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**Gaining knowledge by asking the right questions;  
re-evaluation of outcomes of care**



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# Gaining knowledge by asking the right questions; re-evaluation of outcomes of care

Inaugural lecture delivered by

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at the acceptance of Professor by special appointment,

in Nephrology: outcomes of care

Leiden University,

on Friday 15 March 2019



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*Esteemed rector, members of the board of St Antonius Hospital, trustees of this bestowed chair, members of the Supervisory Board of the Leiden University Medical Center, highly esteemed listeners,*

I will take you back in time. A young knight was wandering around the country. After many years, he reached his goal. He found a fortress, where a sick, old king was living. He didn't know the right questions to ask the king and had to continue wandering for several years before he found the fortress back again and was now able to ask the right questions. In doing so, he freed the king<sup>1</sup>.

Ladies and gentlemen, in healthcare, do we ask the right questions; to our patients, and to ourselves?

I will take you on a journey. A journey into value based healthcare in the consulting room, the hospital and health care.

### **Introduction Value Based Healthcare**

How do we deal with the major challenges we face in healthcare? The population is aging, the amount of people suffering from a chronic disease is growing, technology is developing very rapidly, and costs are increasing, as are staff shortages.

What does the patient see?

They see that care for the patient is not always organized efficiently and that the conversation is not always about aspects that he/she feels are important.

What do you see when you look at healthcare from a distance? Then we see variations in outcomes of care, slow adoption of good practical examples and rising costs.

In 2005, Porter and Teisberg described a solution for these problems in their book, "Redefining Healthcare". The essence of their proposal is expressed in the subtitle of this book:

"creating value-based competition on results". This subtitle introduces both "value", "outcomes of care" and "competition". Value is defined as the outcomes of care in relation to the costs. Almost without realising it, we are taking a significant step in the discussions about healthcare. With care outcomes in the numerator and the denominator, we shift the focus of the debate on costs to the outcomes of care.<sup>3,4</sup> I will come back later to the competition.

For Dutch people, it is logical that costs are part of the outcomes. Dutch is the only language where the word "KOSTEN" is embedded in the word "uitKOMSTEN".

Shifting the focus in particular from "costs" to "outcomes in relation to costs" is probably one of the explanations for the enthusiasm among patient representatives, doctors, hospitals, insurers and the government. Quality improvement appeals to the intrinsic motivation of care professionals, whereas for the government and insurers this perspective is attractive due to the more effective use of resources.<sup>5</sup> The Dutch Federation of Medical Specialists defines value based healthcare as a starting point for the delivery of care<sup>6</sup>. In the coalition agreement "Trust in the future", and in the, in 2018, concluded outline agreement for Medical Specialist Care 2019-2022, value based healthcare is an essential ingredient in the agreement between parties in healthcare<sup>7,8</sup>.

Value based healthcare describes a conceptual framework to make care more effective and keep it affordable. That is in essence achieved by:

1. Choosing the patient's perspective as the starting point when organising care
2. Measuring the outcomes of care that matter to patients
3. Using outcomes and cost analyses to improve the care
4. Amending the reimbursement models.

To put these starting points into practice, Porter describes a



strategic agenda with six points: integrating the organisation of care in so called integrated practice units (IPU's), measuring outcomes and healthcare costs, transferring to outcome-oriented payments, integrating care across locations and geographical expansion; all this being supported by information technology <sup>2,9</sup>. A part of this agenda is based on the American scale of healthcare.

What is value? Although academically this is mainly a question for economists and philosophers, we cannot evade asking ourselves this question. Porter does not define value in dollars as you might expect from a professor at Harvard Business School, but as value for the patient. He "calculates" this value by dividing the relevant outcomes for patients by the costs. Using a formula gives the impression of an objective value for medical practice. This is not the case. In the numerator of the formula, objective outcomes such as survival and medical complications and patient reported outcomes are by definition subjective; the denominator is in euros. Here lies the paradox in value based healthcare. Value based healthcare stands for the precise measurement of outcomes, but the value itself cannot always be calculated. The value is mostly subjective, built up from different outcomes that are partly subjective. Therefore, we cannot always calculate value, but we can always substantiate it. Improved outcomes? Decreasing costs? Are we heading in the right direction? When outcomes are improved, and costs decrease as a result of an intervention, there is no problem; if the outcomes improve with higher costs, then we need a debate.

Nietzsche spoke of a "Umwertung aller Werte" (revaluation of all values) when the fixed and universal truth of Christianity made way for the more personal and therefore more subjective interpretation of the term value. In healthcare, we are now experiencing a similar paradigm shift. We are moving from Evidence Based Medicine with protocols that are mainly based on survival benefit, to medicine where the voice of the patient is added; a culture in which subjective outcomes of care are also included.<sup>10</sup> This is also a change in which the universal

truth, that of the protocol, is linked to subjective valuations, namely those of the patient.

There are more initiatives and developments that are focused on the strengthening of the role of the patient and on raising the quality and efficiency of care. These are:

- Strengthening of the position of the patient <sup>11,12</sup>.
- Joint decision making by the patient and the doctor <sup>13</sup>.
- Quality improvement through feedback on results of care <sup>14</sup>.
- Transparency about outcomes of care <sup>4,5</sup>.
- The Triple Aim concept: better patient and care provider experience and raised health outcomes against lower costs <sup>15</sup>.
- Reduction of unnecessary care, as described in the Choosing Wisely campaign, and research into which care is effective <sup>16,17</sup>.
- Efficient organisation of care with methods such as LEAN, the Theory of Constraint or care paths<sup>18-20</sup>
- Use of big-data, home measurements and artificial intelligence <sup>11</sup>.

Value based healthcare forms a logical framework to connect and integrate these developments. I believe that the integration of these initiatives leads to more quality improvement than carrying out separate projects.

### **Criticism**

There is also criticism about value based healthcare. Is it really something new? The patient is surely always at the centre of care? If we are honest, care is not always optimally organised around the patient, and, if we already measure outcomes of care, they are not always relevant outcomes for patients. Furthermore, professionals don't always receive feedback; more about this later.

Value based healthcare is also described as a buzzword or a hype, which people often understand and interpret in their own way <sup>21,22</sup>. Today, I will give you my interpretation!



The hypothesis that value based healthcare leads to quality improvement must be tested. Also for value based healthcare itself outcomes should be in relation to the efforts made and the costs incurred.

### Value based healthcare in practice

The nature of my chair "Nephrology, outcomes of care" means that I primarily focus on the kidney patient and the evaluation of outcomes. I'll now take you with me to explore the consulting room, the hospital and the health care system.

#### 1. The Consulting room:

I have become familiar with the power of working with outcomes from my own consulting room. Older patients whose kidney function deteriorates have to choose whether they want to be dialysed or not. My mentor Kolff carried out the very first acute dialysis treatments in 1944. Chronic dialysis has been carried out since the 1960s. Initially, there was a shortage. The technical possibilities and the capacity increased. Older patients were given treatment. Then, the question arose whether, for each person, the advantages of the treatment outweigh the disadvantages<sup>23</sup>. Some smaller studies show that older patients who also suffer from other illnesses, on average do not live any longer with dialysis than without.

Analysis of our own data has taught us that the time that dialysis adds to life declines at an advanced age, and is no longer significant over the age of 80, or even earlier for patients with comorbidity<sup>24</sup>.

These data, analysed by the PhD student Wouter Verberne have been adopted in the guidelines and are now used in the consulting room. Not in the sense that starting with dialysis is actively advised against; more as an opening to the conversation; starting with dialysis is not the only option, not starting is also an option that must be considered.

Subsequent questions immediately arise. If the length of life does not differ, what about the quality of life? While patients at an advanced age regularly indicate finding the quality of the rest of their life to be more important than the length of life, few studies have been carried out to compare the quality of life with and without dialysis<sup>25</sup>.

Outcomes of treatment differ greatly per individual. Can we make a better estimate of the disease progression and the effect of treatment in advance? Age alone predicts insufficiently. In oncology, the frailty defined by the physical and mental condition and activities performed in daily life predict the outcome of care. Such a "geriatric assessment" appears to change a quarter of the patients' treatment decision and leads to adapting the supportive care in three quarters of the patients. On balance, better treatment results are achieved<sup>26</sup>.

Nephrology is catching up in this field. The mental functioning of older patients before and after dialysis, and the value of the geriatric assessment is being investigated<sup>27,28</sup>.

In the Polder study, in which LUMC and St Antonius Ziekenhuis play a leading role, we implement the geriatric assessment as standard care in the phase when the patient must decide<sup>29</sup>. Soon we will start a nationwide study in which the course of the quality of life with and without dialysis will be examined. I would like to mention Dr van Buren, Dr Mooijaart and researcher Carlijn Voorend as important Leiden colleagues in these initiatives. We hope in the future to be able to give more precise treatment advice to the individual patient.

In this way, data from the field will be analysed and, in a patient accessible way, brought back to the consulting room as part of the shared decision-making. That process of decision-making is literally described by Gawande<sup>30</sup>. We accept that a doctor no longer decides everything, and do not want a doctor who lists the advantages and disadvantages and then lets the

patient sort it out them self. We are looking for doctors who explore the advantages and disadvantages together with the patient to come to a joint decision.

At the LUMC, considerable knowledge is present of the field of shared decision-making in Professor Stiggelbout's group. The coming years, in cooperation with Santeon hospitals, the Kidney Patient Foundation and the LUMC, we will conduct practical research into the decision-making process among kidney patients. Where the possibility for the older patient to avoid dialysis has often received insufficient attention, the younger kidney patient can gain length and quality of life with an early transplant. We are investigating if the choice process, and the ultimate treatment results can be improved based on outcome-based information; information given to the patient and their family and/or friends at home <sup>31</sup>.

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#### *Patient reported outcomes*

How do we determine what is really relevant for a patient? A good conversation in the consulting room, you would think. Many complaints are systematically given too little attention in standard consultations. I refer to the example of incontinence or tiredness after prostate surgery <sup>32</sup>. The majority of patients have a different idea of what they are troubled by than their doctor. With questionnaires, PROMS, Patient Reported Outcome Measures, we can systematically have a picture of relevant daily life outcomes <sup>33,34</sup>. PROMS give the individual patient, and their physicians, insight into their daily functioning and the limitations they experience thereby. The use of PROMS is not an impersonal interpretation of person-oriented care <sup>35</sup>, but the starting point for a better conversation, focused on the complaints that the patient is affected by the most in daily life <sup>34,36,37</sup>. The willingness to repeatedly complete questionnaires mainly depends on discussing the answers in the consulting room. In addition, it is important for patients to compare the course of their illness, or their recovery after an intervention with that of fellow patients <sup>38</sup>. Through systematic follow up of PROMS, the results can

give shape and direction to the treatment strategies <sup>39,40</sup> or be used for quality improvement projects <sup>32</sup>. Do we know whether the use of PROMS is worthwhile? The use of PROMS raises the quality of the conversation and is useful for identifying patients' complaints. The proof that outcomes of care are really improving is increasing <sup>34,37</sup>.

There are generic PROMS, that question a number of domains that are relevant for everyone, and disease specific PROMS. Kidney patients suffer, more often than other patients, from several comorbidities <sup>41</sup>. For them, it is more practical to not have to complete different questionnaires for each practitioner. For kidney patients, it is therefore especially relevant to use generic PROMS where possible <sup>42</sup>. In the Netherlands, the PROMS and PREMS working group from the Linnean initiative discuss the use of generic PROMS <sup>43</sup>.

In nephrology, PROMS were introduced and evaluated by Dr Hemmelder, the director of Nefrovisie, Professor Dekker and Yvette Meuleman and Esmee vd Willik researchers at the clinical epidemiology department of the LUMC. I am looking forward to working together on the evaluations of PROMS in different categories of kidney patients.

Now we are at the beginning of broader use of PROMS, we must ask ourselves if we always ask the right questions with the current PROMS <sup>44</sup>. The most frequently used PROMS question the quality of life viewed from a medical perspective. Patients and doctors, in general answer the question of what relevant outcomes are, differently. Doctors often state the length of life as the most important outcome measure, followed by medical complications. For patients, the quality of life is more important <sup>45</sup>.

When we ask Dutch people what health means, dimensions are mentioned which are only partly asked in the current PROMs. The concept 'positive health', based on a broad set of questions about what health means, places less emphasis on



the presence or absence of illness, and more on the possibility of people to take on challenges and manage their own life. In this new health concept, 6 dimensions are distinguished, namely: physical function, mental function, a spiritual/existential dimension, quality of life, societal participation and daily functioning<sup>46</sup>. It would be enrichment for positive health if it were possible to quantify the functioning of the six axes of health and to use the outcomes in the supervision of patients. For value based healthcare it can be enrichment when in addition to measures associated with the illness, we use measures that measure health.

Finally, there is a completely different way of evaluating health. With PROMs we now think of questionnaires. Measurements at home, of blood pressure, weight, number of steps taken per day, are other measurements reported by the patient which give a meaningful view on health and are easier to gather!

## 2. The hospital

In the Netherlands, value based healthcare is approached from two sides. Some university medical centers begin organizing care for patients with a specific disease in so-called Integrated Practice Units 'IPUs'<sup>47</sup>. Improving quality through feedback on results of care is the starting point for several quality registrations and the Santeon hospital chain<sup>10,14,48</sup>.

### *Organisation of care*

How do we organize optimal care for the patient? In Integrated Practice Units (IPUs), all professionals, who are involved with the care for the patients with a specific disease, provide integrated care. In IPUs initiatives are met which would otherwise all call for attention. I mentioned shared decision-making, standardisation and efficient organisation of care, and measuring and evaluation of the outcomes of care, including patient-reported outcomes. Tailor-made ICT is urgently needed to continuously show results of care both individually as well as at an aggregate level. Enthusiasm and drive of all professionals involved are the most important ingredients.

Conversely, the presence of these opportunities makes it attractive for the scarce professionals to work together in a place developing this integrated care for the future.

In society, there is great demand for care at a human scale. In IPUs, permanent, well-attuned teams, provide the care. Working in IPUs can, also in large institutions, be an answer to the demand for the human scale.

The way IPUs are set up and used varies<sup>49</sup>. The LUMC has chosen a gradual increase of the number of IPUs<sup>47</sup>, rather than a sudden total reorganisation according to care themes, the so-called tilting. Scientific evaluation of value based healthcare is a core theme.

It is a privilege to give direction to the implementation and evaluation of value based healthcare in LUMC together with Professor van Buchem. With a powerful management team supported by an enthusiastic implementation team and expert working groups, we set up the care of the future. Within nephrology, transplantation care has already been organized along the lines of an IPU under the guidance of Dr de Vries. Together with Dr Teng, and researcher Ebru Dirikgil, I hope to contribute to the organisation and evaluation of care for patients with ANCA-associated-vasculitis, an inflammation of the small blood vessels, which is often accompanied by inflammation of the glomeruli, the filter apparatus of the kidney.

The effectiveness of several of the above-mentioned components when setting up an IPU has been described. What do we know about the effectiveness of an IPU as a whole? Improvement of efficiency and short-term results has been proven<sup>50-52</sup>.

Organisation forms cannot be researched with RCTs.

Comparing organisation and outcome of care before and after the implementation is a more feasible model<sup>53</sup>.

We must ensure timely measuring outcomes of care to be able to evaluate the effect of the changed organisation.



### *Quality improvement initiatives*

The question we should repeatedly ask ourselves is whether we are delivering good care. Insight into the effect of our treatment and comparing the outcomes of others is a powerful tool for improving. Doctors of the seven Santeon hospitals compare care outcomes and working methods. Best-practices are identified and implemented by local, multidisciplinary, improvement teams. A real cultural change is the participation of patients in these local teams. My personal experience is that the conversation changes directly as a result of this. A subsequent change is that the outcomes of care are published when several cycles have been gone through<sup>10,48</sup>.

8 With the nephrologists of the Santeon hospitals, we started a similar project headed by Dr van Dorpel and Ellen Parent from the Maasstad Hospital. I am proud of the openness with which we compare data from 7 hospitals and the enthusiasm of the local improvement teams in Nieuwegein.

Quality improvements based on outcome registrations have been less described in medical literature; they can be counted on three hands<sup>54</sup>. In the Netherlands, complications and mortality of patients with a colon carcinoma have decreased by sharing outcome details with surgical centres<sup>55,56</sup>. In cardiothoracic surgery, best practices, that were identified in outcome registrations have led to a rise in quality<sup>57</sup>.

Improvement of care on the basis of international comparisons is a more viable model for rare diseases, where often, insufficient patients have been treated to carry out randomized studies.

### *Which outcomes are we going to measure?*

Before we can measure outcomes of care, we must establish which data are suitable. Precise definitions are required to make meaningful comparisons and to derive data automatically from electronic patient files<sup>58</sup>. In the Netherlands, there has been experience in gathering data

through disease specific registrations for years<sup>14,59,60</sup>. The International Consortium for Health Outcome Measurement (ICHOM) defines internationally outcome sets to be used for specific pathologies.

The Dutch government has indicated that they would like to use these ICHOM sets<sup>62</sup>. As chair of the international ICHOM working group for kidney diseases, I plead to take well-functioning Dutch registrations as a starting point and from there, build up the system. The ICHOM sets are a goal here; not a departure point.

In nephrology, Renine has registered diagnosis, length of dialysis and mortality for years, whereas the Dutch transplant registration registers all transplantation details. Nefrovisie is now working on a system for all treatment phases, the chronic kidney disease phase, dialysis, transplantation, and conservative treatment. The number of measured outcomes is gradually increasing and moving into the direction of the ICHOM set.

At every comparison of data, participants question whether their data is correct and comparable. We appear to not all be the best and many people go through some of the Elisabeth Kübler-Ross stages of grief such as denial, anger, bargaining and acceptance. When comparing the outcomes, the thought often crosses one's mind "my patients are more ill than yours". Correction for differences is vital for an adequate comparison. That can change the interpretation of the outcome differences<sup>63,64</sup>. Whether the differences in outcomes are the consequence of differences in medical policy can only be examined after correction. To enable this analysis, in Santeon projects a number of patient and process indicators are measured in addition to outcome measurement<sup>10,48</sup>.

### *Transparency*

Is transparency subsequently necessary to improve outcomes? Society asks for transparency of outcomes of care<sup>4,5,62</sup>. Transparency enables aforementioned "competition on

outcomes", provides a base for trust in the work of doctors and allows patients to choose the hospital where they want to be treated. For professionals, a strong motive seems especially wanting to keep up with colleagues<sup>5,65</sup>. The proof that transparency in itself leads to improvements is limited. Introduction of transparency is often combined with quality improvement initiatives<sup>48,66</sup>, or a result-oriented reimbursement system is commenced<sup>67</sup>. The DICA-registrations show that a lasting quality improvement is possible when the treatment outcomes are only visible for the participating centres and not for the outside world<sup>68</sup>. Another limitation of transparency is that the outcomes of care are not only the result of the quality of the care provided but are also dependent on the place where a hospital is located, for example, in a deprived area, and the characteristics of the patients who are treated.<sup>69,70</sup>

Transparency is not an aim in itself. We need to ask ourselves which aim we are pursuing, and what information is required to realize this. When we publish the outcomes of care, we need to realize that different outcomes measures do not always point in the same direction<sup>64,71</sup>. A hospital can score well on one measure, and worse on another. This means that we cannot present "the" quality easily. Using a composite measure, based on a combination of various outcomes, can be an option<sup>71,72</sup>, presenting several outcomes is another option.<sup>48</sup> For the acceptance of publication amongst professionals, it is essential that the participating centres first go through several cycles to deliver reliable data and are given the opportunity to improve on points where one unconsciously scores worse than others<sup>48</sup>.

#### *Measure risks of outcomes.*

The use of outcomes measures also carries risks. The freedom of choice of the patient should not be impeded. An area of tension exists between striving for optimal survival, on which Evidence Based Medicine (EBM) is essentially based and striving for the freedom of choice for patients<sup>3,73</sup>. I challenge you to sit in my chair. You are talking to a

65-year-old kidney patient. You need to inform the patient about dialysis treatment and kidney transplant. You know that 65-year-olds live longer with both dialysis as well as a transplant, than without. You propose these treatments. The patient indicates that such intensive treatments do not fit in his life. You will agree with me that the patient should have the opportunity to take this decision and you will also agree with me that your department should not be held account for the shorter survival of patients who consciously have foregone a life extending treatment.

Patients' conscious choices, more often than common at present, need to be registered. This counts both for bigger decisions such as those concerning transplant, dialysis or conservative treatment, as well as "smaller" choices that influence outcomes, such as, for example, stopping using cholesterol lowering medication if these cause complaints. The apparent contrast between striving for optimal outcomes and personal preferences can also be diminished by giving patient relevant outcomes such as quality of life a more prominent place, both with quality comparisons, as in EBM.

Reporting of outcomes can lead to doctors avoiding risks and prefer not to treat patients with a high surgical risk. This is not always the case when comparing outcomes.<sup>56,72</sup> I take you with me to one of my patients, an older dialysis patient with a constricted aortic valve. Risk scores indicate that the chance of dying around the operation lies at 30%. Sufficient reason for the heart surgeon to reject a heart valve replacement. The patient states that life with a diseased valve is unbearable and that he is prepared to take that risk! Another heart centre, which at that moment does not yet participate in the quality registration, is prepared to operate. The operation is indeed complicated by cardiac arrest. Fortunately, resuscitation is successful. The patient still regularly confirms to me how happy he is that he and the surgeon took the risk.

Adjusting outcomes for treatment choices and risks appropriately can partially limit the dilemma when treating



high-risk patients. Furthermore, we should not only measure the outcomes with patients who have undergone certain treatment, but also patients with the same illness who have rejected the intervention. The avoidance of interventions among high-risk patients can lead to worse results for these patients. We can only prevent such an undesirable waterbed effect by measuring outcomes of all patients with a certain medical condition.

### 3. Society

The goal of healthcare is to provide good, safe, efficient and affordable care. Staff shortage presents maybe an even greater challenge. Efficient organisation is a dire necessity.

#### Costs

My expertise does not lie in the field of costs and reimbursement. I limit myself to some considerations. Value based healthcare is regularly presented as a system that leads to better outcomes for lower costs. That is not automatically the case. We need not think long about realizing better outcomes for lower costs. We must simply do it. In the initiatives I describe, examples can be found.

Neither do we need to think long about interventions that lead to worse outcomes. We don't do those. Treatments that enhance care, but also make it more expensive, require more extensive consideration. The conceptual framework of value based healthcare provides no ready-made answer. The balance between the expected treatment result and costs and burden of treatment have to be drawn up; the patient and his doctor determine suitable care for this patient, the hospital must decide which care they provide, and society must decide which treatments are reimbursed. Cost effectiveness of new treatments is now determined by the Care Institute, according to cost per gained QALY, quality adjusted life year <sup>74</sup>. Reevaluation of outcomes can lead to redefinition of the term quality in the QALY. An independent institute that assesses what care is valuable and deserved reimbursement remains indispensable.

#### Calculating costs and reimbursement of healthcare

The current reimbursement system is complex. A detailed system based on diagnosis related codes (DBC's) to reimburse treatment has been added to an older more detailed system of registration of care processes. This complexity causes high administration costs, both on the side of the healthcare providers as well as the side of the health insurers <sup>75</sup>. How much value does this detail administration add, when the hospital and insurer settle a prior agreed contract price per year?

I think it's worthwhile to deploy part of the manpower that we now use for financial administration to use for registering the outcomes of care.

Should we change to a value driven reimbursement system <sup>75</sup>. In the current DBC-system, individual treatments are reimbursed (fee-for-service) to a certain ceiling, the aforementioned contract price. Extra treatments, also those for complications are mostly reimbursed. Outcome driven reimbursement can consist of combined payment for a whole course of treatment or a bonus/malus system for over or under average performance. In both cases, there is a financial incentive to improve the outcomes of care. Costs of complications are borne by the healthcare provider. In 2006, the Health Council and the Board of Health and Care concluded that intrinsic motivation to improve healthcare motivates professionals more strongly than extrinsic stimuli such as a remuneration system<sup>5</sup>. Proof that outcome driven reimbursement leads to better care in the long term is still lacking<sup>65</sup>. The direct linking of financial incentives of quality improvement can even lead to lack of intrinsic motivation. In the United States of America, a Quality Incentive Program (QIP) for dialysis treatments has recently started. Below average functioning leads to a maximum of 2% less payment. Although quality scores improve, nephrologists experience QIP as a system of Quality Improvement *Penalties*. In the Netherlands, objections were raised and a strong decrease in willingness to work with PROMs arose when PROMs were used for reimbursement of mental healthcare.



I suggest first following the intrinsic motivation of the care professionals, and focusing on value based healthcare for quality improvement. Reimbursement on the grounds of outcomes can be discussed when current experiments<sup>75</sup> are successful. More effective delivery of care can also be a reason for making new payment agreements.

*Opposing interests* - The current reimbursement system creates opposing interests; a new reimbursement system will create new opposing interests.

An example: for an older kidney patient it can be wise to forego dialysis. The hospital, in the current reimbursement system, is insufficiently reimbursed for the capacity necessary for the talks, and foregoes production. This choice is financially favourable for society (+--+). Major surgery can be valuable for the patient, production for the hospital, but costly for society (+++). From the media, we know examples of patients who ask for their valuable treatments with expensive medicine, which are costly for hospital and society (+--+).

Value based healthcare does not create shared interest automatically (+++). In current experiments, attention must be given to old and new contradictions.

#### *Quality Assurance*

Can we improve supervision of quality of care? Internal supervisors, quality and safety departments, and external regulators, such as the inspectorate judge individual cases, departments and the functioning of the hospital as a whole. Medical associations visit specific hospital departments. The majority of quality systems are based on the judgement of numerous structure and process indicators. How is the hospital organized and how are processes secured?

The use of healthcare outcomes during supervision enhances that supervision. It opens the way to stop registering many structure and process indicators. This discussion is a hot topic in nephrology at the moment. Other fields have preceded us, of which orthopedics is a particularly a good example<sup>77</sup>.

When we change to a visitation system based on outcome measures, we need to make an in between step. I strongly recommend not directly "settling" on outcomes, but first evaluating how departments have dealt in reaction to deviating outcomes<sup>77</sup>.

#### *Technology*

##### *Information Technology*

An efficient IT-environment is a prerequisite for gathering outcome-data and simultaneously minimizing the registration burden<sup>62</sup>. Quick feedback on results of their own action is the strongest stimulus for professionals to adapt behaviour. This quick feedback is often lacking in healthcare.

Good IT offers the possibility to organize care more efficiently by supporting the "care paths". Home measurements and electronic consultations make it possible to move care from the hospital to the home<sup>78,79</sup>. Inflammatory bowel diseases and oncology have shown that using an app in which patients regularly report their complaints and symptoms leads to less outpatient visits when the condition is stable, and to reduction of the number of admissions because patients are seen quicker when complaints increase<sup>78,80,81</sup>.

The segmentation of the Dutch healthcare system forms an obstacle for data exchange. Healthcare providers support patients for only part of their course of treatment. Essential treatment data are kept elsewhere. Exchange of data is necessary. The introduction of the General Data Protection Regulation has increased this obstacle. The government has recently taken the initiative to oblige the exchange of information for referral.<sup>82</sup> I call the government to not only focus this initiative on referral information but also on collection of outcome data.

In the LUMC the workgroups for value based healthcare and data driven care have recently merged. Structured access to patients' data strengthens value based healthcare; data driven

care directly has an important clinical application. An adequate data platform forms the basis for patient care and all forms of clinical research. The next step is to use all this data for Artificial Intelligence to customise care for the individual patient in a better way.

It is enriching to work together in the LUMC with ITers such as Bert van Haarlem and Barbara Schooneveld, big data, clinical applications and explore the usage of AI with professors Steijerberg, Atsma and Hommes, and, in nephrology, to use the experience of Dr. vd Boog, a forerunner in collecting data in nephrology.

#### *Technology in nephrology*

Kidney patients can also be helped with entirely different technologies. The rigid dialysis schedule of 3 treatments in hospital per week has a great impact. Kolff's old idea to develop a portable artificial kidney is now being developed by the Nierstichting<sup>83</sup>. As a member of the Neokidney board I can contribute modestly to the development of a portable artificial kidney, which makes it possible to undergo home dialysis at times that fit the patient's life.

Regenerative medicine aims at recovery of the renal function. Treatment is no longer aimed at slowing down the decline or curing symptoms, but on health recovery. Recovery of renal function with the use of stem cells or kidney transplantation generated by the patients' stem cells form the future perspective for the kidney patient<sup>84</sup>. Under Professor Rabelink's supervision, the department of kidney diseases of the LUMC is making great progress in this field.

#### *Prevention*

Value based healthcare focuses particularly on hospital care. Prevention can also create value. The costs of prevention are relatively low; the revenues can be substantial. In nephrology, considerable substantive and financial profit have been calculated as being possible to realise through prevention, slowing down the decline of renal function in earlier phases

of renal insufficiency and having more transplants<sup>85</sup>. It is therefore important that quality symptoms in nephrology that now mainly focus on dialysis and transplantation, also focus on the early phase. The ICHOM outcome set for chronic kidney disease has already been set up for kidney patients<sup>42</sup>; relating to Santeon we are extending the nephrology project to the phase of chronic kidney insufficiency where we focus on slowing down the loss of renal function and stimulating (preemptive) transplantation. Nefrovisie is preparing to add the pre-dialysis phase to the national nephrology quality registration.

For the LUMC, there is a chance to research the value of prevention in the region. The the Hague Healthcampus and partnerships with the the Hague hospitals provide a platform.

#### *Education*

When we work according to these principles, you will meet other doctors in the future. Education is required, starting with the people who are now involved with initiatives of value based healthcare. In addition to theoretical knowledge, mainly practical knowledge is necessary. How do we work together in IPUs, how do I organize my practice? Which outcomes can I collect? How do I analyse the outcomes and how do I bring back the outcomes of care and PROMs to the consulting room? How do I use the data to improve quality?

Doctors of the future also need to be educated, starting with doctors who are now in training to general practitioners or medical specialists. Value based healthcare aligns with the 28 by CanMeds defined core competences<sup>86</sup>; they set high standards for a number of competences and strengthen other competences. Knowledge (1.1) and evidence-based approach (1.2) remain the core of our profession. Providing effective and ethical care (1.3) is strengthened. The strengthening of the patient's perspective requires better communication (2.1-2.4). Continual feedback improves the expertise (4.3, 4.4), contributes to expanding specialist knowledge (4.2) and



recognizing own boundaries. The health of the patient and society are encouraged, and continuous feedback can prevent incidents (5.4). Value based healthcare is especially suited for organizing care more effectively (3.1-3.4, 6.2) and applying available resources, including applying information technology optimally (6.3, 6.4).

During the study of medicine, firstly becoming a medical expert is central. Attention for the remaining competences comes later during the studies<sup>87</sup>. In Leiden, in the first year, without making any adjustments to the national framework for the study of medicine, attention is paid to parts of value based healthcare. I learned this from direct communication from the lecture hall through the family app!

Patients need to be included in the more active role they can play. Some subjects are already part of current campaigns, such as the campaign for deciding together<sup>13</sup>. The use of PROMs is another subject, especially now we are asked to complete a question form after every visit to a garage, plumber or telephone help line.

I am looking forward to contributing to innovative forms of education together with Prof Reinders.

#### ***Dilemmas and Friction between the 3 levels***

Towards the end of my speech I will discuss a number of dilemmas. You want to get started. Where do you begin? Just like the LUMC with organisation of care, or like St Antonius hospital with measuring of outcomes? In my view these are 2 valid starting points and both paths lead to improvement. Both approaches strengthen each other.

Value based healthcare is defined as a leading principle for organising care by professionals, care institutions, insurers and the government<sup>6,7,8</sup>. Do these parties who know their own rationality, language and time<sup>88</sup>, share the same perspective? Currently this seems to be the case.

In 2019, value based healthcare is implemented to raise effectiveness by delivering care at the right place, avoiding unnecessary care, preventing over and under treatment, raising quality and decreasing complications. We are looking for initiatives where better results are achieved against lower costs. In this, many interests of the patient to the government are aligned.

The playing field is more complex than it seems, there are three questions, which in my opinion will not be solved by value based healthcare.

#### ***1. Focus on the numerator or focus on the denominator?***

In the consulting room, the professional focuses mainly on the numerator, on the optimal outcomes. Although the government by using the term outcome driven care also seems to focus on the numerator<sup>89</sup>, cost management remains the primary steering framework of the government and the health care insurers<sup>73,88</sup>.

#### ***2. Revaluation of outcomes, how do we form the numerator?***

In defining medical outcomes, the primary responsibility lies with quality registrations of medical associations<sup>14,60</sup>. Outcomes that are relevant for patients are now added. I think we need to think more broadly. Today, in 2019, we need to consider whether to include both the social<sup>73,90</sup>, and the ecological impact<sup>91,92</sup> in our valuation.

#### ***3. How much is a treatment worth?***

The conceptual framework of value based healthcare, redefines outcomes, but gives, as argued earlier, no answer to the question of how much reaching better outcomes may cost. Here, the interests of patients, hospitals and the government can clash.

In anticipation of a shared definition and reevaluation of outcomes doctors and hospitals must, with their stakeholders, make the balance of outcomes and costs. Professionals



and hospitals are responsible for the quality of individual patient care; Dutch care agreements place the responsibility of cost management more firmly on hospitals<sup>8</sup>. Due to this, professionals and hospitals are the first to indicate where and how value will be created. This is our professional responsibility, which starts in the consulting room!

Universities must also show how they create value. Companies earn considerably with products whose foundation has been laid in universities; a foundation in publicly financed institutes, that create societal value, but who, just like hospitals<sup>73</sup>, are mainly seen as an expense<sup>93</sup>. Universities and hospitals have to participate in the debate initiated by Mazzucato about value creation. They must show which value they create to be able to invest the reward for this value creation in further innovations.

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Lastly, a warning. With our intentions to improve care, are we creating a technocratic system with extra burden of registration and bureaucracy which we will never be able to get rid of<sup>90</sup>?

This concern is justified! I have several answers. To limit the burden of registration, we must only accept the indicators that can automatically be extracted from patient files! Only in this way can the burden of registration be limited! Furthermore, we must seize the opportunity to improve the organisation and quality of care with value based healthcare and at the same time customize care by giving a better definition of what is important for the individual patient. It aligns, thus, with the core of our professional responsibility.

I began by asking questions. Maybe you also now have questions. Unfortunately, you cannot ask them during an inaugural address! What is the essence of this story? Are we not stating the obvious? A composer can write a new symphony with existing notes. I hope I have shown you that major improvements in outcomes of care are possible with a combination of patient orientation, focus on outcomes and continual improvement through feedback. These well-known

ingredients are brought together and strengthened by the conceptual framework of value based healthcare and by new technical possibilities. In the coming years, I hope to contribute to the organisation and evaluation of this form of care, both in the LUMC as well as in the St Antonius Ziekenhuis.

Back to the wandering knight, who after a long trip was able to ask the right question. Experts recognise Parcival. Courage and detachment and compassion characterise Parcival.

Courage and detachment are required to change our way of working, and to evaluate openly. Courage is also required for the patient who considers foregoing treatment. Compassion is essential for all patient contact, and also with the shared evaluation of each other's outcomes of care.

Ladies and Gentlemen, Parcival taught us that asking the right question is the most important. I attempt to summarise my speech in one simple question, which we can ask ourselves every day, or in every consultation: Am I creating value with what I do?

#### Acknowledgements

**Rector magnificus**, members of the board of the Sint Antonius Ziekenhuis, and members of the board of the Leiden University Medical Centre, I thank you for the appointment and for the faith placed in me.

In particular, I would like to thank Professors Rabelink and Spaan for their invitation to come to work at the LUMC and Professor Biesma for following this request and being prepared to establish this special chair. Although I have never worked in the LUMC before it feels like coming home.

That I am standing here today is partly thanks to all those who have made it possible for me to become who I now am and to do what I have described to you.

PROF.DR. W.J.W. BOS

I think of patients, patients with whom I have had personal talks exploring what is of real value for them.

Professors Schalekamp and Krediet trained me. I learnt the real, for an internist essential deep thinking, from Dr Tjiong.

Scientifically, I have been formed by many, in Groningen, Salt Lake City, Amsterdam, Rotterdam, Nieuwegein and now in Leiden. Dr Mohammad laid the foundations in Salt Lake City, Dr van Montfrans and Professor Wesseling supervised me during my Phd. Professor Kolff was a special category, an inventor, and extremely brave. Kolff still challenges me to this day to pose the question: what is really important for the patient. In St Antonius Ziekenhuis, patient care has been combined with significant and patient related research for many years. This brought me to Nieuwegein nearly twenty years ago and motivates me daily. I refer to the cooperation in the pneumonia research group and the 7 Santeon hospitals that connect value based healthcare with a strategic research agenda.

Working in a partnership with 40 staff is unique. I am proud of the high quality, our education programme and the highly collegial way of working.

Within the Linnean initiative, enthusiastic participants from all stakeholders in healthcare accelerate the use of outcome measures. Thanks to all participants; in particular, the working groups chairs and my co-chair Professor Franx.

Formation begins at a young age. Here I would like to thank my parents. Patient care and science were present at an early age. As a child, I grew up with a dermatological practice at home, and the desk, which I still work at daily, was the graduation gift to my great grandfather who was promoted by 3 Nobel Prize winners.

Dear Josephine, you make so much possible for me and our

children, and you sharpen our minds! Jurriaan and Lisa, from a solid common basis each one of you are developing in your own direction. Coincidentally, two teams have emerged, a legal-economic team, which is the more musical team and the Leiden medical team. Josephine, Jurriaan en Lisa, daily I realise that you three are the most valuable to me.

Thank you.



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