



A guide for embracing digital health technology and big data through value-based partnerships with all Belgian players

Insights from the round table held on March 14, 2022 on proposals and recommendations for a checklist and roadmap for value-based partnership implementation

Report

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Colophon

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Executive Summary

Context and aim of this round table report

To date, Belgian healthcare has been pharma-centric: focused on product differentiation, partnering with health care providers, and pricing strategies to increase patient access to drugs. Today, this focus is shifting to place more value on patient and payers outcomes, using outcome-based pricing through value-based contracting, improving patient outcomes and payer capacity.

The aim of this report is to provide guidance on how to deliver shared value in the Belgian healthcare system by encouraging and implementing shared-value partnerships in digital health technology and big data projects.

This report defines a framework to create value-based partnerships using digital health technology and big data that allows all stakeholders to work collaboratively and create shared value together. An initial digital health survey was carried out to investigate the impact of digitalization on daily clinical practice, which revealed a demand for support from data and AI tools to improve quality of care for patients. A multi-stakeholder round table was formed of Belgian medical, research experts but also a Data Privacy Officer, etc. During this multi-stakeholder round table 3 main topics were discussed: the challenges and hurdles that need to be addressed to create value for all, a checklist was established to define the minimal criteria for value-based partnerships and finally a roadmap of the crucial steps to realize such shared value for all.

Current challenges to partnering

Healthcare providers and hospitals are suspicious of big data companies using sensitive medical data for unethical means. Added to this are concerns about GDPR compliance and repercussions for inadequate data protection. These factors together suggest that it is essential to develop a solid real-world data framework that allows maximal access to data (open source?) by encouraging free exchange while respecting privacy to foster trust and improve collaboration between all partners involved in these projects.

There are three main challenges considered in this report which can all be addressed by the creation of a clear framework to define methodology and appropriate incentives, and provide clear roles and responsibilities for all stakeholders.

- Data processing: encouraging data exchange, how to collect, use and re-use data, including how to ensure quality, perform analysis.
- Enabling foundation: how to encourage good data governance & access, including financial incentives, while ensuring privacy & security.
- Creating value for all: how to increase trust between partners through transparent communication, as well as proactively identifying and sharing needs, benefits and risks, creating joint objectives, encouraging government participation, and ultimately ensuring the focus remains on improving patient care.

A framework for creating value-based projects

The checklist below can be used as a tool to support partnering discussions and define the optimal partnering model and lead to more valuable projects.



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The following steps can be used as a road map for building successful value-based partnerships for shared value creation: from identifying a specific need to project implementation and evaluation.



Example cases and pilot suggestions

Value-based partnerships have already been created for cytomegalovirus (CMV and me, CMV at home and CMVai) and Takeda and its partners are currently exploring four visions where partnerships can bring value in thrombotic thrombocytopenic purpura (TTP): early screening, smart diagnosis, collaborating to increase the patient voice and drive research, and creative ways to overcome data scarcity.

In addition, the advisors provide a list of areas that could benefit from the collaboration at the heart of value-based partnerships:

- Prevention
- Early detection / screening
- Early diagnosis
- Zero line
- Dashboards
- Data-enabled support
- Value-based healthcare
- Patient follow-up



1. Context and objective

The aim of the round table roundtable was to discuss how to implement 'shared value partnerships' for digital health technology and big data projects in Belgium. This document provides the key insights from the meeting on March 14, 2022.

Takeda conducted a digital health survey on the impact of digitalization on daily clinical practice. This revealed a demand for data and AI-supported tools and solutions for several applications, to improve quality of care and the clinical practice. As a result, Takeda would like to set up projects with partners based on shared value (so called value-based partnerships).

Data and digital tools have great potential to improve the effectiveness of medical practice and overall quality of care. However, there are specific challenges in their implementation, requiring close collaborations to define appropriate solutions and maximize value for all stakeholders.

The round table was formed to create a how-to guide for value-based partnerships to facilitate multistakeholder projects. The subjects discussed were the key needs and requirements for implementing digital health and big data solutions in Belgium, with a particular emphasis on how to deliver the full potential and value of such projects based on shared value partnerships. In order to support a swift and optimal integration of solutions into medical practice, this board discussed three main items to create shared value and embrace the full potential of data and digital health technology as shown in figure one.



Figure 1: The three key questions that were discussed to embrace the full potential of digital health technology and big data projects

1.1 Defining value-based partnerships

During the round table meeting, it became clear that a new type of partnership will be required to provide a new way of working that ensures that big data and digital health technology is used to its full potential to improve both individual and population health. These value-based partnerships will be best supported with a how-to guide for the various players. This report contains recommendations and an action plan, that can be used as a manual and checklist to set up shared value projects in Belgium. It will be distributed to all participants of the round table.

2. Value-based partnerships

The aim is to contribute consistently to delivering shared value in the healthcare system, with value-based partnerships being the defining element to reach the optimal future state.

Historically, the focus of healthcare has been pharma-centric, focusing on product differentiation (safety, efficacy, etc.), partnering with healthcare providers (HCPs), and using financial pricing strategies to increase patient access. This focus is evolving to place increasing value on patient and payer outcomes, creating an ecosystem based on outcome-based pricing through value-based contracting and solutions to improve patient outcomes and improve payer capacity.

The vision for tomorrow's healthcare consists of value-based partnerships to create shared value. Building on the partnership ecosystem that shares a common purpose of improving population health, patient experiences and healthcare system outcomes, will ultimately achieve sustainability and improve efficiency. This evolution can be seen in figure two.



Figure 2: The proposed evolution of the healthcare system, from pharma-centric to focused on outcomes, to creating value throughout the system.

Value-based¹ partnerships are a new paradigm for global healthcare and healthcare suppliers, with the value being defined as a ratio between outcomes that matter to patients and the cost of delivering those outcomes. This represents a new way of working where partners share risks. Such an approach requires trust between the partners, with openness and honesty about the objectives. Ultimately, the results will be better value for the patients while also benefitting the partners.

To facilitate the shift to a value-based model several digital health solutions could be impactful. For example: early diagnosis of (rare) diseases via artificial intelligence (AI) algorithms could be developed, the detection of treatment outcomes such as response, remission via (digital) biomarkers; as well as remote monitoring of patient outcomes using different telemedicine solutions including several wearables. These digital health solutions will assist in the evaluation of several critical factors, including:

- Treatment tolerability and effectiveness in daily clinical practice
- Epidemiological data on incidence and prevalence
- Burden of illness studies
- Comparative effectiveness of treatment patterns and sequencing
- Safety studies
- Patient quality of life in a real-world setting

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3. Current challenges and opportunities

To ensure the successful implementation of data and digital health technologies, the collection, quality and analysis of data need to be carefully considered. We give more details and advice about how to address the challenges of data processing, initiating the foundation and creating a framework for real-world data to ultimately create value for all stakeholders.

3.1 Data processing

3.1.1 Data collection

The goal and purpose of the data collection is often unclear, and there are many variables, such as the required format and interoperability, or how to deal with increasing data volumes. Electronic health records (EHRs) are an ideal source of real-world data but there are many different systems and formats which adds complexity when setting up data collection and administration. Such data will come from separate silos which need to be combined in order to gain a complete overview. In addition, once data is collected, the legal context of a clinical trial applies, with the associated pros and cons. Non-clinical data may also need to be included in any overview.

3.1.2 Data quality

Often, the quality of data collected retrospectively is insufficient for the required purpose. The lack of standardized data infrastructure can negatively impact data quality and hospitals often lack the financial means to correct this. Furthermore, real-world data is often perceived as less reliable, which means that healthcare providers invest less time in collecting data than in clinical trials.

3.1.3 Data analysis

Customized dashboards are necessary to effectively visualize data for follow-up and monitoring. The culture of monitoring progress is lacking in Belgium, therefore it will be challenging to improve. For example, patients have no access to data on the performance quality of hospitals or care providers, such as mortality rates. Developing multi-stakeholder

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dashboards will provide essential insights into both clinical and non-clinical data.

3.1.4 Future expectations

A clear framework will need to be created in Belgium describing how to collect, use and reuse data, including not only how to ensure data quality and perform data analysis, but also the roles and responsibilities of stakeholders in these data processing steps. One "IT layer" will need to be created above the current electronic patient database (EPD) systems to facilitate data query, extraction and exchange.

3.2 Enabling foundation

3.2.1 Data governance & access

Data governance is often executed at several different levels, e.g. federal, regional or organizational, which makes it difficult to evaluate the whole system. Guidelines are missing that describe how data should be accessed outside of clinical studies. Furthermore, data entry is seen by many HCPs as a burden, not as a solution, due to the complicated procedures for doctors and hospitals to access and enter data. There is also little awareness about the potential of data use for secondary purposes, which could be seen as an added incentive for more complete data collection.

3.2.2 Data privacy & security

There are many legal and ethical considerations surrounding the use of personal data, and an incomplete understanding of regulations such as GDPR can discourage its use. However, patients are usually willing to share their data as long as it is anonymous. Recent innovations with personal data spaces can allow every citizen to have full control over the sharing and use of their data, with granulated opt-ins per data usage request. (e.g. SOLID pods and the We Are initiative²)

3.2.3 Funding & incentives

Prospective data collection is of great value, but entering data in EHRs for use beyond the primary use is not incentivized in the current system. HCPs are not compensated for dealing with data entry administration beyond their routine practice. This means that a compensation mechanism or a dedicated service will need to



be put in place to incentivize the completion of these additional efforts.

3.2.4 Future expectations

A clear framework describing how to organize data governance and access will enable funding and ensure data privacy is maintained, as well as clarify the roles and responsibilities of stakeholders. A cohesive legal guidance framework will ensure that all stakeholders interpret GDPR in a consistent and compliant way for data re-use. This will require a common data access model for all hospitals in Belgium, to be established by a Data Access Committee consisting of decision makers from different disciplines (data protection officers (DPOs), legal, management and medical staff).

3.3 Towards a real-world data framework

The real-world data (RWD) framework proposed below was created to provide a structure for multi-stakeholder discussions and decisionmaking around secondary (and primary) use of RWD for quality of care improvement, research, outcome-based healthcare and reimbursement, and economic and ecosystem development.



Figure 3: A re-use framework for real-world data.

3.4 Creating value for all

The primary issue to overcome is insufficient trust between partners. This impedes open communication about data, especially since some hospitals are suspicious of pharma misusing data. Important to know is that pharma in the majority of cases is only interested in analysis on cohort level resulting in numbers of patients reaching for example a certain outcome, which directly implicit a privacy guarantee at

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individual patient level. Stakeholders need to be encouraged to share and discuss individual perspectives to improve understanding. However, these multi-stakeholder partnerships are difficult to set up.

Proactively identifying needs and matching them to opportunities will forge connections between complimentary stakeholders for innovative projects. This can be facilitated by identifying the benefits and risks for each case from a multistakeholder perspective to intensify engagement and partner connections.

3.4.1 Clear joint objectives

When setting up partnerships, there is often a difference in expectation between stakeholders due to unclear communication about objectives and strategy. In particular, clinicians and government are often not aligned.

Initiatives to produce clearly defined finalities that add value for all stakeholders must be put in place from the bottom-up and top-down in consultation with all stakeholders. This will install ongoing systematic communication and engagement to further develop the partnerships.

3.4.2 Value and risk sharing between all stakeholders

At present, most partnerships are limited to one or two parties and have not created much impact. These are more focused on one-on-one relationship management, rather than true alliance management where large partnerships are managed on multiple levels to strengthen ties and steer towards value and impact for all parties. Current partnerships lack insight from lessons learned during past successful projects and lack KPIs to monitor progression.

Setting up broader, creative alternative partnerships based on mutual gain and risk sharing will help to build key alliance capabilities. These will encourage the strategic insight, professional engagement skills and optimal team work needed to define the right KPIs to monitor project value.

3.4.3 Improved use of data for better quality of care (QoC)

Belgian healthcare does not have a culture of monitoring clinical evolution, which makes it difficult to improve treatment processes. Effective data visualization in appropriate dashboards is required for follow-up and monitoring of patient data. Leveraging this data is key for collaborative



learning to build progressive insights that allow all stakeholders to learn and offer innovation to patients. Furthermore, patients have no access to data on the performance quality of hospitals or care providers, such as mortality rates.

Installing a data culture will allow continuous improvement and advance insight generation, by using benchmarking and shared dashboards, and publishing performance and quality transparently. A systems approach that considers the entire healthcare system as a whole will deliver benefits on both a societal and population level.

3.4.4 Focus on the patient

Ensuring the right patient receives the right treatment at the right time is essential. This is best achieved by integrated care and monitoring along the entire the patient journey, which is connected to an appropriate data infrastructure. Early detection is of great importance for all stakeholders involved and monitoring individual patients via smart watches, sensors, wearables (collectively called telemedicine) etc., can be considered as the baseline here. This care without demand, and often without a healthcare environment or staff, is seriously underestimated today and is not connected to the current health data infrastructure.

Data-enabled, patient-centric partnerships will improve patient quality of care and outcomes. Connecting telemedicine solutions to the health data infrastructure can allow this additional data to be used in medical decision making, without an direct data input needed by the HCPs.

3.4.5 Role of the government

The government is often unwilling to step into new projects when they require investment in data infrastructure and efforts to standardize data. Therefore, a clear alignment is needed on the government's responsibility, and incentives need to be offered for education, population and professional literacy, including clear and understandable communication. Setting up the correct definition of data transparency for the right level will be key in obtaining the right insights with the right access for the right people.

The government should impose data standards and take an active role in initiating projects and data education. A focus is needed here on funding for data infrastructure, similar to that of countries such as Finland, Germany, the Netherlands, Denmark and Sweden.



4. Why are value-based partnerships important?

The central driving element for all stakeholders must be the joint objective of improving quality of care for the patient.



The joint objective for all stakeholders must be improving quality of care for the patient. This should be the central driving element for all.

Figure 4: The joint objective of healthcare must be improving quality of care for patients.

Data should be collected to generate improved insights that lead to better quality of care. In addition, auditing, data-based benchmarking and feedback can improve quality of care for all.

Although many claim patient-centricity, we are not yet there. Clinical and non-clinical follow-up of the patient is often incomplete, both during hospital admission and after treatment. The patient's situation is not well understood beyond the clinical outcome and patients are not motivated to complete questionnaires for data collection purposes.

For continued success, stakeholders will need to go beyond *in vivo* delivery of the target product profile (TPP) to real-world delivery of experience and outcomes.

Big data and digital health technologies are key for improving health on both a population and an individual patient level. They can support the shift from the TPP to target experience profile (TEP) and target outcome profile (TOP), adding multiple value layers across the whole product life cycle.



Figure 5: The layers to be considered to go beyond in vivo drug delivery to enhance real-world experience and outcomes.

Upgrading partnerships to create more value and impact on individual, population and healthcare system levels

Improving the quality of care on an individual patient level will require thinking beyond the treatment itself to achieve the best outcomes and an improved overall patient experience. On a larger scale, a systems approach to benefit the population level will require policies to improve healthcare system outcomes and create valuebased healthcare with increased cost efficiency that will add value for all actors.

These approaches will require a new way of working, where the individual partners share not only the value, but also the risks, with each other. This will create ecosystem-based partnerships with a common purpose. For this it is essential that trust is built between partners, and that they are open and honest about the objectives. Technological innovations about data-control and data-ownership are currently paving the way for more fine-grained decisions about when citizens want to allow the usage of data or when to opt-out which are also applied to medical data (e.g. the SOLID project). Improving healthcare at a system level will result in wins for all involved: patients, partners and the healthcare system as a whole.



5. A checklist for creating value-based partnerships

The following steps should be carried out to ensure successful value-based partnerships for shared value creation:



Figure 6: The recommended steps to successfully create shared value through value-based partnerships

To support the partnering discussions and define the optimal partnering model, the following value-based partnering checklist can be used as a tool to lead to more valuable projects.

Value-based partnering checklist



Figure 7: A checklist for developing value-based partnerships. More information about points (a), (b), (c), (d) are included in section 5.1 below.

Once the appropriate value-based project and partnering model has been defined, the project can start with designing the solution, followed by implementation, leading to shared value creation. The figure below outlines the steps from solution design to implementation and value delivery for all involved stakeholders.



Figure 8: Steps for successful value-based partnerships for shared value creation: from solution design to implementation

Recommended solutions

(a) How to create a win-win-win for all involved

Creating value for healthcare providers

Improving the quality of care will ensure that the right patient receives the right treatment at the right time. Passive remote monitoring of disease and symptoms between consultations can support the HCP in prescribing and adjusting the therapy to ensure the best quality of life for the individual patient based on symptoms and dataenabled decision making.

A personalized approach to patient care will result in more efficient care provision and outcomes, but this impacts both time and cost. Tailored longitudinal data and triaging dashboards for each patient offers the potential for automated care pathways and digital patient support via online chats and teleconsultations.

Creating value for patients

From a patient perspective, good care is synonymous with a good quality of life. They want to live their lives in the best way possible, which requires monitoring and longitudinal follow-up, as well as care optimization. In addition, patients need to feel supported through specific information, emotional and practical support. However, this need is different for each patient and requires personalization. Moreover, patients want to participate in their own care and want to be heard. Including the patient's perspective in individual reports is the best way to achieve this, through patient report outcome & experience measures (PROM & PREM). From assessing existing health solutions, it is clear that patient and HCP values such as quality of life, personalization, participation and inclusion, quality and efficiency of care are not the only benefits from digital health technology. Data analysis can generate additional insights independently of treatment type and can be either free or reimbursed to add financial incentives for participation. Monitoring would not be bound to a single partner, but will encourage collaborative developments between the academic and medical worlds. Such collaborations are likely to result in one service that will cover all value touchpoints, providing an easy integration into current medical practice and low effort from the patient.

(b) Recommendations for creating purpose and strategy for using realworld data

Partners will need to decide which data should be collected and create a strategy for using both primary and secondary data. Such RWD infrastructures should ideally fulfill a broad spectrum of medical, clinical, research or societal objectives, as well as serving all partners involved. The strategy should be based on a purposeful, disease-based approach, rather than focusing on specific therapies. It should also reflect the needs of all stakeholders, for example:

- Follow-up patients long-term after clinical trials
- Support physicians in medical decision making
- Support well-founded decisions on pricing and reimbursement
- Facilitate post-marketing surveillance and fulfilment of post-marketing obligations



(c) Data processing steps

Data collection

The first step should be to ensure that all data collection tools are validated, suitable for use in practice, and capable of extracting EHR data without too much effort from HCPs. Up-to-date EPD systems and data repositories are essential to support the exchange of data. Many hospitals will have to prepare their databases or even establish a usable EPD. Data warehouses will need to be set up for hospitals, together with the infrastructure for automated data harvesting from different sources to reduce effort needed by HCPs.

We would recommend keeping data on site. However, this will require the creation of health data spaces in Beneluxa (Benelux, Austria and Ireland) and the rest of the EU that are aligned with international and EU core data sets, to allow better health data exchange and access. Data should be granular, focused on long-term outcomes, and include disease-specific quality of life measures. It is also important to allow capacity for additional datapoints to be added over time.

Data quality

Investment in data quality is key, and should include such considerations as data cleaning, curation, completing missing data, control & validation of data quality monitoring and auditing. Data should be collected with harmonized definitions based on a common coding system (international codification standards such as for example the common data model of OMOP) and common data entry procedures which are imposed by the government. Quality checks and validation at data entry must be carried out by a dedicated data validation group for data analysis.

Data analysis and reporting

Data analysis must be performed by medical experts with sufficient knowledge and expertise to identify causal insights, in collaboration with data scientists. Academia, industrial third parties, and payers may be granted access if the request is part of the agreed purposes. An alternative would be to use a Data Permit Authority, such as Sciensano, to act as the main data processor for carrying out tasks such as data gathering, (pseudo)anonymizing, analysis and reporting.

(d) Enabling foundation

Governance

A new framework will be required to obtain consent and approval for re-use of data, to include data access procedures and committee. Data should either be kept in a centralized location which could be public or private, or federated on the premises. Clear communication is essential to ensure full transparency and to inform the public about the data use.

We recommend the creation of a national charter, inspired by Finnish law, to describe data collection, handling and use. In addition, a legal framework for national consent and an approval model (opt-out model) for re-use of data is required. All data access decisions should be governed by a multistakeholder representation of clinicians, authorities, industry (pharma.be), patient representatives and others, based on FAIR principles (findability, accessibility, interoperability, reuse). Alternatively one could opt for a more novel citizen-centric approach, based on many, but more detailed opt-ins, fully controlled by the patient. The We Are² partnership is committed to creating a sustainable civil-scientific ecosystem for personal health data.

Funding and incentives

In order to set up and maintain the necessary infrastructure, some form of funding will be required, either private or public. Financial compensation should be provided for "data quality efforts" (on a fee-for-service basis) to encourage participation. Financing to hospitals should be linked to the obligation that they supply the requested data in an appropriate format and based on milestones where penalties are imposed for missed deadlines.

Data privacy and security

A light consent model and legal framework for data re-use in a GDPR conformant way is required, with preference for a federated data model within a privacy-preserving infrastructure. Depending on the request, access to raw, aggregated or synthetic data should be available with the appropriate data de-identification, pseudonymization, or anonymization.



6. Example cases and suggestions for pilots

Two examples of value-based partnerships are described below.

6.1 Example case: Thrombotic thrombocytopenic purpura

For thrombotic thrombocytopenic purpura, Takeda is exploring four visions where partnerships can provide the foundation for success:

- Screen early to enable early detection, through newborn or pregnancy screening programs
- Get smart with diagnosis by integrating more intelligent clinical decision support rare disease diagnosis can speed up
- Collaborate to innovate throughout the care pathway, by increasing the patient voice and drive research to improve outcomes
- Sweat the data: think creatively to overcome the data scarcity, collect and combine data to create the foundation for better care

6.2 Example case: Cytomegalovirus (CMV) value-based partnerships

There are already several partnership projects for CMV which have the potential to offer even more value to all involved by introducing further partners.

CMV and me

This project combines an awareness platform, shared decision-making aid and an outcome database to improve patient outcomes.

Potential partners:

- Medical societies to provide expert opinions on the content and ensure the relevance of information provided. Primary partner: ESOT
- Patient associations to ensure solution is relevant for patients and used by the target group.
 Partners: EUCAN level e.g. European Kidney Patients Federation, Canadian Transplant Association
- 3. **Tech partners** to develop the platform required for the ideas Partners: to be defined

CMV at home

This project investigates remote, optimized posttransplant care to improve system efficiency and free up hospitals' and patients' time.

Potential partners:

- Local transplant centers and hospitals in selected countries, to better understand remote opportunities (FR, IS, IT, Nord.) Partners: to be defined with LOCs
- Medical societies for joint research and funding a call for proposals from transplant centers
 Partners: ESOT, EBMT, ESCMID
- Remote diagnostics / telehealth for the provision / development of required tools
 - Partners: additional research needed
- Patient associations to capture the needs and relevance of certain functions and ensure ease-of-use Partners: European / local patient organizations

CMVai

Early CMV risk and progression analysis to ensure the right treatment reaches the right patient at the right time.

Potential partners:

4. Clinical / academic partners to define the relevant data and provide access to recent patient cohorts with the newest immuno-suppressant and antiviral treatment. Partners: EBMT, ESOT, Transplant center,

Barcelona hospital clinic, CMI trial, GETH group collaboration

 Al / tech partners to develop the algorithm and technological platform. Partners: BioLizard, Anaxomics biotech, small bioinformatic companies or startups

6.3 Potential pilots

This section contains a list of project proposals made by the multi-stakeholder round table participants that could be considered as the basis of new value-based partnerships.

Early detection/ screening

- Testing individuals to identify those with a specific disease before any symptoms appear
- Value:
 - Progression analysis to ensure the right treatment reaches the right patient at the right time

• Prospective data collection

Prevention

- Actions to decrease the chance of getting a disease or condition (population health)
- Value: Reduce cost and effort

Early diagnosis

- Detecting symptomatic patients as early as possible
- Value: The right treatment to the right patient at the right time

Zero line

- Care without demand and often without healthcare environment or staff empowered by telemedicine solutions
- Value: Care efficiency, reduced costs

Dashboards

- Longitudinal data dashboards consider the patient holistically, throughout the care pathway
- Benchmarking between hospitals
- Value:
 - Observation, closer follow-up
 - Supports a self-learning and continuous improving system

Data-enabled support

- Data and digital enabled coach for the patient
- Value: Supports patients anytime, anywhere

Patient follow-up

- Follow patients between consultations
- Value: Care efficiency, reduced costs

A necessary model shift towards 6.4 shared value

These projects represent a model shift towards shared value for all participants, based on mutual trust and understanding.

Today's healthcare system in Belgian faces several challenges in improving its efficiency and effectiveness, to provide the best possible service to patients while reducing costs and efforts. The current system relies heavily on a combination of separate inputs, such as:

- Evaluation of treatment effectiveness and tolerability in daily clinical practice
- Epidemiological data on disease incidence and prevalence and
- Burden of illness studies
- Evaluation of comparative effectiveness and treatment patterns and sequences
- Safety studies
- Patient quality of life data in a real-world settina

Value-based partnerships with shared value can be developed through a combination of remote monitoring of patient outcomes and AI algorithms for early diagnosis of (rare) diseases or detecting certain treatment outcomes (response, remission, etc.).



7. Conclusions

The aim of this report is to create a framework to encourage the creation of more value-based partnerships using big data and digital health solutions. Health related data is a very sensitive subject, so healthcare providers are often reluctant to share it with third parties, even though the majority of patients usually consent to sharing their data provided they remain anonymous. To counteract this, it is crucial to have clear guidelines that ensure all partners understand the aims, roles and responsibilities of everyone involved.

The ambition of this multi-stakeholder round table was to identify the challenges and barriers to creating value-based partnerships and create a framework that can be used to encourage trust and understanding between all partners to create successful partnerships using big data and digital health solutions.

The recommended steps for creating shared-value partnerships

- 1. Identify the specific need
- 2. Identify partners
- 3. Partner discussion using the checklist below to identify a win-win-win solution
- 4. Define optimal partnering model
- 5. Contractual agreement
- 6. Start project with a kick-off meeting
- 7. Design the solutions
- 8. Build the solution
- 9. Implement the solution
- 10. Evaluate
- 11. Create value for all

The checklist below has been created to support the process of building value-based partnerships, and should be used as a recommendation to support conversations between partners.

Value-based partnering checklist



Ultimately, ensuring health data is used to the fullest extent possible is an important duty towards the Belgian population and society as a whole. The recommendations in this report suggest some clear guidance to make this happen for the benefit of all involved: the involved partners, the healthcare system, and last but by no means least, the patients.



Abbreviation list

Benelux / BeNeLux	Political and economic union of Belgium, the Netherlands, and Luxembourg
Beneluxa / BeNeLuxA	Pharmaceutical initiative involving Belgium, the Netherlands, Luxembourg, Austria and Ireland
DPO	Data protection officer
EHR	Electronic health record
EPD	Electronic patient record
HCP	Healthcare providers
KPI	Key performance indicators
PREM	Patient report experience measures
PROM	Patient report outcome measures
QoC	Quality of care
RWD	Real-world data
TEP	Target experience profiles
TOP	Target outcome profile
TPP	Target product profile



Reference list

- 1. Michael E Porter 2010 NJEM 363:26
- 2. we-are-health.be/nl