Final Report

May 2023

VALUE AGENDA NL
ValueBasedHealthCare

The Value Agenda for the Netherlands 2023

No patient centered care without data

Five key actions towards better data availability to collectively work on better patients outcomes

#ValueAgendaNL

THE DECISION GROUP

Made possible by:

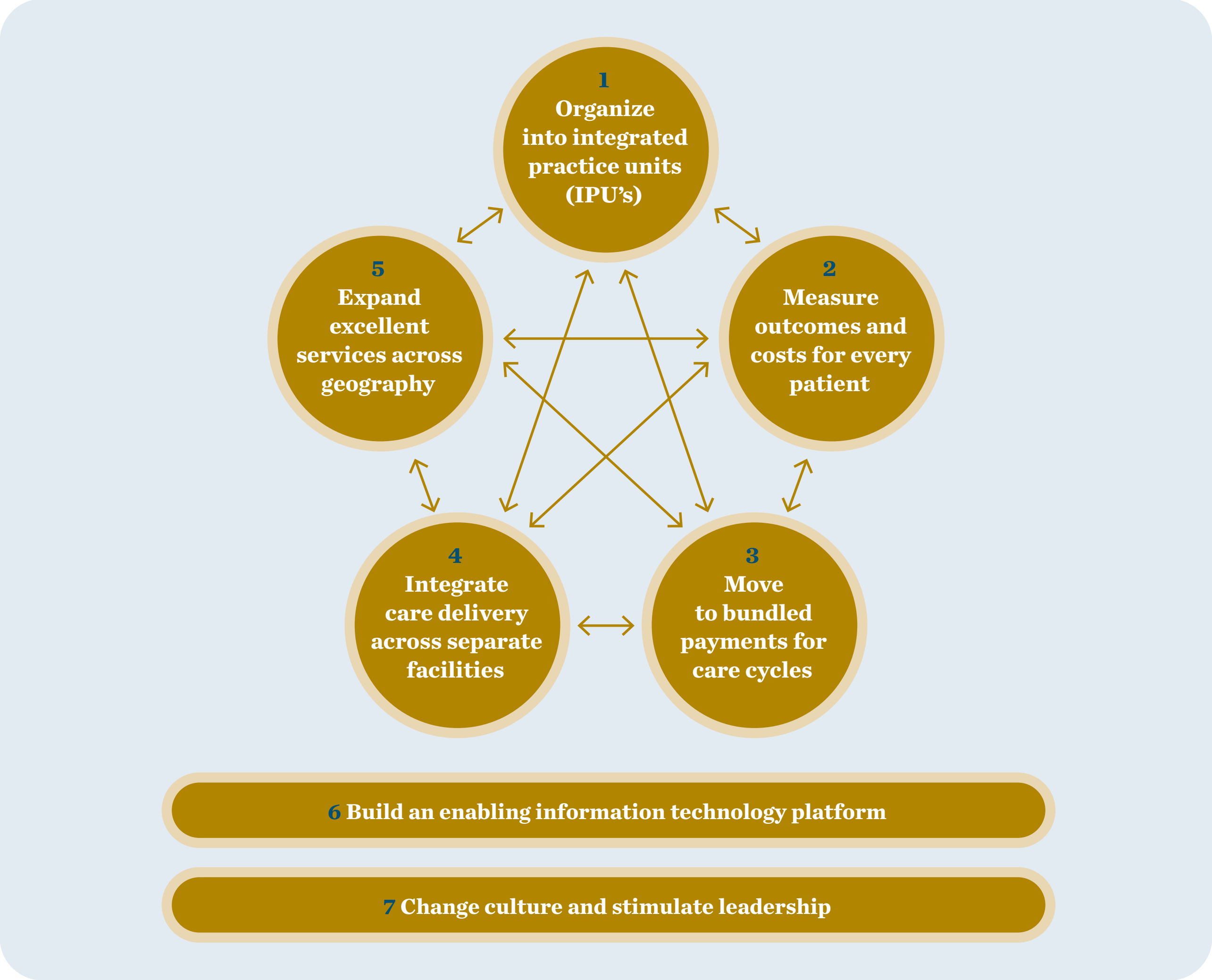
AMGEN Roche

Preface

Background and history of the Value Agenda NL

Since the appearance of the book Redefining Health Care in 2006, outlining the core principles of Value-Based Healthcare, the Netherlands has been one of the leading countries in the adoption of this patient-centered approach to healthcare. In 2017, with over a decade of experience and knowledge, we observed that nation wide implementation was still in its infancy (even though the sense of urgency to change the way we provide healthcare was felt). Therefore, the Value Agenda NL was set-up to try and move the needle on VBHC-implementation.

In 2017, together with founding father Prof. Porter, the initial Value Agenda was defined, containing the seven most important VBHC implementation themes (see below). Each year, a specific VBHC theme is selected that is deemed most urgent and for which the climate for implementation within our traditional healthcare system should be improved. During a pressure-cooking session, decision makers in healthcare define key actions that help to accelerate the implementation on that topic, reported in the yearly Value Agenda NL.



Preface

Over the course of six years, with the help of renowned (inter)national experts, various topics of the agenda have been taken on and actions were formulated (see below). This years theme was focused on: ‘No patient-centered care without data’.

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VBHC Working Session 2017
Value Agenda and IPus
With Prof. Michael Porter, PhD

2

VBHC Working Session 2018
Dealing with outcomes and variation
With Dr. Richard Bohmer & Prof. Matthew Cripps

3

VBHC Working Session 2019
Patient outcomes and trust in data usage
With Prof. Elizabeth Teisberg, PhD

4

VBHC Working Session 2021
Pay for outcomes, pay for innovation
With Dennis van Veghel, PhD & Paul Cremers, PhD

5

VBHC Working Session 2022
Pay for value 2.0
With Peter Langenbach & Hans Feenstra

6

VBHC Working Session 2023
No patient centered care without data
Expert Group - Cases in Practice by: Hans Paalvast & Pieter de Bey

Content

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Theme and outline

Value Agenda NL 2023: ‘No patient-centered care without data’

The transition towards VBHC is gaining ground, but the pressure on our healthcare system and accompanying budgets increases similarly. With that, the tension between the underlying two different starting points, micro vs macro environments (see Exhibit A) and becoming more apparent in discussions. However, both micro and macro environments have in common that it is key that effectiveness of treatments and the value created should be examined. In the end, only care that adds value for patients should be provided. Also, it is crystal clear that data is needed and therefore it should be possible to (easily) exchange data wherever en whenever needed, independent from the specific quality measures that are used.

This years’ theme of Value Agenda NL is: “No patient-centered care without data”. The focus of the session was focused on the availability of data for all stakeholders. Better data availability will allow different stakeholders to gain insights from data they need to further improve their (data-driven) contribution to better outcomes for patients.

Short outline of the day

The theme of data availability was perfectly introduced by two short keynotes. Hans Paalvast presented the vision of the Dutch Healthcare on data availability and its relation to suitable care (passende zorg) and accompanying maturity model moving towards a Dutch Health Data Space (DHDS) (more details can be found here). Pieter de Bey and Renske Veenstra of Santeon presented their Health Intelligence Platform (HIPS) to show how data availability between at Santeon is arranged and is used to create a learning environment (more details can be found here).

The pressure-cooking session started directly after the keynotes, with an exercise to step into the shoes of a specific stakeholder in healthcare and identify which data they would most likely need to contribute to better suitable care. Subsequently participants were asked to identify the most important hurdles at this stage that obstruct data availability. Each group decided which one/two hurdles were deemed most problematic and made a start to define recommendation(s) that could help to overcome these hurdles. After each group reported their main line of thinking back, the session was closed by Carmen van Vilsteren (figurehead of the topsector Life Sciences & Health) providing her reflections and point of view.

The main recommendations posed by the different working groups are summarized in this report.

General consideration

Because of the mix of stakeholders present, discussions were fierce at times, a great depiction of the current era in healthcare. It became clear that there were opposing views by different stakeholders, which was incredibly valuable for the discussion. Although there was no consensus on some of the proposed actions and recommendations, there was a consensus on the adagio of the day with regards to implementation: “Think big, start small, act now”. A great phrase that captured the urgency felt to start as soon as possible, in an implementable way, without compromising on the bigger picture.

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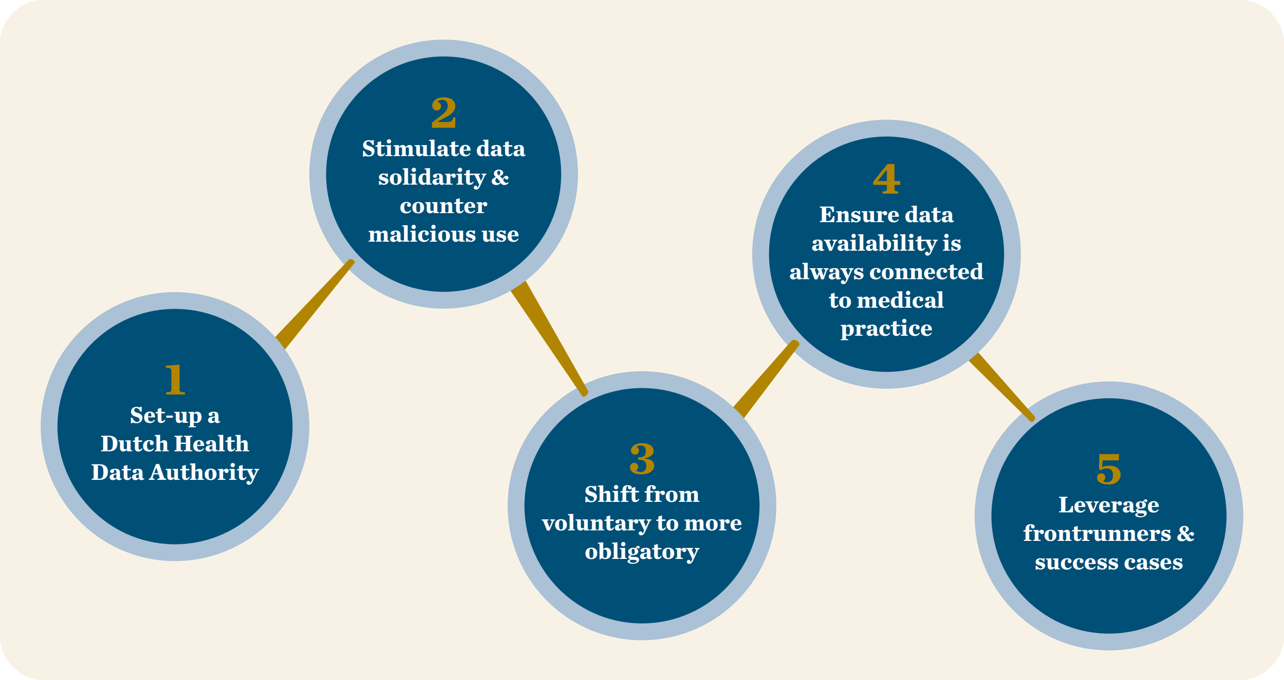
Five actions to better patient outcomes by improved data availability

Various lines of thinking were reported back, based on the working groups, but also during the plenary session. These main thoughts are captured below, extended with an action-oriented keyline.



1. Set-up a Dutch Health Data Authority

During the discussion it became apparent that there were opposing views to what extent the government should provide direction and take a more directive role. Participants showed concerns for both a long “polder” trajectory or a centralized power approach.
To move beyond pointing fingers it was raised (in line with the European Health Data Space) to set up a governing body to provide more direction. Therefore, the working title of Dutch Health Data Authority (DHDA) was raised.

The DHDA should define how data should be collected and shared. The DHDA is not in charge of the content (the what), which lies with the professional associations.
In line with the EHDS, the authority, responsibilities, and duties of the DHDA should Ibe carefully defined. To avoid any dominance in focus it is recommended to set up a new authority and not an existing organization to take on this role/authority by extension of their current role, tasks, and duties.

2. Make the shift from voluntary to more obligatory

It was acknowledged that, in line with the lack of direction, there currently is a high degree of freedom to change or move towards better data availability. Most steps taken are driven by intrinsic motivation or strong leadership. The lack of commitment was mentioned frequently and from different angles, therefore included as a separate point in this agenda.
Multiple ideas were mentioned in which more obligation could help, for example with regards to the technical/infrastructure part which can then be seen as a pre-condition to make data available (for instance, making transparent reporting of results mandatory like Santeon does voluntarily or transitioning towards FAIR data).

3. Stimulate data solidarity & counter malicious use

Solidarity is one of the fundamentals of our healthcare system. Using health data of all our citizens will allow to learn faster and improve healthcare for all. Therefore, it is important to take along citizens and inform them on the importance and benefits of sharing health data beyond your individual doctor/hospital. For instance, using campaigns on how their health data can help to improve treatment for him-/herself, others or entire populations.

An important pre-condition for acceptance of citizens is to ensure data is shared in the safest possible way and protected from malicious use. The three most frequently mentioned justifications to citizens for safe data usage were:
a. Individual health data is used anonymously and is not traceable to the individual patient/person.
b. Sharing of data is performed with highest safety standards and complies with all (privacy) regulations in place, f.i. the AVG
c. Good governance is in place on personal health data – ensuring confidential usage by healthcare professionals (examples like Estonia where patients receive an alert when a doctor has opened a medical record of you)

4. Ensure data is always connected to healthcare delivery

Over the past years, a lot of initiatives and pilots started capturing and sharing data for learning purposes. From these initiatives, numerous valuable insights or interventions came forward. These insights or new practices are not automatically fed back to all healthcare professionals yet and are mostly dependent on existing connections and networks. The next step is to make sure that insights from data or new practices reach clinical practice and the individual patient/doctor interaction faster. These insights will help in decision making and will immediately show the clinical benefit to patients and healthcare professionals.

For example, at Intermountain Healthcare in the US a paper was published containing a model on how that may work. Intermountain Healthcare is a great example showing how data is tracked by following or deviation from (clinical) guidelines with the purpose to learn and continuously improve those guidelines in and by practice (by double-loop learning).

5. Leverage frontrunners & success cases

Despite the large number of proposed actions and ideas during the working session it was also clear there are already great examples and initiatives, both nationally and internationally, that have solved part of the entire data availability puzzle. For example, multiple initiatives have found ways to ensure their data architecture is set-up to ensure data availability for care delivery and clinical research (f.i. NHR, Santeon & Intermountain Healthcare). Other initiatives, like the Dutch Cardiovascular Alliance, can serve as an example in setting responsibilities and duties in setting-up a Dutch Health Data Authority. Other countries, like Estonia, have tackled multiple facets with regards to data solidarity and avoidance of mis usage of data. All these initiatives can and should be leveraged more, both in adoption of good practices and involvement of these leading initiatives/experts in the next steps to be made.

Pragmatic additions

Next to the five main actions stated in this report, there were various other pragmatic statements, and ideas captured. Below, you can find five pragmatic additions, written in a similar action-oriented format.

- **Prevent proliferation of existing coalitions – and dare to stop**
  Innumerable coalitions have formed aiming at improving healthcare and patient value; data-related coalitions and alliances being no exception. Many coalitions continue after their initial goals are achieved (or failed) because a new ambition or objective is formulated resulting in a growing number of coalitions. To prevent the rapid growth of coalitions it is highly recommended to build-in a check on the relevance, overlap and impact of coalitions and if needed dare to decide to merge or stop.

- **Alignment of insurer contracts and avoid fragmentation of needed data**
  Contracts between health insurers and care providing organizations are negotiated and signed individually, an enormous amount. In each contract it can be decided to include quality metrics to specifically focus on or differentiate upon. In practice this means a huge variety of metrics/KPI's that need to be measured and monitored. More alignment by insurers on the contracts with care providing organizations could have a huge impact on the amount and fragmentation of data needed for the contracts. For instance, by determining two lead insurers to negotiate and define these metrics with the care providing organization and other insurance companies have to follow these metrics, while leading the negotiation in other regions.

- **Let the ongoing debate on public versus private interests not interfere with implementation speed**
  On many topics in healthcare there is always debate and distrust on the intentions and interests of private companies. Data availability is also a sensitive point in that respect and by the increase in Public Private Partnerships (PPPs) the division of roles and responsibilities can become blurrier. More discussion is needed to further demarcate these differences.

- **Commercial parties should clearly define their research questions**
  In line with the public vs private discussion mentioned, it was noted that commercial organizations should pro-actively bring their research questions to the table. Transparency on their research question and which insights are needed will help mutual understanding and builds trust. For more information on this topic, please see the whitepaper of the Association of Innovative Medicines on this topic (which can be found here)

- **Stop complicating the data discussion with terms like primary and secondary use of data**
  In order to differentiate between various options and levels of data usage, terms like 'primary' and 'secondary' data usage arise. While this seems innocent it can also increase complexity and cause confusion as secondary use is eventually to improve the primary use of data. Be aware of terms and phrases that may cause confusion and try to limit these.

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Next steps

Five main actions are set for the Value Agenda NL 2023; now it is about moving forward on these actions. To do so, we have shared the report with the participants of the session and the Value-Based Healthcare Community to act as ambassadors and actively act upon these actions.

Next to that, this report will be presented to large group of organizations and coalitions that work on the topic of data availability and representatives/spokespersons from political parties. Particularly aimed to show and recommend the urgent need for the establishment of a Dutch Health Data Authority to take control and provide direction for data in healthcare. An authority with a clearly defined role, responsibilities, and duties, and in which health outcomes for patients are valued and secured.

For the establishment of the DHDA, we:

a. Call-out for help to get this important topic on the political programs/agenda.

b. Encourage all to reach-out and learn from organizations and coalitions that have found ways to embed a good level of authority and responsibility in their setting.

Finally, we ask everyone who strongly feels that better data availability is key for better patient care, to share this report and act on the five key actions in this report.

Want to help or participate in the Value Agenda NL?

If you have any additions or suggestions to this report or the follow-up actions, please do not hesitate to contact Steven Buijs via S.Buijs@thedecisiongroup.nl.

Are you or is your organization interested in providing input or attending the Value Agenda 2024? Please send your contact details to Steven Buijs to be timely informed on the topic of the Value Agenda 2024 and the possibilities for you or your organization to join.

Exhibit A

Micro versus macro perspective

In healthcare, the micro perspective focuses on the individual patient level and his/her interaction with healthcare professionals. For VBHC, this perspective is the starting point with the aim to provide the best possible outcomes against lowest cost on patient level.
On the other hand, the macro perspective takes a broader view, analyzing healthcare systems en policies with a focus on population health trends. For the government, this perspective is the starting point with the aim to ensure affordable, accessible, and high-quality care at society level.

The macro and micro perspectives therefore inherently differ because they focus on distinct levels of analysis (individual patient and treatment versus population level and systemic issues).

One theme both perspectives have in common despite the level of analysis is the fact that they want to evaluate and assess care practices and quality & effectiveness of care. This can only be done if data is collected and made available, hence the importance of this topic from both perspectives. In the end, data can objectively help us to focus on providing the right care (micro focus) but also to stimulate and provide payment for care that works (macro focus).

Health systems' mangement levels adopted by Ortún (Holder & Ramagem, 2012).

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