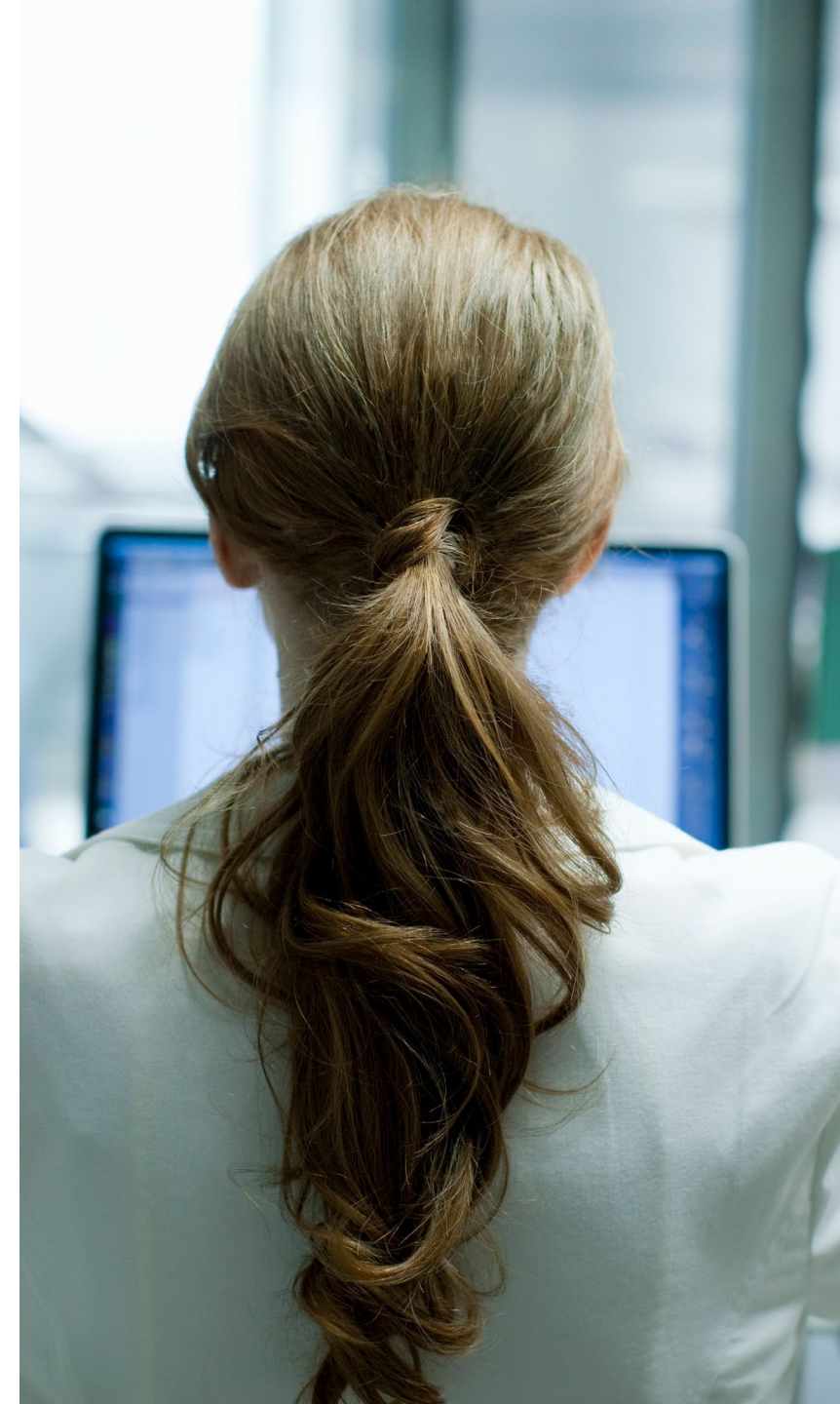
The **culture of the organization** can be a key enabler or challenge in transitioning toward a more data-driven future. The cultural shift will have to be driven “from the top” to be effective. An example of a leading organization in this area is one where staff at all levels use data-driven insights in their day-to-day work.

The level of complexity of the solution should match the **infrastructure and resources** available to support it. Organizations in early stages will need to begin by developing the IT infrastructure and resources to collect clean, consistent and reliable data on their service provision. An example of a leading organization in this area is one that can embed analytics-driven insights into its service delivery pipeline.

Together with the available infrastructure and resources, **analytics** capabilities will determine what use cases are possible in the short term and what solutions will require further development work. An example of a leading organization in this area is one that can leverage analytics to plan for future supply and demand of services and can personalize them to ensure they are targeted to its population’s needs.

Projects that require increasingly sensitive data to be collected and linked should be matched by an increasingly robust information governance plan. As the organization’s capabilities develop, it will want to ensure it is meeting all data management requirements and, ideally, going beyond minimum requirements. An example of a leading organization in this area is one that is helping set the standards of **information governance** in the sector.

The use of data and analytics should be part of a broader organization **strategy**, with a clear road map of needs and milestones to achieve. In the early stages, organizations will need to start by developing a data and analytics strategy. An example of a leading organization in this area is one that can establish commercial partnerships with the wider ecosystem (e.g., private businesses, entrepreneurs and start-ups) to secure cutting-edge innovation for the benefit of the population it serves. While commercial partnerships are by no means the ultimate strategic aim for leading HHS organizations, the readiness to establish them is more common in leading organizations than in those at earlier stages.



Introduction

Due to COVID-19, HHS have had to quickly adapt and increase capacity, sometimes over days or weeks. While governments and organizations have used emergency funding to adapt to the immediate crisis, the long-term economic impact of the pandemic means that organizations will have to become ever more nimble and creative to “do more with less.” More importantly, they will need to be prepared for an increased demand for services, given the long-term impact the pandemic will have on people’s health and vulnerability. Data and analytics solutions offer the opportunity to achieve this through improved efficiency and effectiveness in the delivery of care.

According to Bernardo Mariano, CIO of the WHO, “The question is not if, but when. There should be no option to not go digital.” This is reflected in WHO’s Global Strategy on Digital Health 2020-2025: “The vision of the global strategy is to improve health for everyone, everywhere by accelerating the development and adoption of appropriate, accessible, affordable, scalable and sustainable person-centric digital health solutions to prevent, detect and respond to epidemics and pandemics, developing infrastructure and applications that enable countries to use health data to promote health and well-being, and to achieve the health-related Sustainable Development Goals and the triple billion targets of WHO’s Thirteenth General Programme of Work, 2019-2023.”²

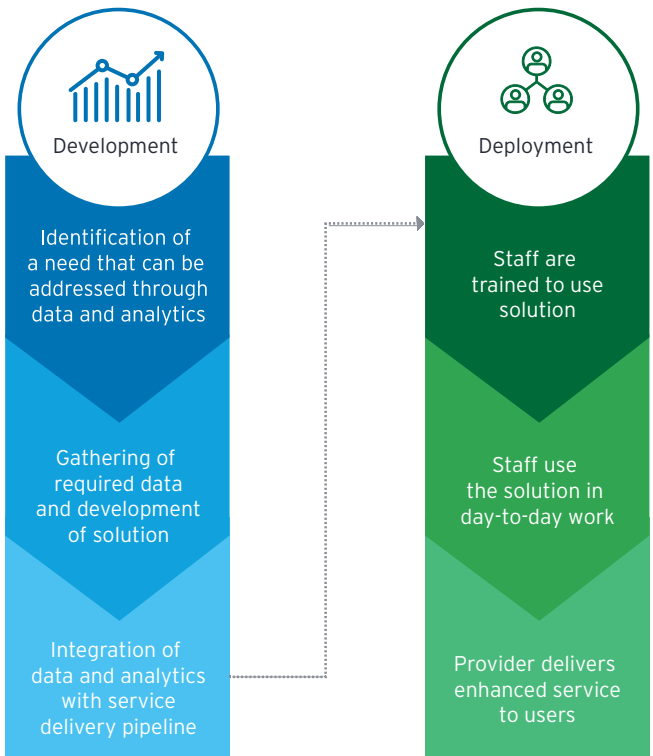


While some digital solutions have been widely adopted, such as telehealth and electronic medical records (EMRs), there is large variation in the scale at which data and analytics are used across HHS. The sensitivity of HHS data and severe service demand pressures are contributing factors to this. A multi-country survey (conducted as part of our report [Embracing digital: is COVID-19 the catalyst for lasting change?](#)) found that the uptake of digital technologies and data solutions doubled during the pandemic. Nevertheless, mental health services reported lower uptake of solutions compared with physical health or social services before and after the pandemic.

Social services generally lag their health counterparts in the adoption of data and analytics solutions, but they are quickly catching up. According to the Social Care Institute for Excellence and the British Association of Social Workers (BASW), “Social workers require good digital skills and capabilities to support their complex role. A wide range of stakeholders – from practitioners and people who use services, to tech developers and educators – have a role to play in supporting the development of digital capabilities.”³

In this report, we draw on insights from secondary research, expert interviews and case studies from organizations across the world that are successfully harnessing data to improve the lives of the citizens they serve. We use a general, inexhaustive model (Figure 6) to position these insights and learnings along the development and deployment path of successful analytical solutions in HHS organizations.

Figure 5: Diagnostic for assessing HHS readiness for data and analytics solutions



In the first chapter of this report, we explore the **benefits** of using data and analytics in HHS. In the second chapter, we discuss the **challenges** faced by HHS organizations as they follow this journey. In the third chapter, we raise a word of caution and discuss the **risks** that organizations should consider. In the fourth chapter, we discuss the key **enablers** that successful organizations have used to harness the power of data and successfully embed analytics into their service delivery. And in the final chapter, we provide a **diagnostic** for HHS organizations to assess their readiness for data and analytics solutions based on their digital maturity.

Case studies at a glance

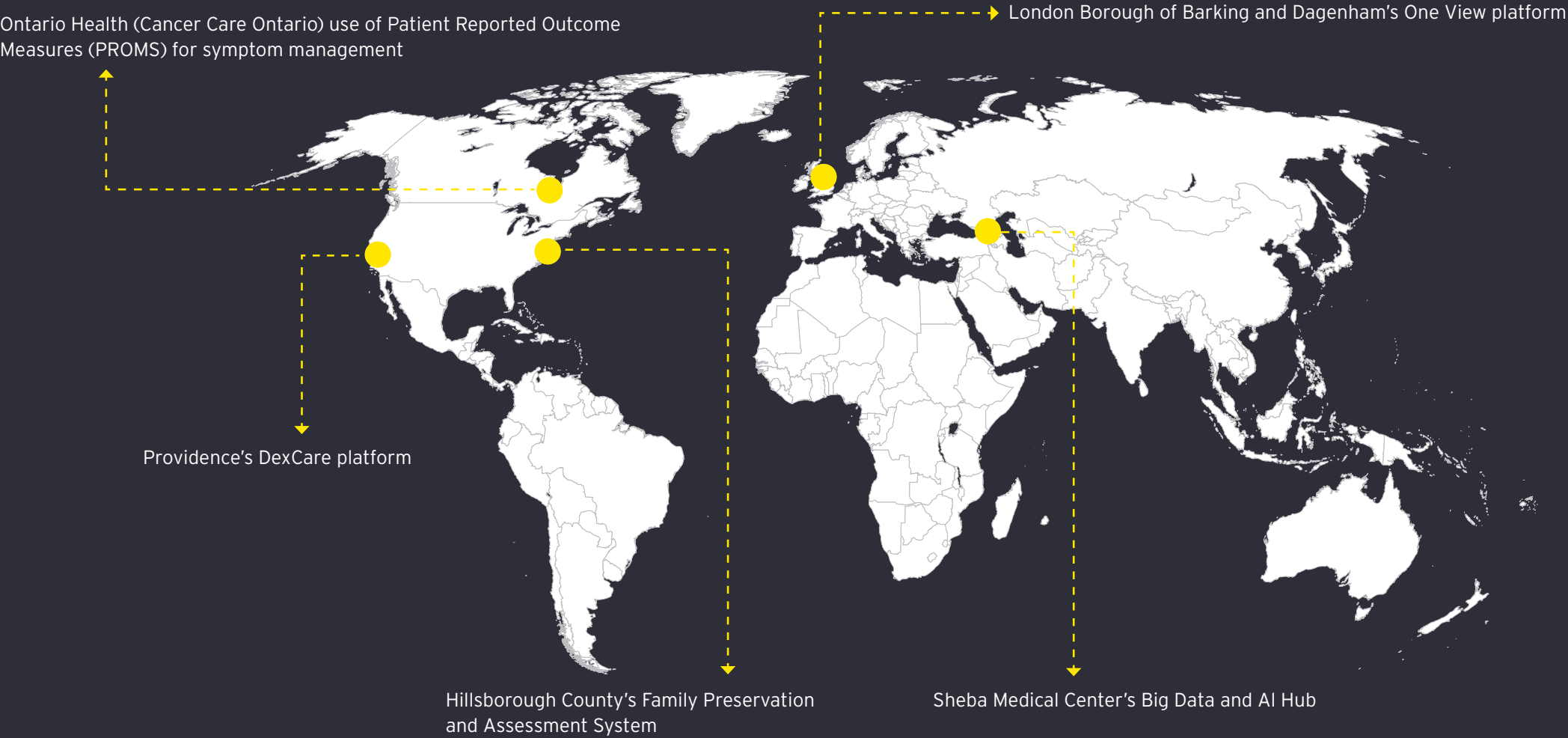
This report draws on the experiences of five organizations from across the world that are leveraging data and analytics to improve the services they provide and the well-being of their citizens (Figure 7) overleaf. This group of organizations is purposefully diverse: they are spread across the globe, are at different levels of digital maturity, have different ownership and organizational models, and involve different use cases. This has allowed for the extraction of lessons learned that are universally applicable to HHS organizations.

Summaries of the case studies are provided in this section.

Full case study reports can be found [here](#).



Figure 7: Case studies included in this report



Use of Patient Reported Outcome Measures (PROMs) for symptom management Ontario Health (Cancer Care Ontario)

Summary

Ontario Health (Cancer Care Ontario) is the principal cancer advisor to Ontario's government. Its mission is to equip health professionals, organizations and policy-makers with the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality patient care. Since 2007, it has been collecting PROMs data to encourage conversations between clinicians and patients about symptoms. With the largest PROMs dataset in Canada (as of January 2021), Ontario Health (Cancer Care Ontario) is using analytics to inform care improvements on a patient and population level. The data is also used to inform policy and planning at the system level, including development of patient and clinician symptom management resources patient education and self-management tools.

Interviewees

- ▶ Colleen Fox, Director, Person-Centered Care
- ▶ Narges Nazeri Rad, Team Lead & Methodologist
- ▶ Joanne MacPhail, Patient and Family Advisors representative
- ▶ Christine Peters, Regional Oncology Lead for Person-Centered Care
- ▶ Richard Smith, Director, Product Management
- ▶ Natalie Coburn, Clinical Lead for Patient Reported Outcomes and Symptom Management



Family Preservation and Assessment System Hillsborough County, Florida

Summary

Hillsborough County's Family Preservation and Assessment System is a county-wide data-sharing platform in the children services sector. The purpose of the Family Preservation and Assessment System is to enable the unification of multiple sources of data regarding families with a child at risk of being abused or neglected, or a child in care. Hillsborough County, in collaboration with EY, has designed this tool to help realize the vision of preservation of families through targeted early intervention and support. The tool has been deployed in the community since March 2021.

Interviewees

- Ramin Kouzehkanani, CIO, Hillsborough County
- Commissioner Sandra Murman, Hillsborough County
- Patrick Minzie, II, Director, Department of Children's Services, Hillsborough County
- Christopher Card, Chief of Community-Based Care, Eckerd Connects
- Heather Cazzola, Director of Diversion & Prevention, Eckerd Connects



One View

London Borough of Barking and Dagenham, London, UK

Summary

In 2019, the London Borough of Barking and Dagenham (LBBD) was the most deprived borough in London. LBBD Council has collaborated with EY and Xantura to create a master data management, analytics and predictive modeling platform called One View. This tool brings together historically disconnected datasets (child and family, adult, and homelessness services) to provide a single view of any resident or family they serve. It provides case workers with a comprehensive view of their families. It also uses modeling to flag to case workers when a family is at higher risk, which enables them to intervene earlier.

Interviewees

- Rhodri Rowlands, Head of Programmes for Community Solutions
- Katy Brown, Programmes and Strategy Officer
- Pye Nyunt, Head of Insight and Innovation
- Gill Wilson, Service Manager
- Charlesworth Benedict, Service Manager
- Jill Gallagher, Service Manager



DexCare and Providence Washington, US

Summary

An analytics solution called DexCare has been designed by Providence, a nonprofit health care provider and one of the largest health systems in the US, to provide a connected digital health care service for consumers. DexCare is a platform that allows Providence to optimize its capacity and service delivery by matching user demand and service availability from health care providers. This also enables the collection of data on how users interact with Providence so that frictionless and more effective services can be provided. Originally focused on retail care, DexCare's success has led to its use in other service lines across the health system.

Interviewees

- Sara Vaezy, Chief Digital Strategy and Business Development Officer
- Maryam Gholami, Group Vice President, Chief Products Officer at Digital Innovations, Providence
- Marcee Chmait, Executive Director of Digital Business Development, Providence
- Derek Streat, Entrepreneur-in-Residence and CEO of DexCare
- Sean O'Connor, Entrepreneur-in-Residence and CCO (Chief Commercialization Officer)
- David McAughan, Executive Director of Express Care and Line of Business Leader, Providence
- Amanda Ashley, Director of Operations of Express Care



Big Data and Artificial Intelligence Hub Sheba Medical Center, Ramat Gan, Israel

Summary

Sheba Medical Center's Big Data and Artificial Intelligence (AI) Hub is the largest health innovation center in Israel. The Big Data and AI Hub is one of six hubs within Sheba's innovation program called ARC (Accelerate, Redesign and Collaborate). ARC is a global ecosystem that has started from Sheba and expanded to include more than 100 members including other leading hospitals around the world, industry partners, academic partners and startups. The purpose of this hub, which was established in 2017, is to provide a unified source of medical data and analytics for Sheba to streamline processes, inform decision-making and improve care quality. Sheba has developed a data lake that brings together historically disconnected datasets from across the hospital, which enables the creation of solutions to some of the clinicians' most pressing analytics needs. The hub has a model of partnership with start-ups and commercial organizations that allows their data and clinical expertise to be combined with cutting-edge technological capabilities. This has resulted in financial sustainability for the hub and access to innovative data-driven solutions for the hospital.

Interviewees

- Nathalie Bloch, Former Head of the Big Data and AI Hub
- Jeanette Tuval, Chief Operating Officer of the Hub
- Robert Klempfner, Clinical and Scientific Director of the Hub
- Sigal Sina, Chief Data Scientist
- Nisim Rahman, Data Architect and Team Lead
- Avi (Abraham) Tsur, OBGYN expert and Director of the Women's Health Innovation



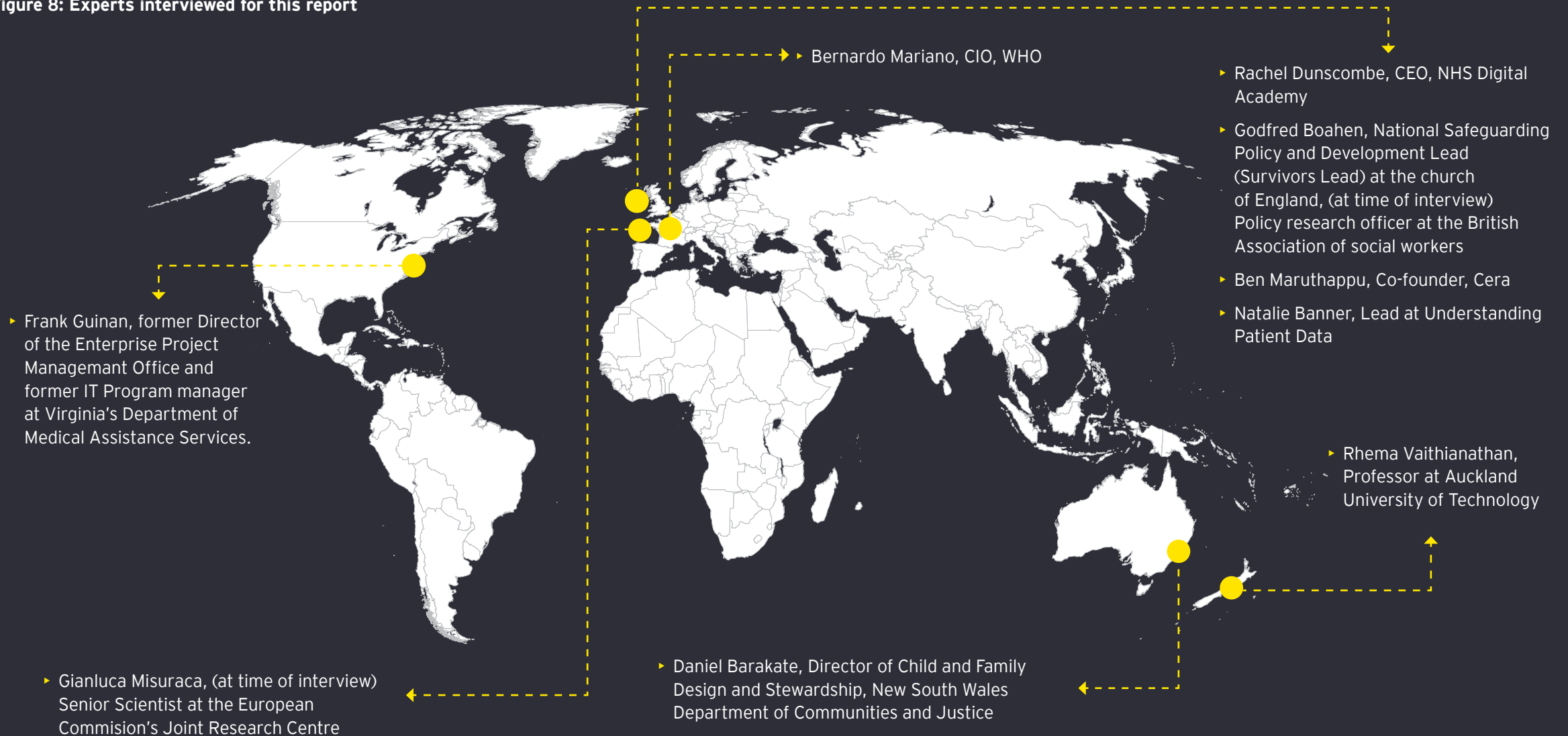
Experts at a glance

This report draws on the thoughts and knowledge of nine experts from across the globe (Figure 8 overleaf). Their expertise spans a variety of sectors, services and disciplines:

- ▶ It includes experts in health, social care, and child and family care.
- ▶ It covers global, regional, national and state-level organizations.
- ▶ It spans a variety of key stakeholder groups, including IT program management, third-sector digital solutions, patient advocacy groups and academia.



Figure 8: Experts interviewed for this report



Bernardo Mariano

Bernardo Mariano is the CIO of the World Health Organization (WHO) and is responsible for coordinating the organization's digital health vision and strategy. Prior to joining WHO, he was the Senior Regional Advisor to the Director General at the International Organization for Migration (IOM). He also held the position of Regional Director for the Southern African Office, CIO and Director of Information Technology and Communications, all at the IOM. Bernardo was responsible for the development of technology-driven solutions that improved IOM's field operations management.

Rachel Dunscombe

Rachel Dunscombe is the CEO of the NHS Digital Academy, a virtual organization set up to lead the development of a new generation of digital leaders who can drive the information and technology transformation of the NHS. Commissioned by the NHS, it is delivered by a partnership of Imperial College London, the University of Edinburgh and Harvard Medical School. Rachel was previously the Director of Digital at Salford Royal NHS Foundation Trust and provided IT leadership for Pennine Acute Hospitals NHS Trust.

Godfred Boahen

Godfred Boahen is the National Safeguarding Policy and Development Lead (Survivors Lead) at the Church of England. He is also an Honorary Research Fellow at the University of Birmingham. Prior to joining the Church of England, Godfred Boahen was the Policy, Research and Practice Improvement Lead at the British Association of Social Workers, where he led the development of the Digital Capabilities Statement for Social Workers. Godfred holds a Ph.D. in sociology and social work.

Ben Maruthappu

Ben Maruthappu is the co-founder of Cera, a home health care company focused on elderly care in England. He also co-founded the NHS Innovation Accelerator, a program that seeks to accelerate the adoption of new health care technologies in the NHS. Ben is a physician, entrepreneur, academic researcher and health policy specialist.

Rhema Vaithianathan

Rhema Vaithianathan is a Professor of Health Economics and Director of the Centre for Social Data Analytics (CSDA), a translational research center located in the School of Social Sciences and Public Policy at Auckland University of Technology (New Zealand). She is also a Professor of Social Data Analytics at the Institute for Social Science Research at the University of Queensland (Australia), where she leads a second CSDA node. Rhema is recognized internationally for her work in using data science for social good, and the implementation of machine learning tools in high-stakes government systems such as child protection.

Frank Guinan

Frank Guinan is the former Director of the Enterprise Project Management Office for the Commonwealth of Virginia's Department of Medical Assistance Services. Frank oversaw a range of health care information technology responsibilities, including program management, project management, vendor management, procurement management and client management.

Gianluca Misuraca

Gianluca Misuraca is an independent researcher and policy advisor who works with academic institutions, think-tanks and consultancies. He was formerly a Senior Scientist at the European Commission's Joint Research Centre, where he led research in digital governance and social innovation. Gianluca also coordinated research in digital government transformation as part of the Digital Economy Unit of the Directorate for Growth & Innovation.

Natalie Banner

Natalie Banner is the Lead for Understanding Patient Data (UPD), an initiative hosted at the Wellcome Trust to support conversations about patient data use in care and research. Natalie formerly led Wellcome's policy work on General Data Protection Regulation and data protection, seeking to ensure UK legislation and regulation create a supportive, trustworthy environment for health research using patient and health-related data.

Daniel Barakate

Daniel Barakate is the Director of Child and Family Design and Stewardship at the New South Wales Department of Family and Community Services (FACS), Australia. He has worked in frontline health, disability and child protection, in policy development and operational management, as well as program leadership roles. He leads significant evidence-informed program and policy design initiatives at FACS. Daniel has a passion for project, program and change management and for facilitating meaningful change that improves outcomes for the children, young people and families of New South Wales.

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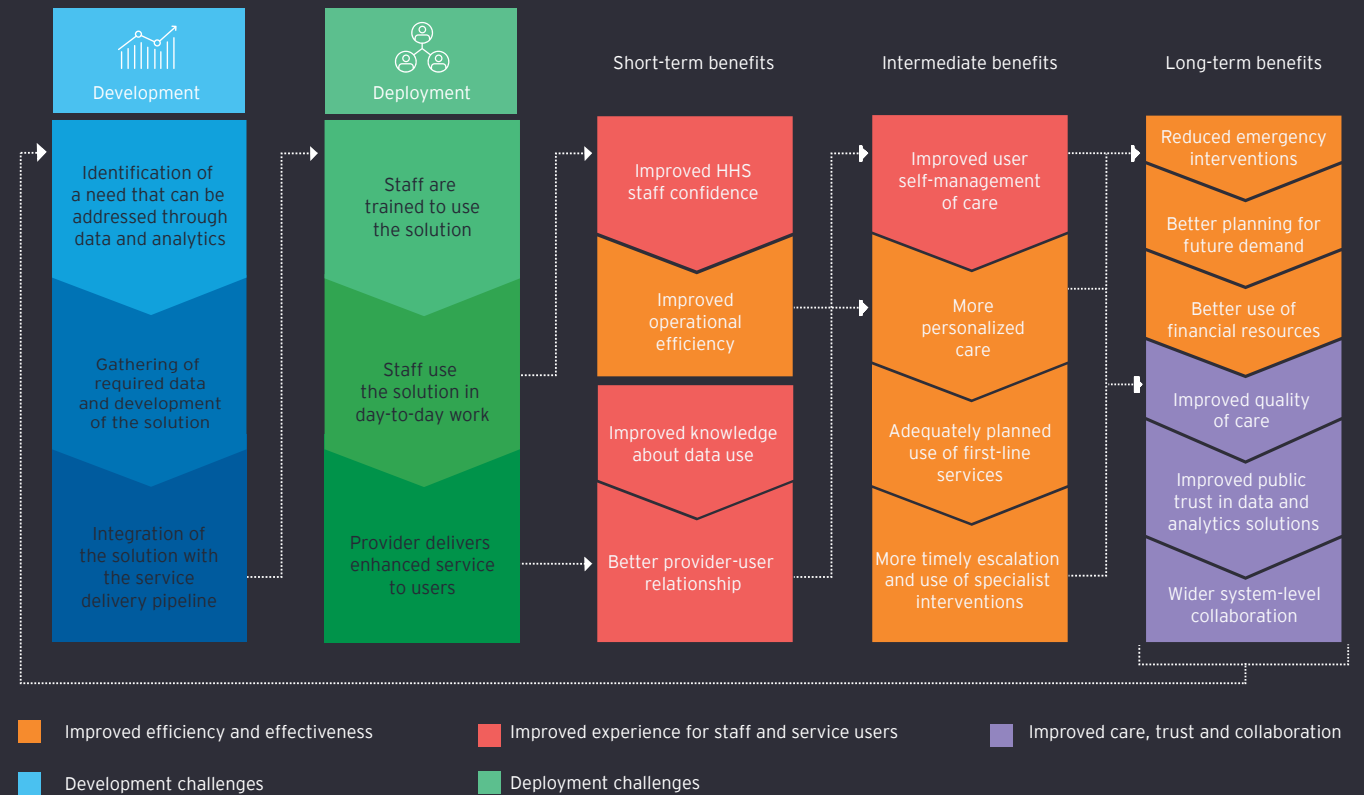
Benefits of data and analytics in HHS

Parker et al.⁴ proposed a model to look at the short-term, intermediate and long-term benefits of using electronic, mobile and telehealth tools for vulnerable patients with chronic disease. We propose a generalized, technology-agnostic model of the benefits that can be achieved after developing and deploying data and analytics solutions in HHS (Figure 9). We build on Parker et al.'s model in the following ways:

- We expand its applicability to cover data and analytics solutions across HHS.
- We consider public trust as a fundamental benefit of successfully implemented solutions and an enabler to secure the development of new analytics solutions in the future.

Figure 9 presents these benefits in a linear sequence for illustrative purposes, but the succession of these may vary across organizations. In general, the short-term, intermediate and long-term benefits identified can broadly be grouped into three categories: a more efficient and effective system; an improved experience for staff and service users; and improved care, trust and collaboration.

Figure 9: Short-term, intermediate and long-term benefits of the implementation of data and analytics solutions in HHS (adapted from Parker et al.⁴)



1. Improved efficiency and effectiveness

Data and analytics can allow HHS providers to improve the efficiency and effectiveness of service provision. Demonstrated benefits include **improved operational efficiency, adequately planned use of first-line services, more personalized care, more timely escalation and use of specialist interventions, reduced emergency interventions, better planning for future demand** and, ultimately, **better use of financial resources**.

1.1 Improved operational efficiency

The wealth of data collected from HHS users can have a significant impact on how services are delivered and how people access them. Currently, different services may hold different data points for a single person or family, leading to redundancies and inefficiencies around data collection.⁵ Adult social services staff from LBBB in the UK said that this can also be frustrating. “It’s time-wasting and stressful for residents to have to keep telling their story every now and again. People expect us to be more efficient than that. We should be able to have information from one side and share it with the other side of the service,” reported Charlesworth Benedict, Service Manager, LBBB.

An integrated database that allows HHS providers to have a single view of the population they serve may lead to more accurate and timely interventions, increasing staff productivity. It may provide crucial health information to a social worker, or relevant child welfare information to an accident and emergency (A&E) department. Having an integrated platform across different services and users can decrease data redundancies and

make the data more accessible to improve the service in the long term.⁶ For example, the implementation of ‘EMRs’ can streamline processes of information access, enable better decision-making and increase service effectiveness, ultimately leading to improved clinical outcomes.⁷ As such, the use of EHRs has been linked to a 52% reduction in adverse drug events and a reduction of the number of unnecessary laboratory tests for patients.⁸

1.2 Adequately planned use of first-line services

HHS organizations are leveraging online applications that allow them to organize and coordinate the delivery of care more efficiently.⁹ This has been especially important during the COVID-19 pandemic. Our report [Embracing digital: is COVID-19 the catalyst for lasting change?](#) found that phone and video consultations have seen the greatest uptake of all digital tools. Survey respondents reported that, as of September 2020, phone consultations were being offered by 81% of HHS organizations (compared with 39% before the pandemic) and video consultations were available from 71% of organizations (compared with 22% before the pandemic).

Prior to the pandemic, real-time data was already being used to increase efficiency in the delivery of services. For example, East Kent Hospitals in the UK provides real-time A&E waiting times for different hospitals. Patients can therefore make more informed decisions about the hospital to attend based on distance and waiting times.¹⁰ This helps patients receive care faster and allows hospitals to distribute the pressure of the service more evenly.

Many organizations have repurposed their existing solutions to cope with increased demand due to the COVID-19 pandemic. This has allowed Providence in Washington, US, to cope with an exponential increase in demand for virtual consultations in its retail clinics in a matter of weeks. At the height of the pandemic, the vast majority of its retail consultations were virtual, particularly in areas where physical locations were shut down due to COVID-19. The expectation is that, post-COVID-19, virtual retail consultations will settle at 20%-30%, according to Derek Streat, Entrepreneur-in-Residence and CEO of DexCare, Providence. Similarly, LBBB has leveraged its existing platform, One View, to provide staff with relevant information to prioritize reaching out to the most vulnerable members of the community during the pandemic. Both examples are described in detail in our dedicated case studies.

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It’s time-wasting and stressful for residents to have to keep telling their story every now and again. People expect us to be more efficient than that.

Charlesworth Benedict
Service Manager, LBBB

1.3 More personalized care

Service user data can be leveraged to reassess care pathways and create newer, personalized forms of care. In New South Wales, Australia, FACS has worked to develop personalized support packages. These are provided to families based on regular assessments of the child's needs.¹¹

By integrating demographic, personal, medication and EMRs, machine learning algorithms can create dynamic models by which people can be stratified depending on their risk of developing a disease or condition. By better identifying people at risk, resources can be better allocated and more tailored support could be provided.¹²

At Sheba Medical Center (Sheba) in Ramat Gan, Israel, predictive analytics models have been developed to understand which patients are at a higher risk of developing anastomotic leaks following a colostomy. Identifying these patients before the surgery will allow clinicians to have discussions with the family about potential risks and ultimately make a more informed decision about the best care pathway for the patient, according to Nathalie Bloch, Former Big Data and AI Hub Lead at Sheba.

1.4 More timely escalation and use of specialist interventions

Advanced analytics are helping frontline HHS staff intervene at the right time. Digital whiteboard systems have been designed to help A&E departments keep track of patients' traffic for the UK's National Health Service (NHS). Being able to view the patients' waiting time in real time alongside other relevant clinical data has allowed nurses to assess which patients need to be seen first. This helps health care providers meet their targets while providing efficient care to citizens.¹³

It also makes patients feel cared for. Cancer centers in Ontario collect PROMs ahead of outpatient appointments. These can be filled out at kiosks at the center itself. Joanne MacPhail is a Patient and Family Advisor representative (PFA) for Ontario Health (Cancer Care Ontario), and also a survivor of cancer. Joanne recounted how, one day when she was feeling particularly bad, she flagged this in the questionnaire: "I answered 9 across the board - the highest score you can give is a 10, which is the worst possible situation for you. Due to entering this high score, my oncologist and nurse promptly addressed my concerns and got me some help for the extreme pain I was in at the time."



1.5 Reduced emergency interventions

Across the globe, social service organizations are aiming to shift from reactive to proactive, preventative interventions. LBBD has implemented a system that brings multiple data sources together and flags potential families at risk of homelessness. Similarly, Hillsborough County in Florida, US, is developing a system that will allow them to bring together traditionally siloed datasets to more quickly identify children at risk and, by intervening early, prevent children from having to be removed from their families.

1.6 Better planning for future demand

Predictive analytics can be used to strategically assign resources based on the expected demand services will face. The UK's NHS has implemented a Sickness Surveillance System that monitors trends to provide early signs of winter seasonal illnesses. This allows hospitals to have preplanned responses to changes in hospital admissions, rearrange wards or set up isolated areas for infectious patients in advance.¹⁴

Forecasting methods can be used to determine the effect of future extreme weather events on the health of the population and on HHS infrastructure.¹⁵ They can also be used to determine how a demographic change, such as an aging population, will affect the use of services in the future.¹⁶ Being able to account for changes in the longer term can help HHS organizations prepare their workforce and identify new digital technologies that can be put in place to ensure the quality of the services is not affected.

1.7 Better use of financial resources

Implementing data and analytics solutions can require a significant upfront investment. Nevertheless, there are long-term savings that can be realized from the more efficient use of resources.

Remote management of chronic conditions can lead to overall reduced health care costs. For example, remote management programs for diabetes have been shown to reduce costs by US\$88 per patient enrolled per month within the first year of implementation.¹⁷

Preventative social service interventions are widely acknowledged to be more cost-effective than reactive ones. In our case study, LBBD highlighted that preventing homelessness by supporting families at risk earlier can lead to increased council revenue (through tax collection) and lower council costs (by reducing the demand for temporary housing). “If people are unable to pay their bills, this has a knock-on effect, not only on the council but on the local economy. Doing the targeted work that allows us to turn their financial situation around has a massive impact. The biggest impact, of course, is preventing evictions, preventing homelessness. The cost to the council is phenomenal in this area. If we just prevent evictions, that alone is massive,” stated Gill Wilson, Service Manager, LBBD.

Hillsborough County has been supporting a multimillion-dollar system of foster care and temporary accommodation for children removed from their families. Through its Family Preservation and Assessment System, explored in detail in our case study section, the county expects to significantly reduce the cost of child services by preventing emergency situations in the home and, if needed, placing a removed child with family instead of county facilities.

As a nonprofit, Providence is acutely aware of the mantra “no margin, no mission.” At the global forefront of innovation in health care, the organization has leveraged data and analytics to ensure that it can meet patients’ expectations for care where they want it, when they want it. DexCare was born of this effort to make retail care more accessible to patients. Thanks to its success, it will be spun out as a stand-alone for-profit company in which Providence will have equity interest.

Sheba partners with start-ups and industry to ensure that its data and analytics solutions are financially sustainable. A paperless hospital since 2004, Sheba’s data and clinical expertise are attractive to industry partners who can provide the technical expertise and funding to develop cutting-edge analytics solutions.

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If people are unable to pay their bills, this has a knock-on effect, not only on the council but on the local economy. Doing the targeted work that allows us to turn their financial situation around has a massive impact. The biggest impact, of course, is preventing evictions, preventing homelessness. The cost to the council is phenomenal in this area. If we just prevent evictions, that alone is massive.

Gill Wilson

Service Manager, LBBD

2. A better experience for staff and service users

Data-driven solutions have the potential to improve the experience of service provision for both staff and service users. This can occur through improved HHS staff confidence, better provider-user relationship, improved user knowledge about data use, and improved user self-management of care.

2.1 Improved HHS staff confidence

Staff favor solutions that allow them to do their jobs better. A solution such as One View in LBBBD brings together different datasets that are relevant to a vulnerable individual's case. With a trusted, clean and up-to-date dataset that reflects all the interactions that a family has had with the system, the social worker can more confidently make decisions about care. "If anyone is like me, hang up your skepticism on the back of the door to begin with and accept the help, accept the challenge, go with it. If you have the right system, used in the right way, by the right people, it can only help you get the help that is needed to the people who need it the most, quicker," stated Jill Gallagher, Service Manager, LBBBD.

At Sheba, clinicians have realized the potential that analytics solutions have to improve the quality of care provided. While they are not analytics experts, they are comfortable working with the Big Data and AI Hub to develop analytics solutions and deploy them in their practice. This is a point of pride for both clinicians and technical experts at Sheba.

2.2 Better provider-user relationship

Efficiency gains from analytics solutions can lead to frontline staff having more time available to invest in relationships with the service users that need them the most. When the UK Government developed the lists of people most vulnerable to COVID-19 (known as shielding patients), LBBBD's One View tool was repurposed to identify who in the community should be prioritized during the crisis. The gratitude of the people who were contacted and the broader community was not only evident but was also a clear departure from the more strained relationship that the council and the community had had in the past. "Quite often, the council gets a lot of flak from what it hasn't done or what it isn't doing. For the first time, we've had some really positive feedback about the proactive calls we're making," stated Jill Gallagher.

Analytics-driven solutions can also help service providers identify users' preferred channels for service delivery. Providence's DexCare solution was born from its patients' need for quick, affordable care for nonurgent issues. This platform allows patients to book their preferred method of consultation (in person, video call or phone call). By integrating DexCare with the provider's EMR, the provider has all the information it needs about the patient prior to the consultation, meaning that the actual interaction time can be devoted exclusively to discussing the patient's needs. Providence interviewees stated that the success of DexCare is demonstrated by a customer satisfaction score of 94 (net promotor score), surpassing scores of nonhealth organizations with traditionally high satisfaction ratings such as Amazon and Netflix.

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If anyone is like me, hang up your skepticism on the back of the door to begin with and accept the help, accept the challenge, go with it. If you have the right system, used in the right way, by the right people, it can only help you get the help that is needed to the people who need it the most, quicker.

Jill Gallagher
Service Manager, LBBBD

2.3 Improved knowledge about data use

Data and analytics solutions are often viewed as only relevant to the HHS provider. Organizations develop these solutions, and the outcomes are only received by service users in the form of more streamlined care delivery, better access or improved quality of care. HHS providers are finding that not raising awareness with the public about how their data is used can be a missed opportunity. In Hillsborough County, some team members believe that the public could have been involved earlier in the development of the Family Preservation and Assessment System.

In the public sphere, there is understandable apprehension about the use of HHS data. The public will favor solutions that result in an improved service experience for them. For example, they may be asked to repeat something multiple times that may have been a traumatic experience. Solutions such as the Family Preservation and Assessment System in Hillsborough County, or One View in Barking and Dagenham, have the potential to reduce the need for this. Explaining the value of these solutions can lead to a better understanding by service users and the public of the need for data collection and analysis.

A better understanding by the public of how analytics are used to improve service delivery can increase user confidence in the methods and the organization's intent. Ontario Health (Cancer Care Ontario) has been using PROMs data since 2007 for symptom management, with patients and families playing an active role in shaping the program. They can see how the data is used by their providers to improve their care and this increases their engagement.

2.4 Improved user self-management of care

Personal health records (PHRs) have been proposed as the next iteration of medical records. The idea behind PHRs is to provide citizens with a more direct way of interacting and sharing their own health data,¹⁸ making them active agents of their health. A key difference between EMRs and PHRs is that the latter allow users to have ownership of their data and the ability to grant access to their data to other parties. PHRs can improve medication adherence and overall patient outcomes,¹⁹ as well as help patients by allowing them to track their progress, access up-to-date information about their health and feel reassured about care.¹⁸

Ontario Health (Cancer Care Ontario) PROMs program provides patients with guidance on how to self-manage certain symptoms once they have been reported in the online system. Patients can be more involved in their treatment by being an active part of the process. The use of mobile phones and SMS approaches, particularly those that implement two-way communication systems between care providers and patients, have been linked to benefits in HIV patients' psychosocial well-being, particularly in less developed countries.²⁰ They have also been linked to improved adherence to treatment for patients with chronic conditions.²¹

In recent years, there has been an increased interest in the use of medical-grade wearable devices and apps, thanks to their ability to passively collect data. This allows patients to better monitor their own care and reduces the burden of attending hospital visits to have measurements taken. As examples, these devices can record different health metrics related to asthma or patient progression during chemotherapy²² while being minimally invasive. Having this data collected in real time allows the patient to better understand and manage their condition.



3. Improved care, trust and collaboration

The benefits described previous sections illustrate how data and analytics can ultimately lead to improved care. HHS organizations that are able to successfully realize gains in operational efficiency, care effectiveness, and staff or user experience will be able to deliver higher-quality care to the citizens they serve, improving their community's well-being.

Successful data and analytics solutions offer the opportunity to raise awareness about their value with service users, patients and the public. When the use of analytics leads to tangible improvements in care, there is a higher likelihood that communities will trust increasingly innovative uses of data and analytics. This increased trust can open the way for a more inclusive discussion around co-development and prioritization of solutions.

In addition to the direct benefits of a given analytics solution, it is important to highlight the interplay between HHS sectors. Successful implementation of a new technology in social care can lead, for example, to people being more involved with their health and, subsequently, fewer hospital attendances. Similarly, more effective delivery of health care can lead to a reduced need for certain types of social care.²³ This highlights the importance of system-level awareness and co-development of solutions.

Bringing together stakeholders from the wider system (public sector, nonprofits, civil society, etc.) to co-develop analytics solutions sets a precedent for collaboration that may spill over into other areas of work. This has been the experience of Hillsborough County through the development of the

Family Preservation and Assessment System: the broad range of stakeholders that have come together for this original purpose are collaborating in additional areas as well. For example, Hillsborough County's Blue Ribbon Committee for Child Safety (BRCCS) brought together community partners in law enforcement, the judiciary, crisis centers, juvenile justice, education, child care, and other local child welfare and behavioral health service providers. The creation of this network of stakeholders has highlighted common goals and developed relationships that can lead to the further identification of new opportunities for data and analytics, as well as wider collaboration more generally.

Collaboration can also extend beyond HHS. The wealth of data in HHS, and the opportunities for impact, have attracted players from the start-up and big tech sectors to engage in partnerships that are mutually beneficial. LBBBD has partnered with Xantura, a technology start-up, to develop the One View platform. Similarly, Sheba established a model of partnership with commercial and tech firms to develop advanced analytics solutions with its medical data. At Providence, a significant portion of staff come from big tech backgrounds, and the organization's interdisciplinary teams have fostered an environment of creativity and innovation.



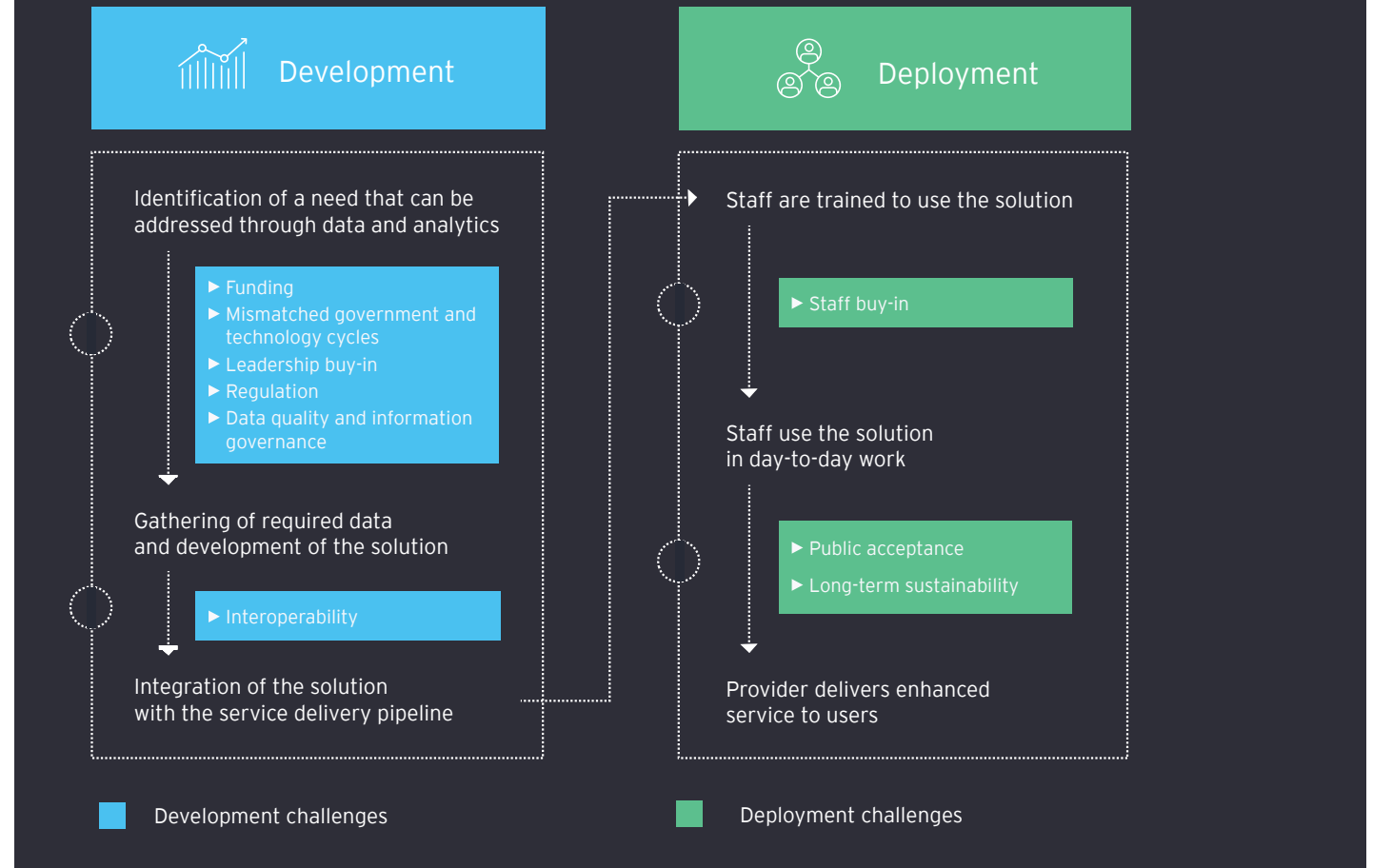
02

Challenges to leveraging data and analytics solutions in HHS

The opportunities offered by data and analytics solutions in HHS rely on effective development and deployment. This journey is complicated by challenges that are, in some instances, quite unique to the HHS sector. This chapter explores the most common challenges based on secondary research, expert interviews and our case study organizations' own experiences.

HHS organizations face development and deployment challenges, as shown in Figure 10. Each challenge is positioned at the phase of the project where we believe it is most relevant, but it is important to note that they can all affect data and analytics projects at any stage. Furthermore, they will continue to exist beyond deployment of solutions and into the future.

Figure 10: Overview of challenges faced by HHS organizations when trying to implement data and analytics solutions



1. Development challenges

1.1 Funding

Government funding for investments in data and analytics can help organizations kick-start analytics programs, but this funding may not always be readily available. In times of very stretched government budgets, the adoption of analytics solutions may be limited by HHS funding cycles and procurement processes.

Analytics solutions can require a substantial investment of funds and time, and it can be difficult for HHS organizations to justify these investments when immediate evidence of cost savings is lacking. Analytics solutions that allow for service expansions may actually uncover an unmet demand that leads to higher costs in the short and medium term.²⁴

Analytics and data science professionals are in high demand in the global job market. This means that HHS organizations are having to compete for talent against commercial companies with much higher budgets and resources. One option that organizations have is to train and redeploy existing staff, but this also requires funding that may not be readily available.

The lack of funding for large-scale transformation projects means that organizations often have to develop data and analytics solutions in a piecemeal fashion, which can lead to the interoperability challenges.

Even with government funding available to incentivize digital solutions, organizations have struggled. The procurement processes of these organizations are not always well suited for analytics solutions. Frank Guinan, former Director of the Enterprise Project Management Office at Virginia's

Department of Medical Assistance Services, US, highlighted that smaller companies that may be more cost-effective may not meet the necessary requirements for public organizations' procurement processes.

1.2. Mismatched government and technology cycles

The timescale of digital transformations can contrast with the traditional short-term planning and political cycles of HHS organizations that are often under financial pressure. Many solutions offer long-term financial benefit but require short-term investment. "People are so focused on managing year-within-year budgets, or even month-on-month, that making a big investment today, which may benefit you three, five years down the line, isn't necessarily something that you want to do," stated Ben Maruthappu, co-founder of a digital solution for elderly care.

Rhema Vaithianathan, Professor of Health Economics and Director of the Centre for Social Data Analytics at Auckland University of Technology, New Zealand, suggested that there is a lack of understanding of how long it takes governments to adopt digital solutions, which hinders investment: "New governments get elected in, look at what is there and say 'oh, that old government was planning on using an old technology, there's now something better,' so they try to implement that. Government adoption cycles and technology depreciation cycles are mismatched. When you have mismatched adoption cycles, this means that you're always adopting old technology and therefore you're always choosing not to adopt."

1.3. Leadership buy-in

The best analytics solutions will not get far without leadership buy-in. Because analytics solutions are relatively new in the HHS sector, investments in this area can still be perceived by leadership as too high risk. As Ben Maruthappu put it, "A chief executive who has been in post for 15 years may not necessarily have the experience of working with new technologies, let alone rolling them out, monitoring how successful they are, and tweaking and improving them." Executives may not see how analytics solutions fit within their strategic vision.^{24,25} Together with tight financial budgets, this can often lead to analytics talent and solutions being deprioritized.

There is also a risk that, due to misaligned expectations, leadership will become frustrated with solutions that are taking too long to deliver impact. "In Ontario, a [PROMs] pilot will often take two years, and I think that can be a frustration for the regional leads. We see this great opportunity but often it takes a two-year pilot, and of course you want to do it right, but I think finding that balance between being responsive to the needs of the system and perfecting the system can be tough. I think that can lead to some frustration from leadership," said Christine Peters, Regional Oncology Lead for Person-Centered Care in Ontario.

1.4 Regulation

Regulation often does not keep up with the pace of data and analytics innovation. Additionally, regulatory bodies may take a long time to approve technologies, and they may already seem outdated by the time approval is given.²⁶ These requirements can seem restrictive or misguided to organizations eager to implement digital solutions. Ben Maruthappu shared his experience: “When we got inspected a couple of years ago, the inspector said, ‘so where are the filing cabinets?’ We’re fully digital, so everything is more in computers and smartphones than in filing cabinets. We had to actually buy lots of filing cabinets, print out all the records and put them there to meet the inspector’s requirements.”

HHS organizations are having to lead the way to demonstrate the need for regulatory change. The advanced analytics that Sheba wanted to carry out required cloud computing, and regulation in Israel at the time did not allow for patient data to be processed in this environment. Through discussions with regulators, Sheba was able to convince regulators of the value of cloud computing, which led to its approval.

A second challenge comes from the lack of clarity. Unlike sectors such as pharma, regulatory pathways and evidence standards for digital and data-driven solutions in HHS are not clear. This lack of clarity raises an unprecedented risk in times when governments and HHS organizations are trying to act fast to cope with increased demand and save lives, such as during the COVID-19 pandemic. The fast-tracking of digital technologies raises the risk of allowing solutions to reach the market before they have been adequately trialed and tested. Similarly, the increased demand for research related to COVID-19 is putting unprecedented pressure on research ethics regulatory systems, which have created fast-track review guidance for COVID-19 studies.²⁷ Future research will be needed to assess the impact of these temporary measures on the quality of findings and solutions.



1.5. Data quality and information governance

HHS organizations face the challenge of ensuring that they have consistently reliable and high-quality data before they can benefit from analytical and digital solutions. This process begins with aligning on data collection and codification itself.

Rachel Dunscombe, CEO of the NHS Digital Academy, shared her experience in leading the digital transformation of an NHS Trust. She “vastly underestimated” the time it would take to revamp legacy data and align on how to codify data going forward: “Let’s take diabetes, for example. How are we going to codify it in an acute setting so it is meaningful to a nurse who sees it in the community? How are we going to map that to plain language, and how will we do this in an intuitive way without displaying 5,000 values?” Her view was shared by Frank Guinan: “We were trailblazers for transforming from a mainframe system that had its own databases to interfacing with multiple unique vendors and multiple applications. From a data standpoint, normalization is a much heavier lift than people expect.”

Once the HHS organization has aligned on data codification, it faces the challenge and cost of developing processes and workflows to aggregate, clean and convert information into reliable, consistent and analyzable datasets.²⁸ Sheba has been a paperless hospital since 2004, but has historically held data across dozens of disconnected information systems. Only in the past three to four years has it been able to build a data lake that brings historically disjointed datasets together.

Effective solutions may require linking data from organizations that have unique information governance and access policies. One of the biggest challenges in Hillsborough County’s journey has been achieving memorandums of understanding (MoUs) and data sharing agreements (DSAs) that allow it to link the three initial data sources that the Family Preservation and Assessment System will require. This process can take years of negotiation and is never fully completed. At LBBB, for example, this continues to be an issue. While One View has most of the information that staff need to support their families, there are still gaps that staff need to fill by contacting other colleagues and accessing other systems. These are largely due to information governance restrictions from the different data owners.

1.6. Interoperability

HHS organizations’ ability to benefit from analytics solutions has been limited by their lack of interoperability and standardization.

Having a system in which infrastructure, data and platforms can communicate with each other can greatly increase the efficiency of the system.²⁹ However, local HHS providers have, in many instances, developed technological solutions to their needs in a bespoke fashion. The lack of shared standards, both from a regulatory perspective and within digital solutions themselves, has led to inefficiencies and delays in achieving the benefits of data and analytics.

Godfred Boahen, former Policy, Research and Practice Improvement Lead at the British Association for Social Workers, suggested that this was a challenge: “There is a lack of standardization around the systems that social workers use. Ironically, the availability of choice can sometimes hinder people’s adoption because there’s always the search for the new, the search for something that can do things differently.” This was echoed by Ben Maruthappu, who stated, “Having consistency across the system, or better interoperability, is much harder when there is so much variation. Social care providers and health care providers are not told what standards to adhere to.”

The lack of standardization in digital solutions has led to varying levels of quality across providers and has limited the system-wide benefits of data and analytics. This is further exacerbated by the fact that some solution providers may in fact be incentivized to avoid further interoperability.³⁰

Bernardo Mariano mentioned that WHO is working to create a global interoperability standard and a “minimum electronic patient health record to ensure portability, which is not here today.” The lack of standardization has been quantified in the UK health care sector. Between April 2017 and April 2018, 77% of the UK’s NHS trusts used EHRs, while 23% relied on paper records. Of those that used EMRs, 79% used a single commercial system (one of 21 different ones in total), 10% used multiple systems and 11% used in-house systems. These systems are not interoperable, and data cannot easily be shared between them. This is particularly challenging for HHS organizations with users who attend multiple hospitals, so there is no single view of their entire medical history.³¹

2. Deployment challenges

2.1. Staff buy-in

Analytics transformations require a substantial commitment from frontline staff who may already be overburdened. HHS workers may feel like digital technologies detract from their interactions with their patients and add an extra layer of work to their day-to-day routine. The constant pressure of being connected to work by emails, pagers or messages from users, or having to learn and adapt their work routine to a new technology, can further increase these negative feelings.³² This will be particularly challenging where a clear vision from leadership is lacking³³ and where HHS workers feel that the digital technology is compromising their autonomy.³⁴

Godfred Boahen stated that: “There is a crisis of cynicism around digital technologies in the social services sector because the benefits are not articulated clearly.” The lack of transparency and communication can affect the willingness of frontline staff to adopt digital technologies. It may also lead to a mismatch of needs and expectations between local authorities, IT developers and frontline staff.³⁴

HHS organizations also face the challenge of varying levels of technological proficiency among staff.³⁵ In Bernardo Mariano’s view, this challenge comes from the fact that health care workers are not exposed to digital technologies enough during their training. It is therefore up to HHS organizations to ensure that all levels of staff are adequately trained and empowered to benefit from digital technologies in their day-to-day work.

2.2. Public acceptance

Crises such as the COVID-19 pandemic can lead to increasing requests for the public to make their data available to governments to guide policy-making. The ability of governments and HHS organizations to do this successfully relies largely on government transparency and public trust.

Studies have found that users are typically willing to share their personal health data when their privacy concerns are met, when they trust their clinicians and when they understand the benefits that can be derived from data sharing.³⁶ Nevertheless, this varies greatly by geography. A [survey](#) on public perceptions of data sharing in the US and the UK found that the majority of respondents in both countries were willing to share their data with their doctor, but in the US, more than a third were not.³⁷ The multicountry study conducted with 12,000 respondents found that 48% supported the use of their personal health data to set priorities for local health services, while 52% supported the use of their data to help with disease prevention and tracking.

Citizens worry about their personal information being disclosed to family, employers or friends, or used by private industries or government organizations without their knowledge.³⁸ Furthermore, data breaches and perceived lack of security around personal data can discourage users. In the US, it is estimated that the HHS sector suffered over 300 data breaches between 2012 and 2016, affecting over 14 million individuals.³⁹ Data breaches are discussed further in the following chapter.

Not all citizens may be willing to share the same data. Across the world, vulnerable groups and ethnic minorities have started to advocate their own data protection measures. For example, the Māori in New Zealand have established the Te Mana Raraunga as the Māori Data Sovereignty Network, which advocates for “Māori rights and interests in data to be protected as the world moves into an increasingly open data environment.”⁴⁰ HHS organizations need to be flexible enough to allow users to select which elements of data they wish to share and which they do not.⁴¹ Most importantly, they need to ensure that those who do not share their data are not left behind in terms of access to high-quality services.

300

data breaches between 2012 and 2016,
affecting over 14 million individuals in the
HSS sector

2.3. Long-term sustainability

Long-term government funding for analytics-driven solutions is of paramount importance. Changes in regulation and funding to focus on innovative data and analytics solutions have allowed Hillsborough County to develop and deploy the Family Preservation and Assessment System as a pilot, but the organization is certain that this will only be sustainable if the state takes on long-term funding for the project.

Long-term sustainability can be difficult when financial pressures require governments to make trade-offs between long-term investment and short-term needs such as funding for staff and equipment, especially if the value of the long-term investment isn't immediately clear. Daniel Barakate, Director of New South Wales Department of Family and Community Services (FACS), Australia, stated, "We're not quite there yet. We still can't say, 'here's Joe, and by doing this with Joe, we saved X dollars.'" In his view, HHS organizations need to make the financial benefits "more real" to clearly convey the benefits of long-term investment from government.

The COVID-19 pandemic has led to increased funding for HHS organizations in many countries to support digital solutions. In the UK, each provider was able to access £20,000 of funding to roll out Attend Anywhere, the chosen video consultation platform for secondary care in the NHS.⁴² More broadly, our report [Embracing digital: is COVID-19 the catalyst for lasting change?](#) finds that a significant percentage of respondents across countries (from 36% in the US to 73% in the UAE) indicated that the introduction of digital technologies and solutions was a temporary measure in response to the pandemic. While some COVID-19-specific solutions may not be needed after the pandemic, others will have unlocked efficiencies in the system and will be desirable in the long term. HHS systems should support the long-term adoption of solutions that, during this time, have proven their value.⁴³



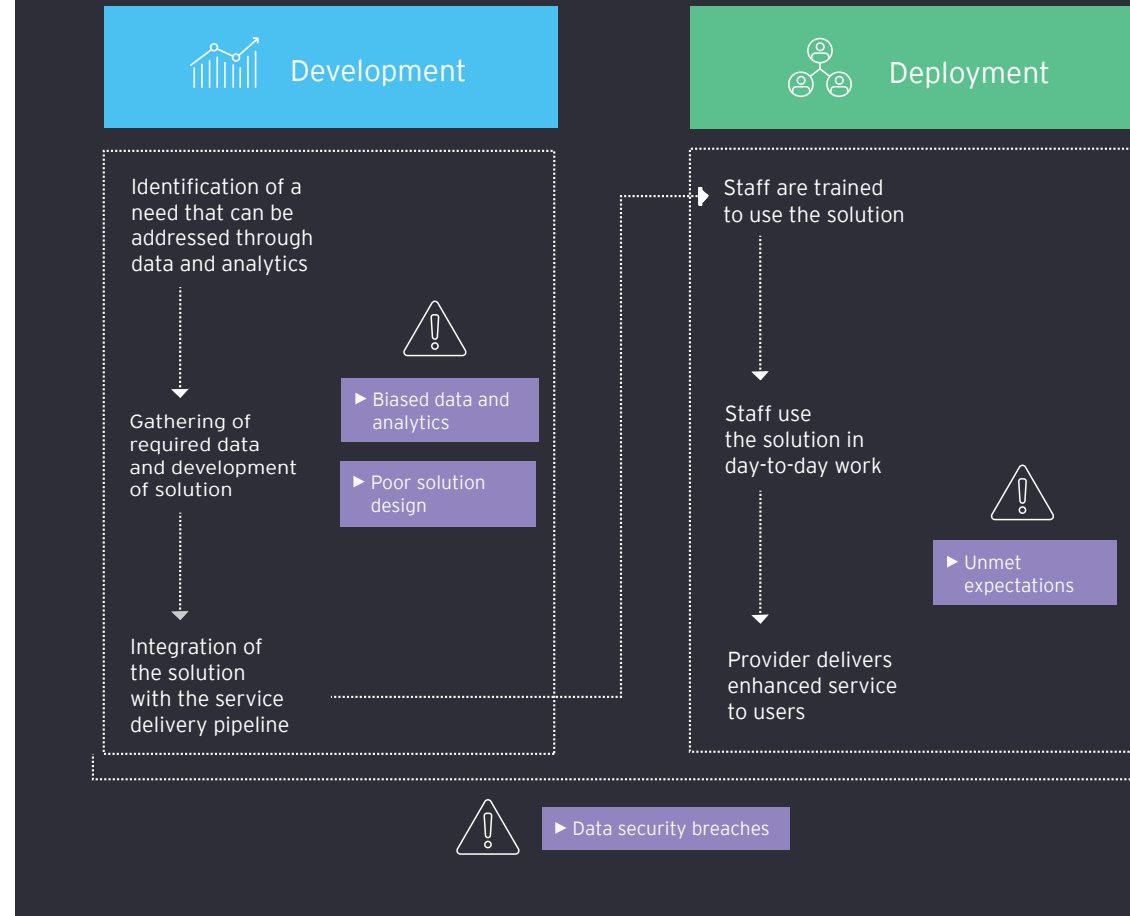
03

Risks of the use of analytics solutions in HHS

While there are clear benefits to successfully deployed analytics solutions in HHS, there are also significant risks (Figure 11). The impact of these risks, if left unaddressed, ranges from hindering the effectiveness of analytics to, in the worst cases, harming organizations and citizens. Because of these potentially catastrophic consequences, HHS as a sector has historically been very risk-averse. The enablers described in Chapter 4 offer actionable suggestions on how to mitigate and overcome these risks.

Each risk is positioned next to the step of the project where we believe it is most relevant, but it is important to note that they can all affect data and analytics projects at any stage. Furthermore, they will continue to exist beyond deployment of solutions and into the future.

Figure 11: Risks of the use of analytics solutions in HHS



1. Biased data and analytics

One of the main risks of digital and analytics solutions is that they may give HHS organizations the wrong answers. Predictive analytics have been used, for example, to determine the risk of an individual developing a specific disease⁴⁴ or to support a judge in deciding whether to release an individual awaiting trial.⁴⁵ Potential bias in the underlying data and algorithms themselves can have catastrophic consequences for individuals and populations. For example, certain algorithms used for predictive policing have proven to be unreliable due to racial biases in data collection.⁴⁶

Furthermore, machine learning algorithms are often referred to as “black boxes.” The combination of values that leads to a particular outcome is often unclear, which makes the identification of biased systems difficult.⁴⁷

Bias in underlying data may arise from pre-processing (i.e., how the data is collected and manipulated), processing (i.e., how the algorithm processes the data) or downstream applications of the algorithm (i.e., how the results are implemented).⁴⁸ Bias in algorithms often stems from unconscious bias by the creator or programmer. Although methods have been proposed to try to minimize bias during data processing,⁴⁸ bias in data collection still remains one of the biggest challenges for predictive analytics in HHS.⁴⁶

2. Poor solution design

Solutions that are poorly designed will not have the desired impact, even if built on sound data and analytics.

From a staff perspective, poor solution design can lead to cognitive burden and burnout. One study in the US found that doctors spent 50% or more of their day “clicking pulldown menus and typing rather than interacting with patients,” with an emergency room doctor making up to 4,000 mouse clicks per shift.⁴⁹

Digital technologies that hinder staff’s ability to do their work correctly will be met with resistance. “A poorly designed digital technology can lead to social workers having to either comply with an inflexible system that may not be the optimal path for their clients or find ways to bypass the system to do their work,” Godfred Boahen stated.

From a service user perspective, poorly designed solutions may lead to increased health inequalities.⁵⁰ Studies have shown that the younger, more educated and higher-income population is associated with an increased likelihood of accessing the internet for care purposes.⁵⁰ While the younger population expects to access services digitally,⁵¹ older adults and individuals earning minimum wage are less likely to have internet access.⁵² It is important to note that the digital divide is not necessarily delineated by age and income alone: for example, people in remote areas may have poor internet access irrespective of age or income. In the UK, a digital-first policy means that the internet is required to access core government services (e.g., benefits), placing citizens in “data poverty” (those who lack access to broadband or mobile data) at a clear disadvantage.⁵³

Even with access to digital services, confusing displays may limit their use. There is evidence that the usefulness of different interfaces varies by age group.⁵⁴ HHS organizations that do not adapt user-facing interfaces to their target audiences risk developing solutions with limited usefulness to staff and service users.

Solution design must also be considered in choosing between off-the-shelf solutions or in-house development. Providence had to build DexCare internally because it did not find any solution available in the market that would integrate seamlessly with its EMR system. LBBD, on the other hand, chose to partner with EY and Xantura for the development of One View because of their proven expertise in building similar platforms in Australia.

Solutions that are poorly designed will not have the desired impact, even if built on sound data and analytics.

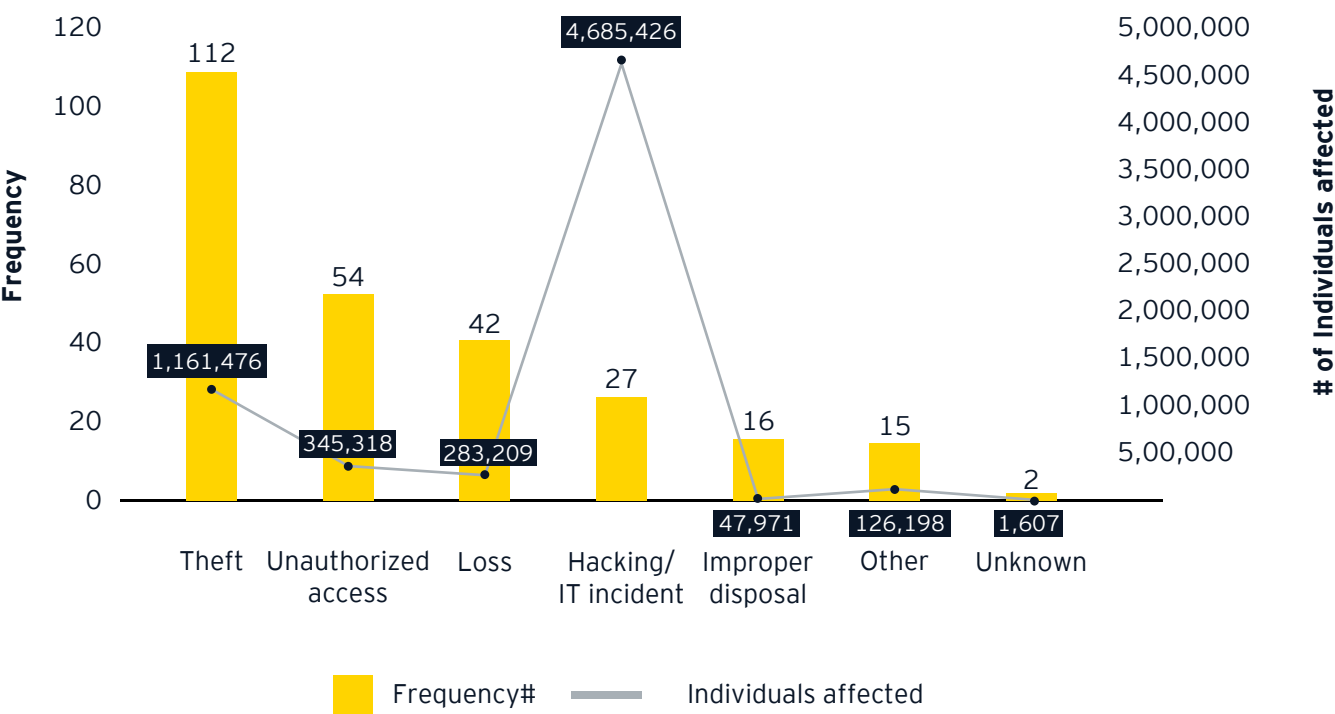
3. Data security breaches

Due to the sensitive nature of HHS data, security measures are paramount. HHS organizations must protect against attacks that are rising in number and complexity. This includes protecting against a variety of events, such as identity theft, compromised encryption, unauthorized data access and malware attacks.⁵⁵

Not being prepared can be extremely costly and put lives in danger: for example, the UK's NHS suffered a ransomware attack by the WannaCry digital virus in 2017. The inability of hospitals to see patients during this time was reflected in a decrease of 6% in hospital admissions attributable to WannaCry and an estimated loss of £5.9m overall.⁵⁶

Worryingly, the number of data breaches in the health sector has steadily risen over the last decade,⁵⁷ with IT-related breaches having the largest patient impact. A study that looked at health care data breaches in the US between 2009 and 2016 found that while hacking and IT incidents were not the most common, they affected by far the largest number of people (Figure 12).⁵⁸

Figure 12: US hospital data breaches affecting 500 or more individuals by type of breach, 2009-16
Image taken from Gabriel et al., 2018



Due to the sensitive nature of HHS data, security breaches in this sector tend to be met with a stronger public backlash than similar breaches in other industries. Experts interviewed for this report from across the world agreed that these breaches can “make or break” digital initiatives in the sector through their impact on public trust.

The COVID-19 pandemic has led to increased risk in multiple ways:

- ▶ HHS staff are using less secure communication channels. In the UK, clinicians were told that they could use messaging services such as WhatsApp “where the benefits outweigh the risk.” Furthermore, they were told that they were allowed to use their own devices to support video consultations “where there is no practical alternative.”⁵⁹
- ▶ Hackers are increasingly targeting remote workers and the health care sector during this time,⁶⁰ with at least one attempt to breach the WHO network⁶¹ and multiple attacks on the US’s Centers for Disease Control and Prevention (CDC).⁶²
- ▶ Systems are stretched, with IT departments having to cope with unprecedented demand and cyber risks not always being prioritized.⁶²
- ▶ The lack of central oversight on the content that is included in mobile app platforms results in an increasing dissemination of misinformation appearing to be informal clinical guidance.⁶²

4. Unmet expectations

Analytics may not always be the panacea it is made out to be. Often, solutions that have been developed for one environment may not perform as well in another, hit unexpected limitations or take longer than expected to be fully deployed. Solutions that do not meet expectations may limit top-level support and funding, reduce staff and user buy-in and acceptance, and limit the organization’s ability to further leverage data and analytics solutions in the future.

Hackney Council in East London, UK, had to abandon its analytics in child care because of the difficulties of matching data from different sources.⁶³ What Works for Children’s Social Care, an organization in the UK, has examined the effectiveness of predictive analytics in the sector and believes that there is an issue of organizations being offered “a silver bullet” when, in reality, it does not exist.⁶³

Furthermore, the availability of data may not necessarily translate into useful insights. Data passively captured by wearable devices and apps, for example, may not be easily integrated into the existing data systems of service providers.

Finally, there is a risk that data collection is seen as a goal in itself. There is a high likelihood of disappointment when staff, patients or service users are asked to provide data but do not see the value of it. Cancer survivor and PFA representative Joanne MacPhail said this was the biggest risk of using PROMs for symptom management: “There is a risk that patients are asked to complete the survey but then clinicians don’t use it.

My frustration is with the doctors who are not paying attention to the data.” This leads to patients feeling like they’ve wasted their time, which discourages them from completing screenings in the future. Colleen Fox, Director of Person-Centered Care at Ontario Health (Cancer Care Ontario), agreed that this was the main risk in their PROMs program: “If we are putting out the tool and asking patients when they come in to report their symptoms and nobody does anything with it, it’s a frustration for patients: why are you collecting this data if you’re not using it? The primary intention of the data is to inform the clinical care and decision-making, so why collect it if you’re not going to use it and actually work to improve the care of the patient? I think it’s a risk in terms of continued buy-in and support for this type of work.”



04

Key enablers for harnessing the power of data and analytics in HHS

There are many examples of HHS organizations that have successfully harnessed the power of data to improve their service delivery. These span geographies and sectors and can be found across the digital maturity spectrum. In this chapter, we explore the key enablers that have allowed successful organizations to effectively develop and deploy data and analytics-driven solutions. These can be classified as **system-level**, **organization-level** and **solution-level enablers** (Figure 13). For each enabler, we list the specific challenges and risks that they can help address, but it is important to note that many of these will be cross-cutting.

Figure 13: Key enablers for harnessing the power of data and analytics in HHS

System	<div>Government leadership and political will</div> <div>Innovative funding models</div> <div>Cross-sector knowledge-sharing</div>
Organization	<div>Shared vision and alignment of expectations</div> <div>Management support</div> <div>Robust cybersecurity framework</div> <div>Robust information governance framework</div> <div>Trust-building with the public</div>
Solution	<div>Tailored solutions</div> <div>Early involvement of all stakeholders</div> <div>User-centered design</div> <div>Service delivery champions</div> <div>Clear feedback mechanism</div>



1. System-level enablers

System-level conditions that incentivize the development of data and analytics solutions can immensely help HHS organizations on their digital maturity journey. **Government leadership and political will, innovative funding models** and a culture of **cross-sector knowledge-sharing** are key conditions that can help to foster this environment.

1.1. Government leadership and political will

Government can lead the way toward an increased use of data and analytics in HHS directly by implementing national-level platforms and frameworks, or indirectly by making funding available for local HHS organizations to implement bespoke solutions.

Government can play a significant role in enabling and supporting data-sharing and interoperability. Estonia, a leader in this field, has implemented nationwide software that allows the country's public and private sector e-service information systems to communicate seamlessly, virtually eliminating interoperability issues.⁶⁴

In 2011, Statistics New Zealand created its Integrated Data Infrastructure (IDI), an unprecedented de-identified database. The IDI includes education, social welfare, migration, justice, health and survey data on the citizens of New Zealand. It is used by policy-makers, researchers and analysts from government and beyond to shape government policy and frontline services.⁶⁵ As just one example, Oranga Tamariki (the New Zealand child protection agency) uses the data to understand vulnerable families and children, design its service offering to target

services at the most vulnerable, and intervene as early as possible in those families' lives before crisis occurs.

In 2018, the Australian Government released a new Data Sharing and Release Act that promotes better sharing of public sector data by making it mandatory for all government agencies to use open standards for interoperability.⁶⁶ It also recently implemented a system of national-level data sharing for child protection. According to Daniel Barakate, this is making an immense difference to their work, as national agreed standards reduce the need for data transformation and linkages: "The more you transform data, the more room for errors there is." In his view, having national frameworks for consistent data reporting is more efficient and less prone to error.

In 2020, the Ministry of Health and Family Welfare in Bangladesh began developing e-health data and interoperability standards that will benefit the Ministry, other government agencies, the private sector and civil society.⁶⁷

In response to the COVID-19 pandemic, many government organizations have been able to make rapid progress on information-sharing agreements. The urgency of the situation has demonstrated what organizations are able to do at speed when there is political will. For example, in less than a week, the Information Governance Group for London was able to put in place data-sharing agreements that allow boroughs to share data on children who depend on free school meals.⁶⁸

While data quality and information governance are largely addressed at the organizational level, governments can provide standards and frameworks for data quality in the public sector.

For example, the UK's Data Quality Framework, launched in 2020, provides a structure for organizations to consider data quality issues and practical tools for improvement.⁶⁹ Government can also support the development of data science capabilities within public sector organizations.⁷⁰

Government can reform procurement practices, reducing reliance on larger contractors and extending access to a wider variety of potential suppliers. This can help HHS organizations access more cost-effective, innovative solutions from nontraditional companies (e.g., start-ups). For example, the UK Government introduced Spark, a technology innovation marketplace that allows government organizations to purchase innovative solutions through a dynamic purchasing system (DPS).⁷¹ In South Australia, the Go2Gov "provides local startups and early-stage businesses with the opportunity to pitch novel solutions to solve state government challenges."⁷²

Challenges and risks this enabler can help address:

- Funding
- Regulation
- Interoperability
- Data quality and information governance
- Long-term sustainability

While the adoption of data and analytics in central government is outside of the scope of this paper, leadership can also be shown by governments in their prioritization of their own data and analytics solutions. A survey conducted by the Government Business Council, an organization in the US, and EY found that only 6% of respondents in the public service front lines were very satisfied with the data access their organization provides to support their decision-making process. The report recommends that government agencies make better use of the abundance of data analytics tools available to optimize their missions.⁷³

1.2. Innovative funding models

As described in Chapter 2, funding challenges can limit HHS organizations' ability to invest in long-term data and analytics capabilities. There is an opportunity for governments to incentivize organizations to shift from a short-term costing mindset to a long-term benefit view.

Governments can play a role in encouraging organizations to evaluate the cost of not abandoning legacy, inefficient systems. US states have the opportunity to leverage two federal provisions as they embark on identifying and implementing their prevention plans to support families at risk of entering the child welfare system. These provisions are the Family First Prevention Services Act and the Comprehensive Child Welfare Information System (CCWIS). The latter paves the way for child welfare agencies and state departments of children and families to invest in interoperable systems that are conducive to data sharing, in contrast to the current legacy monolithic systems that the Federal Government promoted previously. According to Ramin Kouzehkanani, CIO for Hillsborough County, "Government

agencies are remiss if they allow the cost of adopting and implementing a CCWIS strategy to deter them. I believe the cost of not doing it is ultimately greater than the cost of doing it, especially when they understand and consider the prevention outcomes and the maintenance and operational cost of their legacy systems."

Furthermore, governments can encourage HHS organizations to think beyond immediate costs and attempt to quantify long-term benefits. This will help address the challenge of short political cycles against technological investments that may take significantly longer to demonstrate results. This "actuarial approach" is what led the New South Wales Department of Communities and Justice to reform its home care system: "If we look at our out-of-home home care system, we completely reformed our service system to move away from a unit cost-based system to a flexible package-based system where flexible packages incentivize permanency and well-being for children. That involved greater expenditure upfront to work with urgency to get kids back home. But it has massive benefits, both from a cost perspective and more generally across the human service.", shared Daniel Barakate.

Challenges and risks this enabler can help address:

- Funding
- Mismatched funding and technology cycles
- Long-term sustainability

“

If we look at our out-of-home home care system, we completely reformed our service system to move away from a unit cost-based system to a flexible package-based system where flexible packages incentivize permanency and well-being for children. That involved greater expenditure upfront to work with urgency to get kids back home. But it has massive benefits, both from a cost perspective and more generally across the human service.

Daniel Barakate

Director of New South Wales Department of Family and Community Services, Australia

Additionally, governments can redesign the way services are funded to incentivize the development of cross-sector analytics solutions. For Rachel Dunscombe, having an integrated care system made all the difference: “We had a single budget in a single system. Everything from acute trauma to adult social care. We owned some of the GP practices. We owned the care homes as well. Within that system, the commissioning friction was removed. We were able to take some of the budget from acute medicine and put it directly into social care interventions. That took two weeks instead of the maybe 18 months it would have taken with the old siloed system.” This has allowed the integrated care system to commission new services based on what they see in the data, and deliver services dynamically. Furthermore, it has made it easier to make decisions around funding an intervention in social care that reduces hospital attendances, for example.

Governments can also encourage nontraditional funding mechanisms for HHS solutions. Gianluca Misuraca, former Senior Scientist at the European Commission’s Joint Research Centre, believes social impact investment (SII) is an avenue of funding for social services that will become increasingly relevant, given government budget pressures. Through SSI, the private sector makes investments that have social and financial impact. Governments can play a role in creating a conducive regulatory environment, encouraging transparency and helping develop the market.⁷⁴ In Portugal, since 2014, political and government support has played a key role in the development of the country’s SSI ecosystem, ensuring that funding programs match market needs.⁷⁵ Meanwhile, the UK, one of the most advanced social investment markets in the world, published its strategy on supporting the social investment sector in 2016.⁷⁶

1.3. Cross-sector knowledge-sharing

While each HHS organization will have unique needs and circumstances, there is an opportunity for organizations to learn from those leading the way. Marcee Chmait, Executive Director of Digital Business Development at Providence, urged organizations to do this: “Go to the people who have done it, who have proven success and copy paste. We encourage that. We’ve just spent tens of millions of dollars building something. Don’t spend tens of millions of dollars investing in something that’s already proven. Go to the market where there’s best practice. Don’t think you have to reinvent the wheel - you don’t get more points for being original if the idea’s already out there.”

According to Natalie Banner, Lead for Understanding Patient Data, HHS organizations should also share their experiences with third-party providers of analytics solutions: “There could be huge value in health care organizations sharing insights into what they’ve learned from working with different partners. Creating more of that culture of community and shared learning could help organizations not feel like they are having to make decisions from scratch every time, with a bespoke solution and a bespoke approach to negotiations with partners.”

- Cross-sector knowledge sharing can help address all of the challenges and risks described previously in this report

“

Go to the people who have done it, who have proven success and copy paste. We encourage that. We’ve just spent tens of millions of dollars building something. Don’t spend tens of millions of dollars investing in something that’s already proven. Go to the market where there’s best practice. Don’t think you have to reinvent the wheel – you don’t get more points for being original if the idea’s already out there.

Marcee Chmait

Executive Director of Digital Business Development

2. Organization-level enablers

HHS organizations can take steps to ensure they are better equipped to face the challenges of leveraging data and analytics solutions. Key steps include establishing a **shared vision and alignment of expectations**, securing management support, establishing a **robust cybersecurity framework**, creating a **robust information framework** and trust-building **with the public**.

2.1. Shared vision and alignment of expectations

The development and deployment of analytics solutions in an HHS organization may require cross-departmental coordination and agreement. While there will be varying levels of required involvement, it is important for all stakeholders to have a clear sense of the overall vision of their organization and how data and analytics fit in. Hillsborough County has created a shared vision of the future of child services across the county. Every person interviewed, from the Commissioner to the private contractors, was able to identify and articulate Hillsborough County's vision for the Family Preservation and Assessment System: to enable the provision of targeted early intervention and support for families under stress and imminent risk of entering the foster care system. Having a clear, shared vision also reduces the risk of a project being abandoned if its main champion leaves the organization.

A clear, shared vision provides a constant reminder of the goal. Solutions should be continuously evaluated against that goal and revisited if they are not working. "There is an issue of consistency bias, where we'll say 'we're committed to this now, so we're sticking to it,'" Daniel Barakate stated. In Nathalie

Bloch's words: "Be ready to fail, fail, fail, fail, fail, and only then to maybe succeed. We see it again and again. We work on projects and models, and we think that we are going in the right direction, but then it turns out that it's not working well, or it's not the right question, or the model shows us features that, actually, physicians won't really appreciate. You need to be very patient to see results."

A shared vision also ensures alignment of expectations, which will reduce the risk of disappointment after the solution is designed and deployed. According to Robert Klempfner, Clinical and Scientific Director of the Hub at Sheba, disappointment comes from a lack of shared understanding between staff and solution delivery providers: "Disappointment comes from not discussing enough with clinicians and start-ups to really understand if the goals are achievable, to look at the data that is available, to look at the options realistically at hand. If you don't do this initial homework (which is quite extensive sometimes), you witness lots of disappointment."

Challenges and risks this enabler can help address:

- Leadership buy-in
- Staff buy-in
- Long-term sustainability
- Unmet expectations



2.2. Management support

All case study organizations interviewed for this report had one thing in common: management support for data and analytics solutions. At Hillsborough County, this was manifest through Commissioner Murman’s personal commitment to the success of the Family Preservation and Assessment System; at Sheba, commitment was demonstrated through significant investment in establishing the Big Data and AI Hub. For LBBD’s Service Manager Gill Wilson, top-level support was key: “When you get buy-in from the top, it will happen. That’s how we can do the things we do, because we’ve got senior management that think outside of the box. They’re not constrained by the way things were done before; they’re very forward-looking. One View has been driven by the top. That’s making it happen.”

At Providence, management leadership and vision have been key to positioning the organization at the forefront of innovation. “Having an organized vision that is well resourced and has autonomy within the system is pretty key. Lots of initiatives in health systems die because you don’t have an organization that is pointing out at a mountain on the horizon saying, ‘that’s the mountain we’re going to climb, and here’s how we’re going to resource it, and here are the resources, and here is how we’re going to staff it,’” stated Derek Streat, Entrepreneur-in-Residence and CEO of DexCare, Providence.

Challenges and risks this enabler can help address:

- Staff buy-in
- Long-term sustainability

2.3. Robust cybersecurity framework

In Chapter 3, we describe cybersecurity breaches as one of the main risks of using data and analytics in HHS. The only way that organizations can mitigate this risk is by putting in place a robust cybersecurity framework. While no cybersecurity practice is perfect, better-prepared organizations are less likely to suffer data breaches and are more likely to recover quickly from them.⁶² LBBD has developed a robust approach to handling security breaches in its One View Data Ethics Workbook. This document outlines the security specifications that are put in place to protect One View data, as well as the steps that must be followed in the event of a security breach. These span from who to report the incident to (e.g., the information governance office or ICO, if required) to making further checks to ensure the breach does not happen again.

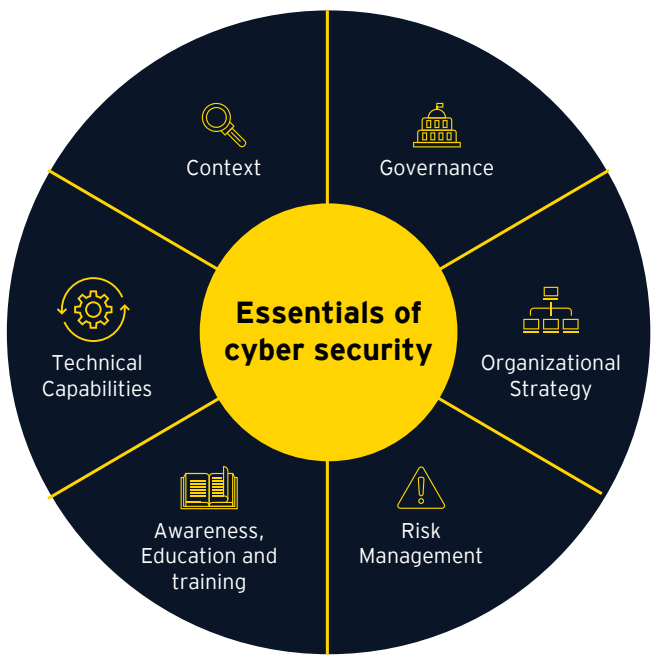
A helpful tool for HHS organizations aiming to strengthen their cybersecurity is O’Brien et al.’s Essentials of Cybersecurity in Healthcare Organizations (ECHO) framework, which is largely applicable across the HHS sector (Figure 14). It encompasses considerations around context, governance, organizational strategy, risk management, awareness, education and training, and technical capabilities. “The ECHO framework is based on components identified by a panel of global experts as the most important elements of a global cybersecurity framework for health care.

Challenges and risk this enabler can help address:

- Data security breaches
- Public acceptance

It outlines the six primary dimensions to consider when scaling up cybersecurity in a health care organization. The framework offers a common language for the essential issues that need to be addressed. It may be viewed as a ‘minimum guide’ or an aspirational checklist, depending on an organization’s cyber maturity and resources.”⁶²

Figure 14: The ECHO framework⁶²



2.4. Robust information governance framework

All case study organizations interviewed agreed that a robust information governance (IG) approach was key to the success of their analytics solution. This allows them to provide oversight, direction and accountability for progress. Multidisciplinary advisory boards, for example, can provide independent and nontechnical guidance on ethical considerations in data and analytics use cases.⁷⁷

Ontario Health (Cancer Care Ontario) has a governance framework that covers all its data, not just PROMs. “There are very specific governance pieces that we need to go through to actually get access to the information. There’s an approval process, there are data sharing agreements that allow us to use the information for very specific purposes. We have data stewards that are responsible for understanding and providing access to the information for very specific purposes. We have governance processes in place for researchers to request access to information that needs to go through a very specific process and get approved. There’s a number of different governance processes in place for accessing and using any information we collect,” explained Richard Smith, Director of Product Management.

Challenges and risks this enabler can help address:

- Data quality and information governance
- Data security breaches
- Public acceptance
- Staff buy-in

Strong protocols that govern the sharing and use of data can also mitigate risks, safeguard from harmful outcomes and build the trust that is needed to maximize the use and benefit of analytics solutions.⁷⁷ For example, New Zealand lowers the risks of potential individual privacy violations by ensuring that its aggregate dataset (IDI) is completely de-identified.⁶⁵ Pseudonymization can also be explored as a way to increase the privacy of individuals while allowing re-identification if required (e.g., if a specific risk is flagged).

For Gill Wilson, Service Manager at LBBB, IG gives her confidence that she’s using the data appropriately: “One View has got a very, very good structure to it, that embeds the Data Protection Act, GDPR [the EU’s General Data Protection Regulation], so that you know whenever you go in, you only get access to what is at your level. The formal process around the data protection, but also the formal process around the governance structure with the board and everything, it all feeds into the management board. It’s very good. It’s very strong.”

2.5. Trust-building with the public

Trust-building around data and analytics has often been an afterthought for HHS organizations. In Natalie Banner’s view, there needs to be a mindset shift: “There is a mindset that the public need to trust in what’s happening to their data, as though members of the public kind of owe it to them, whether it’s the government, providers or academic researchers. There is this view of ‘of course we’re doing things for the public benefit, why would you question us?’” In her opinion, this needs to be demonstrated and proven. Organizations need to be receptive and responsive to public views and values in the way they design the system to effectively build trust and confidence.

Furthermore, HHS organizations need to be very specific about what data is being used or shared, with whom, and for what purpose. This allows the public to make their own judgment on the value of data sharing and analytics solutions.

Building trust can be facilitated by engaging “familiar faces.” At Hillsborough County, the team believes this is a fundamental reason why change should be driven by organizations that are already in the community. Natalie Banner echoed this: “Having clinical champions, particularly in primary care, for the use of data and for digital technologies has an enormous impact on the willingness and understanding of patients and the public in terms of how they see the use of data.”

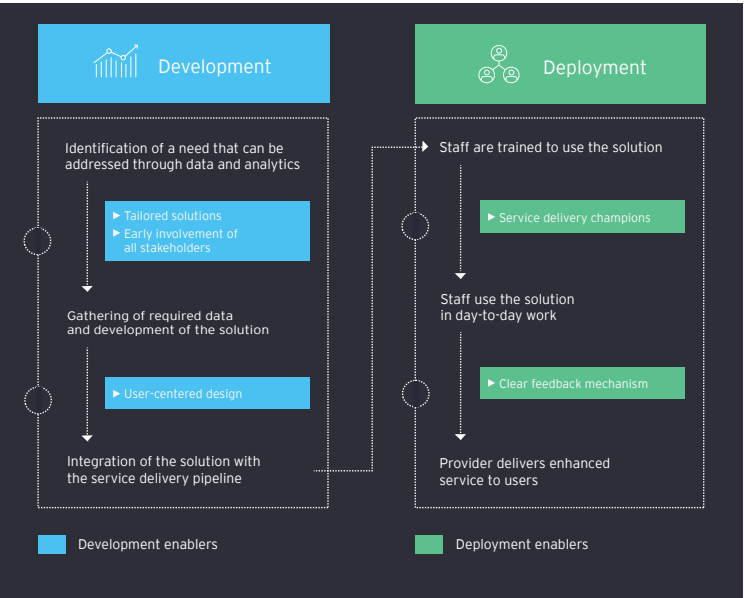
Challenges and risks this enabler can help address:

- Public acceptance
- Unmet expectations

3. Solution-level enablers

The third tier of success factors in the use of data and analytics in HHS organizations relates to the development and deployment of the solution itself. Solution-level enablers include ensuring that the solutions are tailored to the organization's needs, leveraging user-centered design, identifying service delivery champions, involving all relevant stakeholders early on and providing a clear feedback mechanism for solution users, as shown in Figure 15.

Figure 15: Key solution-level enablers for harnessing the power of data and analytics in HHS



3.1. Development enablers

3.1.1. Tailored solutions

Each HHS organization will have unique needs and circumstances. To ensure that the use of data and analytics is effective, it must be tailored to the organization. This requires clearly articulating the organization's internal needs, aligning the solution to the maturity level of the organization, and recognizing internal limitations.

Sara Vaezy, Chief Digital Strategy and Business Development Officer at Providence, believes that identifying the problem first is the key to Providence's success in harnessing the power of data: "We've always taken a problem-first approach or an opportunity-first approach, and that has made us laser-focused on what are all of the other supportive things, including the data and the analytics, that we need to demonstrate the value of what we're trying to solve for. I think that's the first thing. There's no data analysis for its own sake. It's in service to understanding the problem and then understanding how to tackle it, then measuring the performance of what you're doing in order to tackle it."

Heather Cazzola is the Director of Diversion & Prevention at Eckerd Connects, the private contractor that provides child and adolescent social services in Hillsborough County. She shared her experience working with EY to adapt a platform that had originally been developed for an Australian context: "It gave us an idea of something to start with, but the framework and everything we've done is very different from the platform in Australia because our needs are different. They've really been able to adapt to our specific county and state needs, as opposed

to just taking something that is cookie-cutter and trying to make it work."

Bernardo Mariano believes that "The prioritization of the digital health investment should be aligned to the maturity level of the organization to ensure that the design addresses the basics. If a country that does not have the basic infrastructure tries to leapfrog to implement a cutting-edge technology that requires, for example, EHRs to be in place, that investment will not be sustainable." In his view, it is about assessing the maturity level of the organization and determining the road map for investment to ensure sustainability over time.

This view was echoed by Pye Nyunt, Head of Insight and Innovation at LBBD, who further emphasized the importance of maturity and timing: "In the first two years of the Insight Hub, we needed to learn lots of different things. We couldn't have just gone 'let's start One View.' The organization just wasn't there culturally and technologically." After two years, having demonstrated the value of early data-driven solutions internally and externally, LBBD was ready to partner with an external organization that could enable its vision of a large-scale platform to support 400+ staff.

Challenges and risks this enabler can help address:

- Data quality and information governance
- Interoperability
- Staff buy-in
- Poor solution design
- Biased data and analytics

Recognizing internal limitations involves also understanding that having data does not equate to being able to use it. Sigal Sina is the Chief Data Scientist at Sheba's Big Data and AI Hub. In her view, "even though we have a lot of data, not all of the data can be used." Her team's main challenge is to collect and pre-process the data that sits in more than 40 siloed repositories across Sheba. Her team is slowly trying to combine all data into one data lake that can be used for internal reporting and clinical research, but it is a complex and ongoing process. Each project that it completes helps build its capabilities in this area. "Each project is a POC [proof of concept] and it's done in two directions: one is about doing the best we can for this project, and the other is to learn from it for the future and build on our infrastructure."

Solutions that enable interoperability will become increasingly important for HHS organizations to fully realize the value of data and analytics. As Sigal Sina described above, it is a gradual process that will require building micro-ecosystems of data and aggregating them over time. EY's report [How will you design information architecture to unlock the power of data?](#) Creating the right data environment for a connected health ecosystem provides a useful framework for organizations to begin developing the architecture required to ultimately achieve system-wide interoperability.⁷⁸

3.1.2. Early involvement of all stakeholders

Data and analytics solutions will often require internal and external collaboration. Tools may require linking datasets that are owned by different departments and may have unforeseen implications for external stakeholders. It is important to ensure

that all relevant stakeholders are "in the room" from the early stages of planning. While this may seem inefficient at the beginning, it can be a great enabler of success.

Hillsborough County has proactively pursued relationships with a variety of stakeholders to create a full network of potential input into the Family Preservation and Assessment System. Its strategy has been to build relationships over time and develop trust. "It's a personal relationship. Different entities are just people that we know," stated Christopher Card, Chief of Community-Based Care at Eckerd Connects. All the stakeholders interviewed commented on how much the services benefited from just "being in the room" together and working in a more collaborative way during the development of the Family Preservation and Assessment System.

The process of involving all stakeholders early on takes time. "You need to collaborate, bring people together and take the time necessary to get them onboard with the shared vision. It takes time, but that's a worthwhile exercise in making sure people are buying into the project. Then, include them in the execution to the extent possible, so that it's an execution at the local level, so they stay bought in and they stay aware and they stay on your team getting this done. This is the biggest lesson learned to me," stated Christopher Card.

Rhodri Rowlands, Head of Programmes for Community Solutions at LBBB, shared how colleagues from across the organization had been involved early on. While frontline practitioners, commissioners and IG staff have worked alongside the technical team throughout the process, his view is that they could have done more: "At different stages, depending on where we were

with design and delivery, we've had a different mix of staff involved. If I were to look back at doing some of these things again, I'm not sure we had the right mix. We've been very mindful that some of what we're seeking to achieve requires input from service areas, and they obviously have lots of other priorities. We've tried to keep things light touch, and I think that hasn't always worked."

One approach to involving staff early on can be the development of standardized, mandatory training. This is one thing that Colleen Fox, Director of Person-Centered Care at Cancer Care Ontario, believes they could have done better in their use of PROMs for symptom management: "I think a comprehensive training program could have been effective. We do training with providers, with the volunteers, with clerical staff – that type of thing. There's never been a formalized training program around this. I've always wondered if that could have helped, even in the early days, to set us up for success. To have something that was more comprehensive, mandatory, instead of ad hoc, based on the staff we had at the time and what the hospital was doing at the time. It's something that I would do differently if we were starting over."

Challenges and risks this enabler can help address:

- Leadership buy-in
- Staff buy-in
- Public acceptance
- Poor solution design
- Unmet expectations

3.1.3. User-centered design

The success of any given analytics solution is dependent upon staff embedding it into their day-to-day work. Solutions that are designed around the end-user's needs and preferences will therefore have a higher likelihood of success.

Nisim Rahman is the Data Architect and Team Lead at the Big Data and AI Hub at Sheba. If he could give one piece of advice to organizations across the world looking to develop data-driven solutions, it would be to listen to the customers. In his view, "to build a system that will help the doctors, you need to listen to the doctors, to understand exactly what they want." This was echoed by Sigal Sina: "Each client wants something different from the model. Some want decision assistance, some want capacity prediction, or prediction of medical outcomes. In each case, we need to decide with the clinician what will be the research question and how the solution will be used. In this process, we are developing a common language across data scientists and doctors. We need to make sure that everyone understands one another."

Providence has followed this approach in its development of DexCare. Maryam Gholami, Group Vice President, Chief Products Officer at Digital Innovations, Providence, stated: "This product is really a co-development effort with others in critical business and operation lines. We partner with them closely throughout the entire product development cycle and iterations including planning, requirement gathering and analysis, design iterations and reviews and even engineering, testing and troubleshooting. Although these folks have their own full-time jobs, they have a great deal of interest and enthusiasm in helping us define the product and make the platform successful. Our teams

collaborate through various mediums, including chat channels in Slack or Microsoft Teams, so we can exchange ideas and ask questions throughout the whole process at any time. Having really good collaboration with the business and operation lines and co-developing it is a major reason for success." This sentiment was echoed by Amanda Ashley, Director of Operations of Express Care at Providence and one of DexCare's main customers: "I feel privileged that I've had as much input as I've had. The people running our clinic day to day have had input into the system. I think this is very unique. We've developed a platform that's really centered around the way that a clinician and a front-office person work. They've looked at it and said, 'OK, this is what would work for us,' so they've really built something that I feel works well."

In New South Wales, FACS co-developed ChildStory to replace 14 disparate legacy systems with a single cloud-based platform for improved collaboration between family, caregivers, caseworkers and service providers.¹¹ ChildStory was co-designed with FACS staff, NGO partners, carers, children and families. By using techniques such as workshops, interviews and shadowing frontline workers, FACS staff were able to ensure that ChildStory was built around its end-users' needs.⁷⁹

Challenges and risks this enabler can help address:

- Staff buy-in
- Poor solution design
- Unmet expectations

3.2. Deployment enablers

3.2.1. Service delivery champions

Service delivery champions are great enablers of the successful deployment of data and analytics solutions. Ideally, they will be the members of staff that have co-developed the solution with the technical team. They understand its benefits and limitations and can support other staff in learning how to use the solution in their day-to-day work. Most importantly, they can reassure staff that the tools should be used to enhance (and not replace) their judgment.

Challenges and risks this enabler can help address:

- Leadership buy-in
- Staff buy-in

“I feel privileged that I've had as much input as I've had. The people running our clinic day to day have had input into the system. I think this is very unique.

Amanda Ashley
Director of Operations of Express Care at Providence



According to Nathalie Bloch, “The champions are the key to success. After you have buy-in from management, which is a first, champions are the ones that will make it happen. If I’m trying out a model at the cardiology department but I don’t have the cardiologist with me on that specific project, I won’t be able to make it. It doesn’t matter how good my data is and how intelligent my data scientist is. Data scientists need clinical champions.”

This was echoed by Rhodri Rowlands: “There is a whole range of frontline practitioners who have been involved through the evolution of the design and implementation of the platform. They are what we call One View champions. They have played roles like helping to shape the training and guidance for practitioners on how to use the tool, how to access it.” This “train the trainer” model is also being followed by Hillsborough County in its plans for deployment of the Family Preservation and Assessment System.

3.2.2. Clear feedback mechanism

HHS organizations’ needs and requirements from data and analytics are continually evolving. To ensure that solutions are delivering results, a key enabler is to establish a mechanism of continual feedback and improvement. Providence’s DexCare team has ensured that user input is captured. Staff can provide continual feedback on the tool and are also looped in for future developments. “From time to time, they will consult with our clinical staff and our providers to get input on specific launches, ideas or pilots that we want to do,” stated Amanda Ashley.

“You need to get feedback from staff because they are the people using it day in and day out, and they are very honest. They are going to tell you if it’s no good,” stated LBBD Service Manager Jill Gallagher. LBBD has achieved this for One View by ensuring that staff know who to report issues to. The team also has weekly meetings chaired by solution collaborator, EY. In these meetings, EY shares metrics around One View, and the staff discuss what is working and what isn’t. For example, they may decide to adjust the criteria that is used to select specific user cohorts. “These meetings have really helped us to understand what we’re doing and how we’re doing it”, shared Jill Gallagher.

Challenges and risks this enabler can help address:

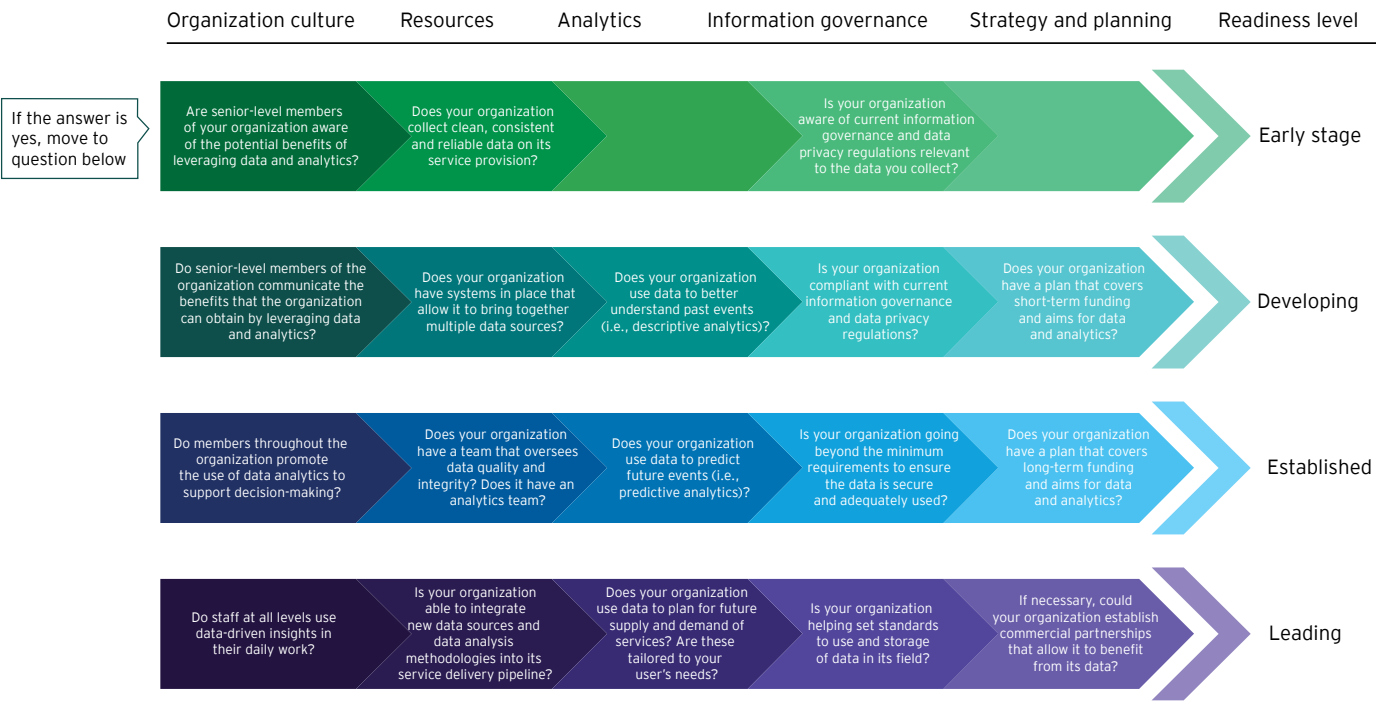
- Staff buy-in
- Public acceptance
- Biased data and analytics
- Poor solution design

05

A diagnostic for assessing HHS readiness for data and analytics solutions

As discussed in Chapter 4, solutions must be tailored to the digital maturity level of the organization to be effective. There are many questions that organizations can consider to determine their readiness for data and analytics solutions. The diagnostic provided below (Figure 16) includes some of the questions that HHS organizations can begin to discuss internally and with potential analytics partners to ensure that solutions are tailored to their unique needs and circumstances.

Figure 16: Diagnostic for assessing HHS readiness for data and analytics solutions



The **culture of the organization** can be a key enabler or challenge in transitioning toward being more data-driven. Organizations that are in the early stages of the analytics journey will want to make sure that senior-level staff members are aware of the potential benefits of leveraging data and analytics. The cultural shift toward becoming more data-driven will have to be driven from the top to be effective. Once there is leadership buy-in, organizations will need to focus on extending buy-in to senior managers and frontline staff. A leading organization will be one where staff at all levels use data-driven insights in their day-to-day work.

The level of complexity of the solution should match the **infrastructure and resources** available to support it. Organizations that are in the early stages of leveraging data and analytics must start by collecting clean, consistent and reliable data on service provision. As organizations become increasingly sophisticated in the use of data, they will want to bring multiple datasets together, ensure they have dedicated resources to monitor data quality and integrity, and establish an analytics team. Ultimately, a leading organization will be one that is able to integrate multiple data sources, identify the appropriate analytics methodologies to use, and embed insights into the service delivery pipeline.

In addition to the availability of data, the availability of **analytics** capabilities will determine what use cases are possible in the short term and what solutions will require further development work. In the early stages, it is possible that the organization will not have a dedicated analytics team – nontechnical staff may be analyzing data at a basic level as part of their day-to-day work. As the organization develops its capabilities, a dedicated analytics resource should start by looking at historical data and using descriptive statistics to understand the service. This may help identify gaps in the data that should be addressed early on. Building on this, the organization will be able to use data in increasingly sophisticated ways. A leading organization in this area will be one that can leverage analytics to plan for future supply and demand of services.

Projects that require increasingly sensitive data to be collected and linked should be matched by an increasingly robust IG plan. Organizations in the early stages of leveraging data and analytics will need to start by ensuring they are aware of the existing IG and data protection regulations that are relevant to the data they collect. As the organization's capabilities develop, it will want to ensure it is meeting all data management requirements and, ideally, going beyond minimum requirements. A leading organization will be one that is helping set the standards of IG in the sector.

Finally, the use of data and analytics cannot be a goal in itself. It should support a broader organization **strategy**, with a clear road map of needs and milestones to achieve. In the early stages, organizations may not have a data and analytics strategy. The first step in this journey is therefore to develop a strategy and a plan for funding it. An example of a leading organization in this area is one that can establish commercial partnerships with the wider ecosystem (e.g., private businesses, entrepreneurs and start-ups) to secure cutting-edge innovation for the benefit of the population it serves. While commercial partnerships are by no means the ultimate strategic aim for leading HHS organizations, the readiness to establish them is more present in leading organizations than in those at earlier stages.

Discussing these questions internally and with potential technology partners will give organizations a better idea of where they are along the journey and where they should focus their development efforts. Having clarity on what use cases can be enabled in the short, medium and long term will ensure that analytics are most effectively used to improve the provision of services and, ultimately, citizen well-being.

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- Rachel Dunscombe, CEO, NHS Digital Academy, 17 December 2019
- Bernardo Mariano, CIO, World Health Organization, 21 January 2020
- Godfred Boahen, National Safeguarding Policy and Development Lead (Survivors Lead) at the Church of England, (at time of interview) Policy Research Officer at the British Association for Social Workers, 31 January 2020
- Ben Maruthappu, co-founder, Cera, 13 February 2020
- Rhema Vaithianathan, Professor at Auckland University of Technology, 24 February 2020
- Frank Guinan, former Director of the Enterprise Project Management Office and former IT Program Manager at Virginia’s Department of Medical Assistance Services, 2 March 2020
- Gianluca Misuraca, (at time of interview) Senior Scientist at the European Commission’s Joint Research Centre, 4 March 2020
- Natalie Banner, Lead at Understanding Patient Data, 13 July 2020
- Daniel Barakate, Director of Child and Family Design and Stewardship, New South Wales Department of Communities and Justice, 29 September 2020

Case study interviews

Ontario Health (Cancer Care Ontario)'s use of PROMs for symptom management, Ontario, Canada

- Colleen Fox, Director, Person-Centered Care, 19 November 2020
- Narges Nazeri Rad, Team Lead & Methodologist, 19 November 2020
- Joanne MacPhail, Patient and Family Advisors representative, 20 November 2020
- Christine Peters, Regional Oncology Lead for Person-Centered Care, 20 November 2020
- Richard Smith, Director, Product Management, 23 November 2020
- Natalie Coburn, Clinical Lead for Patient Reported Outcomes and Symptom Management, 25 November 2020

Hillsborough County's Family Preservation and Assessment System, Florida, US

- Ramin Kouzehkanani, CIO, Hillsborough County, 25 August 2020
- Commissioner Sandra Murman, Hillsborough County, 1 September 2020
- Patrick Minzie, II, Director, Department of Children's Services, Hillsborough County, 27 August 2020
- Christopher Card, Chief of Community-Based Care, Eckerd Connects, 27 August 2020
- Heather Cazzola, Director of Diversion & Prevention, Eckerd Connects, 28 August 2020
- Jatin Gola, Data and Analytics Lead, EY, 18 September 2020



Case study interviews

LBBD's One View platform, London, UK

- ▶ Rhodri Rowlands, Head of Programmes for Community Solutions, 5 November 2020
- ▶ Katy Brown, Programmes and Strategy Officer, 22 October 2020
- ▶ Pye Nyunt, Head of Insight and Innovation, 30 October 2020
- ▶ Gill Wilson, Service Manager, 22 October 2020
- ▶ Charlesworth Benedict, Service Manager, 23 October 2020
- ▶ Jill Gallagher, Service Manager, 30 October 2020

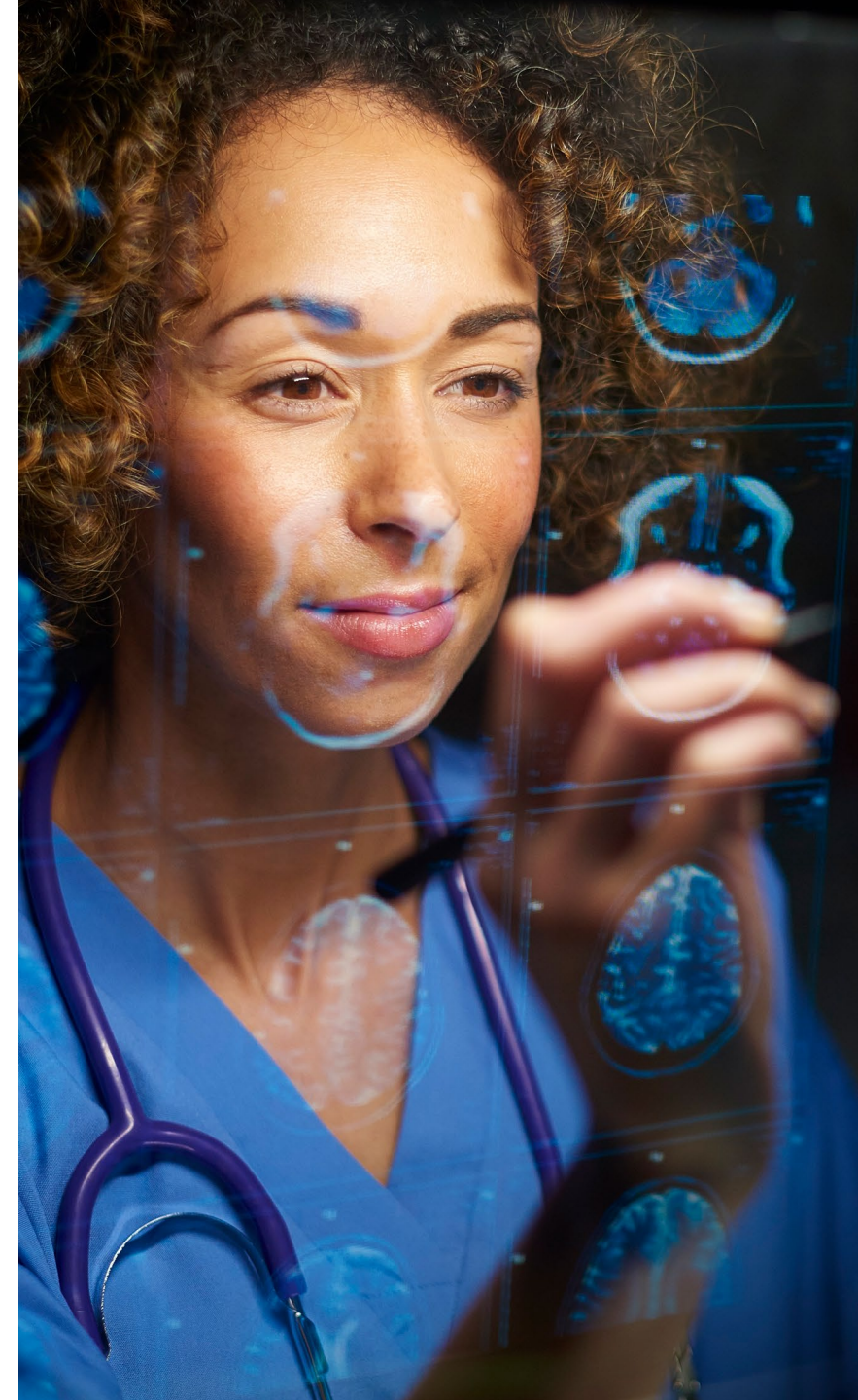
Providence's DexCare solution, Washington, US

- ▶ Sara Vaezy, Chief Digital Strategy and Business Development Officer, Providence, 9 October 2020
- ▶ Maryam Gholami, Group Vice President, Chief Products Officer at Digital Innovations, Providence, 8 October 2020
- ▶ Marcee Chmait, Executive Director of Digital Business Development, Providence, 1 October 2020
- ▶ Derek Streat, Entrepreneur-in-Residence and CEO of DexCare, 13 October 2020

- ▶ Sean O'Connor, Entrepreneur in Residence and CCO (Chief Commercialization Officer) of DexCare, 2 October 2020
- ▶ David McAughan, Executive Director of Express Care and Line of Business Leader, 13 October 2020
- ▶ Amanda Ashley, Director of Operations of Express Care, 9 October 2020

Sheba Medical Center's Big Data and AI Hub, Ramat Gan, Israel

- ▶ Nathalie Bloch, Head of the Big Data and AI Hub, 21 October 2020
- ▶ Jeanette Tuval, Chief Operating Officer of the Hub, 14 October 2020
- ▶ Robert Klempfner, Clinical and Scientific Director of the Hub, 19 October 2020
- ▶ Sigal Sina, Chief Data Scientist, 19 October 2020
- ▶ Nisim Rahman, Data Architect and Team Lead, 20 October 2020
- ▶ Avi (Abraham) Tsur, OBGYN expert and director of the Women's Health Innovation Center, 22 October 2020



Bibliography

1. Human Services Edu. What is Human Services? Accessed January 5, 2021. <https://www.humanservicesedu.org/what-is-human-services/>
2. World Health Organization. Global Strategy on Digital Health 2020-2025.; 2020. Accessed December 7, 2020. https://www.who.int/docs/default-source/documents/g4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf?sfvrsn=f112ede5_68
3. Digital capabilities for social workers: Stakeholders report | SCIE. Accessed November 26, 2020. <https://www.scie.org.uk/social-work/digital-capabilities/stakeholders>
4. Parker S, Prince A, Thomas L, Song H, Milosevic D, Harris MF. Electronic, mobile and telehealth tools for vulnerable patients with chronic disease: A systematic review and realist synthesis. *BMJ Open*. Published online 2018. doi:10.1136/bmjopen-2017-019192
5. Verbrugghe J, Cardinaels L, Haesen M, et al. A qualitative study to evaluate strategies for changes in the assistive technology service delivery in Flanders. In: *Studies in Health Technology and Informatics*. ; 2015. doi:10.3233/978-1-61499-566-1-626
6. Tech for Good: How tech is transforming social services in Singapore. Accessed November 12, 2020. <https://www.tech.gov.sg/media/technews/tech-for-good-how-tech-is-transforming-social-services-in-singapore>
7. NHS Executive. Information for Health: An Information Strategy for the Modern NHS 1998-2005: A National Strategy for Local Implementation.; 1998.
8. Hoover R. Benefits of using an electronic health record. *Nursing (Lond)*. Published online 2016. doi:10.1097/01.NURSE.0000484036.85939.06
9. Imison C, Castle-clark S, Watson R, Edwards N. Delivering the benefits of digital health care | The Nuffield Trust. Nuff Trust. Published online 2016.
10. WaitLess | NHS Innovation Accelerator. Accessed November 12, 2020. <https://nhsaccelerator.com/portfolio/waitless/>
11. EY UK. How can data tell a story that keeps a child safe? Published 2018. Accessed January 5, 2021. https://www.ey.com/en_uk/government-public-sector/how-can-data-tell-a-story-that-keeps-a-child-safe-
12. Ngiam KY, Khor IW. Big data and machine learning algorithms for health-care delivery. *Lancet Oncol*. Published online 2019. doi:10.1016/S1470-2045(19)30149-4
13. A&E Whiteboard Patient Tracking System for Hospitals. Accessed November 12, 2020. <https://www.bbconsult.co.uk/casestudies/aewhiteboard>
14. NHS England » NHS uses sickness data as early warning to cope with winter surges. Accessed November 12, 2020. <https://www.england.nhs.uk/2017/12/nhs-uses-sickness-data-as-early-warning-to-cope-with-winter-surges/>
15. Curtis S, Fair A, Wistow J, Val D V., Oven K. Impact of extreme weather events and climate change for health and social care systems. *Environ Heal A Glob Access Sci Source*. Published online 2017. doi:10.1186/s12940-017-0324-3
16. Vrhovec J, Tajnikar M. Population ageing and healthcare demand: The case of Slovenia. *Health Policy (New York)*. Published online 2016. doi:10.1016/j.healthpol.2016.09.007
17. Whaley CM, Bollyky JB, Lu W, et al. Reduced medical spending associated with increased use of a remote diabetes management program and lower mean blood glucose values. *J Med Econ*. Published online 2019. doi:10.1080/13696998.2019.1609483
18. Personal Health Record user needs, accessibility and buy-in - NHS Digital. Accessed November 12, 2020. <https://digital.nhs.uk/services/personal-health-records-adoption-service/personal-health-records-adoption-toolkit/initiating-a-personal-health-record/how-to-understand-your-personal-health-record-users#how-to-make-your-phr-accessible>
19. Flaumenhaft Y, Ben-Assuli O. Personal health records, global policy and regulation review. *Health Policy (New York)*. Published online 2018. doi:10.1016/j.healthpol.2018.05.002
20. Jongbloed K, Parmar S, van der Kop M, Spittal PM, Lester RT. Recent Evidence for Emerging Digital Technologies to Support Global HIV Engagement in Care. *Curr HIV/AIDS Rep*. Published online 2015. doi:10.1007/s11904-015-0291-7
21. Goldzweig CL, Orshansky G, Paige NM, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency and attitudes, a systematic review. *Ann Intern Med*. Published online 2013.

Bibliography

22. Garg S, Williams NL, Ip A, Dicker AP. Clinical Integration of Digital Solutions in Health Care: An Overview of the Current Landscape of Digital Technologies in Cancer Care. *JCO Clin Cancer Informatics*. Published online 2018. doi:10.1200/cci.17.00159
23. Dilnot A. The Report of the Commission on Funding of Care and Support. Fairer Care Funding. Published online 2011.
24. Rahimi K. Digital health and the elusive quest for cost savings. *Lancet Digit Heal*. Published online 2019. doi:10.1016/S2589-7500(19)30056-1
25. Ellimoottil C, An L, Moyer M, Sossong S, Hollander JE. Challenges and opportunities faced by large health systems implementing telehealth. *Health Aff*. Published online 2018. doi:10.1377/hlthaff.2018.05099
26. Alami H, Gagnon M-P, Fortin J-P. Digital health and the challenge of health systems transformation. *mHealth*. Published online 2017. doi:10.21037/mhealth.2017.07.02
27. Fast track review guidance for COVID-19 studies - Health Research Authority. Accessed November 19, 2020. <https://www.hra.nhs.uk/covid-19-research/fast-track-review-guidance-covid-19-studies/>
28. EY. Realising the Value of Health Care Data: A Framework for the Future.
29. NHS digital, data and technology standards - NHS Digital. Accessed November 19, 2020. <https://digital.nhs.uk/about-nhs-digital/our-work/nhs-digital-data-and-technology-standards>
30. Mandel JC, Kreda DA, Mandl KD, Kohane IS, Ramoni RB. SMART on FHIR: A standards-based, interoperable apps platform for electronic health records. *J Am Med Informatics Assoc*. Published online 2016. doi:10.1093/jamia/ocv189
31. Warren LR, Clarke J, Arora S, Darzi A. Improving data sharing between acute hospitals in England: An overview of health record system distribution and retrospective observational analysis of inter-hospital transitions of care. *BMJ Open*. Published online 2019. doi:10.1136/bmjopen-2019-031637
32. Spinelli WM, Fernstrom KM, Britt H, Pratt R. Seeing the patient is the joy:: A focus group analysis of burnout in outpatient providers. *Fam Med*. Published online 2016.
33. Survey finds biopharma companies lag in digital transformation | Deloitte China | Life Sciences & Health Care. Accessed November 19, 2020. <https://www2.deloitte.com/cn/en/pages/life-sciences-and-healthcare/articles/survey-finds-biopharma-companies-lag-in-digital-transformation.html>
34. Safi S, Thiessen T, Schmailzl KJG. Acceptance and resistance of new digital technologies in medicine: Qualitative study. *J Med Internet Res*. Published online 2018. doi:10.2196/11072
35. MacLure K, Stewart D. A qualitative case study of ehealth and digital literacy experiences of pharmacy staff. *Res Soc Adm Pharm*. Published online 2018. doi:10.1016/j.sapharm.2017.07.001
36. Abdelhamid M, Gaia J, Sanders GL. Putting the focus back on the patient: How privacy concerns affect personal health information sharing intentions. *J Med Internet Res*. Published online 2017. doi:10.2196/jmir.6877
37. Ghafur S, Van Dael J, Leis M, Darzi A, Sheikh A. Public perceptions on data sharing: key insights from the UK and the USA. *Lancet Digit Heal*. Published online 2020. doi:10.1016/S2589-7500(20)30161-8
38. O'Connor S, Hanlon P, O'Donnell CA, Garcia S, Glanville J, Mair FS. Understanding factors affecting patient and public engagement and recruitment to digital health interventions: A systematic review of qualitative studies. *BMC Med Inform Decis Mak*. Published online 2016. doi:10.1186/s12911-016-0359-3
39. Choi SJ, Johnson ME, Lehmann CU. Data breach remediation efforts and their implications for hospital quality. *Health Serv Res*. Published online 2019. doi:10.1111/1475-6773.13203
40. Te Mana Raraunga. Our Data, Our Sovereignty, Our Future. Accessed November 19, 2020. <https://www.temanararaunga.maori.nz/>
41. Tiffin N, George A, Lefevre AE. How to use relevant data for maximal benefit with minimal risk: Digital health data governance to protect vulnerable populations in low-income and middle-income countries. *BMJ Glob Heal*. Published online 2019. doi:10.1136/bmjgh-2019-001395
42. NHS Providers. Accelerating digital. Published 2020. Accessed November 19, 2020. <https://nhsproviders.org/topics/covid-19/coronavirus-member-support/emerging-practice-and-innovation/accelerating-digital>
43. Neves A, Lygidakis H, Fontana G. The technology legacy of COVID-19 in primary care. *bjgp life.com*. Accessed November 16, 2020. <https://bjgp life.com/2020/04/15/the-technology-legacy-of-covid-19-in-primary-care/>
44. Hayes DF, Markus HS, Leslie RD, Topol EJ. Personalized medicine: Risk prediction, targeted therapies and mobile health technology. *BMC Med*. Published online 2014. doi:10.1186/1741-7015-12-37

Bibliography

45. Monahan J, Skeem JL. Risk Assessment in Criminal Sentencing. *Annu Rev Clin Psychol*. Published online 2016. doi:10.1146/annurev-clinpsy-021815-092945
46. Lum K, Isaac W. To predict and serve? Significance. Published online 2016. doi:10.1111/j.1740-9713.2016.00960.x
47. Borgesius F. Discrimination, Artificial Intelligence, and Algorithmic Decision-Making.; 2018.
48. Calmon FP, Wei D, Vinzamuri B, Ramamurthy KN, Varshney KR. Optimized pre-processing for discrimination prevention. In: *Advances in Neural Information Processing Systems*. ; 2017.
49. Schulte F, Fry E, Shulte F, Fortune EF. Death By 1,000 Clicks: Where Electronic Health Records Went Wrong. *Kaiser Heal News*. Published online 2019.
50. Estacio EV, Whittle R, Protheroe J. The digital divide: Examining socio-demographic factors associated with health literacy, access and use of internet to seek health information. *J Health Psychol*. Published online 2019. doi:10.1177/1359105317695429
51. Orłowski S, Lawn S, Matthews B, et al. The promise and the reality: a mental health workforce perspective on technology-enhanced youth mental health service delivery. *BMC Health Serv Res*. Published online 2016. doi:10.1186/s12913-016-1790-y
52. Smith B, Magnani JW. New technologies, new disparities: The intersection of electronic health and digital health literacy. *Int J Cardiol*. Published online 2019. doi:10.1016/j.ijcard.2019.05.066
53. Lucas PJ, Robinson R, Treacy L, Nesta A. What Is Data Poverty?; 2020.
54. Huh J, Koola J, Contreras A, et al. Consumer Health Informatics Adoption among Underserved Populations: Thinking beyond the Digital Divide. *Yearb Med Inform*. Published online 2018. doi:10.1055/s-0038-1641217
55. Filkins BL, Kim JY, Roberts B, et al. Privacy and security in the era of digital health: What should translational researchers know and do about it? *Am J Transl Res*. Published online 2016.
56. Ghafur S, Kristensen S, Honeyford K, Martin G, Darzi A, Aylin P. A retrospective impact analysis of the WannaCry cyberattack on the NHS. *npj Digit Med*. Published online 2019. doi:10.1038/s41746-019-0161-6
57. McCoy TH, Perlis RH. Temporal trends and characteristics of reportable health data breaches, 2010-2017. *JAMA - J Am Med Assoc*. Published online 2018. doi:10.1001/jama.2018.9222
58. Gabriel MH, Noblin A, Rutherford A, Walden A, Cortelyou-Ward K. Data Breach Locations, Types, and Associated Characteristics Among US Hospitals. *Am J Manag Care*. Published online 2018.
59. Downey A. Clinicians told they can use WhatsApp to share data in face of Covid-19. Accessed November 19, 2020. <https://www.digitalhealth.net/2020/03/clinicians-told-they-can-use-whatsapp-to-share-data-in-face-of-covid-19/>
60. COVID-19 Cyber Threats: Hackers Target DNS Routers, Remote Work. Accessed November 19, 2020. <https://healthitsecurity.com/news/covid-19-cyber-threats-hackers-target-dns-routers-remote-work>
61. Hackers Target WHO, COVID-19 Research Firm with Cyberattacks. Accessed November 19, 2020. <https://healthitsecurity.com/news/hackers-target-who-covid-19-research-firm-with-cyberattacks>
62. O'brien N, Martin G, Durkin M, Ghafur S. SAFEGUARDING OUR HEALTHCARE SYSTEMS A GLOBAL FRAMEWORK FOR CYBERSECURITY SAFEGUARDING OUR HEALTHCARE SYSTEMS A GLOBAL FRAMEWORK FOR CYBERSECURITY Report of the Leading Health Systems Network 2020.
63. Is it right to use AI to identify children at risk of harm? | Society | The Guardian. Accessed November 16, 2020. <https://www.theguardian.com/society/2019/nov/18/child-protection-ai-predict-prevent-risks>
64. Interoperability services – e-Estonia. Accessed November 27, 2020. <https://e-estonia.com/solutions/interoperability-services/>
65. Moffitt T, McDowell A. New Zealand's Integrated Data Infrastructure: Linking data for better science and policy. *Administrative Data Research UK*. Published 2019. Accessed January 5, 2021. <https://www.adruk.org/news-publications/news-blogs/new-zealands-integrated-data-infrastructure-linking-data-for-better-science-and-policy-123/>
66. Data Sharing and Release Reforms | Department of the Prime Minister and Cabinet. Accessed November 27, 2020. <https://www.pmc.gov.au/public-data/data-sharing-and-release-reforms>
67. United Nations Department of Economic and Social Affairs. E-Government Survey 2020 Digital Government in the Decade of Action for Sustainable Development With Addendum on COVID-19 Response.

Bibliography

68. Copeland E. Beyond the crisis: How might local government build a positive legacy after Covid? Medium. Published April 19, 2020. Accessed January 6, 2021. <https://medium.com/loti/beyond-the-crisis-how-local-government-can-build-a-positive-legacy-after-covid-3ac6e3d32a24>
69. Government Data Quality Hub O of NS. The Government Data Quality Framework. Published December 3, 2020. Accessed January 6, 2021. <https://www.gov.uk/government/publications/the-government-data-quality-framework/the-government-data-quality-framework>
70. Williams S. Building the public sector's data science capability. UK Auth. Published online December 17, 2020. Accessed January 6, 2021. <https://www.ukauthority.com/articles/building-the-public-sectors-data-science-capability/>
71. Spark DPS - CCS. Accessed January 6, 2021. <https://www.crowncommercial.gov.uk/agreements/RM6094>
72. Go2Gov SA | business.gov.au. Accessed January 6, 2021. <https://business.gov.au/Grants-and-Programs/Go2Gov-SA>
73. Government Business Council and EY. Transforming Government From Aspiration to Transformation: Insights from Public Sector Leaders.; 2019.
74. Social Impact Investment. OECD; 2015. doi:10.1787/9789264233430-en
75. MADURO M, PASI G, MISURACA G. Social Impact Investment in the EU. Financing Strategies and Outcome Oriented Approaches for Social Policy Innovation: Narratives, Experiences, and Recommendations.; 2018. doi:10.2760/159402
76. Government Outcomes Lab U of O. Social impact investing. Accessed November 27, 2020. https://golab.bsg.ox.ac.uk/the-basics/social-impact-investing/#what-is-social-impact-investment__why-is-social-investment-used-in-contracts-for-the-delivery-of-public-services-or-social-interventions
77. EY UK. UK public sector driving strategic value with intelligent automation. Published July 24, 2020. Accessed January 6, 2021. https://www.ey.com/en_uk/intelligent-automation/uk-public-sector-driving-strategic-value-with-intelligent-automation
78. EY. How Will You Design Information Architecture to Unlock the Power of Data?
79. Family & Community Services NSWG. The co-design process - ChildStory. Accessed January 6, 2021. <https://facs-web.squiz.cloud/about/reforms/children-families/childstory/chapters/co-design-process>



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