

Mission: ‘patient centricity’

How technology can help achieve personalised care for rare disease patients

The following white paper summarises the findings of research conducted by PwC as commissioned by Takeda and is complimented by an interview with Chris Easton, Global Commercial Lead at Takeda. All opinions and statements express personal views of the authors.



Introduction

Personalised health and digital solutions provide the potential to drive enhanced outcomes while improving the patient and HCP experience. The benefits of these solutions are being realised in several therapeutic areas but the progress in others, such as rare bleeding disorders, is lagging behind.

In this whitepaper, PwC sits down with Takeda's Chris Easton to gain insights into Takeda's efforts to drive towards personalised health and digital solutions in rare bleeding disorders and how Takeda might approach their development. Following this, PwC and Takeda jointly explore the core building blocks for successful personalised health solutions and examine how these solutions could be leveraged for rare bleeding disorders.





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Changing the way patients

manage their diseases

Chris Easton – Senior Director, Global Commercial Lead: Personalised Health Strategy for Takeda – sat down with Chris Isler – Senior Executive Advisor at PwC – to give his opinion on the role of personalised health and digital solutions in rare bleeding disorders and discuss the results of a joint whitepaper. What follows is an excerpt from their discussion and the full whitepaper.



Interviewee

Chris Easton

Senior Director, Global Commercial Lead
Takeda

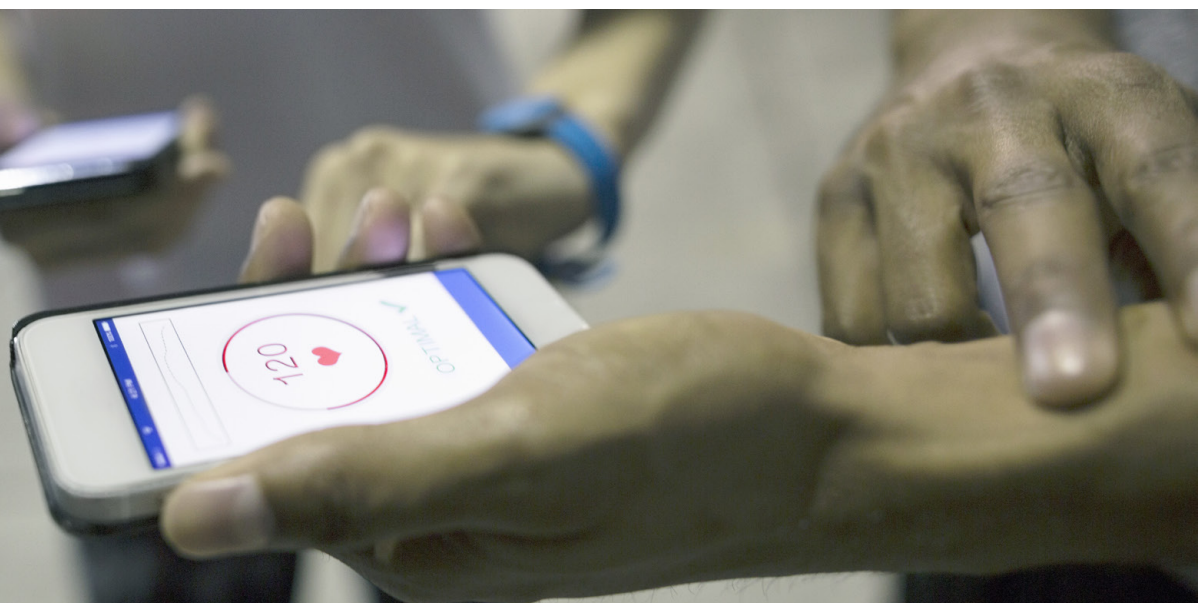


Interviewer

Chris Isler

Senior Executive Advisor
PwC

Chris Easton is a Senior Director, Global Commercial Lead and member of the Global Rare Hematology Franchise Leadership Team at Takeda; where he leads Personalised Health Strategy via creative ideation, insight generation and drives end-to-end delivery of innovative services, platforms and partnerships that may improve patient outcomes.



PwC Interview with Takeda:

Personalised health and digital solutions

How does Takeda define personalised digital solutions? How are they changing the way patients manage their disease?

Takeda's approach to personalised health and digital solutions is to focus on developing a platform or ecosystem that builds connectivity and communication to allow patients flexibility to interact in a way that suits them. What's important is that the solution should provide a better experience for patients. This encourages them to engage, which will generate more data, and ultimately

deliver better outcomes. A key benefit of personalised healthcare solutions is that they support not only the therapy and clinical outcomes, but also the wider needs of the patient, HCP and payer – whether that's the generation of real-world evidence or a more complete service package for the patient. An example of this would be supporting the management of chronic pain or mental health on top of drug therapy.

For rare blood disorders, personalised health and digital solutions are less well utilised. What benefit do you think they can provide in this therapeutic area?

The first thing to note is that there hasn't been huge digital innovation in the rare bleeding disorder space compared with other therapeutic areas, such as diabetes. There have been transformative steps around PK modelling to build a more personalised approach to factor therapy, but the

journey towards personalisation is still being defined. It's important that Takeda learn from other therapeutic areas what works in personalised care. Takeda can then leverage what solutions exist to make a difference for rare bleeding disorder patients. We don't want to reinvent the wheel.

In recent years there has been a push towards gene therapy and non-factor approaches, including at Takeda. What impact will this have on the need for personalised health and digital solutions?

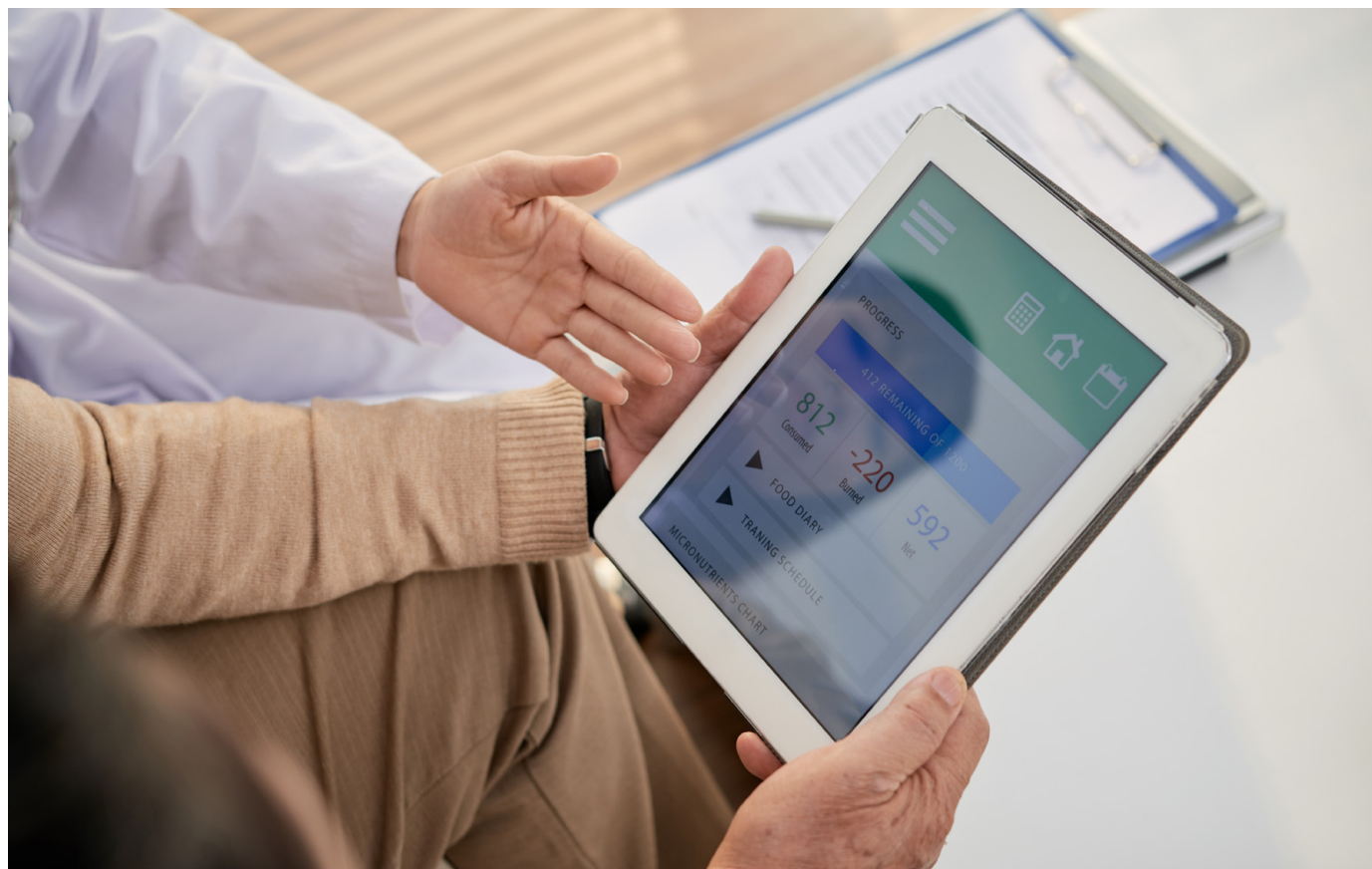
In my opinion, there is perhaps a misconception that gene therapy will be the 'cure'. I still believe it will be innovative and bring huge benefit to patients, but I also think there will be the need to maintain a holistic approach and provide all patients with meaningful personalised services. Even for gene therapy patients, there will still be a patient journey that personalised health and digital solutions can add value to.

If I think about the Takeda pipeline, it's important to establish now what works and what doesn't in terms of personalised health solutions. Takeda can then make sure that the solutions are integrated into the delivery of the pipeline project at an early stage. We need to prove and establish the technology so it becomes an expectation for future pipeline products.

How important do you think passive data capture is, and how do think this will benefit rare bleeding disorder patients?

For me, passive data capture is one of the top things to master when developing digital solutions. If I think back to old analogue systems or early digital solutions that asked patients to fill out calendars and enter all their own data, there was a huge data drop-off and patients just didn't stick with it. Passive data capture can collect all this information in the background, for example bio-parameters like factor

level, or movement and health data. It significantly reduces the burden on patients to avoid the data drop-off. There will still be a requirement for some manual patient validation, but the data can be captured and collated passively for the patient to cross-reference or validate. For Takeda, it's very important to integrate passive data capture into personalised care solutions.



You mentioned that not all data can be captured remotely. How do you think digital solutions can keep patients engaged to capture additional data?

To understand how to engage patients, Takeda must first understand their behaviours. Different patients will respond to gamification, rewards and nudges in different ways. We need to personalise the solutions and find a balance for patients; for some it may be about rewards for compliance, for others it might be more gamification. What this whitepaper has confirmed for us is the use of bite-sized sessions. If I look at successful solutions in the medical and non-medical worlds, people want on-demand access that can be consumed in quick sessions.

Takeda could use intelligent software to personalise any microcontent and microlearning to utilise nudges, gamification and rewards in a way that takes patients' behaviour into account.

Another aspect to keep in mind is the need to evolve solutions as patients change – both in terms of moving with them through life, and as trends change in society. The patient journey becomes the consumer journey. Takeda needs to consider the behaviours people have and how these can change. We can use technology to help us do this.

We have spoken about collecting RWD and keeping patients engaged. How can Takeda use these data and personalise the experience to add value for patients?

The most important thing is to demonstrate to patients the value we're generating with their data. Takeda needs to show we're using it in a meaningful way, for example generating digital biomarkers to become more predictive. The research has shown that this will help reduce patient concerns around data sharing. Experience from other therapeutic areas has shown that coaching, whether delivered via a human or an AI-driven coach, is a

powerful tool to personalise treatment. What's important is that any coaching functionality learns from the patient data and enable patients to set goals, and then help them achieve those goals. Coaching is also a great tool for education. It can link together data and outcomes to inform patients, who then seek a more individualised approach that may improve adherence and produce better outcomes.

With a lot of patient care moving into a digital space, how do you think remote patient care needs to support this?

Covid-19 has given us examples of how patient care can be provided remotely, with online group meetings, training and support. For Takeda, patient care is about finding the balance and link between remote and online care: reviewing generated data and making

decisions using online communication tools. This communication can be with the whole multidisciplinary care team if required. That could include physiotherapy, mental health and/or coaching support; it's not just about the therapy regimen.

We have discussed many of the benefits that personalisation using digital solutions can have for patients, but with payers increasingly looking to improve outcomes and reduce costs, what benefits can Takeda provide for them using personalised solutions?

For payers, it's all about outcomes. Personalisation should support better outcomes. If Takeda can generate the data to show that personalisation drives better outcomes, including better adherence, reduced long-term costs and also the clinic performance and efficacy of a multidisciplinary team, then we can better respond to the needs of the patients and the healthcare system.

If Takeda focuses on improving outcomes for patients by taking a holistic approach, using personalised health and digital solutions to their optimum, this should demonstrate value to payers.

What is the role for Takeda (Pharma) in this space?

Takeda should take on the role of the conductor. It's about having a clear strategy and identifying the right partners in the health technology, patient engagement and consumer space. Our role should be to identify existing solutions from other therapeutic areas, connect with these partners, and build the ecosystem to scale and pull

these solutions into the rare bleeding disorder community to bring value to patients. If a solution doesn't exist in another therapeutic area then we can build this; but as there is a lot of great technology and platforms out there, it makes sense to collaborate with them and not have to work from the ground up.

Takeda puts a strong emphasis on its Takeda-ism values – how do these values guide your efforts towards creating such a personalised care ecosystem?

Takeda's values build the foundation of the work we do in personalised care. As an example: Our first value is to **put the patient at the centre**, hence orchestrating a care ecosystem built around the patient, incorporating lifestyle and personality needs, rather than pushing it on the patient. This needs to be closely linked to our second value **building trust with society**.

Interacting more closely with patients puts a strong responsibility on Takeda, for example when it comes to the way we deal with patient data. Here we need to focus on driving personalisation with full transparency on how we treat personal data and how we ensure full compliance with all applicable privacy regulations.

What will it take to succeed and realise the value for personalised digital solutions?

To succeed in this area, Takeda needs to be a pathfinder and trailblazer. We need to be brave and create an innovative, fail-fast culture that connects different partners and technologies and is willing to adapt, drop or take on new approaches to deliver value to patients and all stakeholders quickly. Takeda needs

to invest in areas that generate actionable data that we can, and do, use. If we can do all this, we can start to show the value personalised health and digital solutions can bring to patients, caregivers, HCPs and payers. Appropriate use of data has the power to advance outcomes.

Mission ‘patient centricity’: how technology can help achieve personalised care for rare disease patients – insights from rare blood disorders

Addressing the increasing complexity of disease management requires novel and personalised solutions

Managing a disease and keeping up with a treatment and lifestyle regimen¹ can be complex for many patients and caregivers, and can contribute towards growing concerns about low patient adherence and the negative impact on outcomes. Alongside this, many payers and providers are moving away from the one-size-fits-all model and embracing more personalised treatments supported by technology. Which then again adds new complexities such as how to ensure personal data is collected and used in a fully compliant and transparent manner. For these reasons, personalisation of care using digital solutions is becoming an integral part of care for disease management. Highly prevalent diseases such as diabetes have seen a strong push towards personalised digital solutions in recent years, while rare disease, and rare blood disorders more specifically, have not seen the same developments.

Market research suggests that personalised digital solutions provide value for rare bleeding disorder patients and caregivers² across the care pathway, from diagnosis and treatment selection to management of the disease and symptoms. Interviews with patients and caregivers, combined with social media listening³, have revealed that rare blood disorder patients do not see their care as personalised, and managing their disease can cause anxiety and stress and negatively impact their quality of life. In addition, payers are increasingly looking to reduce costs and improve outcomes. Our analysis of digital health trends and feedback from digital health experts⁴ support the shift towards combining digital tools and services with traditional therapy, with the aim of delivering a more patient-centric experience.

Rare blood disorders have yet to fully harness the value digital personalised care solutions can provide in terms of patient adherence, quality of life, generation of real-world evidence and improving medical and non-medical outcomes. The current landscape for digital solutions in rare blood disorders is fragmented, with no clear leaders or ecosystem in place. Our research into current digital solutions has revealed that novel health technologies are less prevalent in rare blood disorders, and that fewer of the emerging technology players focus on rare conditions with low patient numbers. There has also been an increased focus on more curative gene therapy and non-factor approaches, but our discussion with experts suggests digital personalised solutions may still be required alongside these new technologies.


To understand how personalised solutions can provide value for patients and caregivers in rare blood disorders, we should first explore what elements are employed by solutions in more mature therapeutic areas including diabetes, cardiovascular disease, oncology, mental health and chronic pain. Over the course of our research and expert interviews, the key themes and elements were categorised into several building blocks:

1	Passive data capture
2	Gamification, nudges and microcontent
3	Coaching, AI-generated insights and HCP management
4	Remote patient care

This report will provide analysis on each of the building blocks, including success stories from other therapeutic areas, benefit to patients, caregivers, HCPs and payers, and applicability to rare blood disorders. This report will also include analysis on how to build these personalised digital solutions and the role of partnerships and a clear ecosystem.

Passive data collection to enable personalisation of care

Passive data collection should be the foundation of any digital personalised care solution, as it provides the data needed to drive other features and initiatives such as AI and predictive algorithms, coaching, disease tracking and population management. Our discussions with industry leaders in digital health strongly support the importance of generating real-world patient data to provide information for data analytics and AI-generated insights to facilitate the personalisation of care. Passive data capture is designed to make it as easy as possible for patients to gather and share their data with little or no input by using connected devices, wearables and smartphone-based approaches. Passive data capture allows a consistent approach with less burden placed on the patient or caregiver – a key driver when it comes to integrating a solution into a patient’s daily routine and generating real-world data.



Examples of passive monitoring solutions in other therapeutic areas

- Smart injectors that automatically log injections and upload to a linked app
- Smart insoles that track and upload gait information to monitor patients' movement
- Connected smart scales that can log multiple health indicators
- Continuous glucose monitoring devices to track blood glucose levels passively
- Motion tracking via a smartphone to analyse movement during physical therapy to evaluate performance and health



Wearables and sensors are the enabling technology that provides data for AI and machine learning to personalise care.

Rani Shifron, CEO, Healthier Globe

Passive data capture is widely used in other therapeutic areas, including the evolution of digital biomarkers in clinical trials for incorporation into mature offerings for digital personalised care solutions.

Generating outcome data is an additional benefit of passive data capture. Outcome measurement is important to not only keep patients motivated and HCPs informed, but also to support discussions with payers and demonstrate treatment effectiveness. Our research and interviews highlighted that payers are increasingly looking to move beyond clinical-trial-supported efficacy claims and establish data collection and analytics capabilities to measure outcomes, generate insights and reduce costs. Pharma companies must therefore demonstrate added value (improved adherence, Rx cost reduction, reduced work absence, etc.).

Passive data collection is currently not widely leveraged in rare blood disorder solutions, but many of the key features utilised in the examples could be applied successfully. Motion coaching that tracks patients during physical therapy could be used to monitor joint health over time, while movement and gait tracking using a smart insole could provide data to detect deterioration in joint health. Passive linking with a patient's calendar could help match physical activity with pain protectors and triggers. Smart injectors could link to a disease management app to automatically log factor injections without manual input, providing an accurate adherence picture over time. Blood monitoring, which could be paired with injection tracking, could be used to detect blood biomarkers for bleed identification and monitor the coagulation factor level.

Gamification, rewards and microcontent: interactive approaches to maintaining patient engagement

Patient adherence with a treatment regimen is a major challenge for many pharmaceutical companies, as it can severely affect outcomes.⁵ Personalised digital solutions are resolving these issues by achieving behavioural change using innovative and interactive solutions that utilise gamification, rewards, nudges and focused microcontent to better integrate into patient routines and make interactions more beneficial for patients.

Gamification and rewards can be used to incentivise patients by using nudge theory to positively reinforce patient compliance with a treatment regimen to improve overall adherence. Focused microcontent can be used for either education or treatment sessions, for example physical therapy, to develop content that can be consumed on demand in bite-sized sessions to integrate into a patient's routine. Personalisation can further enhance these approaches by tailoring the experience to individuals or groups of patients.

Solutions that draw on these methods to increase patient engagement can provide additional real-world evidence and PRO (patient-reported outcome) data by creating a more interactive environment for patients to record data when passive data collection is not possible. Overall, the benefits of using interactive and engaging content by way of gamification, rewards, nudges and microcontent can drive improved outcomes by increasing patient adherence, educating patients and increasing patients' interaction with their disease and treatment.^{6,7,8}



We often underestimate the importance of understanding patient behaviours and how they will react and use technology. This is one of the reasons we haven't seen large adoption in the mass market.

Michael Morgan-Curran, Chief Clinical Officer and Digital Technologist, MyCognition



Examples of interactive solutions used in other therapeutic areas

- Goal-setting and continuous feedback that uses patient-collected data to demonstrate progress and motivate patients
- Free online video game to educate patient on their disease and the importance of adhering to treatment schedules
- Partnerships with entertainment organisations (e.g. Nintendo) to provide rewards schemes for complying with a treatment regimen
- Library of on-demand microcontent on focused topics, for example how to inject, that can be accessed as part of a disease management app
- Short physical therapy sessions that draw exercises from a library and personalise them based on patient-centric criteria



Coaching, AI-generated insights and HCP management solutions in other therapeutic areas

- Continuous uploading of blood sugar and biomarker data for coaches to link changes in diet and lifestyle to disease outcomes in daily or weekly updates
- Patient management tool using AI to flag patients with blood sugar outside of a normal range and link to patient's adherence and activities
- Solution using patient reported pain levels to identify pain triggers and protectors and recommend activities to reduce chronic pain

Coaching, AI-generated insights and HCP management: generating value with patient data

Successful personalised care solutions leverage the data gathered via passive collection and other approaches to provide AI-generated insights and coaching to personalise the solution for patients and improve adherence and motivation.^{9,10,11} Coaching is widely used in mature personalised digital solutions, and can perform a range of functions such as motivating patients, monitoring adherence, providing treatment nudges and educating patients on the link between adherence, activities and outcomes. Coaching can be provided by AI-driven or human coaches, but all major solutions utilise patient data to personalise the experience. AI-generated insights can also be used to assist HCPs in patient management by analysing data and using predictive algorithms to flag patients at risk, or with potential for optimisation, and recommending treatment changes.

Sophisticated coaching or AI-driven approaches to disease management are not widely leveraged in digital solutions for rare blood disorders, instead they often provide features similar to an e-diary. Embracing coaching and AI-generated insights may improve outcomes for patients by increasing patient adherence, motivation and education. Harnessing the data collected from patients to enable more effective population management for HCPs will allow adjustments and interventions to be made in a more timely manner to improve outcomes and increase personalisation for patients.



The key is to crack the value proposition for patients and really show the benefit of sharing data... use data to educate patients on the benefits of adherence, use coaching to allow them to see the impact of their behaviour.

Marcelo Duhalde, Vice President, BrightInsight

Remote patient care and connecting multidisciplinary care teams

As digital personalised care solutions become more prevalent, there is greater demand for functionality to enable patient care and coordination of care teams remotely. Along side, interviews with patients and caregiver revealed that travel to treatment centres and lack of remote access to HCPs between clinical visits are significant challenges. These challenges are compounded by the requirement for multidisciplinary care teams in rare blood disorders, as remotely enabling care could be conceived as more complex.

Remote patient care solutions for multidisciplinary care teams provide functionality allowing offline (e.g. messages) and on-line (e.g. virtual sessions) communications channels between patients and their primary HCP, as well as with their multidisciplinary care team if required. The solutions enable patients to share real-world data with their HCP in real time, and can also consolidate patient data for the multidisciplinary care team to review.

Multiple benefits can be realised from successful implementation of a remote patient care solution. From a patient and caregiver perspective, offline and online communications channels enable convenient access to HCPs to optimise treatment, respond to concerns and questions, and share health data without the need to travel to the clinic. For multidisciplinary care teams, remote patient care solutions enable the consolidation and review of real-world patient data to optimise and adjust treatment as required, and review disease and symptom progression over time on a patient and population level. Overall medical and non-medical outcomes would be expected to improve thanks to increased patient motivation and adherence as well as greater personalisation and optimisation of treatment from the analysis of real-world data between clinic visits.

Remote patient care solutions are not widely available in current digital solutions for rare blood disorders. Functionality from existing solutions could be leveraged to expedite this process.

Generating value for all stakeholders

The focus of the above-mentioned building blocks is to provide patients with new solutions and experiences to enable a more personalised approach to disease management. Alongside the benefits to patients, technology-enabled solutions provide valuable evidence and insight generation capabilities to deliver value for multiple healthcare stakeholders.

For payers, information on adherence, outcomes, cost reduction and quality of life can be a source of evidence to improve outcomes and control costs, while also providing an understanding of patient behaviours. Comprehensive personalised care solutions may support outcome-based approaches (clinical and non-clinical outcomes can be included) that can only be established if sufficient data generation mechanisms

Examples of remote patient care in other therapeutic areas

- Providing instant messaging and secure video conference capabilities to connect patients to their multidisciplinary care teams
- Functionality to collect and share patients' health data with their care team in real time
- Consolidation of patient data and presentation of data in secure video conferencing for multidisciplinary care teams to review
- Family and caregiver access, e-prescriptions and medication management for holistic remote solutions



The future involves ecosystems where all parties will have a part to play, from pharma to technology companies and payers. We do not see a lot of this currently.

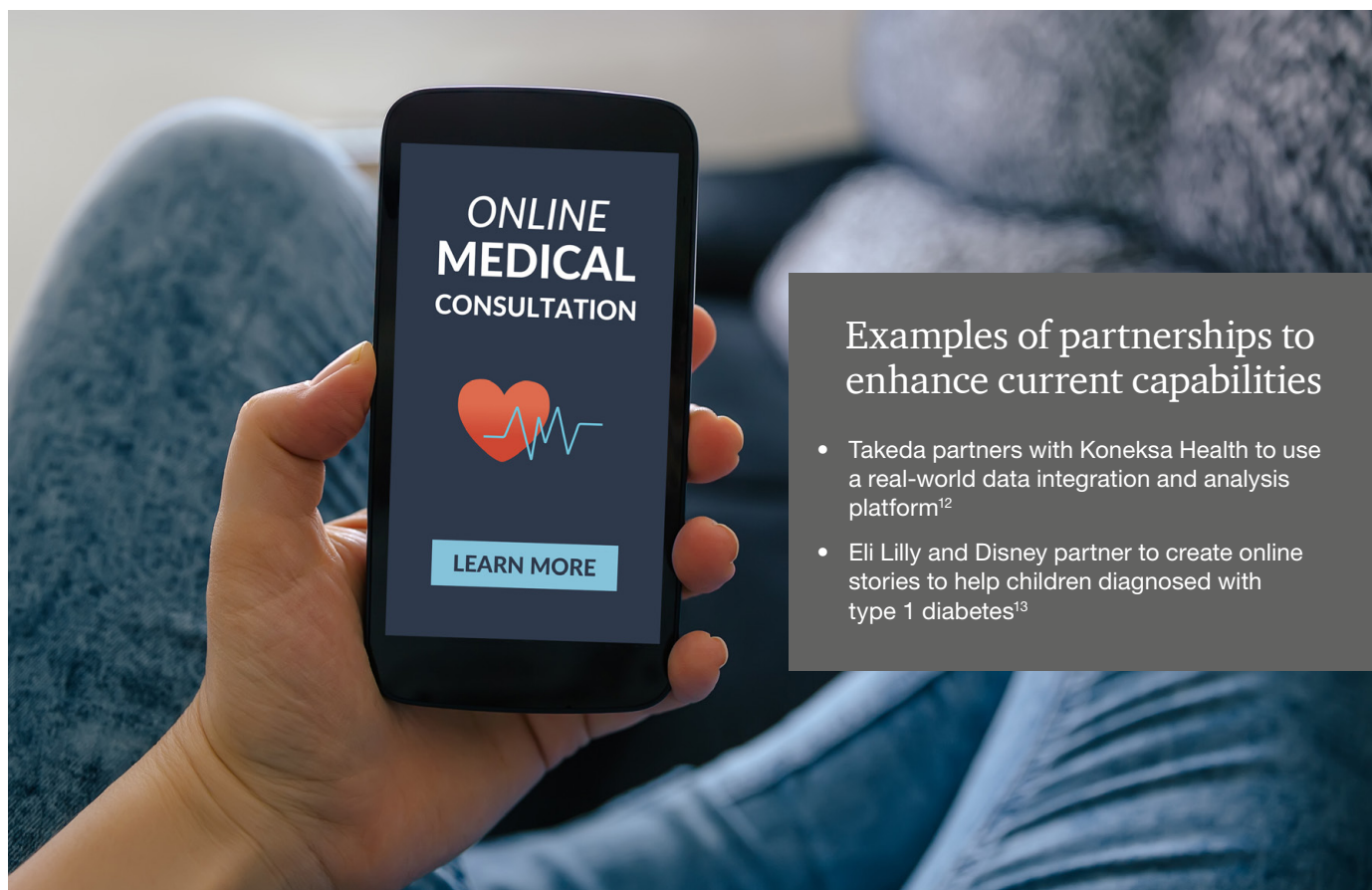
Rani Shifron, CEO, Healthier Globe

are in place. For HCPs and healthcare providers, personalised care solutions give greater transparency on a patient's condition between clinic visits, and could in the future inform treatment adjustments and actionable updates for great population control.

Collecting real-world data from rare blood disorder patients is an opportunity to further understand the whole therapeutic area, and could inform future R&D efforts and treatment protocols to give further benefit to patients in the long term.

Considerations for developing digital personalised care solutions

Developing personalised care solutions encompassing the building blocks highlighted in this report requires different approaches and considerations than traditional drug development. This is in part due to the different capabilities needed to develop digital solutions. It is also due to the direct to customer (patient, HCP and payer) relationships and the need for more immediate integration into patient routines.



Examples of partnerships to enhance current capabilities

- Takeda partners with Koneksa Health to use a real-world data integration and analysis platform¹²
- Eli Lilly and Disney partner to create online stories to help children diagnosed with type 1 diabetes¹³

When developing personalised digital solutions, pharma should:

- Create ecosystems and platforms to enable a flexible, modular approach that can provide different solutions and features depending on the customer need
- Leverage partnerships to repurpose solutions and technologies that are successful in other therapeutic areas to bring value to patients quickly
- Establish innovative partnerships with non-pharma organisations to generate novel solutions that can help patients and caregivers normalise their disease and treatment regimen to create significant added value outside medical intervention
- Develop data collection, governance and access systems in compliance with data privacy requirements
- Create and manage the ecosystems to improve customer relationships and experience while utilising partnerships to own patient level data and provide functionality, features and aggregated data as required.

Before a successful ecosystem can be created, you have to establish a clear partnership strategy. This includes understanding the parts of the ecosystem you own and what you want your partner to provide. Considering where the digital solution will fit into the care pathway and the level of integration required are vital to the success and scalability of a solution. Without a clear partnership strategy, you are likely to invest in technology and solutions that don't fit into an overall vision or aren't scalable.



In personalised care you need capabilities to collect actionable patient data and analyse it. Partnering will enable this, as not many organisations have the capabilities to work with and collect data.

Lou Pillai, Chief Digital Officer, Immunomedics

Overall, successfully developing personalised digital care solutions could reduce the complexity of managing a disease and treatment regimen in a variety of therapeutic areas. Through our research and expert interviews, PwC and Takeda have delineated the key building blocks that combine to produce successful digital solutions that add value for patients, caregivers, HCPs and payers. These building blocks can be repurposed and leveraged to develop solutions to benefit rare blood disorder patients.

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Further reading

- European Commission conclusions on personalised medicine for patients
- European Commission study on Big Data in public health, telemedicine and healthcare



Contacts

PwC
Birchstrasse 160
Postfach, 8050 Zürich



William Nye
Manager, Pharma and LifeScience
Consulting, PwC Switzerland

+41 75 434 93 65
william.nye@pwc.ch



Mylène Jeandupeux
Director, Pharma & digital health
PwC Switzerland

+41 58 792 15 71
mylene.jeandupeux@pwc.ch

Takeda
Thurgauerstrasse 130
8152 Glattpark (Opfikon)



Chris Easton
Senior Director, Global Commercial Lead
Takeda

+41 79 776 60 08
chris.easton@takeda.com

Contributors

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For more information

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