WHITE PAPER ON SUSTAINABLE HEALTHCARE

ADVANCING THE USE OF PATIENT REPORTED OUTCOMES MEASURES (PROMS) TO IMPROVE THE EFFECTIVENESS AND EFFICIENCY OF RHEUMATOID ARTHRITIS TREATMENT AND CARE
What if all rheumatic patients measure their wellbeing on a daily basis and share their findings with their physician 24/7? What if physicians and patients use this data to develop treatment strategies that help patients to do the things that are meaningful in life? What if healthcare providers have a clear insight into the effects of treatment and medication on patient’s daily lives? Would this change the way we improve our healthcare?

The “what if”-questions are already a reality to some rheumatic patients in the Netherlands. Unfortunately however, the means and infrastructure to collect and share patient reported outcomes are not yet available to every patient. In search of means to improve the sustainability of our healthcare system, this seems a missed opportunity. This White Paper aims to leverage the use of PROMs further to improve both effectiveness and efficiency of care for Rheumatoid Arthritis patients in the Netherlands, thereby improving the sustainability of our healthcare system as a whole.

AbbVie and BeBright would like to thank the diversified panel of rheumatoid arthritis experts for their time and expertise in co-developing this paper:

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This White Paper is part of Recipes for Sustainable Healthcare a EU-wide initiative in which AbbVie, jointly with various healthcare partners, is developing concrete ideas and solutions that will help inform a more sustainable, forward-thinking healthcare environment for the future. This White Paper aims to give an incentive towards improving the effectiveness and efficiency of rheumatoid arthritis treatment and care in the Netherlands.

Let's put sustainable policies on the table and improve the standards of care!

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Patient Reported Outcome Measurement (PROMs) is regarded as an imperative step forward in improving results and building a sustainable healthcare system. Nevertheless, currently few patients measure the effects of treatment or medication in daily practice. Few hospitals in the Netherlands share their outcomes with the public. This White Paper aims to leverage the use of PROMs in Rheumatoid Arthritis (RA) treatment and care in the Netherlands. RA is chosen as a focus point in this White Paper because of the impact on healthcare spending and the rapidly improving treatment options and strategies. Three best-case practices in the use of PROMs in Rheumatoid Arthritis treatment and care in Europe reveal the benefits for a successful uptake of PROMs. Also barriers interfering with the full potential of the use of PROMs were identified.

To overcome these barriers, a collaborative approach is required between policymakers, patients, healthcare professionals and providers. First of all, a common approach is needed for data collection & exchange between patient, physician and healthcare provider. Moreover, it is essential for policymakers to advance an integrated approach to our healthcare and our work & welfare systems, focussing on the total social return on investments in healthcare.

To improve the effectiveness and efficiency of healthcare, policymakers should not only focus on reducing spillage and costs but also support initiatives to improve outcome of our treatment strategies.

PROMS IMPROVE EFFECTIVENESS AND EFFICIENCY OF HEALTHCARE
Patient Reported Outcome Measures (PROMs) are key in improving the effectiveness and efficiency of healthcare, resulting in a more sustainable healthcare system. PROMs provide valuable insights in what really matters to patients and stimulate patient involvement, making healthcare more patient-centric. Furthermore, PROMs reveal the impact of treatment & care on the quality of life of patients, allowing both healthcare practitioner and patient to manage care processes and outcomes.

SUCCESSFUL INITIATIVES IN THE USE OF PROMS IN RHEUMATOID ARTHRITIS CARE REVEAL PRACTICAL IMPLICATIONS
Experiences with the use of PROMs in Rheumatoid Arthritis treatment and care in Europe show that in practice it is possible to significantly improve both effectiveness and efficiency of healthcare. Three best-case practices in the Netherlands, Denmark and Sweden show valuable results in how PROMs can be deployed in Rheumatoid Arthritis care.

ESSENTIAL BARRIERS THAT NEED TO BE OVERCOME FOR PROMS TO REACH ITS FULL POTENTIAL
Analysis of these three successful initiatives gives insight into the main factors for success and failure. Three major barriers can be identified which might slow down the design, development and the use of patient platforms:

1. Lack of a common approach for data collection & exchange between patient and physician

For a successful usage of PROMs there is a need for
a common approach for data collection & exchange between patient and physician. Due to competition between healthcare providers a common approach is missing, hindering sound comparison & benchmarking. Mandatory nationwide registries might be the solution.

2. Lack of incentives to invest in PROMs
Financial benefits of improvements towards sustainable healthcare will not automatically return to the investors. Healthcare professionals invest time and effort in providing patients with the means to monitor their health, well-being and experienced quality of life. The return on these investments is mainly found outside the healthcare system in for example more people being fit for work, reducing welfare costs and improving economic growth.10

3. Lack of structural funding
Absence of structural funding hinders the possibilities to invest in the uptake of PROMs. The current activity funding system in The Netherlands is based on the effort professionals put into the care process, not on the generated outcomes. This proves to be a professional dilemma.

AN INTEGRATED APPROACH IS NEEDED TO OUR HEALTHCARE AND WORK & WELFARE SYSTEMS
To overcome these barriers, and for PROMs to reach its full potential, a collaborative approach is required between policymakers, patients and healthcare professionals. The total social return on investments requires an integrated approach to our healthcare and our work & welfare system.

POLICYMAKERS SHOULD SUPPORT INITIATIVES THAT IMPROVE OUTCOMES OF TREATMENT STRATEGIES
The Dutch Ministry of Health invests in programs that define and delete waste and spillage in healthcare. For instance the use and spillage of (expensive) drugs are being investigated. To endeavour the effectiveness and efficiency of healthcare, spillage need to be reduced and outcome of treatment strategies need to be improved. Policymakers should also support the development and uptake of initiatives that have already proven their value to patients and the healthcare system, such as the use of PROMs. As a result, ineffective treatment, waste and spillage will be reduced.
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The Dutch healthcare system is facing enormous challenges. Our population is ageing, partly because of the success of our healthcare system. The effects of ageing will reach a peak in 2040. This results in a higher number of people with multiple chronic diseases who need assistance in their daily lives. These developments put pressure on the quality, costs and ultimately, access to healthcare. The sustainability of our current healthcare system is under pressure and we need ways to improve cost-efficiency to preserve high levels of care for future generations.

A sustainable healthcare system can be pursued by the combination of excellent quality, affordable costs, and good accessibility. Sustainable healthcare refers to improved health and quality of life for more people for an extended period of time through the effective use of resources. Therefore, we define sustainable healthcare as follows:

Sustainable healthcare meets the demands of patients by improving well-being through achieving medical outcomes within the socio-economic possibilities resulting in accessibility for future generations. Healthcare sustainability refers to improved health and quality of life for more people for a longer period of time through the wise, efficient use of resources. 11

The way forward in sustainable healthcare has to be explored. AbbVie, a research-based pharmaceuticals company, has launched a European incentive to exchange and learn from successful healthcare initiatives between countries. As a result, a multi-stakeholder group of experts in the Netherlands has investigated ways to achieve sustainable healthcare, concentrating on the treatment of Rheumatoid Arthritis. Together, a patient advocate, rheumatologist, pharmacist, and a healthy-ageing expert have shared their expertise resulting in a White Paper that presents a clear and realistic approach to improving the sustainability of treatment and care.

In the first chapter Rheumatoid Arthritis and its impact on patients is explained. In the second chapter the four major trends influencing the future of Rheumatoid Arthritis treatment and care are described. The way these trends can be incorporated in innovative initiatives is explained in chapter three. Three cases from Denmark, Sweden and the Netherlands illustrate the existing best practices that contribute to a sustainable healthcare system. In the fourth and final chapter the uptake of sustainable healthcare is explained. Barriers are identified and several suggestions for improvement are presented.
1. IMPACT AND PREVALENCE OF RHEUMATIC DISEASES
A rheumatic disease is a general term for more than 100 diseases of the joints, muscles, and tendons. Rheumatic diseases can occur at all ages. According to the Dutch Arthritis Foundation, close to 2 million people in The Netherlands live with daily pain, stiffness, and fatigue as a result of their illness. Most forms of rheumatic diseases are treatable but not curable.  

**IMPACT OF RHEUMATIC DISEASES ON DAILY LIVES**  
A rheumatic disease is a chronic condition that has an impact on a personal and professional level in the lives of many patients. Although treatment has improved tremendously over the last decade, total control over rheumatic conditions is still an illusion and without concise disease management patients are forced to continuously adjust their lifestyle. A rheumatic disease raises questions, doubts, and the feeling of powerlessness. Learning to accept, understand, and cope with the disease and its consequences is therefore imperative.

The physical effects have a great impact on the daily lives of people with rheumatic diseases and their environment. Simple things, such as opening a letter, often cause difficulties due to pain and stiffness. These symptoms can fluctuate on a daily basis because the disease may be erratic. Rheumatic diseases are often underestimated and/or misunderstood by those who are not familiar with the condition. Rheumatic manifestations are – at least initially – invisible to others, and left to subjectivity. The impact of rheumatic diseases can result in loss of work and income. And above all: rheumatic diseases cause a lower quality of life.

Researchers are working hard to figure out the cause of rheumatic diseases and to find better treatments. The developments in the field of Rheumatology starting in the 15th century are shown in figure 1 below.

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**Figure 1: Rheumatoid Arthritis timeline from 1600 until now, moving from care to cure ©BeBright**
PREVALENCE OF RHEUMATIC DISEASES

Rheumatic diseases are chronic disorders that affect large populations limiting their daily life. The impact on both the patient’s quality of life and the costs of care on a public level are tremendous. In the Netherlands, almost 2.0 million people have been diagnosed with a rheumatic disease. About 80% of these patients, around 1.6 million, are being treated by a physician.\textsuperscript{VI}

The direct medical costs resulting from these numbers are €3.2 billion (2011).\textsuperscript{VIII} On top of these medical costs, rheumatic diseases have a large impact on society and public costs: the total social costs for society are estimated at €16 billion in 2010 in the Netherlands. Studies in England from 1996 indicate that over half of the public costs of rheumatoid arthritis are work-related.\textsuperscript{IX}

Part of work-related costs is caused by work disability. This can be divided into presenteeism and absenteeism. The effects of absenteeism, for instance due to hospital admission, are clear but the impact of presenteeism, showing up for work being sick or unfit, is estimated to be even bigger.\textsuperscript{X}

This White Paper focuses on Rheumatoid Arthritis (RA), one of the most common rheumatic diseases. First of all, RA causes irreversible damage to patients’ joints, muscles, and tendons. Early diagnosis and effective treatment are required to prevent loss of vitality.\textsuperscript{XI} Secondly, the use of more expensive biologic treatments has increased.\textsuperscript{XI} Combined with increasing prevalence of RA due to the aging population this can result in an increase of healthcare costs. Effective and efficient use of medication is therefore required. Third and last, tight control of disease activity and monitoring of patient reported outcomes results in better healthcare outcomes and better quality of life.\textsuperscript{XIII}

The selection of drugs, the implementation of treatment strategies and the monitoring of outcomes requires close collaboration between the doctor and patient. Self-monitoring of treatment effects by patients themselves is part of the treatment strategy. In the future, more specific drugs for smaller and targeted groups are expected to become available. Clinical research is one of the reasons rheumatoid arthritis care is supported by patient platforms such as DANBIO in Denmark (see page 14) or ROMA in the Netherlands (see page 16).
2. TRENDS INFLUENCING RHEUMATOID ARTHRITIS TREATMENT AND CARE
The pace of technological and social innovation in healthcare is increasing. These innovations influence RA treatment and care in the upcoming years. A sustainable healthcare system that meets the demands of patients by improving well-being through achieving medical outcomes within the socio-economic possibilities should incorporate all the relevant trends and developments possible. In this chapter, four trends impacting the future of RA treatment and care are described. The selection of trends is based on a Dutch collaborative study on the future of healthcare.¹xiv

TREND 1: DIGITAL (BIG) DATA

Due to technological innovations, our daily life and work has changed dramatically over the last decade. In healthcare, the development of E-health includes many different innovations impacting the way treatment and care for RA patients is organised. Examples are remote care through video connection, the use of Personal Health Records and tools that support shared decision making. One important aspect is the increasing amount of personal data being gathered and shared between patients and professionals. This includes self-measurement (often described as Quantified Self), medication monitoring and the use of patient reported outcome measures (PROMs). E-Health innovations are a driving force for other trends, for example:

• The systematic analyses of large amounts of data (also known as Big Data) can give insights that are useful for preventive care measures and for choosing the right treatment for the individual patient based on outcome measures including PROMs (trend 2 and 3)
• The increasing digital opportunities are changing the relationship between provider and consumer from a giver-taker relationship to a reciprocal relationship including continuous dialogue. This is leading to a new era of self-management and shared decision making (trend 4)

TREND 2: TOWARDS PERSONAL RHEUMATOID ARTHRITIS TREATMENT AND CARE

A second trend is that healthcare is becoming more personalized; personal diagnosis supported by genetics, personalized treatment strategy and the use of medication tailored to the patients’ needs. Monitoring, data analysis and the resulting insights are very important in the treatment and care for RA patients because of the complex nature of the disease with a high degree of clinical heterogeneity.

This development ultimately leads to more effective patient treatment and care, improved well-being and lower healthcare costs and thereby assuring accessibility for future generations. In clinical trials it is shown that continuous monitoring of disease activity and subsequently adjusting medication when treatment targets are not met is more effective in reaching sustained remission and preventing structural damage than usual care.¹v On top of the fact that it is more effective, studies show that this approach is also cost-effective in the long run.
TREND 3: FOCUS ON OUTCOME MEASUREMENTS INCLUDING PROMS

The government and health insurance companies invest in outcome related research in both cure and care. Quality control, as a result of outcome measurement is one of the major trends in healthcare.

A number of initiatives focus on the outcome of care and cure for (chronic) conditions. The aim of outcome measurement is to gain meaningful insights what matters most to patients by measuring outcomes of healthcare as perceived by patients.

To make outcome measures work, all medical professionals should agree on the valid standards and instruments and gather data uniformly. In the ideal situation, these healthcare outcomes can be measured worldwide so that we can truly compare different therapies and improve quality of care.

TREND 4: POWER TO THE PATIENT

Under pressure of increasing healthcare expenditures (as described in the previous chapter), patients and their spouses are becoming more and more responsible for managing their own care and well-being. Patient empowerment and policy changes in recent years in the Netherlands have shifted responsibility towards patient’s self-management. For instance by introducing shared decision making and co-creation. Technological developments like eHealth solutions enable patients and their families to take on these responsibilities.

Patient’s literacy is improving, and patients are becoming more aware of the ways to positively influence their health. Different digital platforms arise to respond to the transition of responsibilities towards patients and family. Companies such as Apple (Healthbook) and Microsoft (Healthvault) have developed applications that enable users to gather, manage and share their personal health data with professionals. Subsequently privacy issue arise caused by the large amount of personal data being produced and exchanged. Patients and healthcare professionals interact and join forces resulting in initiatives like patientslikeme.com and mijnzorgnet.nl. Greater self-reliance is becoming increasingly associated with greater (perceived) quality of life.

The four trends introduced in this chapter will have a major impact on the future of the healthcare sector. Together these trends create opportunities for a patient-centred healthcare system and for sustainable innovations as is shown by three cases in the next chapter.
THREE INITIATIVES UTILIZING NEW POSSIBILITIES
In this chapter we describe three cases to show the potential of sustainable Rheumatoid Arthritis treatment and care. These examples have one thing in common: they are existing and proven examples that incorporate the four trends described in the previous chapter. At the centre of each initiative is a data platform, built for research purposes, which has the potential to redefine the relationship between healthcare provider and patient. These platforms contain three main elements that reinforce each other: 1) Research and benchmarks on treatment and care improvements, 2) the integration of Professional Clinical Data with PROMs and 3) engagement of patients in treatment and care.

1) RESEARCH AND BENCHMARKS ON TREATMENT AND CARE IMPROVEMENTS

As described in chapter 2, the analyses of large amounts of data give useful insights for preventive care measures and choosing the right treatment for the individual patient. The DANBIO registry from Denmark is a good example utilizing these possibilities:

CASE STUDY FROM DENMARK

In 2000, the DANBIO registry was established in Denmark. The Danish DANBIO registry provides nationwide data on the disease course of patients with inflammatory rheumatic diseases that are being treated in routine care. Since the year 2000, more than 10,000 patients have been included.

The aim of the registry has been twofold. First to be a powerful research database on, for example, treatment effectiveness, adverse events and quality of life. While simultaneously providing a helpful tool in clinical consultation by providing a disease chronicle for the rheumatologist and thus improving the quality of clinical care. The main focus of the research on DANBIO data has so far been on drug efficacy.

DANBIO has published efficacy and drug survival data on patients treated with biologics. Data from DANBIO also demonstrated that during the first years of biological treatment, drug survival was high despite low remission rates, and how a routine-based registration increased the reporting of adverse events several-fold in comparison with the mandatory reporting to the Danish Medicines Agency. In conclusion, DANBIO serves as an electronic patient ‘chronicle’ in routine care, and at the same time provides a powerful research database.

Using nationwide data, individual treatment can be evaluated and modelled to specific patient needs. On a community level benchmarking of treatment strategies and hospital performance is possible. These improvements will impact cost efficient treatment and care. Research shows that monitoring RA patients over time leads to better quality of care and more (cost) effective care.
A recent research in the Netherlands\textsuperscript{xviii} shows that patients and professionals/clinicians determined by significant improvements as perceived by patients and professionals/clinicians. The combination of clinical data and patient reported outcomes can define what is clinically meaningful. Clinically meaningful is determined by significant improvements as perceived by patients and professionals/clinicians.

In the ideal situation, quality of care is measured by incorporating what matters most to patients. The combination of PROMs and professional information creates additional opportunities for research and benchmarking treatment and care. The combination of clinical data and patient reported outcomes can define what is clinically meaningful. Clinically meaningful is determined by significant improvements as perceived by patients and professionals/clinicians.

A recent research in the Netherlands\textsuperscript{xviii} shows that patients receiving biologics as part of their RA treatment might be able to reduce their doses without short term negative effects. The long term effects are not clear yet, so caution regarding therapy adjustment is needed. This research is based on the use of PROMs that reveal the effect of treatment and care. These findings are supported by the worldwide uptake of PROMs in several initiatives such as ICHOM, an initiative started by Harvard and the Karolinska Institute to make outcome measures in healthcare available to everyone.\textsuperscript{xx}

### 2) INTEGRATING PROMS AND PROFESSIONAL CLINICAL DATA

In the ideal situation, quality of care is measured by incorporating what matters most to patients. The combination of PROMs and professional information creates additional opportunities for research and benchmarking treatment and care. The combination of clinical data and patient reported outcomes can define what is clinically meaningful. Clinically meaningful is determined by significant improvements as perceived by patients and professionals/clinicians.

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### CASE STUDY FROM SWEDEN

The Karolinska University hospital, located in Stockholm, Sweden, is the home of the Swedish Rheumatology Quality (SRQ) registry which aims to improve the quality and value of care for people suffering from arthritis and other rheumatic diseases. The SRQ registry is a database that follows patient outcomes over time. The patients enter their data on joint pain and current health status using a secured SRQ website and this information is automatically analysed and mapped. The provider may enter or update the information on the diagnosis, health status, treatment and test results on the same website.

The web-enabled SRQ registry makes use of real time, standardized data provided by patients, clinicians and diagnostic tests to improve the outcomes of care for individual patients, at the point of service as care is provided and in the patient’s home to support self-management, as well as for quality improvement and research. By 2012, 25 of the 64 clinics were using the web services option to generate patient-reported data reports to support care delivery in the flow of care and feedback reports for quality improvement and research.\textsuperscript{xx}

Figure 3 - Integrating PROMs & Clinical Data ©BeBright
3) ENGAGING PATIENTS IN TREATMENT AND CARE
The use of an integrated care platform that shares personal health information and (professional) clinical data should enable the patient and the healthcare provider to manage care processes and outcomes. Patient empowerment (trend 4) as described in the previous chapter is one of the key elements in Sustainable Healthcare. The case study below describes the use of such a patient empowering platform.

CASE STUDY FROM THE NETHERLANDS

ROMA is a Dutch initiative, which stands for Rheumatology Online Monitoring Application. ROMA is a web-based platform that supports the collection of patient related data through direct input by nurses, physicians and patients themselves. ROMA supports the DREAM registries, a multicentre Dutch initiative dedicated to improving clinical care, providing transparency of care and supporting clinical research in rheumatic diseases. The web-based system allows patients to enter their data, fill in questionnaires and view their personal electronic health record at home. ROMA has been developed in consultation with both patients and care-givers.

The ROMA database contributes to Sustainable Healthcare in different ways. Using input from patients and care-givers, ROMA has evolved from a research database to an integrated quality management system. ROMA integrates PROMs and clinical data. The combination of data is used for research focusing on the quality and efficiency of RA care in the Netherlands. As a result, RA treatment and care in the Netherlands is amongst the highest attainable international level.\(^{xvii}\) ROMA supports patient involvement and therapy commitment, it enables communication between care-givers, increases transparency of care and stimulates the efficient use of medication and other resources. ROMA provides benchmarking information and supports clinical auditing to improve quality of care.

![Figure 4 - Engaging patients in treatment & care ©BeBright](image)

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4) INTEGRATED PATIENT PLATFORM
Sustainable Healthcare is about achieving results that are meaningful to patients through efficient use of resources. One way to achieve this is by patients taking ownership in managing their condition. Therefore improvement of health literacy of patients (the ability to obtain, read, understand and use healthcare information to make appropriate health decisions and follow the instructions of treatment), is needed next to the use of PROMs. Sustainable Healthcare platforms are capable of supporting improvement of health literacy of patients. This requires the addition of a third and final element: reliable information on Rheumatoid Arthritis.

From a patient's perspective the future platform could offer the tools patients need to better manage their condition. An Integrated Patient Platform should include valid and reliable information on RA, integrated personal and clinical data and the possibilities to share information amongst patients.

The future platform optimizes patient involvement by offering the means to measure, monitor and improve perceived quality of life. The platform enables patient empowerment by inviting and enabling patients to actively participate in the care process. The tools available on this platform, for instance questionnaires based on PROMs, enable patients to monitor and improve their well-being based on transparent outcomes that are valuable to both patients and professionals. The result is patients taking ownership of maintaining their health and well-being the best way possible.

Figure 5 - An integrated Patient Platform ©BeBright
4. ACCELERATE THE UPTAKE OF SUSTAINABLE HEALTHCARE
The initiatives described in the previous chapter deserve a follow up as they show a way forward in sustainable healthcare. Analysis of these initiatives gives insight into the main factors for success and failure. Three major barriers can be identified which might slow down the design, development and the use of patient platforms.

**BARRIERS**

1) **LACK OF A COMMON APPROACH FOR DATA COLLECTION & EXCHANGE**

Managed competition is blocking the necessary collaboration between hospitals. Collaboration and data sharing requires openness amongst professionals and institutes, while competition between hospitals has an adverse effect. Both cases from Denmark and Sweden clearly show the advantages of a mandatory nationwide registry. The amount of data gathered by cooperation of all involved healthcare providers enables quality improvement through research and benchmarking. A nationwide registry also allows patients to switch providers without a loss of information. Pre-competitive collaboration, for instance nationwide agreements between hospitals and healthcare insurers, could prove a solution to this problem. In the Netherlands this challenge still has to be overcome in Rheumatoid Arthritis treatment and care.

2) **LACK OF INCENTIVES TO INVEST IN PROMS**

Sustainability is not only a healthcare issue. Investing in rheumatoid care can result in cost reduction to society as a whole for instance through patients being able to maintain their ability to work. In the Netherlands the investment in rheumatoid treatment and care is just over 3 billion euros but the costs to society are estimated to be 5 times higher. The financial benefits of healthcare investments will not automatically return to the investors. The social return on investment will be found in more people being fit for work, reducing welfare costs and improving economic growth. Therefore sustainability should be determined on society level.

3) **LACK OF STRUCTURAL FUNDING**

The possibility to reinvest savings into the system should be examined (both on the institutional and community level). Current Dutch DOT (diagnoses related groups) system does not always favour hospitals that invest in innovations supporting patient empowerment or reduction of professional involvement due to the focus on production parameters. Involving patients in treatment leads to a reduction of direct time spend by professionals ultimately reducing the hospitals earnings. Some of the new activities involved in this way of working are not yet recognised as such by the DOT system. The uptake of platforms requires structural financing and the absence of structural funding hinders potentially beneficial initiatives from becoming successful.

**WAY FORWARD**

To overcome these barriers, a collaborative approach is required. Both our healthcare system and our system of work and welfare will have to collaborate with the total social return on investments in healthcare as the focus. The Dutch Ministry of Healthcare, healthcare insurers, care providers and patients, should engage in a conversation on the sustainability of our healthcare system and the way Integrated Patient Platforms can be supported within the DOT system and without hinder from managed competition.

If we succeed in overcoming the barriers limiting the impact of current initiatives, a bright future lies ahead. The future of Rheumatoid Arthritis treatment and care can be defined as outcome driven, supported by a nationwide eco-system based on collaboration in which patients, professionals, healthcare insurers and employers strive towards transparent outcomes that are meaningful to patients.
APPENDIX 1.
THE SUSTAINABLE PLATFORM BUSINESS MODEL IN DETAIL

The design and rationale behind a Sustainable Healthcare Platform is illustrated by the Business Model Canvas (Osterwalder, 2008). It is a visual chart with elements describing the value proposition, infrastructure, customers and finances. The canvas shows the rationale behind a service by presenting the different elements and their relationship. We distinguish four important building blocks in the business model canvas as visualised in the figure below.

1. **Value proposition**: description of the values, which are delivered to the client. It needs to solve customer problems and satisfy customer needs
2. **Relationship and interaction**: how the relationship with the customer (client) is established and in which way the value proposition is delivered (e.g. through communication)
3. **Activities and facilities**: the activities, resources and partners that are needed to make the value proposition possible
4. **Financials**: of the business case (costs vs. income) of the value proposition

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**Figure 6: the four key elements of the Business Model Canvas ©BeBright**
A. PATIENT PERSPECTIVE

On a patient level the **Value proposition** is patient involvement by offering the means to measure, monitor and thereby improve perceived quality of life. The platform invites and enables patients to actively participate in the care process. The tools available on this platform are, for instance, questionnaires based on PROMs. These tools enable patients to monitor and improve their well-being based on transparent outcomes that are valuable to both patients and professionals. The result is acceleration of patient empowerment and ownership with regard to the patient’s health and well-being.

The **Relationship and interaction** between patient, nurse, rheumatologist and pharmacist changes. Collaboration or even co-ownership could be the right words to describe the future relationship between patients and professionals. Due to the shared insights, communication between patients and care providers turns towards co-creation based on the common understanding of the disease process. The relationship becomes more equal. Nurse practitioners serve partly as a coach or guide for patients. Substitution of diagnostics from professionals to patients might result in a more efficient care pathway in the future.

The platform enables patients and healthcare providers to change their interaction. **Activities** like self-management/(self)diagnostics (always under close professional supervision) change the way patients contribute to their own health process. This requires web-based instruments, digital communication tools and training. Next to the face-to-face interaction, the use of web-based instruments and digital communication tools enables the exchange of data online. These means require a different treatment protocol that is both online and offline, for example the use of a face time consult and special consultation rooms for nurse practitioners on the physical location. The patient gains more control over the contact moments in the care process.

![Figure 7: the business model from a patient’s perspective ©BeBright](image-url)
B. PROFESSIONAL PERSPECTIVE

On a professional level, the Value proposition is the availability of outcome data as a basis for research. The ROMA database provides anonymous data that can be used to research and explore the relationship between treatment protocols, the use of medication and the well-being and effects as reported by patients. Cost effect analysis, treatment strategies or benchmarking are a few of the options available. A second part of the value proposition to the professional is the possibility to integrate the way involved professionals collaborate. The centralised and multidisciplinary design of the platform improves communication between both the patient and carer but also between different carers involved. In complex and chronic care pathways there are several hospital disciplines involved such as a specialised nurse, rheumatologist and the pharmacist. Secondly, the primary care service (general practitioner) is involved as well as the drugstore pharmacist. Close collaboration using up to date patient records is needed. For instance, ROMA supports collaboration through the use of a single (web-based) platform for all stakeholders.

The use of PROMs requires the professionals to change their activities the way they work. The patient carries out part of the measurements. Doctors and Nurse Practitioners receive and process the results in preparation for the patient consultation. The level of understanding of the patient can be much higher than before which requires professionals to change both their protocol and their attitude.

For example, the ROMA system is designed, managed and partly funded by a select group of rheumatologists with financial support of AbbVie. Structural financial support is needed. However, the business rationale is uncertain. Structural support can be generated by subscriptions. Institutions pay a small fee per patient if they use the platform which enables them to create value for their clients. The income is used to maintain and improve the system.

Figure 8: The business model from a professional perspective ©BeBright
C. COMMUNITY PERSPECTIVE

All individual care pathways result in a more sustainable RA care model. The most important value proposition from a community perspective is sustainable and efficient healthcare through clear outcomes of medication and treatment. The use of the platform improves the well-being and quality of life for all RA patients without pushing costs of healthcare.²²²

The relationship and interaction between the stakeholders is based on a common goal to improve patient care with quality and efficiency in mind. The managed competition between the healthcare providers should not limit the openness to share results. The platform supports what could be called an ‘ecosystem’ where all the stakeholders act together and start collaboration instead of competing.

The information gathered is input for research activities to improve the effect of treatment and the effect of medication. Treatment plans will be compared to get shared insights on improvements of care and cure.

As stated in the business model from a professional perspective: structural financial support is needed for national uptake and further research. The current DOT system has no incentive to invest in platforms enabling the use of PROMs. The benefits that are generated (e.g. less frequent hospital visits, substitution from medical specialist to nurse practitioner or even substitution from professional care to patient self-management) result in more efficient healthcare. Unfortunately this will not directly benefit the professionals who have invested in the platform because our DOT-system is based on activities, instead of results/outcome. Investing in healthcare will lead to effects such as patients being fit for work and the possibility to reinvest savings into the system has to be examined (both on institutional and community level).

Diagnose Zorginnovatie, over technologie en ondernemerschap, P.J. Idenburg en M. van Schaik, 2013

AbbVie Sustainable Healthcare Initiative 2013

Reumafonds, [http://www.reumafonds.nl/reuma](http://www.reumafonds.nl/reuma)

Reumafonds, Leven met Reuma, [http://www.reumafonds.nl/reuma/leven-met-reuma](http://www.reumafonds.nl/reuma/leven-met-reuma)


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Dose reduction of TNF blockers in Rheumatoid Arthritis: clinical and pharmacological aspects, A van der Maas, 2013

www.ichom.org

Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and GROUP Health.


Transparantie en doelmatigheid in de reumazorg, van der Laar c.s. 2013
ABOUT ABBVIE

AbbVie in the Netherlands is a young, ambitious health business dedicated to putting people first. Because we understand that experience of illness is personal, we care about the things that matter to patients. People and the quality of their lives are most important to us. This directs what we do and how, for those who rely on our medicines and those who work here.

We are a responsive biopharmaceutical company focused on complex health conditions like rheumatoid arthritis, Parkinson's disease and cancer. We feel passionate about the promise of our new discoveries, but we know that treatments alone are not always enough. As a market leader proven to add value beyond our medicines, we are also responsible for improving standards of care and ultimately finding cures.

Our contribution to help improve people's health, as priorities in care constantly change, is becoming a more defining measure of what we do. We always commit to quality in health solutions around our medicines, co-designed with partners in care. Our entrepreneurial spirit means we bring vitality and inspiration in collaboration with others.

Our goal is that people are healthier and fit for work and family life, as part of a strong local community. This is how we touch the lives of men, women and children in Dutch society. We believe in what we can achieve, which is why everyone at AbbVie Netherlands makes a remarkable impact on people’s lives.

www.abbvie.nl

ABOUT BEBRIGHT

BeBright started as a response to the need of organisations to transcend boundaries when exploring new markets, new strategies, new marketing and new products and services. In doing so we don’t aim to create good ideas; we support bringing them to market and internalising the renewal as a whole.

Innovative companies have one common characteristic: a properly set-up innovation process with consistent direction. This well-founded innovation process results in a stable stream of new services and products, which are brought to market successfully.

“Prepare today, to lead tomorrow”

We link knowledge and networks across markets, cultures and organisations, to achieve enduring improvement. This makes them future-proof and able for on-going renewal: Accelerating Innovation. We combine consultancy and creativity. Our strength is to make new combinations, to release limiting paradigms and to explore new perspectives. Our way of working consists of three steps: scan, design and create. The result is organisations which are ‘ready for the future’, which are ‘in the lead’, whatever happens. Ultimately, a strategy is only successful if it results in innovation.

“Impact and results: we colour the world Bright”

We have already sought answers to questions like: What do our clients want over the longer term? Is my company ready for what’s ahead? How do we bring these new products to market? How do we position our new service?
R4SH is a multi stakeholder platform launched by AbbVie in 2013 and supported by AbbVie to find concrete solutions to achieve improved health and quality of life for more people for a longer period of time through wise, efficient use of resources.

www.recipes4healthcare.eu