eHealth Supported Diabetes Management

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PhD Thesis, University of Utrecht, The Netherlands

ISBN: 978-94-6375-303-6
Design and layout: Maaike Ronda & Kitty Lamaker
Cover illustration: istockphoto
Printing: Ridderprint BV | www.ridderprint.nl

The studies in this thesis were funded by The Diabetes Fund (grant no. 2010.13.1369) and Stichting Diamuraal/Huisartsen Eemland. Financial support by the Julius Center for Health Sciences and Primary Care for the publication of this thesis is gratefully acknowledged.

eHealth Supported Diabetes Management

eHealth Ondersteunde Diabetes Management

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag
van de rector magnificus, prof.dr. H.R.B.M. Kummeling, ingevolge het besluit
van het college voor promoties in het openbaar te verdedigen op
donderdag 21 maart 2019 des middags te 12.45 uur

door

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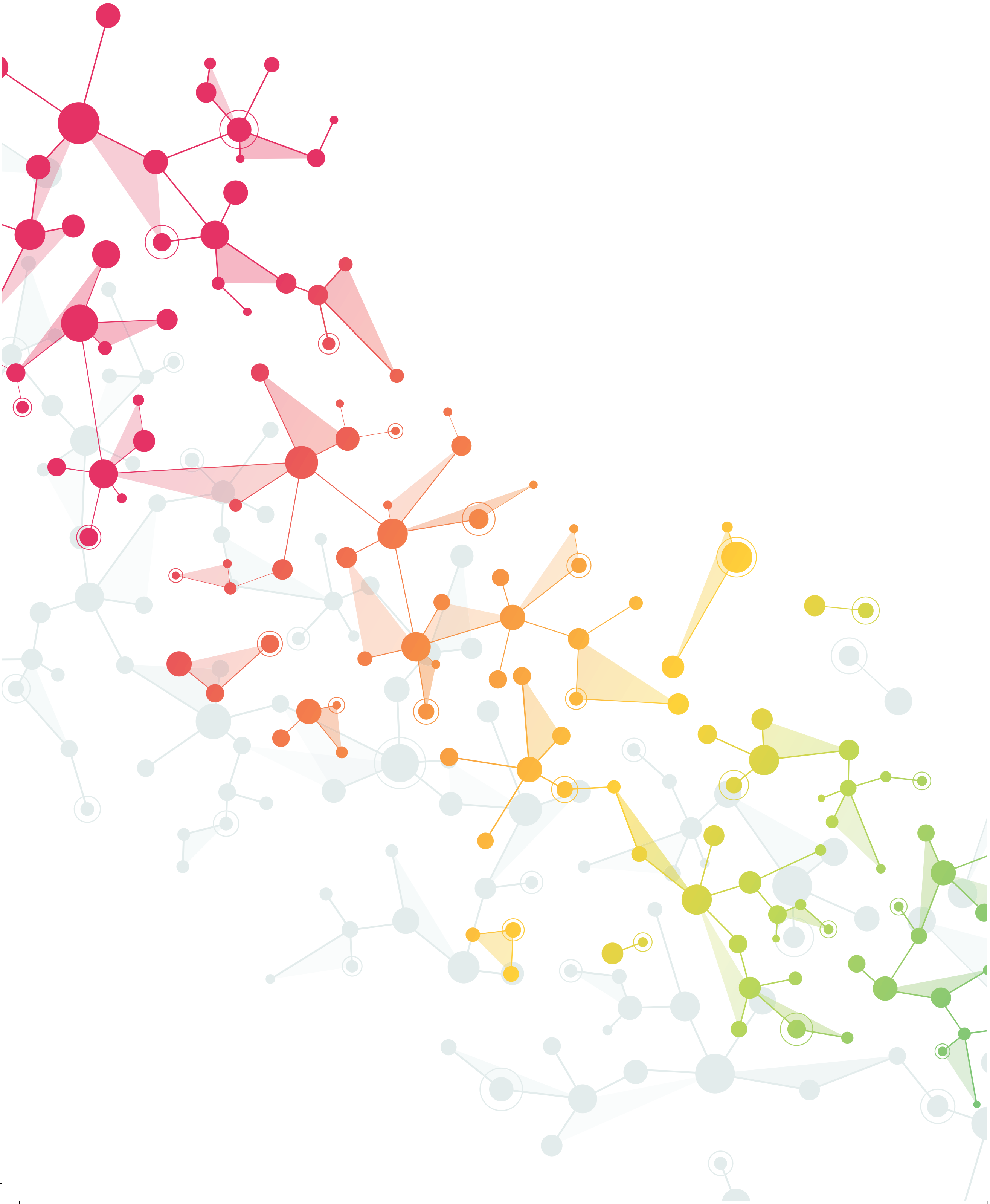
CONTENT



CHAPTER 1

General Introduction

Diabetes mellitus is a chronic metabolic disease with two major forms: Type 1 (caused by an auto-immune reaction leading to deficient insulin production) and Type 2 (caused by a combination of insufficient insulin secretion and insulin resistance). Diabetes is a serious disease, leading to severe microvascular complications, such as retinopathy, nephropathy, neuropathy, and cardiovascular disease, namely myocardial infarction, stroke and peripheral arterial disease. Good metabolic control can delay the onset and progression of diabetic complications.[1] It is estimated that the number of patients will increase from 451 million people worldwide (9.3% of adults age 20-99 years) in 2017 to 693 million people in 2045.[2] In 2017, there were approximately 5 million deaths worldwide attributed to diabetes mellitus, and the global healthcare costs were estimated to be 850 billion USD.[2] In the Netherlands, there are over 1 million people with diabetes, about 90% with type 2 diabetes. In 2015, the costs of diabetes care were 1.6 billion Euros, 1.8% of national healthcare costs in the Netherlands.[3] In the Netherlands, more than 85% of the people with type 2 diabetes are treated in primary care, while people who need more complex diabetes care and those with type 1 diabetes are treated in secondary care.[4] Almost all general practitioners participate in care groups, that assume financial and clinical accountability and in turn, subcontract individual care providers (physicians, dieticians, podiatrists).[5,6] Health insurers pay a single fee to care groups to cover all elements of primary care for diabetes patients (bundled payment system). The bundled payment system and care groups have improved the organisation and coordination of care and led to better collaboration and adherence to care protocols.[4,7] People in the Netherlands are usually covered by a mandatory standard insurance package, which covers the care provided by general practitioners and care groups. Diabetes care services for patients in care groups are free of charge.[8] Most patients are monitored four times a year by their diabetes care providers.[9]

PATIENT WEB PORTALS IN THE ORGANISATION OF DIABETES CARE

To cope with the rising number of people with diabetes and the increasing workload of healthcare providers, the organisation of diabetes care may need to change. In recent years, studies focus on technology to support patients and healthcare providers, and electronic healthcare (eHealth) is often mentioned in this respect. eHealth is a broad term covering health services and information delivered or enhanced through the internet and related technologies.[10,11] These technologies can be used to support patients and physicians in the management of diabetes care. Among these technologies are patient web portals (PWPs) and the functionalities in the electronic medical record (EMR) of the healthcare provider.

Patient web portals are online applications that allow patients to interact and communicate with their healthcare provider.[12] A patient can access his / her personal health information in a secure connection through the internet. Different types of portals give access to different information, but usually portals give access to lab results, physician notes, and medication lists. Furthermore, patients can interact with their healthcare provider through a secured message function ("e-message") and can receive feedback from their provider.

At the start of our studies in 2011, there was information that PWPs could have a positive effect on diabetes outcomes, such as glycaemic control (HbA1c), body weight, blood pressure and lipid levels [13–18] as well as on self-efficacy.[15] At that time, PWPs were slowly adopted by both patients and care providers/clinicians,[19] but not much information was available on reasons for this. Furthermore, there was also hardly any information on the usability of portals for both patients and care providers. In studies about non-diabetes specific PWPs, physicians expressed concerns about workload, confidentiality and security of information, and communication,[20] and one study showed that 60% of physicians were unaware if their patients used some form of personal health record to track information.[21] Interest in portal use by patients was associated with dissatisfaction with the patient-healthcare provider relationship (including direct communication, responsiveness, obtaining medical information and logistical problems with the office).[22] In a study in primary care patients, that assessed the experience of first access to a portal, many found the portal useful but voiced concerns about security and understandability.[23] With regard to specific diabetes PWPs there was no information on how providers use a patient portal and only little about patient use. People with diabetes seemed to be interested in using a diabetes PWP,[24,25] but there were also barriers, e.g. low health literacy,[26] and frustrations (e.g. technical failures and receiving no feedback from the nurse practitioner on uploaded glucose levels) and difficulties to incorporate it in daily routines.[27] The mostly used PWP-features mentioned were: request medication refills, scheduling appointments and e-messaging.[28,29] In one study, patients could fill in an eJournal three weeks prior to a clinic visit (mentioning topics they wanted to discuss) and both patients and providers found it helpful in preparing a consultation with the diabetes care provider.[30]

Diamuraal and its PWP

Diamuraal was one of the pioneer diabetes care groups in the Netherlands. Its name reflects the vision of its founding partners to organise diabetes care in a transmural way, or through (*latin*: dia) the walls, not hindered by physically distinct structures like ambulant clinic and primary care practice nor the separate financing systems for primary and secondary care. This care group, (in 2017 renamed Huisartsen Eemland Zorg, www.huisartseneemland.nl), is situated in the region of Amersfoort in the centre of the Netherlands. Primary care practices and the outpatient clinic of the hospital Meander Medical Center participate in it. Together, they provide diabetes care to over 10.000 patients. Since 2006, all physicians and nurses working in these practices record their data in the same EMR and all diabetes patients can request a login to access their personal EMR. The PWP (www.digitaallogboek.nl) gives access to the entire personal EMR, including clinical notes, results of the physical examination, laboratory results and secured e-message with the physician. Patients can upload the glucose levels measured at home (Figure 1). All patients have a main physician (general practitioner or internal medicine specialist) who has access to their EMR, and when a patient shifts from primary care to secondary care (or the other way around), continuity is kept in the diabetes EMR. The general practitioner always keeps access, also in the case that an internal medicine specialist (temporarily) becomes the main diabetes care provider. Providers can also use the message function of the EMR to consult another physician ("e-consult") who then has temporarily access to all the relevant medical information of the patient.

Part 1 of this thesis: Diamuraal and the use of its Patient Web portal

In 2011, around 25% of the patients had requested a login to the diabetes portal by Diamuraal. Because it was the first care group using a PWP, no reference was available. This led to the first part of this study. We sought to understand which patients are interested in using a PWP in diabetes management and which patients are not; their reasons for this interest or disinterest; how users perceive the patient portal with all its functionalities and how they use it; and what the opinions and working methods of healthcare providers are with regard to the PWP. Diamuraal seemed to be a perfect setting to explore these topics. At the start of this study, the PWP had been implemented for 5 years and provided an excellent opportunity to examine the patients' and providers' perspectives on it.

The first four chapters describe the results from a survey conducted in the care group among patients with and without a login to the portal, and among the healthcare providers. In **Chapter 2** we examined the differences between patients that do or do not request a login to their patient portal. In **Chapter 3** we explored the opinions of patients about a web portal and we identified barriers to use the portal. In **Chapter 4** we aimed to gain insight into patients' actual experiences with the portal to understand how it is being used and how the portal could be improved. **Chapter 5** describes the opinions and working methods of diabetes care providers.

Digitaal Logboek
PORTAVITA

Overzicht diabetesdagboek

Datum 12-10-2018		NA	Voor	NA	Voor	NA	Voor	
Glucosewaarden (mmol/l)	Nuchter	Ontbijt	Lunch	Lunch	Avondeten	Avondeten	Slapengaan	Nacht
	6,5	6,2	**3,4**	8,5	5,2	**10,1**	7,6	
Insulinetoediening	Voor ontbijt		Voor lunch		Voor avondeten		Voor slapengaan	
							14 LW	
wijzigen verwijderen	Opmerkingen:							

Datum 11-10-2018		NA	Voor	NA	Voor	NA	Voor	
Glucosewaarden (mmol/l)	Nuchter	Ontbijt	Lunch	Lunch	Avondeten	Avondeten	Slapengaan	Nacht
	7,5	8,0	8,0	**11,5**	8,0	**11,0**	7,0	
verwijderen	Opmerkingen: *verjaardagsfeestje*							

Datum 10-10-2018		NA	Voor	NA	Voor	NA	Voor	
Glucosewaarden (mmol/l)	Nuchter	Ontbijt	Lunch	Lunch	Avondeten	Avondeten	Slapengaan	Nacht
	7,5	8,0	8,0	**11,5**	8,0	**11,0**	7,0	
Insulinetoediening	Voor ontbijt		Voor lunch		Voor avondeten		Voor slapengaan	
							14/LW	

Datum 01-05-2018		NA	Voor	NA	Voor	NA	Voor	
Glucosewaarden (mmol/l)	Nuchter	Ontbijt	Lunch	Lunch	Avondeten	Avondeten	Slapengaan	Nacht
	7,5	8,0						

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Figure 1: *Example of the glucose diary of the PWP*

ORGANISATION OF DIABETES CARE

As stated above, in the Netherlands, 85% of persons with type 2 diabetes are treated by general practitioners collaborating with practice nurses in a primary care setting.[4] Patients that are in need of more complex care are referred to a hospital-based internal medicine specialist, collaborating with specialised diabetes nurses. In order to evaluate and improve quality of care, general practitioners in care groups have to report quality indicators described in the Dutch Diabetes Care Standard (e.g. the percentage of patients with a yearly measurement of HbA1c; and the proportion of patients with HbA1c < 53mmol/mol (<7%)) to a central data management office aligned to care groups.[31] The role of practice nurses and specialised diabetes nurses, as well as benchmarking and the Diabetes Care Standard are perceived as facilitators of good diabetes care.[32]

Management of type 2 Diabetes Mellitus

Patients with type 2 diabetes in primary care are treated according to national diagnostic and clinical guidelines for type 2 diabetes mellitus[9] and for cardiovascular risk management from the Dutch College of General Practitioners.[33] They advocate personalised treatment goals, depending on age, use of medication and duration of diabetes.[34] Only patients that are in need of more complex care should be referred to a hospital-based internal medicine specialist. Besides these guidelines, there is also a national so-called ‘Transmural Agreement’, a management guideline on type 2 diabetes, which is an agreement between primary and secondary care with regard to the setting in which the diabetes care should take place.[35]

These management guidelines include clear indications for consultation of and referral to an internal medicine specialist, namely

- uncertainty about the diagnosis, suspicion of other types of diabetes;
- problematic glycaemic control (e.g. problems with medication, difficulties with reaching targets, hyper- and hypoglycaemia);
- presence of uncontrollable risk-factors, e.g. persistent high lipid spectrum, hypertension or obesity;
- presence of certain complications, e.g. strongly decreased kidney function, a foot ulcer, problematic neuropathy.

According to the management guidelines, patients should be referred back to the general practitioner when the diagnostic or treatment problem has been solved.[35]

Correct treatment allocation, identifying which patients can be treated in primary care, and which patients would benefit from consultation between the general practitioner and internal medicine specialist about a specific problem or question or a referral to secondary care, is important to improve the quality of and cost-effectiveness of type 2 diabetes care. Patients remain in specialist care much longer than guidelines stipulate.[36] In primary care, e-consultations between general practitioner and internal medicine specialists may provide positive results (e.g. good and timely advice for a new course of action) and e-consultations may postpone referrals or make them unnecessary.[37–39] Also, in patients with type 2 diabetes and with good cardiometabolic control a six-monthly instead of three-monthly monitoring does not compromise outcome and is cost-saving.[40]

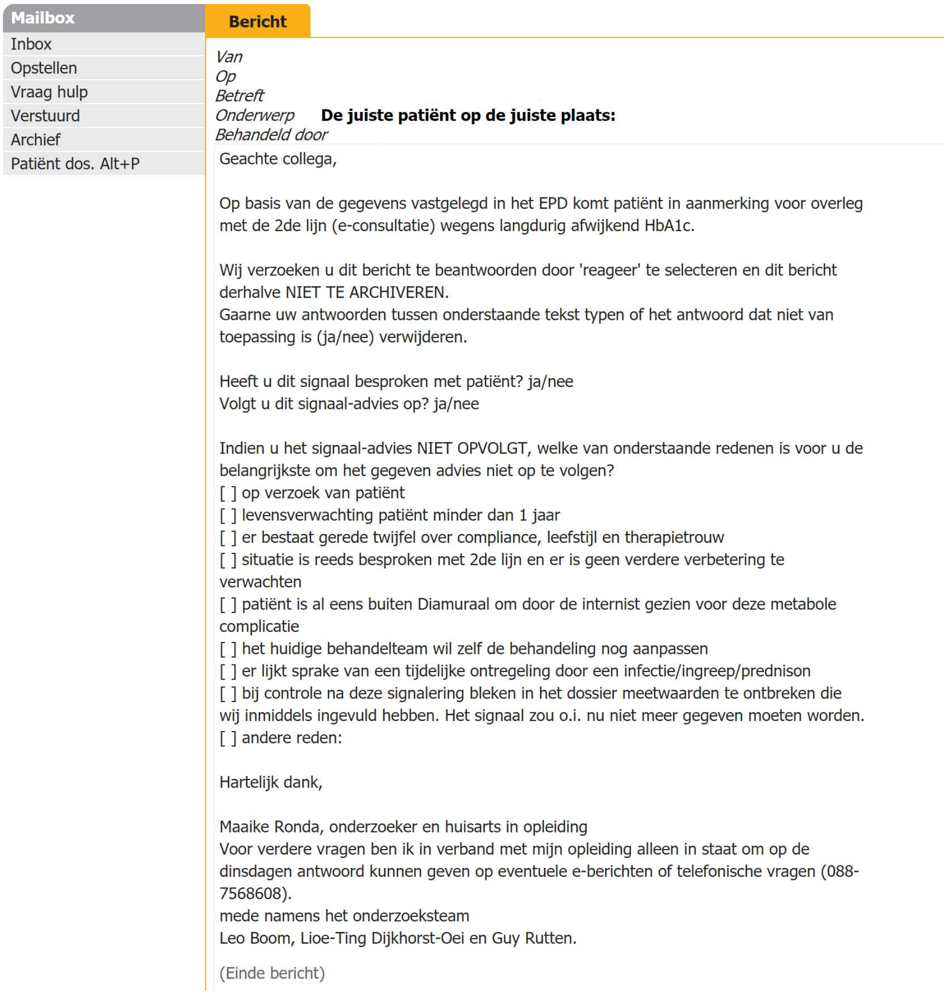
Indicators of quality of diabetes care

Quality of care can be measured with process and intermediate outcome measures. Process measures reflect how often the values of interest have been measured and subsequent actions have been performed, e.g. whether yearly measurement of HbA1c has taken place or if a medication has been prescribed when necessary. Outcome measures are reflecting a patient's cardiometabolic status and include HbA1c, blood pressure or LDL-cholesterol levels. A study in eight European countries found that adherence to process measurements is high in diabetes care with 97.6%, 98.3% and 82.0% yearly measurements of HbA1c, systolic blood pressure, and LDL-cholesterol respectively, but target achievement for intermediate outcome measures is low: 53.6%, 29.0% and 55.0% for HbA1c, systolic blood pressure and LDL-cholesterol respectively. Only 6.5% of all patients achieved all three targets.[41] The link between the process of care and health outcome in diabetes is not strongly established,[42] although compliance with process of care seems associated with fewer diabetes complications and improvements in diabetes outcomes.[43–45] Reminders in the EMR can improve professional performance behaviour and increase testing diabetes parameters and screening for complications.[46,47]

Part 2 of this thesis: Alert messages in the Electronic Medical Record

We designed an intervention in which either the general practitioner or the internal medicine specialist received an electronic advisory message (a 'prompt') in the EMR of the patients who were not treated in the correct setting according to the above-mentioned management guideline (Figure 2). We hypothesised that this would result in better treatment allocation of patients with diabetes, with improvements in the quality of diabetes care and in improved patient satisfaction. The setting of Diamuraal seemed ideal for this, due to all diabetes care providers working with the same EMR. Both general practitioners and internal specialists could receive alerts in the EMR, general practitioners could use the e-consult function in the EMR to confer with the specialist and the PWP could be used for substituting a consult in patients with good cardiometabolic control.

The effectiveness of the intervention is discussed in **Chapter 6**. In this chapter, we also report reasons for not following the advice as mentioned in the advisory message. **Chapter 7** reports the results of the intervention on quality of diabetes care and patient satisfaction in patients in primary care whose general practitioners received the advisory message. This thesis ends with a general discussion in **Chapter 8**, in which we consider our results, interpret them in light of current literature and discuss our methods and intervention, as well as consequences and implications for patients and providers.



Van
Op
Betreft
Onderwerp **De juiste patiënt op de juiste plaats:**
Behandeld door

Geachte collega,

Op basis van de gegevens vastgelegd in het EPD komt patiënt in aanmerking voor overleg met de 2de lijn (e-consultatie) wegens langdurig afwijkend HbA1c.

Wij verzoeken u dit bericht te beantwoorden door 'reageer' te selecteren en dit bericht derhalve NIET TE ARCHIVEREN.
Gaarne uw antwoorden tussen onderstaande tekst typen of het antwoord dat niet van toepassing is (ja/nee) verwijderen.

Heeft u dit signaal besproken met patiënt? ja/nee
Volgt u dit signaal-advies op? ja/nee

Indien u het signaal-advies NIET OPVOLGT, welke van onderstaande redenen is voor u de belangrijkste om het gegeven advies niet op te volgen?
[ ] op verzoek van patiënt
[ ] levensverwachting patiënt minder dan 1 jaar
[ ] er bestaat gerede twijfel over compliance, leefstijl en therapietrouw
[ ] situatie is reeds besproken met 2de lijn en er is geen verdere verbetering te verwachten
[ ] patiënt is al eens buiten Diamuraal om door de internist gezien voor deze metabole complicatie
[ ] het huidige behandelteam wil zelf de behandeling nog aanpassen
[ ] er lijkt sprake van een tijdelijke ontregeling door een infectie/ingreep/prednison
[ ] bij controle na deze signalering bleken in het dossier meetwaarden te ontbreken die wij inmiddels ingevuld hebben. Het signaal zou o.i. nu niet meer gegeven moeten worden.
[ ] andere reden:

Hartelijk dank,

Maaike Ronda, onderzoeker en huisarts in opleiding
Voor verdere vragen ben ik in verband met mijn opleiding alleen in staat om op de dinsdagen antwoord kunnen geven op eventuele e-berichten of telefonische vragen (088-7568608).
mede namens het onderzoeksteam
Leo Boom, Lioe-Ting Dijkhorst-Oei en Guy Rutten.

(Einde bericht)

Figure 2: *Example of the electronic advisory message sent to the general practioner*

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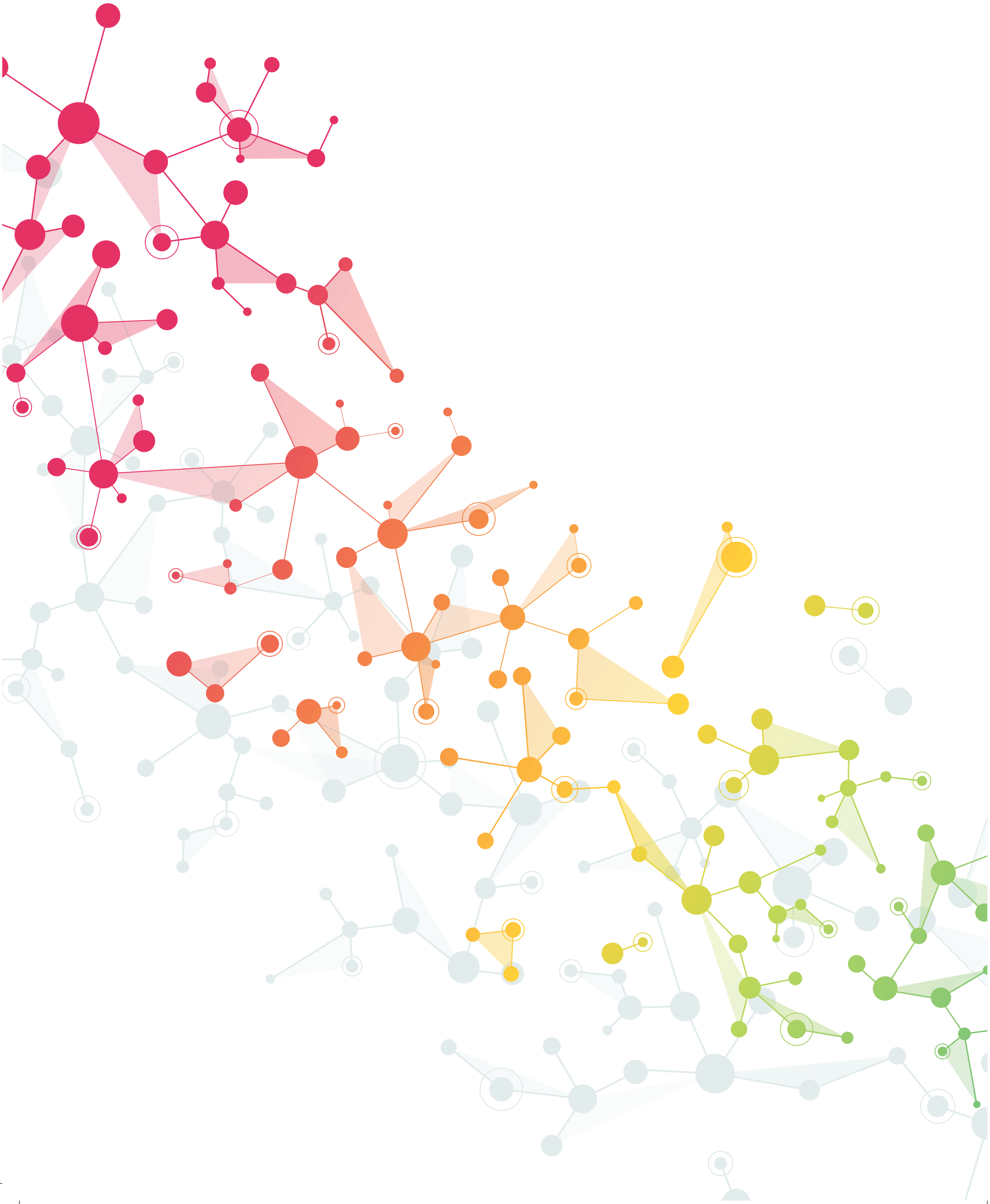
PART I

The use of a patient web portal in the management of diabetes mellitus



CHAPTER 2

Differences between diabetes patients who are interested or not in the use of a patient web portal

M.C.M. Ronda, L.T. Dijkhorst-Oei, K.J. Gorter, J.W.J. Beulens, G.E.H.M. Rutten

Diabetes Technology & Therapeutics. 2013;15(7):556-63

ABSTRACT

Background A patient web portal allows patients to access their personal health record through the internet. It may improve diabetes outcomes, but the adoption is unsatisfactory. We examined the differences between patients with and without a login in order to optimize its use.

Methods A survey among patients from 62 general practices and one outpatient clinic that all use a diabetes web portal. Between November 2011 and March 2012 questionnaires were sent to 1500 patients with and 3000 patients without a login. Patient groups were stratified according to type of diabetes. Demographic and diabetes related variables were analyzed with multivariable regression analysis.

Results The total response rate was 67%. Less than 50% of the patients did request a login. Among 128 patients with type 1 diabetes mellitus, those with a login (89.8%) were younger and more frequently treated by an internist. In 1262 patients with type 2 diabetes mellitus, less patients had a login (41.0%) and the likelihood of having a login was independently associated with younger age, male gender, higher educational level, treatment by internist, longer duration of diabetes and polypharmacy and a lower HbA1c and total cholesterol, more diabetes related distress, higher self-efficacy and better diabetes knowledge (all $p<0.001$).

Conclusions Patients with type 1 diabetes request a login more frequently than patients with type 2 diabetes and patients with a login are strikingly different than patients without. The health care provider seems to play an important role in patients' web utilization. Simply promoting e-health does not make sense. It is important to address disparities between patient groups to optimize the use of a web portal.

INTRODUCTION

Patients with type 2 diabetes should be monitored four times a year.[1] To cope with the rising numbers of people with diabetes in the future,[2,3] and the increasing workload of health care personnel, the organization of diabetes care may need to change. One of the possibilities is to promote information exchange between patients and healthcare professionals that might facilitate a substantial increase of self-care.

Electronic health care (e-Health) is such a method and there are many forms of e-Health,[4] ranging from general health information on the internet to specific health care systems. One type of e-Health is a patient portal, an online application that allows patients to interact and communicate with their physicians.[5] These portals have a positive effect on diabetes outcomes, such as HbA1c and cholesterol,[6–10] and on self-efficacy.[11]

However, many patients do not use the patient portal.[12,13] This may be associated with limited health literacy,[12,14] social disparities,[15] the digital divide,[16] age,[17,18] lack of information like enrollment instructions,[17] or lack of motivation.[17] However, other studies indicate that elderly patients with diabetes effectively use the internet[19] and are interested in patient portals.[19,20] One of the limitations of the existing evidence is that most of the studies about patient portals have been conducted in the general population instead of in a population of only diabetes patients.[16,21] The few studies carried out in a diabetes population did not differentiate between types of diabetes or treatment settings.[14,15]

In the Netherlands 96% of all inhabitants have access to internet, of which 84% is broadband access. Of the people with internet access 87% uses it daily and 11% at least once a week. Men and women have equal access and over 95% of the people up to age 65 have. Above the age of 65 years the access rate is lower (81%). Internet access ranges from 90% in lower education groups to 99% in the groups with the highest education. There is no digital divide due to cost of internet access. Therefore, patient portals can theoretically be used by most of the patients with diabetes mellitus in the Netherlands.[22]

We hypothesize that, with increasing use of a patient portal, patients may become more involved in their treatment.[23] This may lead to less diabetes specific distress and an increase in self-efficacy,[11] diabetes knowledge, treatment satisfaction,[24] and health status. Health care providers should be supported to identify groups of patients that need more attention in order to increase their portal use.

The aim of the present paper is to study the characteristics, the health status, the self-efficacy, the diabetes knowledge and the treatment satisfaction of patients with both type 1 and type 2 diabetes who do and do not have a login for a patient portal.

METHODS

Study design

We conducted a survey in a sample of 12.793 diabetes patients; of whom 3002 patients (23.5%) had a login to the patient portal and 9791 (76.5%) had never requested a login. We randomly selected patients aged 18 to 85 years, 1500 from the login-group and 3000 from the non-login group. The rationale for this ratio is that we anticipated a lower response from the non-login group. Patients were sent an information letter together with a set of questionnaires. A reminder was sent twice in a three week interval. Patients who did not want to participate could declare the reason for non-participation. The survey was conducted between November 2011 and March 2012. The study was approved by the Medical Research Ethics Committee of the University Medical Center Utrecht (protocol number 11-296/C).

Study setting

Diamuraal is an organization that coordinates the diabetes care in a defined geographical area in the center of the Netherlands. It comprises of 62 independent primary care practices and one outpatient clinic of the regional hospital. All physicians and nurses who participate in the care of patients with diabetes collaborate in the same electronic health record.

Since 2006, all diabetes patients in Diamuraal can request a login to access their personal electronic health record, on the condition that their health care providers give their consent. They get access by means of a web-based patient portal (www.digitaallogboek.nl). The information system of this portal was developed by Diamuraal and ©Portavita b.v.. After login, patients have access to their medical records, which include the information provided by their health care provider during medical consultation, such as physical examination, laboratory results, problem lists and treatment goals. Well-prepared patients could be aware of their results before meeting their care provider. It also provides access to general diabetes information and an overview of all examinations and diabetes visits that are needed according to guidelines. Patients can upload the glucose levels measured at home and seek contact with their care provider through secured electronic messaging. The portal is additional; patients who have not requested access receive usual diabetes care according to the Dutch guidelines.[1]

Study measures

Patients' self-reported characteristics

We used a questionnaire for patient characteristics. It contained questions about educational level [no education or completed primary school (low); completed secondary school or university (high)], ethnicity [born in Europe (Caucasian); Suriname, the Antilles, Turkey, Morocco or other (not Caucasian)], living status [alone and independent or with supportive care (alone), together with partner or family or in residential community (with others)], employment [having a paid job, being retired or otherwise (studying, disabled or unemployed)], medication, polypharmacy (the use of five or more medications) and self-reported non-adherence, smoking [current (yes), never or ex-smoker (no)], drinking alcohol, being physical active at least 5 times a week for 30 minutes, fluency in Dutch language, access to internet and having a computer.

Validated questionnaires

To measure satisfaction with diabetes treatment, the Diabetes Treatment Satisfaction Questionnaire (DTSQ)[25] was used. It measures satisfaction with treatment regimen (six items), perceived frequency of hyperglycemia (one item) and hypoglycemia (one item). The score ranges from 0 (very dissatisfied) to 36 (very satisfied).

To measure diabetes-specific distress, the Problem Areas in Diabetes (PAID) questionnaire[26] was used, assessing the general emotional burden of diabetes and distress related to treatment, food choices and social support. The 20 items are scored on a five-point Likert scale yielding a sum score (range 0-100), with higher score representing higher distress. The Dutch PAID scale has good convergent and discriminating validity and high internal consistency.[27]

Health status was measured with the validated Dutch version of the European Quality of Life scale (EuroQol) with five dimensions (EQ-5D-profile, range -0.59 to 1, were 1 indicates perfect health). It covers five domains of health (mobility, self-care, daily activity, pain and anxiety/depression). Each question has three levels of functioning: level one, no problems; level two, some problems; level three, severe problems. Additionally, general well-being was measured by the EuroQol-VAS (score range 0-100, where 100 represents the best imaginable health status).[28]

Self-efficacy was determined with the Diabetes Management Self-Efficacy Scale (DMSES) which is a 20-item scale. The stem phrase "I am confident that…" was used to precede the 20 items and answers were scored using a five-point Likert scale (from "Probably Not" to "Definitely Yes") yielding a sum score (range 20-100), with higher score representing a higher self-evaluation of self-efficacy skills.[29]

Additional diabetes knowledge test

To test diabetes knowledge we used the Brief Diabetes Knowledge Test used in both type 1 and type 2 diabetes patients in the Netherlands.[30,31] The test includes 23 questions, with 14 general items and nine additional ones about insulin use. It is a multiple choice test, with one correct answer per question. We added seven questions about diabetes topics that specifically refer to the content of quarterly or annual monitoring consultations that all diabetes patients receive. These questions test their knowledge about the consequences of smoking and alcohol use, hypoglycemic symptoms, eye examination, physical exercise, normal value of blood pressure and the association of diabetes mellitus and vascular disease. We scored the percentage of all questions answered correctly, both for the standard questions, including the added questions, and for the insulin questions. In case of no answer to a question, we scored that question as wrong.

Patients' medical records

We collected possible determinants for portal use from the patient's electronic health record, such as gender, age, type of diabetes, duration of diabetes and setting of diabetes treatment (general practice or outpatient clinic). In addition we extracted data about Body Mass Index, blood pressure and laboratory values (HbA1c, total cholesterol, HDL-cholesterol and LDL-cholesterol) and the presence of retinopathy, neuropathy, nephropathy, cardiac complications (angina pectoris or myocardial infarction), cerebral complications (stroke or transient ischemic attack) and peripheral arterial vascular disease from the records.

Statistical analysis

Data were analyzed using SPSS for Windows (version 20, SPSS Inc., Chicago, IL, USA). Type 1 and type 2 diabetes were analyzed separately. Patients who requested login to the patient portal were compared to patients who did not. Categorical variables were expressed as percentages and normally distributed continuous variables as means with standard deviation (SD) or with median and interquartile range (IQR) when not normally distributed. We used $\chi 2$ –tests for all categorical variables and unpaired t-test for all normally distributed continuous variables and Mann-Whitney test for not normally distributed continuous variables. We calculated socio-economic status based on zip-codes. The Netherlands Institute for Social Research (CPB)[32] calculated for each zip-code a score for socio-economic status based on income, employment and level of education of the population. The higher the score, the lower the status. For patients with type 1 diabetes mellitus, we could not perform this analysis with a reliable outcome, due to the low number of patients with type 1 diabetes who were treated by an internist.

Univariable logistic regression analysis was used to determine the association between requesting a login and possible determinants. Because of the low number of patients with type 1 diabetes mellitus, we could not perform a multivariable logistic regression analysis to determine which variables were independently associated with the login request.

For patients with type 2 diabetes mellitus, we used a p-value of <0.2 in the univariable analysis to select variables for further multivariable analysis. Multivariable regression analysis, using the enter method was used to identify which of the determinants were independently associated with the use of a patient portal. These determinants were expressed as odds ratio's (ORs) and their corresponding 95% confidence intervals (95% CI). In the variable medication use, we used oral drugs as reference group instead of no medication, because this best represents the clinical situation and has sufficient size to serve as a stable reference group. Among patients that completed the validated questionnaires, there were occasional missing items due to skipping of questions (PAID: 20%, DTSQ: 9%, EQ-5D-VAS: 6% and DMSES: 23%). In order to complete the score on these questionnaires, we used single imputation for these missing items. In the other questionnaires 16 variables had occasional missings (range 0.5- 13%). We used the multiple imputation method to impute the missing values on patient characteristics and diabetes related variables. Simply excluding these participants would have provided biased results, since missing data may not occur completely at random.[33] We generalized five imputed datasets and used Rubin's rules to combine the estimates of the parameters.[34]

RESULTS

From the 4500 questionnaires, 101 questionnaires were undeliverable because 33 patients were deceased and from 68 the correct address could not be traced. From the remaining 4399 patients who were sent a questionnaire 2931 (66.6%) patients responded. In total 1390 (31.6%) patients were eligible for analysis because they returned a completed questionnaire and a signed consent form to access the database for further extraction of data ("participants"). Another 1541 (35.0%) people declared that they did not want to participate ("non-participants") and 1468 (33.4%) people never responded ("non-responders").

The mean age of the participants was 63.9 ± 12.2 years, significantly different from that of the non-participants (69.3 ± 11.0 years, p<0.001) and non-responders (59.6 ± 14.7 years, p<0.001). Among the participants 59.4% was male, among the non-participants 46.6% and among the non-responders 55.9% (p<0.001 and p=0.06 respectively).

Reasons for non-participation included lack of interest or time (18.1%), questionnaire too difficult (6.6%), questions too personal (3.0%), other reasons (22.0%) and no reason given (53.9%). Several people gave more than one reason.

Of the participants 632 (45.5%) patients had a login and 758 (54.5%) had not. The participants with a login were younger compared to those without (59.7 ± 13.2 years versus 67.4 ± 10.0 years; p<0.001). Of the participants with a login 63.1% was male compared to 56.5% of the group without (p=0.01).

Table 1. *Patient related characteristics in requesting a login to the patient web portal*

	Type 1 diabetes mellitus					Type 2 diabetes mellitus				
	Patients with login *(n=115)*		*Patients without login* *(n=13)*			*Patients with login* *(n=517)*		*Patients without login* *(n=745)*		
	N	n (%)	N	n (%)	*P*-value	n	n (%)	n	n (%)	*P*-value
Age (years)*	115	45.3 ± 14.5	13	54.3 ± 11.6	0.03	517	62.9 ± 10.5	745	67.6 ± 9.8	< 0.001
Gender (male)	115	64 (55.7)	13	9 (69.2)	0.35	517	335 (64.8)	745	419 (56.2)	< 0.01
White	114	109 (95.6)	13	13 (100)	> 0.99	511	471 (92.2)	717	639 (89.1)	0.07
Educational level (high)	113	57 (50.4)	13	3 (23.1)	0.06	507	215 (42.4)	710	201 (28.3)	< 0.001
Living arrangements (alone)	113	22 (19.5)	13	1 (7.7)	0.46	511	79 (15.5)	733	192 (26.2)	< 0.001
Working status	114		12		0.20	511		731		< 0.001
Paid job		75 (65.8)		6 (50.0)			196 (38.4)		151 (20.7)	
Retired		11 (9.6)		3 (25.0)			247 (48.3)		476 (65.1)	
Other		28 (24.6)		3 (25.0)			68 (13.3)		104 (14.2)	
Fluency in Dutch (yes)	114					511				
Speaking		113 (99.1)	13	13 (100)	> 0.99		503 (98.4)	734	682 (92.9)	< 0.001
Reading		112 (98.2)	12	12 (100)	> 0.99		497 (97.6)	736	675 (91.7)	< 0.001
Computer access	115	115 (100)	13	13 (100)	-	517	517 (100)	732	512 (69.9)	< 0.001
Internet access	115	115 (100)	13	13 (100)	-	517	517 (100)	596	503 (84.4)	< 0.001
Treatment setting	115		13		0.01	517		745		<0.001
Primary care physician		3 (2.6)		3 (23.1)			297 (57.4)		663 (89.0)	
Internist		112 (97.4)		10 (76.9)			220 (42.6)		82 (11.0)	

Age is expressed as mean ± SD

Table 2. *Diabetes related characteristics in requesting a login to the patient web portal*

	Type 1 diabetes mellitus					**Type 2 diabetes mellitus**				
	Patients with login (n=115)		*Patients without login (n=13)*			*Patients with login (n=517)*		*Patients without login (n=745)*		
	n	mean ± SD or n (%)	n	mean ± SD or n (%)	*P*-value	n	mean ± SD or n (%)	n	mean ± SD or n (%)	*P*-value
Duration of diabetes, years	115	18.4 (11.4-31.3)*	13	27.4 (18.9-32.7)*	0.20	517	9.7 (4.9-15.4)*	739	7.3 (3.7-11.4)*	< 0.001
Blood glucose (BG) lowering drugs	115		13		0.53	516		742		< 0.001
No drugs		1 (0.9) ‡		0 (0.0)			41 (7.9)		91 (12.3)	
Oral BG lowering drugs		1 (0.9) ‡		0 (0.0)			227 (44.0)		507 (68.3)	
Oral BG lowering drugs + insulin		16 (13.9)		3 (23.1)			149 (28.9)		90 (12.1)	
Insulin		97 (84.3)		10 (76.9)			99 (19.2)		54 (7.3)	
Other drugs										
Antihypertensive drugs	108	37 (34.3)	12	7 (58.3)	0.12	474	307 (64.8)	624	336 (53.8)	< 0.001
Lipid lowering drugs	108	28 (25.9)	12	5 (41.7)	0.31	474	305 (64.3)	624	345 (55.3)	< 0.01
Antidepressant drugs	108	6 (5.6)	12	1 (8.3)	0.53	474	25 (5.3)	624	21 (3.4)	0.12
Polypharmacy, yes	108	25 (23.1)	12	6 (50.0)	0.08	474	271 (57.2)	624	271 (43.4)	< 0.001
BMI (kg/m2)	114	25.6 ± 4.6	13	27.2 ± 4.6	0.24	514	29.3 ± 5.3	722	29.3 ± 5.2	0.98
HbA1c (mmol/mol)	115	60.9 ± 11.3	13	62.8 ± 13.8	0.58	516	52.0 (46.0-60.0)*	737	49.0 (44.0-56.0)*	< 0.001
Systolic blood pressure (mmHg)	115	126.3 ± 14.2	13	136.9 ± 20.3	0.02	516	133.8 ± 16.1	735	135.9 ± 15.4	0.02
Diastolic blood pressure (mmHg)	115	74.2 ± 8.7	13	75.0 ± 8.4	0.75	516	77.2 ± 9.5	735	78.2 ± 9.8	0.09
Total cholesterol (mmol/l)	115	4.6 ± 0.8	13	5.0 ± 1.2	0.21	513	4.3 ± 1.0	723	4.4 ± 1.0	0.03
HDL-cholesterol (mmol/mol)	115	1.7 ± 0.5	13	1.5 ± 0.6	0.23	513	1.3 ± 0.39	720	1.3 ± 0.34	0.72
LDL-cholesterol (mmol/mol)	115	2.5 ± 0.8	12	2.8 ± 1.1	0.15	506	2.2 ± 0.9	712	2.3 ± 0.9	0.06
Complications, yes										
Retinopathy	36	10 (27.8)	3	0 (0.0)	0.56	222	15 (6.8)	354	19 (5.4)	0.49
Nephropathy	49	25 (51.0)	7	6 (85.7)	0.12	422	153 (36.3)	555	230 (41.4)	0.10
Cerebral complications	49	4 (8.2)	7	0 (0.0)	> 0.99	429	30 (7.0)	565	53 (9.4)	0.18
Cardiac complications	49	5 (10.2)	7	0 (0.0)	> 0.99	429	100 (23.3)	565	131 (23.3)	0.96
Peripheral arterial disease	49	1 (2.0)	7	0 (0.0)	> 0.99	429	28 (6.5)	565	37 (6.5)	0.99
Neuropathy	99	20 (20.2)	10	5 (50.0)	0.05	396	132 (33.3)	537	161 (30.0)	0.28
Health behavior										
Non-adherence, yes	115	21 (18.3)	13	3 (23.1)	0.71	488	109 (22.3)	700	122 (17.4)	0.04
Smoking, yes	114	14 (12.3)	13	2 (15.4)	0.67	506	67 (13.2)	695	114 (16.4)	0.13
Alcohol, yes	108	67 (62.0)	9	6 (66.7)	> 0.99	491	242 (49.3)	680	288 (42.4)	0.02
Physical active, yes	115	43 (37.4)	12	6 (50.0)	0.54	506	190 (37.5)	726	273 (37.6)	0.99

Normally distributed data are mean ± SD, not normally distributed data* are median (IQR). Continuous variable are total number (percentages).
SD = Standard deviation; IQR = Interquartile Range (25th – 75th percentile); ‡ patient with LADA

Type 1 diabetes

Of the 1390 participants, 128 patients were diagnosed with type 1 diabetes of which 115 (89.9%) with a login and 13 (10.1%) without. Patients with a login were younger and had a higher education (Table 1). Following the guidelines, most type 1 diabetes patients were treated by an internist; however, patients without a login were more frequently found in the general practice. No differences in diabetes related medication was present, but patients with a login used other drugs less frequently. Patients with a login had a better systolic blood pressure and they were less likely to have neuropathy (Table 2). On the additional validated questionnaires, there were no significant differences between patients with and without login, except for the diabetes knowledge test. Patient with a login scored higher on insulin related questions than patients without a login (70.9% correct versus 57.4% correct, p=0.02).

Type 2 diabetes

Of the 1262 participants with type 2 diabetes mellitus, 517 (41.0%) had a login and 745 (59.0%) did not. Patients with a login differed on many characteristics from those without (Table 1). They had been diagnosed with diabetes for a longer time; they used insulin more frequently and also used more other drugs. With the exception of HbA1c, they were better controlled. However, they displayed less required health behaviors (Table 2). Patients with a login perceived more diabetes related distress (30.6 ± 13.5) than patients without (27.7 ± 12.7), more hyper- and hypoglycemic episodes (hypoglycemia: 2.3 ± 1.9 versus 1.5 ± 1.7; hypoglycemia 1.6 ± 1.6 versus 1.1 ± 1.5), but also more self-efficacy (79.5 ± 15.8 versus 72.7 ± 17.8) and better diabetes knowledge (standard questions: 73.8% versus 62.1% correct; insulin questions 55.7% versus 40.8% correct). All differences are significant (p<0.001). There was no significant difference in quality of life and general treatment satisfaction. There is no socio-economic difference between the patients with type 2 diabetes mellitus treated by a general practitioner and patients treated by an internist (mean -0.25 ± 0.82 versus -0.29 ± 0.90; p=0.48).

Multivariable analysis showed that with increasing age, the odds of requesting a login decreased (Table 3). With respect to demographics, the odds or requesting a login increases in males, in patients with a higher education, patients who speak Dutch fluently and patients with a paid job, whereas the odd decreased in patients treated by a primary care physician or living alone. With the diabetes treatment and diabetes related variables, the odds of requesting a login increases with the use of polypharmacy and alcohol and decreases with smoking. In addition, with insulin use, the odds of requesting a login increases compared to patients who use only blood glucose lowering drugs. Duration of diabetes and HbA1c levels hardly influenced the login request independently, as did the scores on patient-reported outcomes and diabetes knowledge.

Table 3. *Multivariable analysis, variables independently associated in requesting a login in patiens with type 2 diabetes*

	OR (95% CI)	***P*-value**
Age	0.96 (0.95-0.97)	< 0.001
Male gender	1.32 (1.15-1.51)	< 0.001
Higher education	1.63 (1.43-1.86)	< 0.001
Living alone	0.55 (0.47-0.64)	< 0.001
Work status		
Paid job	Reference	
Retired	0.76 (0.62-0.93)	0.01
Other	0.65 (0.53-0.80)	< 0.001
Fluency in speaking Dutch	3.06 (2.09-4.48)	< 0.001
Treatment setting: general practitioner	0.32 (0.27-0.38)	< 0.001
Duration of diabetes	1.02 (1.01-1.04)	< 0.001
Blood Glucose (BG) Lowering drugs		
No drugs	1.38 (1.10-1.72)	0.01
Oral BG lowering drugs	Reference	
Oral BG lowering drugs + insulin	1.70 (1.39-2.08)	< 0.001
Insulin	1.37 (1.07-1.75)	0.01
Polypharmacy	1.52 (1.33-1.73)	< 0.001
HbA1c	0.99 (0.98-0.99)	< 0.001
Total Cholesterol	0.87 (0.82-0.93)	< 0.001
Current smoking	0.60 (0.51-0.71)	< 0.001
Current alcohol use	1.16 (1.02-1.32)	0.03
PAID	1.02 (1.01-1.02)	< 0.001
DTSQ hyper	1.08 (1.04-1.12)	< 0.001
DTSQ hypo	0.95 (0.91-0.99)	0.02
DMSES	1.01 (1.01-1.02)	< 0.001
BDKT standard	1.01 (1.01-1.02)	< 0.001
BDKT insulin	1.01 (1.01-1.01)	< 0.001

PAID= Problem Areas in Diabetes Questionnaire; DTSQ = Diabetes Treatment satisfaction Questionnaire; DMSES= Diabetes Management Self-Efficacy Scale; BDKT= Brief Diabetes Knowledge Test

DISCUSSION

This studies shows that there are many differences between patients who requested a login for a diabetes web portal and those who did not. Furthermore, there are differences between patients with type 1 and type 2 diabetes mellitus. Patients with type 1 diabetes request a login more frequently than patients with type 2 diabetes, this difference may be of interest in the further development of diabetes web portals.

Type 1 diabetes mellitus

To our knowledge, this is the first study which compares the characteristics of adult patients with type 1 diabetes mellitus with regard to their logging in on a diabetes web portal. Patients with a login were younger and had received a higher level of education. Younger and better educated patients might have more exposure to computer and internet programs and show an earlier interest in e-Health[35] and new technologies.

The majority of the patients with type 1 diabetes mellitus in our study had requested a login. Almost all of them were treated by an internist, which is the normal situation in the Netherlands. Even with the low number of patients treated by a general practitioner, treatment setting seemed to play a role in requesting a login. In type 2 diabetes we could demonstrate that treatment setting was an independent predictor of requesting a login. Patients are informed about the option of the portal by their health care provider and these providers need to give their consent before patients can receive a login. This can be a barrier on to itself. In the US family physicians were relatively unfamiliar with electronic patient health records and their potential benefits, which may slow adoption.[36] We do not know whether this holds for Dutch general practitioners or not. Besides, the out-patient setting with diabetes nurses who are focused entirely on one disease and working according to a strict outpatient clinic protocol might explain the difference between the number of patients with a login and without in primary care and secondary care. Patients who requested a login scored better on the diabetes knowledge test, especially on the items about insulin. This might partly be because they were higher educated, but it also might be because of the possibility to upload their glucose levels and the subsequent response of the physician.

Type 2 diabetes mellitus

The majority of patients with type 2 diabetes mellitus did not request a login. Age, gender, educational level and work status all play an important role. Patients in our study who do use the patient portal are on average above 60 years old, which is higher than previously found.[19,20] This is in line with the increasing use of internet by the elderly in recent years.[37] Therefore we expect that in the near future this age gap will level off. Physicians and nurses who would like to promote the use of a patient web portal should pay special attention to elderly people, to women and to diabetes patients who received lower education. A second group of patients who are less likely to request a login are those who do not meet their treatment goals and display less of the required health behaviors. We previously demonstrated that not all patients want to take responsibility for their diabetes or are willing to take medication to attain treatment targets.[38] These patients may be not interested in the use of a patient portal to improve their outcomes. Further studies are warranted to examine the best manner to stimulate these patients and to investigate in getting them both taking responsibility and increasing self-care. Patients who are treated at the outpatient clinic, who use insulin, who use more than five different drugs for comorbid conditions and who perceive more diabetes related distress, but also those who have a better knowledge about the disease and a higher self-efficacy are more likely to request a login. Because this study had a cross-sectional design, it is not possible to determine whether these variables are really causative factors. We can speculate that some of the variables that were found to be predictors are in fact markers of the portal use. For example with the use of five or more medications there is an increasing odds of requesting a login. Apparently, patients who need more medication see the usefulness of the additional use of a patient web portal. On the other hand, the use of the web portal might result in polypharmacy. Considering the variables as determinants, there are several possible reasons why they may determine the request of a login. First health care providers might select people because they think the patient will benefit from this portal and therefore recommend its use. Second, because of their more complex disease control, the patients themselves may feel the need to increase their partnership in the disease control, which the portal could facilitate. In this respect it is meaningful that there were no socio-economic differences between those patients who see an internist and those who see a general practitioner. Previous studies have shown that the use of diabetes web portals can lead to improvement of diabetes outcomes,[6–10] which means that HbA1c might be a marker of the portal use. Participating in a patient web portal may lead to a significant decline in diabetes related stress, which could lead to better glycemic control. Definitely distinguishing determinants and markers would request a longitudinal design with a baseline situation.

Finally, in the univariate analysis higher HbA1c levels were associated with a higher odds of requesting a login, but in the multivariate analysis this effect was reversed, although the association of HbA1c with login request was only small.

Study strengths include a large and representative population of patients with diabetes and the evaluation of a diabetes web portal that is already five years in use instead of a web portal used for study purposes. Furthermore, to our knowledge, this is the first study to examine demographic and clinical factors of adult patients with type 1 diabetes mellitus and the request of a login to a diabetes specific patient web portal. Finally, this study included a comprehensive set of potential determinants, some of which not previously investigated in patients with diabetes, like diabetes related distress, treatment satisfaction, self-efficacy and diabetes knowledge.

Nevertheless, there are limitations. First, the cross-sectional design makes it difficult to distinguish cause and effect. For example, we cannot determine whether factors like a better knowledge or self-efficacy leads to a login request or whether it is the other way around. We have found that some variables are associated with requesting a login to the web portal, however a strict distinction between markers and causative factors for portal use cannot be made based on this study because we do not know the baseline situation. A second limitation was the response rate of 66.6%, including patients who expressed that they did not want to participate. However, the response rate is comparable with or even higher than in other studies.[14,19] Our participants were younger than non-participants. We found that a younger age was one of the determinants of requesting a login, therefore in the general population there will be less people with a login than found in our study. However, the non-responders were younger than the participants, which can point to an opposite situation. It is unclear if the percentage of people with a login is an over or underestimation. The participants were more frequently male compared to the non-participants, but did not differentiate from non-responders. Because we found that male gender was one of the determinants in requesting a login, we might have found an overestimation of login requests in our study. We do not have information about the type of diabetes of the non-participants and non-responders; therefore it is uncertain how diabetes type has influenced the participation and response rates. A third study limitation is that the low number of patients with type 1 diabetes mellitus did not allow a multivariable analysis to determine which variables are associated with the use of a web portal. As is common in studies with questionnaires, not all patients filled in all items of the questionnaire. This was also the case in the electronic health records. There was missing data on several determinants. We corrected this with imputation methods.

In conclusion, we observed many differences between the patients who requested a login and the patients who did not. Simply promoting e-health does not make sense. It is important to address these differences in order to maximize the use. If neglected, the groups of patients who could benefit, like the patients who do not meet their treatment goals or display less of the required health behaviors, will fall further behind while especially those patients need the extra attention to their treatment. In the future, we think that patient web portals might be used to reduce clinic visits without compromising quality of care, but before that to happen we need further information on the use of the web portals by patients and health care professionals.

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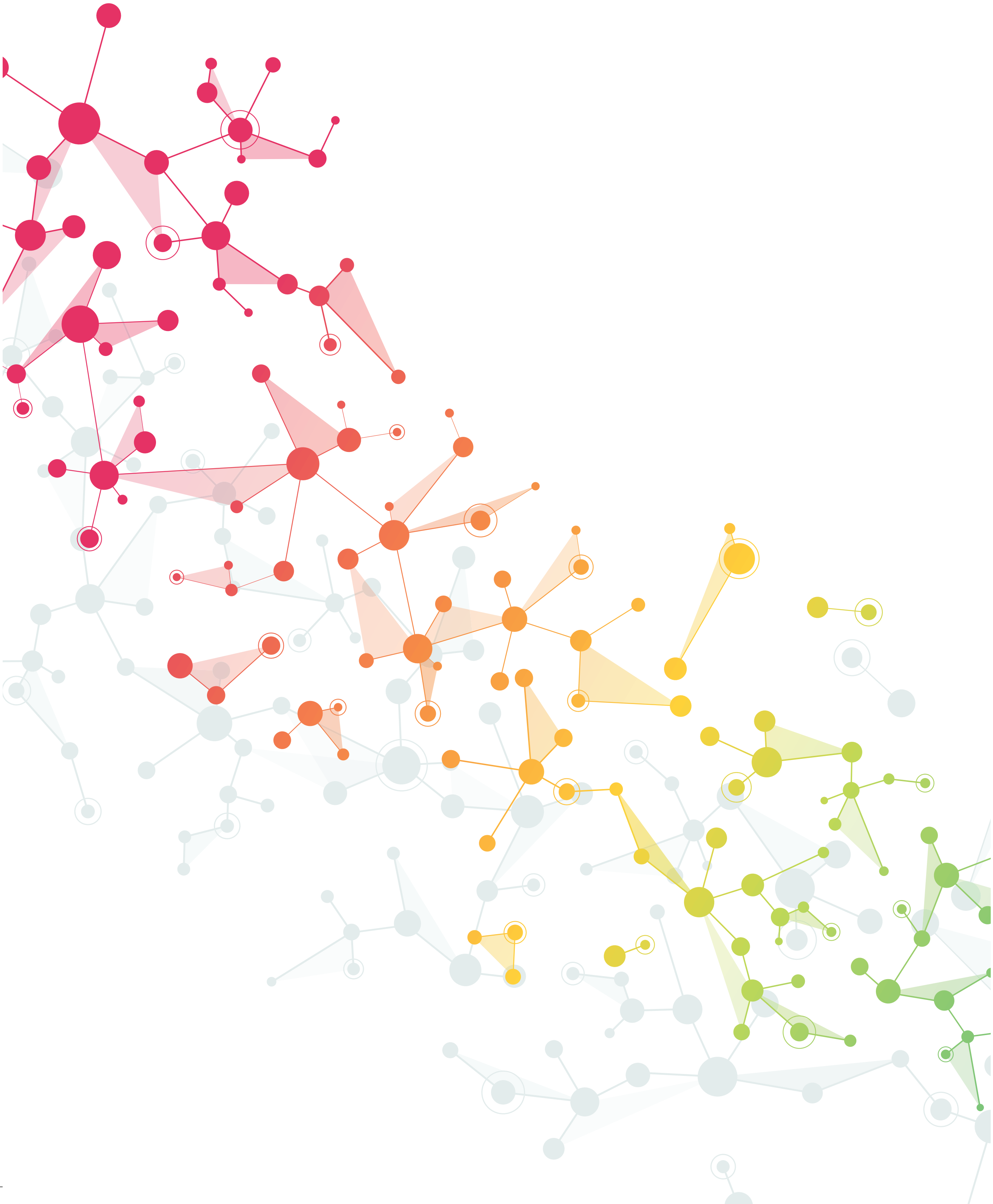

CHAPTER 3

Reasons and Barriers for Using a Patient Portal

A Survey Among Patients With Diabetes Mellitus

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Journal of Medical Internet Research. 2014;16(11):e263

ABSTRACT

Background The use of a patient web portal for patients with diabetes mellitus, in which patients can access their own personal health record, may result in improved diabetes outcomes. However, the adoption by patients is slow, which may be caused by patient characteristics, but also by the content, layout, and promotion of the portal. Detailed knowledge about this could help increase patients' participation in Patient portals. The aim was to study the opinions of patients with diabetes and identify perceived barriers to using a patient portal to optimize its use.

Methods We conducted a survey among patients with type 1 and type 2 diabetes mellitus from 62 primary care practices and 1 outpatient hospital clinic in the central area of the Netherlands that all use the same electronic health record with a patient portal. Questionnaires about patient characteristics, opinions about reasons for use or nonuse, and about portal content were sent to 1500 patients with a login and 3000 patients without a login to the patient portal. Patient groups were stratified according to login frequency. Demographic and diabetes-related variables were analyzed with multivariable regression analysis.

Results The total response rate was 66.6%; 1390 (31.6%) patients were eligible for analysis. There were 413 regular users (login frequency more than once) and 758 nonusers (no login). Most (72.4%) of nonusers stated that the main reason for not requesting a login was that they were unaware of the existence of the portal. Other barriers reported by patients were disinterest in managing their own disease (28.5%) and feelings of inadequacy with the use of computers and Internet (11.6%). Patients treated by a general practitioner were more frequently nonusers compared to patients treated by an internist (78.8% vs 28.3%; $p <0.001$) and more users than nonusers became aware of the web portal through their physician (94.9% vs 48.8%; $p <0.001$). Nonusers perceived specific portal content as not as useful as regular users did, especially access to laboratory values (71.7% vs 92.3%), rereading clinic visits (61.3% vs 89.6%), e-messaging (52.0% vs 74.6%), and uploading results to the glucose diary (45.3% vs 74.0%; all $p<0.001$).

Conclusions Our study shows that unawareness of the patient portal is the main barrier of enrollment. Users and nonusers perceive the usefulness of the portal differently and do not have the same recommendations for additional functionalities. To increase patients' participation in a web portal, the unawareness of its existence and its possibilities need to be addressed by their health care professionals.

INTRODUCTION

The use of eHealth in disease management has been studied, especially in chronic diseases such as diabetes mellitus. In these studies, the focus was on patient web portals where patients have access to their medical health record and can use the web portal for communication with their health care provider. The use of a web portal has several benefits. It can enhance communication between patient and health care professionals,[1] allow patients to play a more active role in their own treatment and self-management,[2] increase self-efficacy,[3] and patients can feel that other nonacute concerns are valued because of an email function.[4] The use of web portals shows promising results in diabetes outcomes, such as improved HbA1c, blood pressure, weight, and cholesterol levels.[5–9] With the growing number of people with diabetes mellitus worldwide,[10] the use of patient web portals for diabetes management becomes more important to cope with the burden on health care.

However, the adoption of web portals is slow, both by patients and health care professionals.[11,12] We previously showed that patient characteristics play an important role in non-adoption.[13] Simply promoting eHealth is ineffective without addressing the differences in patient characteristics.

In the Netherlands, 96% of all inhabitants have access to Internet. Men and women have equal access and more than 95% of people up to age 65 years have access; the access rate is lower (81%) for people older than that age. Access ranges from 90% in lower education groups to 99% in the groups with the highest education. Of the people with Internet access, 87% use it daily.[14] Therefore, Internet access itself should not be a barrier for use of patient portals by most patients with diabetes mellitus.

For both patients and providers, there are several barriers in the adoption of a web portal. Health information privacy and security are major concerns.[15] In addition, the use of medical terms and abbreviations[15,16] and problems arising due to the design,[11] such as navigational problems and unmet expectations about functionality, may also play a role. There is a difference in the potential and actual usefulness of certain features of a web portal.[17] Before using a web portal, patients have certain expectations about how the portal may help them with their disease management and which features may be useful for them. These opinions may change when patients actively use the portal.

However, it remains unclear what reasons patients with diabetes have for using a web portal or not. Previous research has not fully considered the steps that need to be taken before patients decide whether a patient portal can be of personal use. If we want to increase the involvement of patients in their own treatment, the barriers for using a web portal must be addressed. More information is needed about the opinions that patients have when deciding to login for a web portal or not and about their first experiences with its use. With this knowledge the initial barriers of using a web portal could be reduced.

This study aims to study the opinions and barriers of patients with diabetes to request a login and to use a patient web portal. The following research questions were addressed:

1. In what respect do regular users and nonusers of the portal differ?
2. What are the reasons for (or not) requesting a login?
3. How did patients become aware of the portal?
4. Are there any differences in perceived usefulness of the portal between users and nonusers?
5. Are there recommendations for new functionalities?

METHODS

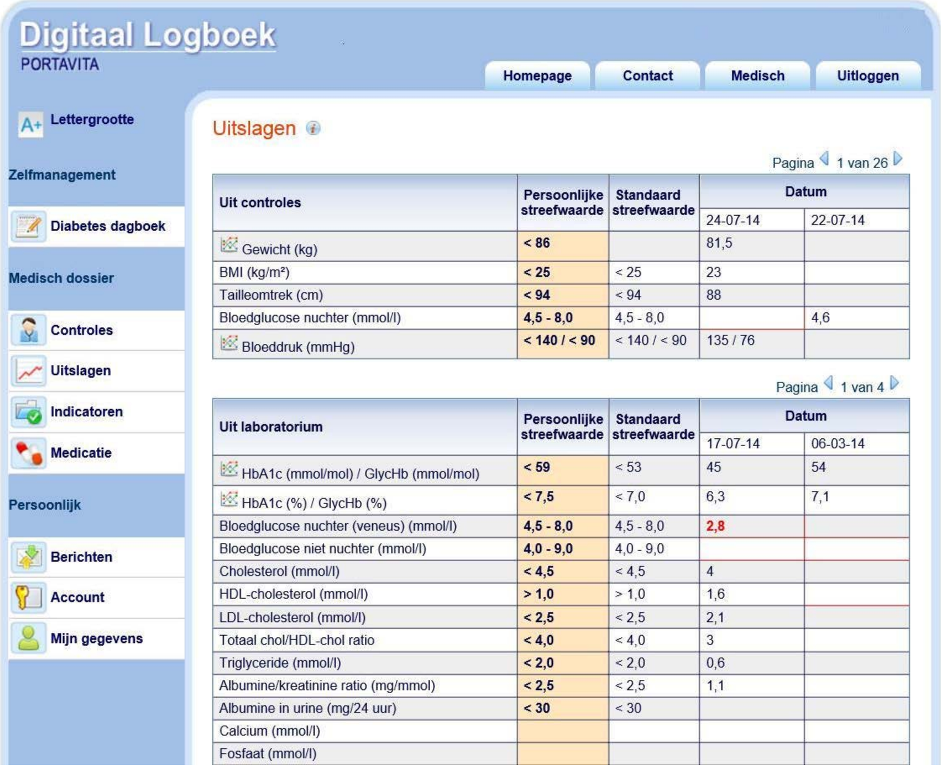
Design

We conducted a survey among a sample of 12,793 patients with diabetes by randomly selecting patients aged 18 to 85 years and asking 1500 patients with a login to the web portal and 3000 patients without a login to participate. Patients were sent a set of questionnaires and a reminder letter twice if necessary. Patients who did not want to participate were asked to state the reason. The survey was approved by the Medical Research Ethics Committee of the University Medical Center Utrecht (protocol number 11-296/C).

Setting

Primary care practices and the hospital joined together in an organization called “Diamuraal” to coordinate the care of patients with diabetes in a defined geographical area in the center of the Netherlands. Currently, Diamuraal comprises 62 independent primary care practices and 1 hospital outpatient clinic. All physicians and nurses who participate in the care of patients with type 1 and type 2 diabetes in Diamuraal use the same electronic health record and patients can request a login to access their personal electronic health records. When a patient wants access to the web portal, he or she needs to sign a registration form which the physician has to cosign. The portal is called “Digitaal Logboek” and was developed by Diamuraal and a private company (Portavita).

Patients have access to their diabetes-specific medical records, including information provided by their physician during medical consultation, such as physical examination, laboratory results, problem lists, and treatment goals (Figure 1). Laboratory results are accessible as soon as the laboratories report them in advance of a medical consultation. The web portal also provides access to general diabetes information and to an overview of all personal diabetes-related examinations and consultations that are needed and/or scheduled. Patients can import and upload the glucose levels measured at home and contact their physician or diabetes nurse through secured electronic messaging. The portal is supplementary; patients who do not request access still receive diabetes care according to the Dutch guidelines. At the start of our survey, 12.793 patients with



Uitslagen

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Uit controles	Persoonlijke streefwaarde	Standaard streefwaarde	Datum	
			24-07-14	22-07-14
Gewicht (kg)	**< 86**		81,5	
BMI (kg/m²)	**< 25**	< 25	23	
Tailleomtrek (cm)	**< 94**	< 94	88	
Bloedglucose nuchter (mmol/l)	**4,5 - 8,0**	4,5 - 8,0		4,6
Bloeddruk (mmHg)	**< 140 / < 90**	< 140 / < 90	135 / 76	

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Uit laboratorium	Persoonlijke streefwaarde	Standaard streefwaarde	Datum	
			17-07-14	06-03-14
HbA1c (mmol/mol) / GlycHb (mmol/mol)	**< 59**	< 53	45	54
HbA1c (%) / GlycHb (%)	**< 7,5**	< 7,0	6,3	7,1
Bloedglucose nuchter (veneus) (mmol/l)	**4,5 - 8,0**	4,5 - 8,0	**2,8**	
Bloedglucose niet nuchter (mmol/l)	**4,0 - 9,0**	4,0 - 9,0		
Cholesterol (mmol/l)	**< 4,5**	< 4,5	4	
HDL-cholesterol (mmol/l)	**> 1,0**	> 1,0	1,6	
LDL-cholesterol (mmol/l)	**< 2,5**	< 2,5	2,1	
Totaal chol/HDL-chol ratio	**< 4,0**	< 4,0	3	
Triglyceride (mmol/l)	**< 2,0**	< 2,0	0,6	
Albumine/kreatinine ratio (mg/mmol)	**< 2,5**	< 2,5	1,1	
Albumine in urine (mg/24 uur)	**< 30**	< 30		
Calcium (mmol/l)				
Fosfaat (mmol/l)				

Figure 1: *Screenshot of the laboratory results and treatment goals of the patient web portal*

diabetes were treated in Diamuraal, of whom 9791 (76.53%) had never requested a login.

Measures

We collected information through a set of questionnaires and by extracting data from the electronic health records. Patient characteristics were obtained from the patients' electronic health records (age, gender, type of diabetes, duration of diabetes, setting of diabetes treatment, HbA1c, and total cholesterol) and from the questionnaires (educational level, ethnicity, living status, employment, medication, smoking, drinking, fluency in the Dutch language, and access to computer and Internet). We did not take blood pressure into account because it was not a determinant for portal use.[13]

Questionnaires

We designed 2 separate questionnaires: 1 for patients with a login and 1 for patients without a login. They were based on characteristics found previously on the use of eHealth in literature.[18,19]

The questionnaire for patients with a login contained multiple choice questions about (1) reasons for requesting a login (influence in disease and management of disease, to reread information at home, others thought it would be useful, discontent with current care, other); (2) the way people were informed about the portal's existence (by a health care provider, a poster, an information pamphlet, through friends or relatives, other); (3) the frequency of portal use (from daily to monthly); (4) the duration of portal use (from less than 15 minutes to more than 1 hour); and (5) the person who added the information to the portal (the user/self, family, friends, or others).

The questionnaire for patients without a login contained questions about their awareness of the patient web portal and, if applicable, how people were informed about its existence (see above) as well as the reasons for nonuse (all yes/no questions). There was room for free text as well.

Both questionnaires contained questions about the use of the Internet for other purposes than the web portal, with regard to frequency and duration and the use of the Internet for searching information about diabetes (from never to monthly). The 9 questions about the perceived usefulness of specific portal components were answered on a 5-point Likert scale ranging from very important to unimportant.

The final question regarded possible improvements to the portal. All recommendations were scored on a 5-point Likert scale ranging from very important to unimportant. There was room for free text.

Questions about specific portal components and the question about recommendations regarding possible improvements were, in case of nonusers, addressed as how nonusers expected the usefulness of that particular component to be.

In addition to these specifically designed questionnaires, the set of questionnaires contained additional validated questionnaires, including the Problem Areas in Diabetes (PAID) questionnaire to measure diabetes-specific distress,[20,21] the Diabetes Treatment Satisfaction Questionnaire (DTSQ) to measure satisfaction with diabetes treatment,[22] the Diabetes Management Self-Efficacy Scale (DMSES) to measure self-efficacy,[23] and the Brief Diabetes Knowledge Test (BDKT) to measure diabetes knowledge.[24,25]

Statistical Analysis

Reason for regular use or nonuse, the answers about content and usefulness of the portal, and about the recommendations were expressed as percentages. The answer categories useful and very useful were combined. The question about reason for nonuse was misread by some patients. We asked for the main reason (1 reason) why a patient did not request a login and provided multiple answers. A total of 59 patients gave more than 1 reason. We used all these answers in the analysis.

We compared patients who requested a login and used it 2 or more times (regular users) and patients who did not request a login at all (nonusers). We decided to perform the analysis only on the regular users instead of all patients with a login because we wanted to compare the patients without a login to a group of patients with actual experience with the patient portal. Based on previous research, we considered the group of nonusers too different from patients who had requested a login but never logged in or logged in only once, the so-called "early quitters." Indeed, early quitters differed from nonusers: they were younger (mean 61.9 ± 12.7 years vs mean 64.7 ± 10.0 years; p=0.001), more often male (63.9% vs 56.5%; p=0.049), and had a higher educational level (39.4% vs 28.2%; p<0.01).

Age and gender of nonparticipants (patients who responded but declared that they did not want to participate) and non-responders (patients who did not respond to the invitation to fill out the questionnaire) of the study are described elsewhere.[13]

We used chi-square tests for all categorical variables and unpaired t tests for all normally distributed continuous variables and Mann-Whitney tests for nonnormally distributed continuous variables. Categorical variables were expressed as numbers with percentages and continuous variables as means with standard deviation (SD) or with median and interquartile range (IQR) when not normally distributed. Multivariable logistic regression analysis, using the enter method, was used to determine the adjusted association between patient characteristics and not requesting a login. We used a *P* value of <0.2 in the univariable analysis to select variables for further multivariable analysis. These determinants were expressed as odds ratios (ORs) with corresponding 95% confidence intervals (95% CI). Data was analyzed using SPSS for Windows version 20 (SPSS Inc, Chicago, IL, USA).

RESULTS

From the 4500 questionnaires, 101 were not answered because 33 patients died and 68 had incorrect contact information. From the remaining patients, 2931 (66.6%) responded; 1541 of these 2931 patients (52.6%) declared that they did not wish to participate. In total, 1390 (31.6%) patients were eligible for analysis ("participants") because they returned a completed questionnaire and signed a consent form. Their mean age was 63.9 ± 12.2 years (nonparticipants: mean 64.5 ± 13.8 years; p=0.11) and 826 of 1390 (59.4%) were male (nonparticipant group: 1539/3009, 51.2% male patients; p<0.001). Of the 1390 participants, 632 (45.5%) had a login and 758 (54.5%) did not ("nonusers").

Differences Between Nonusers and Regular Users

The login frequency of the patients with a login was a mean 10.4 ± 23.0 times and 413 of 632 (65.3%) patients accessed the patient web portal 2 or more times ("regular users"). The latter category differed in many characteristics from nonusers (Table 1). Of the 94 patients with type 1 diabetes, only 13 (13.8%) were nonusers, whereas 745 of 1077 (69.2%) patients with type 2 diabetes were nonusers (p<0.001). There was also a difference in treatment setting: 666 of 846 (78.8%) patients treated by a general practitioner were nonusers, whereas only 92 of 325 (28.3%) patients treated by an internist were nonusers (p<0.001).

Table 1. *Characteristics of the study participants (N = 1171)*

Patient Characteristics	**Regular users** **(n = 413)**	**Non users** **(n = 758)**	***P*-value**
Age (years), median (IQR)	60.2 (51.3-67.5)	68.1 (60.7-75.3)	<0 .001
Gender (male), n (%)	62.7%	56.5%	0.04
Caucasian (yes), n (%)	93.6%	89.3%	0.02
Educational level (high) , n (%)	46.2%	28.2%	< 0.001
Work status, , n (%)			< 0.001
Paid job	47.1%	21.1%	
Retired	37.3%	64.5%	
Other	15.6%	14.4%	
Living arrangement (alone) , n (%)	15.9%	25.9%	< 0.001
Fluency in speaking Dutch (yes) , n (%)	99.3%	93.0%	< 0.001
Access to computer (yes) , n (%)	100%	70.5%	< 0.001
Access to internet (yes) , n (%)	100%	84.7%	< 0.001
Treatment setting, n (%)			< 0.001
General practitioner	43.6%	87.9%	
Internist	56.4%	12.1%	
Type of Diabetes, n (%)			< 0.001
Type 1	19.6	1.7%	
Type 2	80.4	98.3%	
Duration of Diabetes (years) , median (IQR)	11.3 (5.5-17.4)	7.4 (3.7-11.4)	< 0.001
Blood glucose lowering medication, n (%)			< 0.001
None	5.1%	12.1%	
Oral	31.7%	67.2%	
Oral and insulin	30.5%	12.3%	
Insulin	32.7%	8.5%	
Polypharmacy (yes), n (%)	52.7%	43.6%	0.017
HbA1c (mmol/mol), median (IQR)	54.0 (48.0-62.0)	49.0 (44.0-56.0)	< 0.001
Total Cholesterol (mmol/L), mean (SD)	4.4 (1.0)	4.5 (1.0)	0.35
Smoking (yes), n (%)	11.5%	16.4%	0.03
Drinking alcohol (yes), n (%)	52.8%	42.7%	0.004
Validated questionnaires*, mean (SD)			
PAID	31.0 (11.8)	27.2 (11.2)	< 0.001
DMSES	80.7 (15.5)	72.9 (18.0)	< 0.001
BDKT standard	78.7 (14.7)	62.4 (20.0)	< 0.001
BDKT insulin	61.4 (20.6)	42.2 (21.5)	< 0.001
DTSQ status	30.2 (5.0)	30.8 (5.5)	0.10
DTSQ hyperglycemic episodes	2.7 (1.9)	1.6 (1.7)	< 0.001
DTSQ hypoglycemic episodes	2.0 (1.7)	1.1 (1.5)	< 0.001

* PAID: Problem Areas in Diabetes Questionnaire; DTSQ: Diabetes Treatment Satisfaction Questionnaire; DMSES: Diabetes Management Self-Efficacy Scale; BDKT: Brief Diabetes Knowledge Test (one with standard items and one with only insulin-related questions).

The use of the Internet differed between both groups: 321 (77.9%) of the 413 regular users used the Internet daily versus 346 (67.6%) of the 512 nonusers with Internet access (p<0.001). When using the Internet, 184 (44.6%) of the 413 regular users were online for more than an hour per day compared with only 140 (27.3%) of the 512 nonusers (p<0.001). Furthermore, 206 (51.1%) of the regular users declared that they used the Internet for searching for information about their disease compared with only 126 (25.4%) of the nonusers (p<0.001).

Of the 413 regular users, 328 (79.4%) patients declared that they were the main user of the web portal themselves and 79 (19.1%) declared that someone else had access to the web portal and usually accessed the portal. Of the 758 nonusers, 162 (21.4%) patients stated that they would consider using the web portal if someone would help them, 262 (34.6%) did not know if they would use the portal if someone would help, and 293 (38.7%) would not consider using the portal even if someone would help.

Multivariable analysis showed that increasing age and smoking were associated with not using the web portal. On the contrary, a higher educational level, treatment by an internist, using insulin, polypharmacy, better diabetes knowledge, and more hyperglycemic episodes were less likely to be associated with not using the web portal (Table 2).

Table 2. *Independent determinants of nonusers compared to users*

Independent determinant	**OR (95% CI)**	***P*-value**
Age	1.04 (1.00-1.08)	0.03
Educational level (high)	0.59 (0.36-0.95)	0.03
Treatment setting (internist)	0.27 (0.14-0.54)	< 0.001
Blood Glucose Lowering Drugs		
None	0.59 (0.21-1.63)	0.31
Oral	Reference	
Oral and Insulin	0.33 (0.15-0.70)	0.004
Insulin	0.31 (0.12-0.78)	0.014
Polypharmacy (yes)	0.58 (0.36-0.95)	0.03
Smoking (yes)	2.53 (1.30-4.91)	0.006
Diabetes knowledge (standard)	0.98 (0.96-0.99)	0.008
DTSQ (hyper)	0.79 (0.68-0.92)	0.002

Reasons for Requesting or Not Requesting a Login

The main reason for not requesting a login was that 549 of 758 (72.4%) patients were not aware of the portal's existence. Another 216 of 758 (28.5%) stated that the main reason for not requesting a login was that they preferred to leave the disease management to the physician (Table 3).

The reasons for requesting a login among the regular users were to reread information of the consultation at home (312 of 413, 75.5%), the feeling that the portal use would give them influence on their disease and treatment (132 of 413, 32.0%), the fact that the physician or someone else thought the web portal could be useful for them (74 of 413, 17.9%), dissatisfaction with the current care (2 of 413, 0.5%), and other reasons (27 of 413, 6.5%).

Table 3. *Reasons for not requesting a login to the patient Web portal*

Reasons for not requesting a login	Non users (n = 758)
Was not aware that the portal existed	72.4%
Prefers to leave disease management to physician	28.5%
Feels inadequate with computer or internet	11.6%
No access to computer or internet	8.2%
Web portal is difficult to use	7.7%
Privacy reasons	6.1%
Concern for less personal attention by physician	6.3%
Physician / other advised against portal use	2.6%
Language barriers	2.4%

How Patients Became Aware of the Web Portal

Of the 209 patients without a login who stated they were aware of the existence of the portal, 102 (48.8%) knew about the portal because their health care provider told them. In comparison, 392 (94.9%) of the 413 regular users were informed about the portal by their health care provider ($p<0.001$). Other sources of information about using the web portal were posters in the clinic waiting area (nonusers: 4.8%; regular users: 0.7%; $p<0.001$), a pamphlet (nonusers: 1.9%; regular users: 3.6%; $p=0.24$), friends or relatives who used the portal themselves (nonusers: 9.6%; regular users: 1.0%; $p<0.001$), and other reasons (nonusers: 13.9%; users: 2.2%; $p<0.001$).

Perceived Usefulness

Regular users perceived the usefulness of specific portal content in a different way compared to nonusers (Figure 2). Users perceived access to the laboratory values with treatment targets, the possibility of rereading clinic consultations, and having a summary of all controls as the most useful features of the portal. We asked the nonusers if they could speculate on the possible usefulness of portal features for their own disease management. They suggested a summary of upcoming consultations and a summary of their medication to be the most useful parts of a web portal.

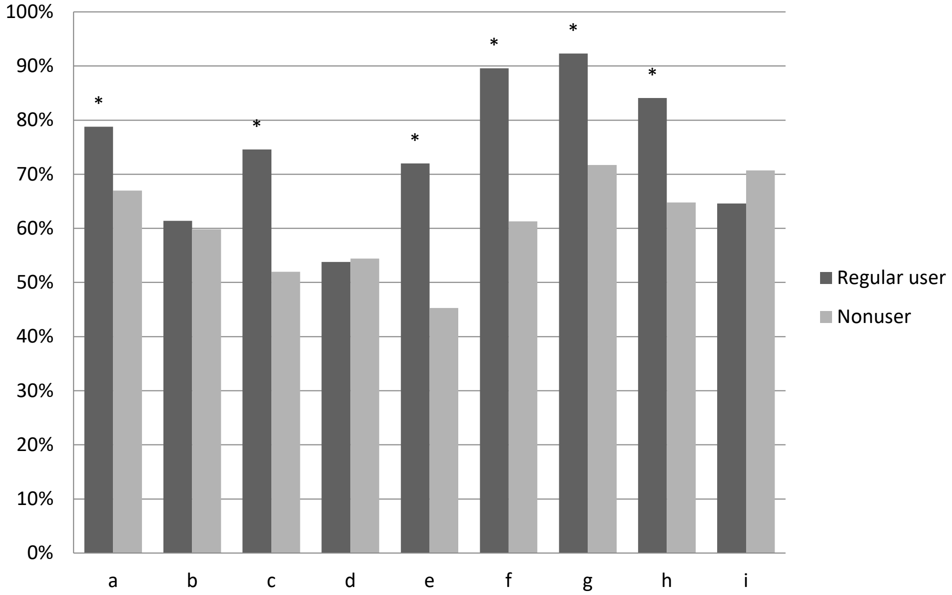

Figure 2: *Differences between regular users (n=413) and nonusers (n=758) regarding the perceived usefulness (very useful or useful) about the content items of the patient Web portal. a: overview of upcoming consultations; b: summary of all health care physicians involved in treatment; c: e-messaging; c: general information about diabetes; e: using the portal to upload the glucose levels measured at home; f: rereading medical record after consultation; g: access to laboratory values and treatment goals; h: a summary of all consultations (history and future); i: overview of medication. * p<0.001*

Recommendations About Functionalities Added to the Web Portal

Regular users and nonusers appreciated additional functionalities that could improve the web portal differentially (Figure 3). Regular users wanted to be able to add their injected insulin units to the glucose diary and to use the portal for supportive care, such as scheduling an appointment and receiving reminders about upcoming consultations. Nonusers felt that a diabetes web portal could benefit mostly from more information about medication and side effects and they wanted to use the portal for medication refills. Overall, regular users scored more possible features as useful or very useful than nonusers did except for information provided in different languages.

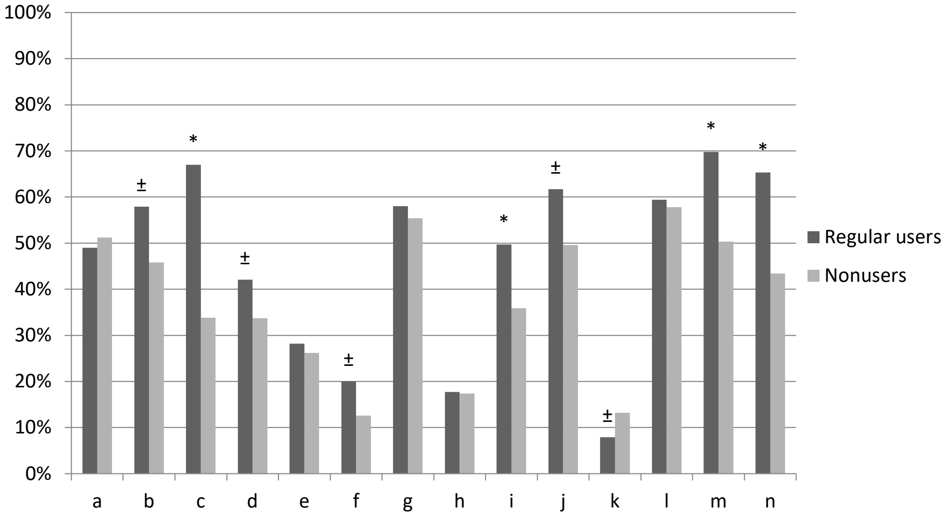

Figure 3: *Differences between regular users (n=413) and nonusers (n=758) regarding usefulness of functionalities (very useful or useful) that could be added to the Web portal. a: Automatic signal to physician when uploading glucose diary; b: automatic upload from glucose meter to portal; c: adding insulin units to glucose diary; d: links to websites with information about diabetes; e: links to websites with lifestyle interventions; f: portal on mobile device; g: request for medication refills; h: forum functionality; i: printing functionality; j: news sites about diabetes; k: information in different languages; l: information about medication and side effects; m: reminder function about upcoming consultation; n: using the portal for scheduling a consultation with physician. * p<0.001; ± p<0.05.*

DISCUSSION

The main reason for patients with diabetes not requesting a login for a patient web portal was that they were not even aware of its existence. This was previously found in a smaller group (3 of 13 respondents) of patients with diabetes mellitus type 2.[26] Earlier studies have provided information on difficulties in usability[11,15,16] and reasons for not using the portal after receiving a login,[27] but not on reasons for use or nonuse before requesting a login. In our study, it seems obvious that many health care providers, especially in the primary care setting, often did not communicate the possibility of using the shared electronic health record with their patients clearly enough. We can only speculate about the reasons. In the Netherlands, more than 99% of the primary care physicians and nurses work with an electronic medical system. However, it might be that they have not included a communication protocol about the web portal for their patients with diabetes; they may not want to share data in a web portal; they may have assumptions about capabilities, skills, and wishes of their patients that do not enhance the web portal's promotion;[28] or that they may not be satisfied of the web portal itself.[29] Whatever the reasons, before trying to get a web portal used by a substantial number of patients with diabetes, such a web portal should be discussed in detail about requirements with all diabetes care providers. The same held true in telemonitoring of patients with heart failure; without transparent and predefined criteria of user requirements, health professionals expectations did not meet actual experiences, leading to disappointment.[30] Another possibility for the patients' ignorance of the web portal is that health care providers did communicate about the portal with their patients, but the latter did not recollect the physician telling them about it, perhaps because they did not understand the topic.

In a previous study, one of the main obstacles of enrollment in a general web portal was that a quarter of the patients did not remember discussing the portal with their providers.[31] In that study, even despite remembering a discussion about the portal, another 63% of patients did not attempt to enroll mainly due to lack of motivation and negative attitudes toward the patient portal.[31] In the 6 years in which Diamuraal has been in use, 76.5% of the patients who could request a login never did. This percentage is more or less similar with other patient portals. In the literature, the actual percentage of users is approximately 32% to 37% for patients with chronic diseases such as diabetes.[31,32] In a general population, there is even less inclination to activate an account.[11] Better strategies have to be found to inform patients about a web portal, how to request a login, and what benefits a patient portal may offer. One study in the general population found a threefold increase in web portal enrollment with the use of aggressive marketing strategies, defined as using more than 5 different means of recruitment, including posters on the waiting area to on-site enrollment with a computer kiosk,[33] illustrating the importance of the health care provider.

Some patients who did not request a login did so because they preferred to leave the disease management to the health care provider. On the other hand, regular users wanted to reread the information given by the diabetes care provider at home and they felt like the portal gave them influence in the management of the disease. This illustrates the difference in opinions about who should be responsible for the management of the disease. In a previous study, we found that only 62% of patients with diabetes agreed to take full responsibility for their disease.[34] Therefore, we cannot expect that all patients will use and benefit from a diabetes patient web portal.

Fear for privacy and security of the web portal did not seem to pose a large barrier in our study in contrast to previous studies.[35] After patients have received access to their health care record, worries about the security may drop; for example, from 47% before to 4% after login when patients were reassured about the use of passwords and unique login numbers.[15] Health technology developers have to warrant the patient's privacy without making the login process a barrier on itself and diabetes care providers should address the fears by informing patients about security measures.

Nonusers were older, had lower education,[26,36] and had less diabetes knowledge. Diabetes care providers need to pay extra attention to this group of patients to help them becoming familiar with a different approach to diabetes care. At least one-fifth of the nonusers stated that they would use the portal if someone else could help them and another third of participants would at least consider using it. Many regular users stated that someone else used the portal as well to read the information provided by the physician. This access to the web portal by family members has been shown to be effective and desirable in cardiac surgery[37] and in pediatric patient portals.[27] For all patients, the joint use of the web portal by the patients themselves and a family member or friend should be discussed.

Patients can encounter difficulties in navigating through a portal to find the information they seek and have problems with interpretation of data.[16,29,38] This study does not provide any information in this respect because we sent questionnaires to nonusers who never logged in to the portal and cannot comment on its attractiveness and ergonomics. However, if we want more patients using a portal, this is a concern that needs to be addressed. We are currently studying the influence of design and ease of use of the portal on persistent use or early discontinuation.

Not only actual barriers can prevent patients from requesting a login; nonusers perceived the usefulness of a patient web portal differently compared to users. Although more users found the features that helped them with their disease control (very) useful, such as laboratory results and treatment goals, fewer nonusers scored those features as useful. Before using a web portal, patients have certain expectations about which features are useful for them with regard to disease management and these expectations and opinions may change after actively using it.[17] The results of our study are another illustration of the fact that we need to inform patients better about what a patient portal can mean for them. To interpret our results correctly, we should keep in mind that we analyzed patients who had logged in 2 or more times. These regular users have other demographics than patients who cease to use the portal in an early stage and are not comparable to regular users or to nonusers. Although there are differences between patients with type 1 and type 2 diabetes in requesting a login to the web portal,[13] we did not distinguish between type 1 and type 2 diabetes in the present study.

To our knowledge, this is the first study about the barriers of the use of a web portal for patients with diabetes, before and during its use. The web portal is used by patients with both type 1 and type 2 diabetes, not only in primary care but also in secondary care. The web portal under study has been used for 6 years, which underpins the relevance of the patients' opinions. Furthermore, we studied a large group of nonusers of a patient web portal for diabetes mellitus, not previously done in the literature.

However, there are some limitations. The first is due to the design of the questionnaire. Several patients gave multiple reasons for not requesting a login instead of 1 main reason, whereas other patients only gave 1 answer as per the instructions of the questionnaire. We are aware that patients can have multiple reasons for not requesting a login, but because most participants were careful in following instructions, they did not mention other reasons even if there were any. This means that our results are likely to be an underrepresentation of reasons for not requesting a login.

Secondly, there was a response rate of 66%; 31.6% of all people who were sent a questionnaire were eligible for analysis. This is comparable with other studies in this area.[39,40] Our participants did not differ in age from nonparticipants, but they were more frequently male. Gender was not a determinant for being a nonuser; therefore, the selective participation will not have influenced our outcomes.

Our study showed that unawareness of the patient portal is the main barrier of enrollment. All patients who were aware of the existence of the web portal were made aware by their health care provider. Users and nonusers perceive the usefulness of the portal differently and do not have the same recommendations for additional functionalities. Currently, the web portal is not communicated at all or not communicated clearly enough by health care providers. To increase participation, the unawareness of its existence and usefulness needs to be addressed by informing the physicians of the possible benefits and subsequently encourage them to discuss the web portal with their patients.

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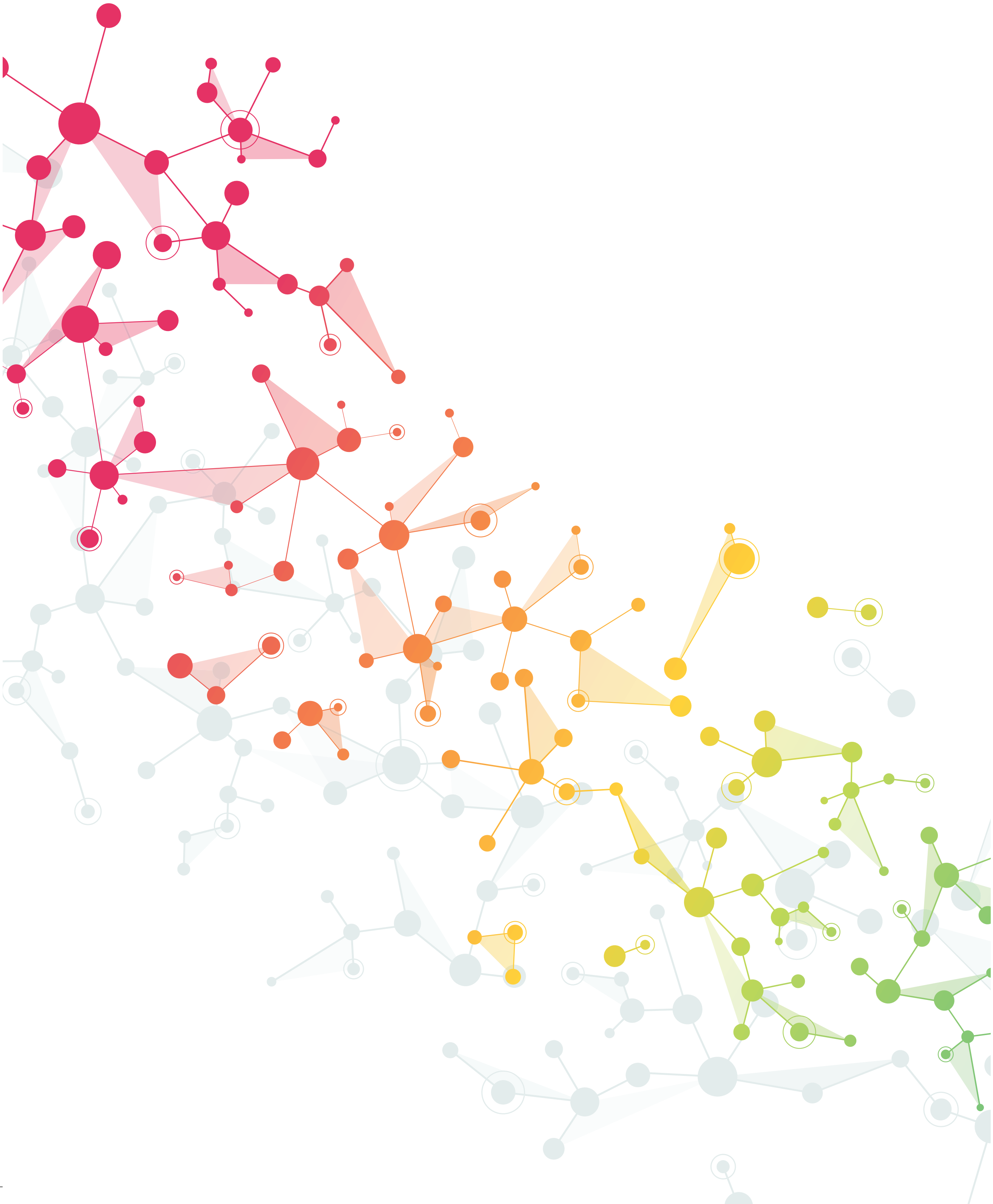


CHAPTER 4

Patients' experiences with and attitudes towards a diabetes patient web portal

M.C.M. Ronda, L.T. Dijkhorst-Oei, G.E.H.M. Rutten

PLoS ONE. 2015;10(6):e0129403

ABSTRACT

Background A diabetes patient web portal allows patients to access their personal health record and may improve diabetes outcomes; however, patients' adoption is slow. We aimed to get insight into patient's experiences with a web portal to understand how the portal is being used, how patients perceive the content of the portal and to assess whether redesign of the portal might be needed.

Methods A survey among 1500 patients with type 1 and type 2 diabetes with a login to a patient portal. Setting: 62 primary care practices and one outpatient hospital clinic, using a combined patient portal. We compared patients who requested a login but never used it or once ('early quitters') with patients who used it at least two times ('persistent users').

Results 632 patients (42.1%) returned the questionnaire. Their mean age was 59.7 years, 63.1% was male and 81.8% had type 2 diabetes. 413 (65.3%) people were persistent users and 34.7% early quitters. In the multivariable analysis, insulin use (OR2.07; 95%CI 1.18-3.62), experiencing more frequently hyperglycemic episodes (OR1.30; 95%CI 1.14-1.49) and better diabetes knowledge (OR1.02; 95%CI 1.01-1.03) do increase the odds of being a persistent user. Persistent users perceived the usefulness of the patient portal significantly more favorable. However, they also more decisively declared that the patient portal is not helpful in supporting life style changes. Early quitters felt significantly more items not applicable in their situation compared to persistent users. Both persistent users (69.8%) and early quitters (58.8%) would prefer a reminder function for scheduled visits. About 60% of both groups wanted information about medication and side-effects in their portal.

Conclusions The diabetes patient web portal might be improved significantly by taking into account the patients' experiences and attitudes. We propose creating separate portals for patients on insulin or not.

INTRODUCTION

A patient web portal (PWP) can help patients increase their knowledge about the disease,[1] improve diabetes outcomes,[2–6] increase self-efficacy[7] and getting patients more involved in their own treatment.[8] However, adoption rates to web portals are slow. Our group and others have found differences between users and non-users of a diabetes web portal on both demographic and diabetes related variables.[9,10] Health care providers need to focus on these differences and give extra attention to patients who could benefit from portal use. We also need to examine the way patients use a web portal and to gain insight into a patient's perspective of the usefulness of a PWP to increase its use.

Patients start using a PWP to increase their self-management,[7] to enhance the communication with their health care provider[11] or because of dissatisfaction with the patient-provider relationship.[12] There are barriers that prevent patients from starting or continuing the use of a web portal, such as fear for privacy,[13] non-feedback frustration and difficulty implementing PWP use in daily life.[14] Some patients may have incorrect assumptions about a PWP leading to expectations that are not met.[15] Furthermore, patients have specific wishes for content and additional personalized online services to improve portals.[13]

Because many portals have been designed by physicians and IT-specialists, and not by patients themselves, redesign of the web portals might be needed to interest as many patients as possible and to address their specific wishes and needs.

We aimed to gain insight into the experiences, motivations and preferences of persistent users and early quitters of a diabetes PWP.

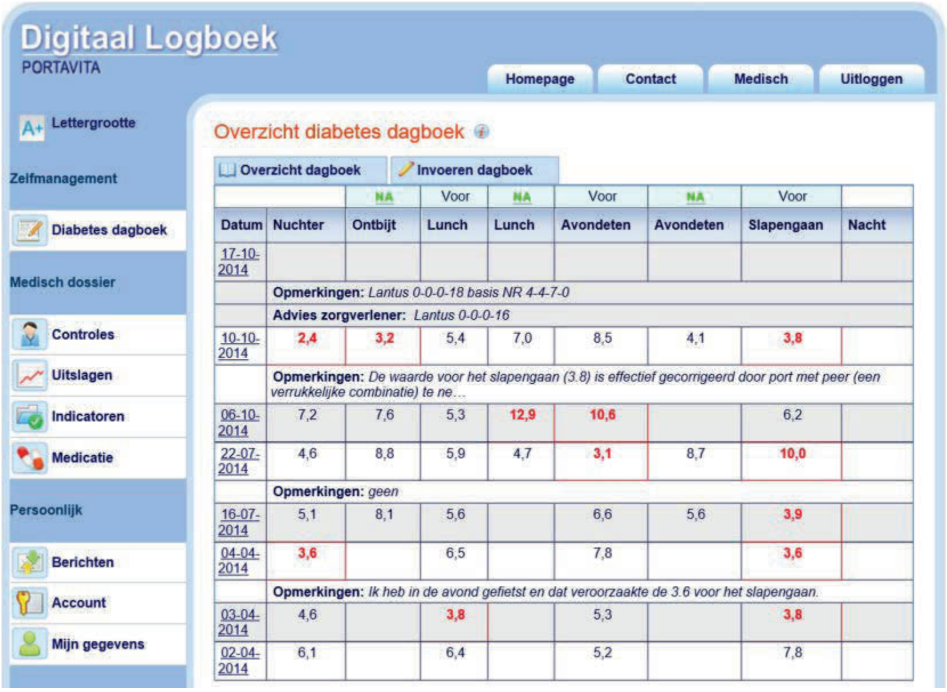
The following research questions were addressed:

1. What are the characteristics of patients who request a login and become a persistent user in comparison to patients who cease to use the portal in an early stage?
2. Why do patients request a login to the web portal?
3. How is the web portal being used?
4. How do patients assess the content of the web portal?
5. What are the patients' wishes for improvement?

METHODS

Study setting and design

'Diamuraal' is an organization that coordinates the diabetes care in a defined geographical area in the center of the Netherlands. It comprises 62 independent primary care practices and one outpatient clinic of the regional hospital that provide diabetes care to over 10.000 patients, working in a care group.[16,17] All physicians and nurses who participate in the care of these patients record their data in the same electronic health record and patients can request a login to access their personal medical records. This portal is called 'Digitaal Logboek' and was developed by Diamuraal and a private company (Portavita). After login, patients have access to the information provided by their physician or nurse during medical consultations. These include full-text of the clinic notes, the results of physical examination, laboratory results, problem lists and treatment goals. Patients can view a list of their current use of medications, however the completeness of this list is depending on the physician because this needs to be manually added. The PWP also provides general diabetes information and an overview of all examinations and visits that are needed in high quality diabetes care. Patients can upload glucose levels measured at home (Figure 1) and contact their personal care provider through secured e-messaging. This portal is an integral part of the EMR, all interactions and messages between patient and provider are stored in the EMR. The portal is additional; patients who have not requested access receive usual diabetes care. We conducted a survey among adult patients with type 1 or 2 diabetes mellitus. The physicians working within the organization of 'Diamuraal' have registered their patients with this organization and all data about patient characteristics and data concerning the disease are recorded in the electronic health record, including if a patient has requested a login to the web portal. For this survey we randomly selected 1500 patients aged 18-85 years with a login to the web portal. As part of our study, we also sent different questionnaires to patients within 'Diamuraal' that are registered as not having a login (non-users).



Overzicht diabetes dagboek

		NA	Voor	NA	Voor	NA	Voor	
Datum	**Nuchter**	**Ontbijt**	**Lunch**	**Lunch**	**Avondeten**	**Avondeten**	**Slapengaan**	**Nacht**
17-10-2014								
	Opmerkingen: *Lantus 0-0-0-18 basis NR 4-4-7-0*							
	Advies zorgverlener: *Lantus 0-0-0-16*							
10-10-2014	**2,4**	**3,2**	5,4	7,0	8,5	4,1	**3,8**	
	Opmerkingen: *De waarde voor het slapengaan (3.8) is effectief gecorrigeerd door port met peer (een verrukkelijke combinatie) te ne…*							
06-10-2014	7,2	7,6	5,3	**12,9**	**10,6**		6,2	
22-07-2014	4,6	8,8	5,9	4,7	**3,1**	8,7	**10,0**	
	Opmerkingen: *geen*							
16-07-2014	5,1	8,1	5,6		6,6	5,6	**3,9**	
04-04-2014	**3,6**		6,5		7,8		**3,6**	
	Opmerkingen: *Ik heb in de avond gefietst en dat veroorzaakte de 3.6 voor het slapengaan.*							
03-04-2014	4,6		**3,8**		5,3		**3,8**	
02-04-2014	6,1		6,4		5,2		7,8	

Figure 1: *Screenshot of the glucose diary of the patient portal*

Information about the latter group of patients has been published elsewhere and is beyond the scope of this paper.[18] Patients were sent an informational letter together with a questionnaire. They received a reminder twice in a three week interval. All participants had to sign a consent form to participate. In the Netherlands, studies involving human subjects need to undergo a medical ethics review if they are subjected to the Medical Research Involving Human Subject Act (WMO). This study was assessed and considered non-WMO applicable by the Medical Ethics Committee of the University of Utrecht, which means that no further ethical approval was required (protocol number 11-296/C).

Study measures

We collected patient data form the electronic health record, such as login frequency, age, gender, type of diabetes, treatment setting, laboratory values, comorbidity and diabetic complications.

The questionnaire about the portal contained multiple choice questions about reasons for requesting a login, the usability of portal features and patient's wishes (Appendix). There were three questions that were scored on a 5-point Likert scale. We combined the two highest categories (very useful and useful; very satisfied and satisfied; very important and important) in the analysis.

We used an additional small questionnaire for asking educational level, ethnicity, living status, employment, medication, current smoking, drinking alcohol, physical activity, access to internet and to a computer. Finally we added several validated questionnaires to measure: satisfaction with diabetes treatment (The Diabetes Treatment Satisfaction Questionnaire, DTSQ);[19] diabetes-specific distress (Problem Areas in Diabetes, PAID);[20,21] self-efficacy (Diabetes Management Self-Efficacy Scale, DMSES)[22] and diabetes knowledge (Brief Diabetes Knowledge Test, BDKT).[23,24] These measures are described in more detail elsewhere.[9]

Statistical analysis

The patients were analyzed according to their login-frequency. We compared two groups: patients who requested a login but never used it or only once ('early quitters') and patients who requested a login and used it at least two times ('persistent users'). This division is based on registered data on the number of actual logins in the patient web portal from the first access to the portal. The period of access may range from about three years to just a few months. Our definition of persistent users and early quitters is comparable to data other studies.[25,26]

Categorical variables were expressed as percentages and continuous variables as means with standard deviation (SD). We used $\chi 2$-tests for all categorical variables and unpaired t-tests for all continuous variables. Logistic regression was used to determine which variables are independently associated with the cessation or continuation of the portal. We used a p-value of <0.2 in the univariable analysis to select variables for multivariable analysis. The reasons for use, the answers about content and usefulness of the portal and about the wishes were expressed as percentages. The answer categories 'useful' and ‘very useful’ were combined. Data was analyzed using SPSS for Windows (versions 20, SPSS Inc., Chicago, IL, USA).

RESULTS

From 1500 questionnaires 24 were undeliverable. Of the 1476 patients who received a questionnaire, 632 (42.8%) patients returned a completed questionnaire and were eligible for analysis (responders). Their mean age was 59.7 ± 13.2 years (versus non-responders 56.8 ± 15.1, p<0.001) and 63.1% was male (versus non-responders 57.1%, p=0.02). 413 (65.3%) patients were ‘persistent users’ (PU) and 219 (34.7%) patients were ‘early quitters’ (EQ).

Characteristics of early quitters versus persistent users

Persistent users were younger and had more often a paid job. More of them used insulin, were treated by an internist and used the internet daily. They had better diabetes knowledge and experienced both more hypoglycemic and hyperglycemic episodes (Table 1). The use of insulin, more frequently perceived hyperglycemic episodes and better diabetes knowledge increased the odds of becoming a persistent user. With a higher HbA1c the odds of becoming a persistent users decreases (Table 2). When using the internet, responders from both groups were mostly over an hour online (PU 45.4% versus EQ 36.0%, p=0.18). Furthermore, 51.1% of the persistent users declared that they used the internet for searching information about their disease compared with only 22.0% of the early quitters (p<0.001).

Reasons for requesting a login

The majority of patients from both groups declared that they ‘discovered’ the existence of the PWP after being informed by their physician (PU 94.9%, EQ 77.6%, p<0.001). For persistent users, the main two reasons for requesting a login were that the portal could give them access to the laboratory results and treatment goals (75.5%) and that the portal could influence disease and management (42.5%). For early quitters, the two main reasons for requesting a login were the access to the clinic notes and laboratory results (42.9%) and the suggested use of the portal by others (20.5%).

The general usefulness and usefulness of specific content

The majority of the persistent users (53.1%) accessed the web portal less than once a month and half of them spent less than fifteen minutes per session. They declared it easy to use (PU 91.9% versus EQ 78.7%, p<0.001); easy to login (PU 96.8% versus EQ 86.0%, p<0.001); they were satisfied with the layout (PU 96.8% versus EQ 85.2%, p<0.001) and assessed the overall information to be comprehensible (PU 97.5% versus EQ 90.4%, p=0.01). The same held true for the comprehensibility of specific web portal items: the meaning of laboratory values (PU 92.0% versus EQ 77.1%, p<0.001), the abbreviations

Table 1. *Characteristics of the study participants (N = 632), mean +/- SD or %*

	Early quitters (n = 219)	Persistent users (n = 413)	*P*-value
Age, years	61.9 ± 12.7	58.5 ± 13.3	0.02
Gender, male	63.9	62.7	0.76
Caucasian	91.2	93.6	0.26
Educational level, high	39.4	46.2	0.11
Paid job	36.3	47.1	0.01
Living arrangement, alone	16.8	15.9	0.76
Fluency in speaking Dutch	97.2	99.3	0.07
Daily use of internet	63.0	77.9	<0.001
Treatment setting			0.01
General practitioner	54.8	43.6	
Internist	45.2	56.4	
Type of Diabetes			0.21
Type 1	15.5	19.6	
Type 2	84.5	80.4	
Duration of Diabetes, years	13.9 ± 11.0	13.3 ± 10.7	0.49
Insulin	45.9	63.2	< 0.001
Polypharmacy*	47.2	52.7	0.21
HbA1c (mmol/mol)	54.0 ± 12.0	55.5 ± 11.2	0.14
Total cholesterol (mmol)	4.3 ± 1.0	4.4 ± 1.0	0.46
Current smoker	16.4	11.3	0.07
Drinking alcohol	49.3	52.8	0.41
PAID (range 0-100)	29.3 ± 11.5	31.0 ± 11.8	0.11
DMSES (range 20-100)	80.7 ± 16.5	80.7 ± 15.5	0.97
BDKT standard (range 0-100)	70.6 ± 18.8	78.7 ± 14.7	< 0.001
BDKT insulin (range 0-100)	58.0 ± 19.2	61.4 ± 20.6	0.15
DTSQ status (range 0-36)	29.8 ± 5.3	30.2 ± 5.0	0.37
DTSQ hyper (range 0-6)	2.0 ± 1.8	2.7 ± 1.9	< 0.001
DTSQ hypo (range 0-6)	1.6 ± 1.6	2.0 ± 1.7	0.01

* Polypharmacy: the use of five or more medications

Table 2. *Independent determinants of becoming regular users compared to early quitters*

	OR (95% CI)	*P*-value
Insulin	2.07 (1.18-3.62)	0.01
HbA1c	0.97 (0.95-0.99)	< 0.01
BDKT Standard	1.02 (1.01-1.03)	< 0.01
DTSQ hyper	1.30 (1.14-1.49)	< 0.001

used (PU 75.8% versus EQ 54.9%, p<0.001), the medical phrasings (PU 69.4% versus EQ 49.0%), p<0.001) and the reasons of why the appointments and check-ups in the clinic are needed (PU 91.7% versus EQ 73.0%, p<0.001). The majority of both persistent users (77.0%) and early quitters (79.3%) declared that they never had contacted the helpdesk for support (p=0.66). Of the people who did contact the helpdesk the main reason in both groups was because of losing their passwords (PU 49.5% versus EQ 64.7%, p=0.28). Both persistent users and early quitters appreciated most that they could reread at their homes the information discussed during consultations, the access to their laboratory values and treatment goals; persistent users rated the usefulness of all these items significantly higher than early quitters (Table 3).

Table 3. *Early quitters and persistant users regarding the perceived usefulness (very useful or useful) of the content items of the patient web portal*

	Early quitters (n = 219)		**Persistent users (n = 413)**		
	n*	**% agree**	**n***	**% agree**	***P*-value**
Summary of upcoming visits	147	65.3	401	78.8	< 0.01
Summary of all physicians / caregivers	144	52.8	396	61.4	0.18
e-messaging	144	56.2	401	74.6	< 0.001
General diabetes information	144	42.4	396	53.8	0.06
Glucose diary	144	47.2	401	72.1	< 0.001
Rereading clinic visit	146	72.6	402	89.6	< 0.001
Laboratory values + treatment goals	147	72.1	403	92.3	< 0.001
Summary of all controls (past and future)	146	67.8	402	84.1	<0.001
Summary of medication	144	62.5	401	64.6	0.90

* number of patients who answered that question

More PU than EQ stated that they know their own HbA1c and cholesterol levels and the targets for weight, HbA1c and blood pressure. When asked if the portal helps with supporting life style changes, about half of PU scored items negatively. The EQ felt significantly more items not applicable in their situation compared to PU (Table 4).

Table 4. *Opinions of early quitters (N = 219) versus persistant users (N = 413) about the way the portal being supportive for care*

Survey question	**Early quitters**				**Persistent users**				
	n*	**% Yes**	**% No**	**% n/a**	**n***	**% Yes**	**% No**	**% n/a**	***P*-value**
Do you know…?									
…the value of your own weight?	189	100			409	99.3			0.24
…the value of your blood pressure?	184	94.6			407	93.1			0.68
…the value of your Hba1c?	184	60.3			402	82.1			<0.001
… the value of your cholesterol?	184	70.7			408	85.3			<0.001
…the treatment goals of your weight?	183	88.0			407	92.9			0.05
…the treatment goals of your blood pressure?	183	84.6			407	91.9			<0.01
…the treatment goals of your HbA1c?	179	62.0			402	82.6			<0.001
…the treatment goals of your weight?	178	96.1			404	83.7			<0.001
Do you believe the portal will help with…?									
…adherence to diet	165	14.5	56.4	29.1	405	15.6	66.7	17.8	0.01
…adherence to sport	166	10.2	56.0	33.7	402	11.4	66.7	21.9	0.01
…losing weight	167	17.4	53.9	28.7	401	17.5	60.3	22.2	0.23
…stop smoking	168	4.2	40.5	55.4	401	3.7	37.4	58.9	0.83
…adherence in taking medication	166	15.7	51.2	33.1	393	21.4	64.1	14.5	<0.001
…diabetes knowledge	166	34.9	39.2	25.9	401	49.4	43.4	7.5	<0.001
…preventing complications	167	21.6	49.1	29.3	403	32.8	55.8	11.4	<0.001

* number of patients who gave an answer to that question

Wishes for improvement

Persistent users and early quitters answer differently about additional items which could improve the web portal (Table 5). PU want to be able to add their injected insulin units to the glucose diary, to receive updates with current medical information about diabetes and to use the portal for supporting the diabetes care, like scheduling a clinic visit. Among EQ the desires concerning reminder functions for upcoming visits, information about medication and side-effects and automatic upload from glucose meters are most often listed. It should be noted that the majority of PU also wish to have these functionalities added to the PWP.

Table 5. *Wishes about additonal functionalities*

	Early quitters (n = 219)		Persistent users (n = 413)		
	n*	**% agree**	**n***	**% agree**	***P*-value**
Automatic signal to physician by uploading glucose diary	164	45.1	402	49.0	0.48
Automatic upload from glucose meter to portal	162	52.5	399	57.9	0.49
Adding insulin units to glucose diary	118	50.8	297	67.0	< 0.001
Links to websites with information about diabetes	170	25.3	397	42.1	< 0.01
Links to websites with interventions	167	24.0	394	28.2	0.58
Portal on mobile device	166	12.7	393	19.8	0.10
Request for medication refills	168	50.0	396	58.3	0.11
Forum	165	15.2	396	17.7	0.69
Printing functionality	163	42.9	396	49.7	0.23
Updates with current medical information about diabetes	167	51.5	395	61.7	0.01
Information in different languages	166	10.1	393	7.9	0.26
Information about medication and side effects	169	56.2	401	59.4	0.75
Reminder function when scheduled / upcoming visit is due	170	58.8	404	69.8	0.04
Using the portal for scheduling a visit with physician	170	42.9	403	65.3	< 0.001

* number of patients who answered that question

DISCUSSION

This study provides insight into the experiences, motivations and preferences of persistent users and early quitters of a diabetes web portal. With this information we can adjust the portal to the potential users' wishes and preferences.

The main reason all patients requested access to the patient web portal was because it could give them access to laboratory results and treatment goals. Apparently patients are interested in using a PWP as a tool in managing their disease. Most patients 'discovered' the existence of the PWP after being informed by their care provider. Among the EQ there was a large group that got interested in the PWP by other means like posters in waiting areas or pamphlets. We assume that most of the latter group did not discuss the PWP with their treating physician. This implies that there is an important role for the health care provider in turning the patient into a PU. Modelling expectations can prevent early quitting due to disappointment.[15] Referral to the PWP during consultations may prompt patients to return to their PWP.

Patients who became persistent users were apparently those with a higher disease seriousness. Also among parents with children with a chronic disease, low level of disease severity was one of the reasons for not using the portal.[27] However, a recent systematic review on the use of electronic portal usage among patients with diabetes showed mixed outcomes in this respect.[28] We may conclude that one uniform portal is not suitable for all patients and we should consider dividing a diabetes web portal immediately after the entrance in two parts: one for patients who are injecting insulin and another for patients who do not. In patients with type 2 diabetes from the same organization, we previously found insulin use is a predictor of requesting a login.[9] Designing different portals will meet the needs of different categories of patients and could also meet the preferences of early quitters to get more information about (oral) medication and its side-effects.

Even two thirds of the persistent users responded that they did not feel the portal supports them in most lifestyle choices. We do not know the reason for this, but it might be because in the current portal most of these items are incorporated in other parts of the portal, like in the free text box at the end of the consult summary. In redesigning the portal, this finding has to be taken into account. A second explanation could be, that most of the users have both a low frequency and a low duration of accessing the portal, as in other studies.[27,29] This low frequency could explain why patients consider it not supportive in incorporating its information about life-style changes in daily life.[14] We could help reminding the patients using the PWP by a simple adjustment in portal functionality, e.g. an automatically generated email to remind patients to log in and evaluate their lifestyle and the agreement they made about it with their physician. If necessary they can use the e-messaging for questions and support when encountering difficulties in the implementation. In other types of web portals, weight and activity logs are implemented to encourage life style changes.[11]

Persistent users perceived the comprehensibility of the portal more favorable than early quitters. One of the reasons of early quitting might be the medical language.

Indeed, medical terms and abbreviations require explanation.[13,30] Besides the already available online manual we could offer a course or workshop on navigating through and understanding the portal. The ideas we offer in this paper for improvement of the patient web portal are against the background that the PWP we studied is a static coded website. Other portals might use technology that allows a more dynamic approach, in which sections appear based on patient characteristics. For new portals that are still in a design phase, this should be taken into consideration.

Study strengths include a large and representative population with both type 1 and type 2 diabetes patients and patients from primary as well as secondary care. The diabetes portal in this study is already 6 years in use, which adds to the value of patients' opinions. Furthermore, besides the survey data about users' opinions we used actual data about number of logins and patient characteristics, derived from the central 'Diamuraal' database, that encompasses all patients with diabetes mellitus treated by primary care physicians and internists who participate in 'Diamuraal'. Nevertheless, there are limitations: only 42.8% of the approached people responded. This percentage is comparable with a previously found willingness of diabetes patients in participating in research.[31] Our participants were slightly older and more frequently male. However, both age and gender were not a determinant for becoming a persistent user; therefore the selective participation may not have influenced the outcomes. It is unclear if we can generalize our results to the entire diabetes population in the Netherlands because there is no national diabetes registry. However, irrespective of the representativeness of our study population, issues raised in this paper about problems with comprehensibility of the portal, supporting lifestyle changes and additional wishes for portal features should be taken into account when designing a patient portal for patients with diabetes. Another limitation is the cut-off point of 2 times login for the definition 'persistent user' or 'early quitter'. To the best of our knowledge there is no definition of how many login times makes a person a persistent user. For that reason we had to make a judgment call based on the distribution of actual logins from the first access to the portal. This paper does not include information about the group of patients that never requested a login (the so called 'non-users'). They are not able to provide information about the use of the portal the scope of this paper. Compared to users, the non-users are older (59.7 ± 13.2 years vs. 67.4 ± 10.0 years) and less frequently male (63.1% vs. 56.6%).

In conclusion, medical terms and abbreviations in a PWP require explanation. Patients who are prescribed insulin, perceive hypoglycemic episodes and have better diabetes knowledge are the ones who become persistent users of a PWP. Persistent users evaluate the portal more favorable and would like to be able to add their injected insulin units to the glucose diary. We consider dividing a diabetes web portal immediately after the entrance in two parts: one for patients who are injecting insulin and another for patients who do not. This suggestion also meets the preferences of early quitters to get more information about (oral) medication and its side-effects.

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APPENDIX. **Questionnaire to the participants**

1. How did you became aware of the Patient Web Portal? (*several answers possible*)

☐ My physician, diabetes nurse or nurse practitioner told me about it
☐ There was a poster about the Patient Web Portal
☐ I received an informational pamphlet about the Patient Web Portal
☐ By means of friend/family who uses it him/herself
☐ Other

2. What is the reason you decided to start using the Patient Web Portal? (*several answers possible*)

☐ Because it would give me influence on disease and management
☐ Because it be convenient to have access to all my data (clinic notes and test results) at home
☐ Because others thought it would be useful for me
☐ Because I was discontent with the current care I receive
☐ Other

3. How often do you access the Patient Web Portal?

☐ Daily
☐ At least once a week
☐ At least once a month
☐ Less than once a month

4. How long do you usually access the Patient Web Portal?

☐ Less than fifteen minutes
☐ Less than thirty minutes
☐ Less than one hour
☐ Over an hour

5. If you have ever needed the helpdesk, what was the reason for this?

☐ I have never needed the helpdesk
☐ I wanted to receive information about the procedure for requesting a login
☐ I lost my username and/or password
☐ I had trouble finding the information I wanted within the Patient Web Portal
☐ I had trouble imputing data in the Patient Web Portal
☐ Other

6. How often do you access the Internet other than the Patient Web Portal

☐ Daily
☐ At least once a week
☐ At least once a month
☐ Never (*skip the next question*)

7. How long do you usually access the Internet per session?

☐ Less than fifteen minutes
☐ Less than thirty minutes
☐ Less than one hour
☐ Over one hour

8. What is the main reason you use the Internet? (*several answers possible*)

☐ For work
☐ For socializing (e.g. email, hyves, facebook)
☐ For looking up information (e.g. on diabetes)
☐ For relaxation (e.g. videogames)
☐ Other

9. Do you use the Internet for looking up diabetes information?

☐ Daily
☐ At least once a week
☐ At least once a month
☐ Never

10. Is the information provided in the Patient Web Portal comprehensible for you, in specific the: (*yes/no*)

☐ Meaning of laboratory values
☐ Abbreviations
☐ Medical terminology
☐ Reason behind the check-ups by different providers

11. Can you indicate the importance of the following features of the Patient Web Portal? (*Scored on 5-point Likert scale ranging from "very useful" to "not at all useful"*)

☐ Summary of upcoming visits
☐ Summary of all physicians/caregivers
☐ The possibility of e-messaging
☐ Access to general diabetes information
☐ Possibility of tracking glucose in the glucose diary
☐ Rereading clinic notes
☐ Access to personal laboratory values and treatment goals (e.g. blood test and weight)
☐ Summary of all controls (past en future)
☐ Summary of your medication

12. How satisfied are you with the Patient Web portal with regard to…
(*scored on a 5-point Likert scale ranging from "very satisfied" to "not at all satisfied"*)

☐ How easy it is to use
☐ Layout, letter type and color
☐ How easy it is to login
☐ Comprehensibility of the overall information displayed (such as background information about diabetes and all your own data)
☐ Helpdesk (*only answer this if you ever contacted the helpdesk*)

13. Do you know the value of your weight? (*yes/no*)

14. Do you know the value of your blood pressure? (*yes/no*)

15. Do you know of the value of your HbA1c? (*yes/no*)

16. Do you know the value of your cholesterol? (*yes/no*)

17. Do you know the treatment goals of your (*yes/no*)

☐ Weight?
☐ Blood pressure?
☐ HbA1c?
☐ Cholesterol?

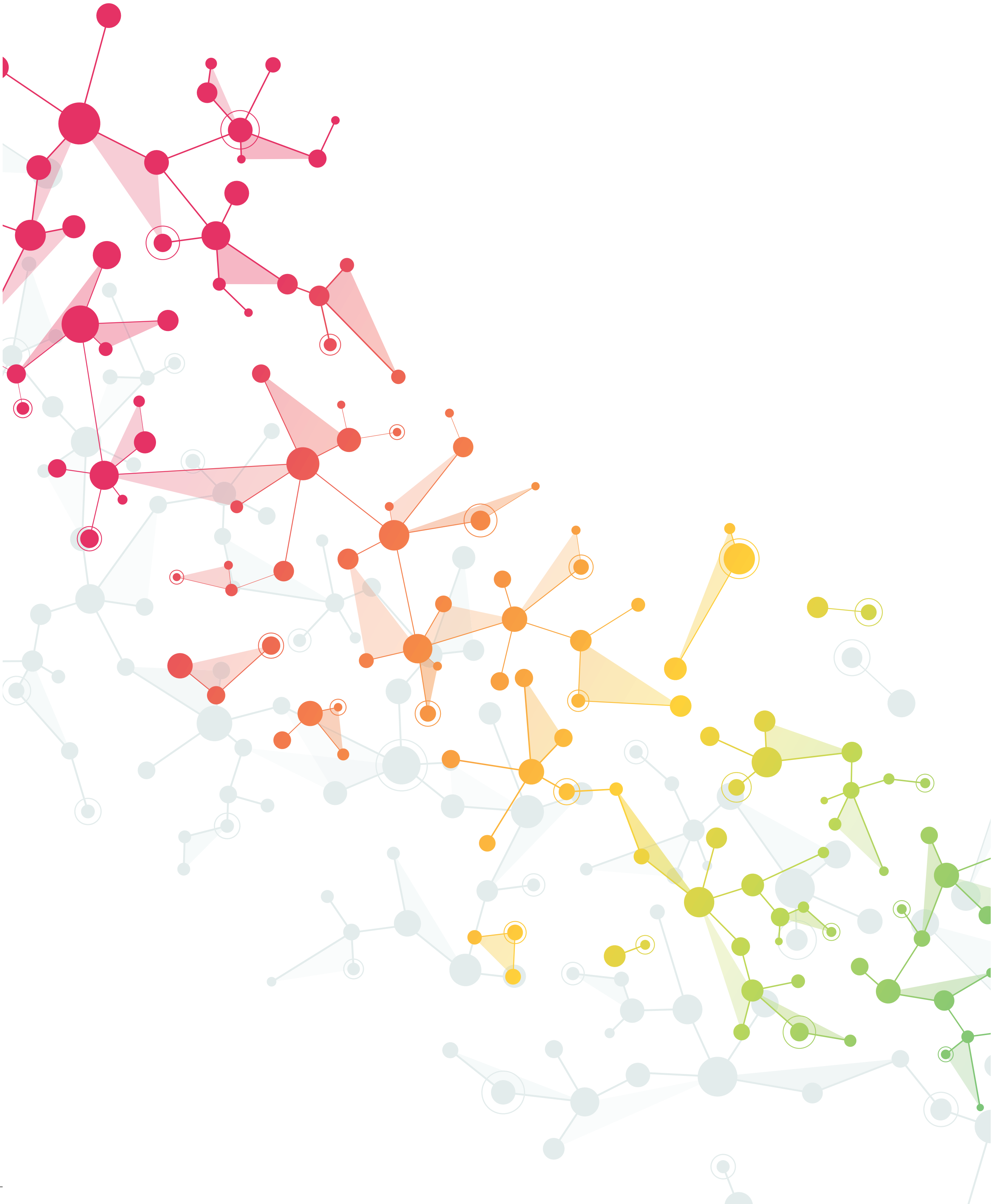
18. Do you believe the Patient Web Portal will help with…(*yes/no/not applicable*)

☐ Adherence to diet
☐ Adherence to sport
☐ Losing weight
☐ Stop smoking
☐ Adherence in taking medication
☐ Improving diabetes knowledge
☐ Preventing complications (such as low blood sugar and feet problems)

19. The following questions are about the future of the Patient Web Portal. We would like to understand if you would be interested in the following possible additional features:
(*scored on a 5-point Likert Scale ranging from "very important" to "not at all important"*)

☐ Receiving an automatic message (reminder) of a clinic visits by means of email or sms
☐ Sending automatic message to the physician when my uploaded glucose levels are too high or too low
☐ Automatic upload from my glucose meter to the glucose diary in the PWP
☐ The possibility of adding the injected insulin units to the glucose diary (*only answer this question if you use insulin*)
☐ Referral to websites with more diabetes information (such as diep.info or a patient association)
☐ Referral to websites that can actively help me met my goals (such as quit smoking or dieting)
☐ Possibility of logging on the Patient Web Portal on the mobile phone (through app)
☐ Request for medication refills
☐ Forum functionality (for contact with peers)
☐ Print functionality
☐ Newsfeed with the latest news on diabetes
☐ Possibility to look at the information in a different language (e.g. Turkish, Moroccan)
☐ More information about the reason why I use the which medications and what the side-effects of these medications are
☐ Scheduling a clinic visit with physician

Thank you very much for completing this questionnaire



CHAPTER 5

Diabetes care providers' opinions and working methods after four years of experience with a diabetes patient web portal

A survey among health care providers in general practices and an outpatient clinic

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BMC Family Practice. 2018;19(1):49

ABSTRACT

Background To gain insight into the opinions and working methods of diabetes care providers after using a diabetes web portal for four years in order to understand the role of the provider in patients' web portal use.

Methods Survey among physicians and nurses from general practices and an outpatient clinic, correlated with data from the common web portal.

Results 128 questionnaires were analysed (response rate 56.6%). Responders' mean age was 46.2 ± 9.8 years and 43.8% were physicians. The majority was of opinion that the portal improves patients' diabetes knowledge (90.6%) and quality of care (72.7%). Although uploading glucose diary (93.6%) and patient access to laboratory and clinical notes (91.2% and 71.0%) were considered important, these features were recommended to patients in only 71.8% and 19.5% respectively. 64.8% declared they informed their patients about the portal and 45.3% handed-out the information leaflet and website address. The portal was especially recommended to type 1 diabetes patients (78.3%); those on insulin (84.3%) and patients aged< 65 years (72.4%). Few found it timesaving (21.9%). Diabetes care providers' opinions were not associated with patients' portal use.

Conclusions Providers are positive about patients web portals but still not recommend or encourage the use to all patients. There seems room for improvement in their working methods.

INTRODUCTION

The burden of diabetes is rapidly increasing worldwide.[1] Patient web portals are of interest in this respect and many studies focused on the use of portals by patients with diabetes.[2,3] A patient portal is a secure online website that gives a person access to his or her personal medical information derived from the physician's electronic medical record. Portals have shown a range of benefits, such as improved diabetes outcomes, increased patient satisfaction and patient-provider communication, and reduced office visits.[4–8] However, the number of patients that use a portal is low.[9–13]

We demonstrated that patients' unawareness of the existence of a portal is an important barrier for starting its use.[14] So the role of the diabetes care provider seems of importance in the use of patient portals. However, healthcare providers are often also unaware of the existence of a patient portal or of its features.[15,16] They may underestimate the number of patients that are actually interested in using it,[15] are hesitant to start a web-based communication,[17] or expect problems with the communication or in the relationship with their patients.[18–20] There is fear for patients experiencing problems with the interpretation of a portal's data,[18,21,22] pessimism about patients' motivation and ability to maintain a personal health record,[16] and fear for an increase in the physician's workload.[23–25] Concerns about reliability, confidentiality, and security of information are other commonly mentioned barriers.[20,24,26–28] However, information about the interaction with patients with regard to portal use is lacking and more insight into the daily practice role of the diabetes care provider in this respect seems warranted.

We aimed to gain insight into the opinions and working methods of diabetes care providers after having used for four years a diabetes specific electronically medical record in which patients have full access ("web portal").

The following research questions are addressed:

1. What are the opinions of the diabetes care providers about the portal and its functionality?
2. How do they communicate the possibilities of the portal and to which patients?
3. What are the perceived consequences of the portal?
4. Are provider characteristics and opinions associated with the patients' portal use?

METHODS

Study setting

“Diamuraal” is a so-called care group, that coordinates the care of patients with diabetes.[29,30] Within this care group there are 62 primary care practices working (with general practitioners and nurse practitioners) and one outpatient clinic (with internists with subspecialty diabetology or nephrology and specialized diabetes nurses). All practices and providers use the same type of diabetes electronic medical record (EMR). The diabetes EMR is used simultaneously with and besides the general EMR of both the primary and secondary care practices.

The patient web portal

The general EMR has no portal option, but patients can request a login to access their personal diabetes EMR, via a web portal that provides access to information about the consultation, laboratory results, the so-called ‘problem list’, treatment goals, as well as to general diabetes information and to an overview of all individual diabetes related examinations and consultations that are needed and/or scheduled. Patients can upload glucose levels measured at home, including comments, and are asked for explanations in case of high and low glucose values (“glucose diary”). They can also contact their physician or nurse by secured electronic messaging. In addition, quarterly monitoring office visits can be substituted by self-monitoring; in that case, the diabetes care provider schedules for a patient to complete a standardized check list in his diabetes EMR. The portal is supplementary; all patients receive regular diabetes care according to the Dutch guidelines.[31]

Study design and measures

A postal questionnaire was sent to all 228 diabetes care providers working in Diamuraal. It contained questions about their opinions about the portal and its functionality, to which patients they recommend or discourage the portal’s use, how they communicate the possibilities of the portal with the patients and how they perceive the consequences of the portal, not only with regard to patient self-management but also for the healthcare provider. Twenty-six questions had to be scored on a 5-point Likert scale, 15 questions on a 3-point Likert scale, eight questions were multiple choice and one was open ended. In addition, six items about provider characteristics were included (Appendix). All issues addressed in the questions were proven relevant based on literature[2,32] and it was pilot tested by 2 general practitioners, an internist and two diabetes nurses from the Diamuraal care group.

Possible respondents received a reminder twice in a three week interval; the first by post, the second by telephone. From the central database of Diamuraal, data were collected about the number of patients with access to the patient portal per practice and about the start date of practices joining Diamuraal.

Statistical Analysis

Categorical variables were expressed as counts with percentages and continuous variables as means with standard deviation (SD). Continuous variables were checked for normality. The characteristics and opinions of different type of health care providers were compared with chi-square tests for categorical and unpaired t-tests for continuous variables. Items with a 5-point Likert scale were transformed into three answer categories by combining the two highest and the two lowest response categories. Linear regression was used to assess the association between the number of patients with a login request and the time the practice had been using the portal, and Spearman's rho was used to assess the correlation between provider's opinions and the number of patients with a login request per practice. Data were analysed using SPSS for Windows (version 21, SPSS Inc., Chicago, IL, USA).

RESULTS

In total 129 (56.6%) diabetes care providers completed the questionnaire. One questionnaire was excluded because of >10% missing values, so 128 questionnaires were analysed. Responders were more often female (75% of participants vs 49% of non-responders, p<0.001) and had a higher proportion of patients with access to the portal in their practices, although the difference was not significant (17.6 ± 11.4% versus
7.9 ± 6.4% (p=0.07).

Respondents' mean age was 46.2 ± 9.8 years (Table 1). On average 157.8 ± 9.1 diabetes patients were treated in a primary care practice (range 52-508); the outpatient clinic treated 2647 diabetes patients. The outpatient clinic had a higher percentage of patients with access to the portal than the primary care practices (52.8% versus 16.9%). The diabetes EMR with portal was used for five years by the outpatient clinic compared to on average 3.8 years in primary care. The medical specialties invited had a differential response rate, ranging from 100% (internists and diabetes nurses) to 76.8 % (nurse practitioners) and 35.7% (general practitioners).

Table 1. *Characteristics of responders (N = 128)*

	General practitioner	**Nurse practitioner**	**Internist**	**Diabetes Nurse**
Number	45	56	11	16
Gender, male	27 (60,0%)	0 (0)	6 (54,5%)	0 (0)
Age, years	51.4 ± 12.8	43.2 ± 9.9	46.4 ± 10.8	49.5 ± 10.3

Table 2. *Opinions about the possible effects of the diabetes web portal. Percentages of respondents*

"I (strongly) agree that….."	**All providers** (N=128)	**General practitioner** (n=45)	**Nurse practitioner** (n=56)	**Internist** (n=11)	**Diabetes nurse** (n=16)	***P*-value**
A patient portal improves the quality of diabetes care	72.7	77.8	67.9	63.6	81.3	0.60
A patient portal can prevent medical mistakes	55.5	60.0	50.0	45.5	68.8	0.33
The diabetes knowledge that patients gain through the portal can lead to improved self-management	90.6	97.7	85.5*	81.8	100	0.30
A positive effect of the patient web portal is that patients can prepare themselves to the diabetes consultation	71.1	73.3	67.9	63.6	81.3	0.76
The use of a patient portal can lead to better self-management in three quarters of my patients	20.3	24.4	16.1	9.1	31.3	0.11
In a cardiometabolically well-controlled patient with portal access, one of the quarterly monitoring visits can be substituted by self-monitoring	69.5	68.9	73.2	45.5	75.0	0.10

* 1 answer missing

Opinions about the portal and its functionality

The two main reasons for respondents to work with the portal was because they felt that it could improve the quality of diabetes care (77/128 providers, 60.2%) and the supposed improvement of communication between the different members of the diabetes team by working with one common medical record (56/128, 43.8%). Most respondents were positive about the use of a patient portal with respect to the quality of care, patient self-care and consult preparation. However, although most respondents (strongly) agreed that the provided diabetes information on the portal could lead to improved self-management, only 20% thought that it would improve self-management in three quarters of their own patients. In general the internists were more sceptical about the portal, but differences between type of health care provider were not significant (Table 2). Most respondents scored the glucose diary (117/125, 93.6%) and the access to laboratory values and treatment goals for the patients (114/125, 91.2%) as (very) important features of the portal. Other features that were scored as (very) important were the possibility to send an e-message (98/124, 79.0%) and the patient's access to clinical notes (88/124, 71.0%). About two out of three (66.9%) respondents scored web-based scheduling consultations (very) important, the same applied to 'insight in the personal care team' (67.7%) and diabetes information (64.8%). Insight into prescribed medication was scored as (very) important by 61.8% of the respondents. Suggestions for improvement of the portal mainly regarded the glucose diary ("difficult to fill in for patients with insulin-pump therapy"), the option to add self-measured blood pressure levels by the patient (which actually was an existing feature, but apparently not known by most diabetes care providers working with this portal), adding of other non-diabetes related laboratory values or patient characteristics (e.g. history, type of work and current diet), and tailored diabetes and medication information.

How do diabetes care providers communicate the portal, and to which patients?

Most often the face-to-face method was reported as to communicate the use of the portal. Additional types of informing the patient and communication about the portal were less often utilized (Figure 1). More than half of the respondents reported that they always or regularly encourage their patients to use the portal for adding glucose values as well as for e-messaging. Preparing a consultation and re-reading the information before and after a consultation were least encouraged (Table 3). Respondents answered that they recommend the portal to most of their patients, but especially to patients with type 1 diabetes mellitus, patients on insulin therapy, younger and higher educated patients (Table 4). Diabetes care providers did not differ in this respect (data not shown).

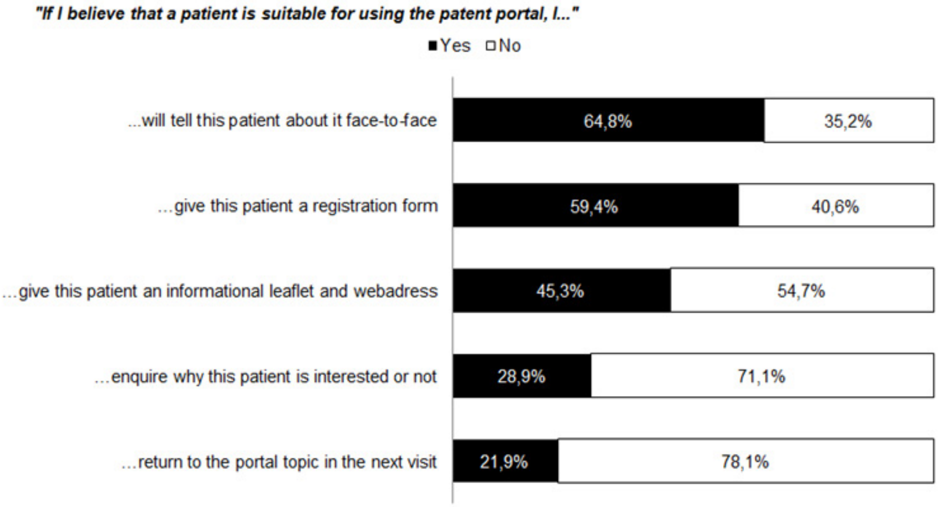

Figure 1: *How to discuss the option of using the portal with patients*

Table 3. *Encouragement to patients to use certain portal features. Percentages of respondents*

"To which extent do you encourage your patient to…"	**N**	**Always or regularly**	**Sometimes**	**Rarely or never**
…send you an electronic message through the portal	122	55.7	15.6	28.7
…upload glucose values more often	124	71.8	16.9	11.3
…re-read information after a consultation	123	30.1	32.5	37.4
…prepare for a consultation by viewing laboratory results and agreed targets	123	19.5	43.1	37.4
…inform you when he/she experiences a problem with the portal	123	43.9	26.0	30.1
…tell you when the meaning of laboratory values is unclear	123	36.6	27.6	35.8
…tell you when medical phrasings used in the health record are unclear	123	39.0	27.6	33.3
…turn to you if he/she has questions about self-management	124	47.6	26.6	25.8

Table 4. *To what patients do the providers recommend the diabetes portal? Percentages of respondents*

	N	Recommend	Neutral	Discourage
Patients with type 1 diabetes mellitus	115	78.3	20.9	0.9
Patients with type 2 diabetes mellitus	125	60.8	39.2	0.0
Patients with good cardiometabolic control	126	65.9	34.1	0.0
Patients with poor cardiometabolic control	126	63.5	27.9	8.6
Patients who do not use diabetes-specific medication	126	28.6	63.5	7.9
Patients who use oral diabetes medication	127	51.2	45.7	3.1
Patients who use insulin	127	84.3	15.7	0.0
Patients without comorbidities	127	55.1	43.3	1.6
Patients with comorbidities	127	52.8	40.2	7.1
Patients without language barriers	126	69.0	30.5	0.0
Patients with language barriers	125	10.2	39.8	47.7
Patients with lower education	126	25.0	48.4	25.0
Patients with higher education	125	73.6	26.4	0.0
Patients < 65 years	127	72.4	27.6	0.0
Patients > 65 years	125	33.6	54.7	9.4

Perceived consequences for the care provider

One third of the diabetes care providers (40/121, 33.1%) declared that the provider's role in the treatment (strongly) improved, whereas two-thirds of the providers (82/121, 67.8%) felt that the involvement of the patient in the treatment (strongly) improved. Other perceived (strong) improvements were the collaboration with the patient (85/121, 70.2%) and the increased knowledge of patients about diabetes mellitus (70/120, 58.3%). The majority of respondents stated that having access to the EMR stimulates self-management and self-correcting behaviour of patients. Most reported that they did not change their way of medical notation and most also stated that the frequency of patient's personal consultations had not changed after the introduction of the portal (Table 5).

Table 5. *Perceived consequences of working with the diabetes patient portal*

	N	Yes (%)
"Access to his/her diabetes EMR via a web portal …"	128	
stimulates the self-management and self-correcting behaviour of the patient		75.8
improves communication during consultation with a well prepared patient		44.5
results in saving time		21.9
results in deceased workload		10.9
"I write the medical information…"	128	
as I always did		63.3
in an easier language than before		37.5
with less information than before		7.8
"I think that patients who use the patient portal…"	122	
have an increased frequency of visits		2.5
have an unchanged frequency of visits		80.3
have a decreased frequency of visits		17.2
"How do you feel about patients sending you an e-message?"	128	
(very) positive		65.6
neutral		28.1
(very) negative		6.3
"How many e-messages do you receive per week?"	124	
0 messages		33.1
1-10 messages		59.7
≥ 11messages		7.3
"Who usually answers the e-message of patients?"	80*	
the health care provider answers only the messages of his/her own patients		31.3
the physician (general practitioner or internist) answers all messages		2.5
the nurse (nurse practitioner or diabetes nurse) answers all messages		66.3

* All respondents who receive e-messages

Are provider characteristics and opinions associated with the patients' portal use?

The proportion of patients with access to the portal was not related to the number of years the practice had been using the portal (beta 0.32 (95% CI -0.15 – 0.78), p=0.17). Except for the statement that it can lead to improved self-management in general (rs-.296, p=0.03), the respondents' opinion about each of the six possible effects of the portal as mentioned in Table 1 was not associated with the proportion of patients within the practice that requested a login to the portal (improving the quality of diabetes care rs -.009, p=0.95; preventing medical mistakes rs .003, p=0.99; patients being more prepared during consultation rs -.164, p=0.22; improving self-management in own patients rs -.211, p=0.12; substitute a quarterly control by self-control rs -.174, p=0.20).

DISCUSSION

The current study explored the opinions of diabetes care providers on the usefulness of an existing web portal and their working methods with regard to the web portal. They feel it could improve the quality of diabetes care and self-management of patients, but do not recommend it to all of their patients. They mostly explain the use of the portal directly with the patient, but they do not provide additional written information nor inquire into the patient's view. The level of active encouragement of specific portal features is low, even when physicians or nurses feel those features are important. Both nurses and physicians are selective in promoting the portal. The suggestion that web portals may save time for the diabetes care provider seems not justified.

Several previous surveys have indicated that health care providers are reluctant to encourage patients to gain access to all medical notes; sometimes they considered patient health records more as a resource for physicians than a tool for patients.[16,33] Physicians expected that patients' access to physician notes would result in greater worry among patients and that they anticipated more questions by patients,[19] while afterwards these expectations did not become reality,[21] and patients felt that access to physician notes led to an improved understanding, a better relationship with their provider and improved quality of care and self-care.[34] Such a gap between physicians' expectations on how patients will perceive the use of a web portal and the actual patients' experience might hinder providers' enthusiasm of discussing a portal with all their patients. Furthermore, health care providers may have insufficient knowledge on the best ways to make use of a web portal as an addition to current diabetes care and they may lack the necessary skills to stimulate patients.

In contrast to what many patients stated about their unawareness of this diabetes portal,[14] the majority of the diabetes care providers reported that they informed their patients about the portal, most often face-to face. However, they rarely address it during the next visit, which might have caused the discrepancy between patients' and providers' answers. It is known that general practitioners rarely assess their diabetic patients' recall or comprehension of new concepts.[35] From the current study we cannot explain why diabetes care providers appreciate for example the portal's glucose diary and patients preparing a consult with the use of the portal, but only encourage the use of these features on a limited scale. With the glucose diary can patients not only upload their glucose levels measured at home, but also must add information to clarify why levels are too high or too low. This is valuable information for the physician who can give the patient subsequent feedback and can also contribute to more self-awareness in patients. Additional training might be necessary to support the providers in discussing the benefits of this with patients, including helping with and checking the patients understanding of the information. Also lack of time might be a reason for the working methods of the diabetes care providers. They perceived no benefits of the portal in terms of time saving and a decreased workload. Patients' office visit frequency was estimated to have remained similar by most respondents, and this perception is likely to be correct. Other studies led to an increase of both e-messaging and telephone encounters between patients and provider,[36,37] whereas in a study in the USA, patients actually turned to their portals after visits, and portal use did not lead to an increase in primary care visits.[38] We expect that with more experience with the full range of possibilities a patient web portal has to offer, the workload may ultimately decrease as patients will start to use the portal for substitution of care.

Despite the positive attitude of our respondents towards the portal for patient use, only 17.6% of their patients had requested access to the portal. We did not find an association between the opinion of a healthcare provider and the proportion of patients within the practice that requested a login to the portal. These findings suggest that other factors determine whether patients will use the diabetes portal, e.g. insulin use, hypoglycaemic episodes and diabetes knowledge. We did find that diabetes nurses are most optimistic about the portal, while the medical specialists at the same hospital are more sceptical. They both treat the same complex patients who are more likely to request a login.[39] This difference of opinions between type of providers within the same setting might be a reason we did not find an association between positive opinions and proportion of patients within the practice that requested a login. Furthermore, it is also possible that health care providers were more positive about the portal in our questionnaire while in daily use they hold a different opinion and therefore do not recommend it more often. Another possibility is that they are positive but due to e.g. time constraints during consultation do not recommend portal use more actively. We might need to stimulate the providers to play a more active role to increase the number of patients with a login to the portal.

The strength of our study is that we evaluated a web portal that has been in use in daily practice for four years. However, several limitations should be considered. First, we have a relatively small surveyed population. Response rates of physician surveys are notoriously low and our rate is comparable to others[40]. One of the researchers works as an internist at the hospital. She had no access to the returned questionnaires, but her position might have influenced the response rate among the diabetes nurses. However, we have no reason to assume that this position influenced the outcomes of the survey. Second, significantly fewer general practitioners responded. However, we found no difference of opinions between general practitioners and internists. Third, the tendency that respondents had a higher percentage of patients with access to the portal than non-respondents might indicate a selection-bias. It is possible that general practitioners who did not return the questionnaire are less positive about using a patient web portal. Finally, our questionnaire was designed based of determinants of patient portal use from literature. It was evaluated by experts but we might have missed information which could have been found if alternative methodologies, such as in-depth interviews, were used. For example, the discrepancy between health care providers' opinions about the portal leading to improvement of self-management and the low number of providers expecting that three quarters of their own patients were able to use the portal to improve their diabetes self-management, might have been the result of the wording ('three quarters') in the questionnaire. It would have been better to phrase it as a more open question.

Implications for clinical practice and further research

Despite positive opinions about the possible effects of a diabetes web portal, diabetes care providers do not offer maximal support and encouragement to patients that are likely necessary to increase the portal use and its possible benefits. They merely discuss the portal with patients face-to-face, hardly provide additional information and hardly check if patients understand how they could benefit from portal use. May be if providers will receive additional training in this respect, the gap between their opinions and their working methods can become smaller. Such training can include teaching care providers how to explore patients' motivation and how to support patients in maintaining their health record and interpreting their data, as well as addressing anticipated problems in electronic communication and the provider-patient relationship. Furthermore, as a result of this study, we are considering adjustments to this web portal to tailor the portal for different categories of patients, for example for patients who use insulin and those who do not.

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APPENDIX. **Questionnaire to the participants**

01. Why have you chosen for working with an EMR with patient portal? *(more than one option possible)*

☐ Decrease workload by substituting one of the quarterly visits at the clinic in a self-control by the patient.
☐ Optimizing coordination with co-workers due to working together in one record.
☐ Improvement of quality of diabetes care.
☐ A majority of my co-workers within our practice wanted to work with this system.
☐ To operate efficiently I chose to connect with the care group and I had to accept the type of system.
☐ Another reason.

02. The following statements are about the electronic medical record (EMR) and about self-management. You can give one answer per row, according to your preferences.

	Strongly agree	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
A patient portal improves the quality of diabetes care	☐	☐	☐	☐	☐
A patient portal can prevent medical mistakes	☐	☐	☐	☐	☐
The diabetes knowledge that patients gain through the portal can lead to improved self-management	☐	☐	☐	☐	☐
A positive effect of the patient web portal is that patients can come prepared to the consultation (e.g. by taking a print-out of their own medical record)	☐	☐	☐	☐	☐
The use of a patient portal can lead to better self-management in three quarters of my patients	☐	☐	☐	☐	☐
In a cardiometabolically well-controlled patient with portal access, one of the quarterly controls can be substituted by a self-control	☐	☐	☐	☐	☐

03. Which part of the patient web portal do you believe is important (for the patient)?

The patient….	**Very important**	**Important**	**Neutral**	**Not important**	**Not at all important**
Can see which controls are still needed	☐	☐	☐	☐	☐
Has an overview of all health care providers involved in the treatment	☐	☐	☐	☐	☐
Can reread the information provided during consultation	☐	☐	☐	☐	☐
Has access to his/her data (e.g. laboratory)	☐	☐	☐	☐	☐
Can upload a glucose diary	☐	☐	☐	☐	☐
Can send me a secured e-message	☐	☐	☐	☐	☐
Has an summary of his/her medications	☐	☐	☐	☐	☐
Can use the portal for general diabetes information	☐	☐	☐	☐	☐

04. Are there features that would improve the patient portal?

….. *(open text)*

05. If I believe a patient is suitable for working with a patient portal, then I… *(more than one option possible)*

☐ Will tell the patient
☐ Give this patient an informational leaflet and web-address
☐ Return to this in a next visit
☐ Enquire why this patient is interested or not
☐ Give this patient the registration form

06. To which extend do you encourage your patients to use the following patent portal features:

	Always	Often	Sometimes	Rarely	Never
Send you an electronic message through the portal	☐	☐	☐	☐	☐
Upload a glucose-diary more often	☐	☐	☐	☐	☐
Reread information after consultation	☐	☐	☐	☐	☐
Prepare for a consult by viewing laboratory results and agreed targets	☐	☐	☐	☐	☐
To inform you when he/she experience a problem with the portal	☐	☐	☐	☐	☐
Tell you when the meaning of laboratory values is unclear	☐	☐	☐	☐	☐
Tell you when medical phrasings used are unclear	☐	☐	☐	☐	☐
Turn to you if he/she has questions about self-management	☐	☐	☐	☐	☐

07. Do you recommend or discourage the portal in the patients mentioned below?

	Recommend	Neutral	Discourage
Patients with type 1 diabetes mellitus	☐	☐	☐
Patients with type 2 diabetes mellitus	☐	☐	☐
Patients with good cardiometabolic control	☐	☐	☐
Patients with poor cardiometabolic control	☐	☐	☐
Patients who do not use diabetes-specific medication	☐	☐	☐
Patients who use oral diabetes medication	☐	☐	☐
Patients who use insulin	☐	☐	☐
Patients with no comorbid conditions	☐	☐	☐
Patients with comorbid conditions	☐	☐	☐
Patients without language barriers	☐	☐	☐
Patients with language barriers	☐	☐	☐
Patients with a lower education	☐	☐	☐
Patients with a higher education	☐	☐	☐
Patients who are younger (< 65 years)	☐	☐	☐
Patients who are older (65 years)	☐	☐	☐

08. With regard to the diabetes treatment of your patients who are using the patient portal:

	Strongly improved	Somewhat improved	Not improved, not worse	Somewhat worse	Strongly worse
Is my own role in the treatment of these patients…	☐	☐	☐	☐	☐
Is the own role of the patient in the treatment…	☐	☐	☐	☐	☐
Is the collaboration with the patient in regard to treatment…	☐	☐	☐	☐	☐
De knowledge about diabetes of patients who use the patient portal is…	☐	☐	☐	☐	☐

09. What perceived benefits or problems are there for you in regard to patients having access to his/her EMR? *(more than one option possible)*

☐ It results in decreased workload
☐ It results in saving time
☐ It stimulates the self-management and self-correcting behavior of the patient
☐ It improves communication during consultation with a well-prepared patient
☐ other… *(plain text)*

10. Through the portal, your patient can reread the information you written during consultation. Does that have consequences for the way you write the information in the EMR or does it have consequences for the amount and type of information you write down? *(more than one option possible)*

☐ I write the information as I always did
☐ I write less information than before
☐ I write in an easier language than before (e.g. simple phrasings, less abbreviations)

11. Do you believe that patients who use the patient portal…

☐ Have an increased frequency of visits
☐ Have a decreased frequency of visits
☐ Have an unchanged frequency of visits

12. How do you feel about patients sending you an e-message?

☐ Very positive
☐ Positive
☐ Neutral
☐ Negative
☐ Very negative

13. How many e-messages do you receive per week:

☐ 0 messages
☐ 1-10 messages
☐ ≥ 11 messages

14. Within your practice, who usually answers the e-message of patients?

☐ We all answer the message of our own patients.
☐ One of the physicians (general practitioner or internist) answers all the messages (despite the main health care provider of the patient).
☐ One of the nurse practitioners / diabetes nurses answers all the messages (despite the main health care provider of the patient).

15. Are you:

☐ General practitioner
☐ Nurse practitioner
☐ Internist
☐ Specialized diabetes nurse

16. I am

☐ Male
☐ Female

17. My age is… *(open text)*

18. The number of patients with diabetes mellitus that are in my care … *(open text)*

19. The number of patients with diabetes mellitus within my practice that use the patient portal are:

☐ Less than 50
☐ Between 50-100
☐ Over 100

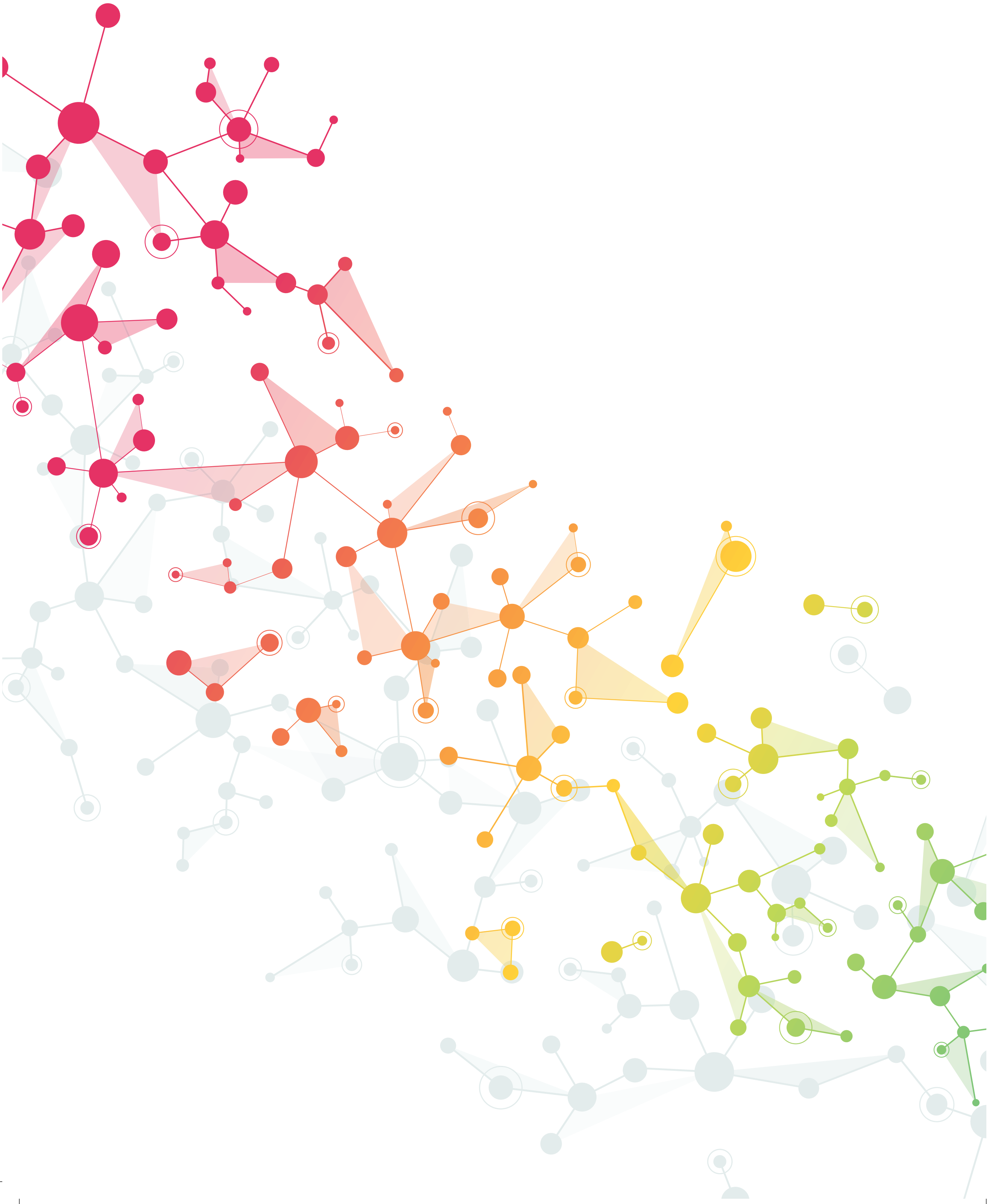
20. How long do you use the EMR with patient portal?

☐ Less than 2 years
☐ Between 2-5 years
☐ From the start

Thank you very much for completing this questionnaire

PART II

The use of electronic personalised alerts in the management of diabetes mellitus



CHAPTER 6

Cluster randomised trial on the effectiveness of a computerised prompt to refer (back) patients with type 2 diabetes

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PLoS ONE. 2018;13(12):e0207653

ABSTRACT

Background Information and communications technology (ICT) could support care organisations to cope with the increasing number of patients with diabetes mellitus. We aimed to aid diabetes care providers in allocating patients to the preferred treatment setting (hospital outpatient clinic or primary care practice), by using the Electronic Medical Record (EMR).

Methods A cluster randomised controlled trial. Physicians in primary and secondary care practices of the intervention group received an advisory message in the EMR during diabetes consultations if patients were treated in the 'incorrect' setting according to national management guidelines. Primary outcome: the proportion of patients that shifted to the correct treatment setting at one year follow-up.

Results 47 (38 primary care and 9 internist) practices and 2778 patients were included. At baseline, 1197 (43.1%) patients were in the correct treatment setting (intervention 599; control 598). Advice most often (68.4%) regarded a consultation with the internist. After one year 12.4% of the patients in the intervention and 10.6% in the control group (p=0.30) had shifted to the correct setting. Main reasons for not following advice were: 1. physician's preference to consider other treatment options; 2. patients' preferences.

Conclusions We could not find evidence that using the EMR to send consultation-linked advice to physicians resulted in a shift in patients. Physicians will not follow the advice, at least partly due to patients' preferences.

INTRODUCTION

Patients with diabetes require regular check-ups by physicians and nurses. Diabetes management needs to become as efficient and cost-effective as possible to deal with the increasing number of patients with diabetes. In the Netherlands about 85% of patients with type 2 diabetes mellitus are treated by general practitioners collaborating with practice nurses in a primary care setting[1] according to national clinical guidelines for primary care.[2] Only patients that are in need of more complex care are referred to a hospital based internist or endocrinologist, collaborating with specialised diabetes nurses. There is national agreement between primary and secondary care with regard to the targets of diabetes care and the setting in which diabetes care should take place,[3] to which we will refer as management guidelines.

Almost all general practitioners are organised in care groups that assume financial and clinical accountability and in turn subcontract individual care providers (physicians, dieticians, podiatrists).[1,4] For many reasons the costs per patient in secondary care are higher than in primary care. Both because of quality of care and of cost-effectiveness, correct identification of patients who might benefit from referral to an internist and identifying patients that can be treated in primary care is relevant. In a recent study in Denmark, patients remained in specialist care much longer than guidelines stipulated.[5] Further, in patients with good cardiometabolic control a six-monthly instead of three-monthly monitoring does not compromise outcome and is cost-saving.[6] A patient portal that provides patients access to their own medical record and with an option of secure electronic communication with the provider can be used as a substitute of an office visit once or twice a year.[7]

We hypothesise that targeted use of information technology by an alert according to the national management guidelines in the patient's electronic medical record (EMR) will result in better treatment allocation of patients with diabetes. Therefore, it was aimed to investigate the effectiveness of such messages provided to physicians and to increase our understanding of the reasons of not adhering to advice.

METHODS

Design and Setting

This cluster randomised controlled trial was performed between October 2013 and October 2014 in 'Diamuraal', a care group of 66 primary care practices and an outpatient clinic with the practices of 10 internists. It provides diabetes care to over 12.000 patients with type 1 and type 2 diabetes mellitus. All health care providers work with the same EMR, with only one physician (general practitioner or internist) designated as main physician. He or she can use the message function of the EMR to consult another physician who then has temporary access (change of treating physician) to the medical information of a patient. All patients can request a login to a patient web portal that gives them access to their entire personal EMR, including clinical notes, physical examination, laboratory results and secured electronic message with their provider (www.digitaallogboek.nl).[7]

All physicians were invited to participate in this study. Practices were only included if all physicians consented to participate. Their patients with type 2 diabetes received an information letter about the trial, stating that after informed consent the final decision to follow advice or not should be a shared decision of patient and treating physician.

The study was approved by the Medical Ethics Committee of the University of Utrecht (protocol number 13-039/C; February 13th 2013). Practices were recruited between March 1st and May 30th 2013, patients were included between April 1st and August 1st 2013. Data were collected from the central database at start (October 9th 2013) and end of study (October 9th 2014). At the end of study period patients received a questionnaire, which was sent between October 1st and October 30th 2014. The study was registered at Clinicaltrials.gov (NCT02229110, August 29th 2014).

Randomisation

Primary care practices were randomised with stratification of 1. Practice size (small or large, with a cut-off point of 150 patients with type 2 diabetes); 2. Practice type (group or single handed practice) and 3. Practice location (city or rural). The 10 internists were randomised separately, stratification for number of diabetes patients of whom they are the treating physician (cut-off point of 100 patients). Randomisation was executed at the research centre via a computer generated sequence by an independent researcher.

Assessment of the setting

All patients were assessed whether they were treated in the right setting according to the management guidelines for primary and secondary care on treatment setting.[3] For example: in a 68 years old patient with an estimated glomerular filtration rate (eGFR) value of 40 ml/min, the primary care practice should plan an electronic consultation with the internist, and a patient with the same age and an eGFR of 29 ml/min should be referred.

In order to assess the correctness of the treatment setting, we created an algorithm (Appendix 1) based on management guideline cut-off values. Some targets in the guideline are subjective; if possible these were objectified by a team consisting of a general practitioner, a specialised diabetes nurse and an internist. At the end of the study all patients were assessed again, blinded for randomisation allocation.

Intervention

If a patient in the intervention group was not treated correctly according to the algorithm a message was provided with advice to change setting. The message was sent to the EMR email box of the treating physician and also presented as a pop up in the monitor screen upon opening it, accentuated in yellow. Besides advice to change the treatment setting of the patient, the message gave an explanation on which marker(s) it was based (Appendix 1). The health care provider was expected to discuss this advice with the patient and to decide to follow it or not. In case it was overruled, the care provider was asked to document the reason for it (Appendix 2). Because either the nurse or the physician sees the patient about four times a year, they were in the position to discuss the advice several times during the study period. The advice was sent at the start of the study and again after six months to physicians who had not yet responded. Patients with access to their EMR also received the message and they were encouraged to discuss it with their provider. No message was sent to providers and patients in the intervention group who were treated in the right setting, according to the algorithm.

A general practitioner could receive 3 different types of advice, namely 1. consult the internist using the EMR; 2. refer the patient to the internist; and 3. instruct the patient to use the patient portal for self-monitoring instead of office visits. The internist could only receive one type of advice: referral back to the general practitioner.

Advice could be based on one or more markers. Even in case of several markers, only one advice type was sent. For example: we could send the physician a message with advice for consultation with an internist because this patient had blood pressure above target or send a similar message because the patient had a combination of high blood pressure and an abnormal lipid profile.

Furthermore, there were patients that had one or more markers leading to advice for consultation and other markers that lead to advice for referral. In these patients both advices were sent simultaneously, for example a high HbA1c could warrant the advice for consultation with an internist while at the same time this patient could also have a high triglyceride leading to advice for referral. In such a situation both messages were sent to both the provider and the patient.

Control group

The patients in the control group received care-as-usual, without any messages sent to their diabetes care provider or to the patients themselves whether or not treated in the right setting.

Outcome measures

The primary outcome was the proportion of patients that changed to the correct treatment setting after one year. Secondary outcomes were the number of different types of advice and the markers they were based on. Furthermore, we measured the reasons for non-adherence to the advice.

At baseline and after one year the following measures were collected from the central database of Diamuraal: patient’s age; current treatment setting; type of diabetes (diabetes mellitus type 1, type 2, LADA or MODY); fasting glucose; HbA1c; systolic blood pressure (SBP); Body Mass Index (BMI); lipids (total cholesterol, LDL- and HDL-cholesterol, triglyceride and total/HDL-cholesterol ratio); kidney function (eGFR, albumin/creatinine ratio, serum creatinine and albuminuria) and the following complications: diabetic ulcer, amputation, retinopathy, myocardial infarction, angina pectoris, heart failure, stroke, transient ischemic attack, peripheral arterial disease. Also the use of oral diabetes medication, insulin (pump), lipid or blood pressure lowering medication, a platelet inhibitor and anticoagulants was assessed.

In the intervention group data were collected whether the physician followed advice and, if not, the reasons for not following it (predefined options with more than one possible reason to give and room for free text) (Appendix 2).

Statistical Analysis

The sample size was calculated on the proportion of patients shifting from an incorrect to a correct setting after one year. We expected that at baseline 25% of patients were at the incorrect setting. After one year this proportion was assumed to be decreased to 12.5% in the intervention group, while in the control group the situation would remain the same. With these assumptions, 2234 patients had to be included to detect a significant difference between groups with 90% power and α of 5%, taking an estimated intra-cluster correlation of 0.075 into account.

Analyses were according to the intention-to-treat principle, with patients lost-to-follow up analysed as 'no change in setting'. Baseline differences between groups were analysed with independent samples t-test for continuous variables and Chi-square test for categorical data. The change in setting within groups after one year was analysed with McNemar's test. The reasons for different advice, physician's adherence to the advice and the reasons for non-adherence were described with counts and percentages. To determine an intervention effect generalised linear mixed model was used, adjusted for clustering, treatment location (primary or secondary care) at baseline and baseline setting assessment. Analyses were performed using SPSS version 21 (SPSS Inc. Chicago, IL, USA).

RESULTS

Of the 66 primary care practices invited, 38 (57.6%) agreed to participate. All 10 internists agreed to participate, but one internist was excluded because he is the main physician of only 17 type 2 diabetes patients. Thus 47 practices were included.

From primary care 6755 patients were invited and 2382 (35.3%) returned the consent form (mean number of returned consent forms per practice 63, range 20-138). From secondary care 1633 patients were invited, 396 (24.2%) returned the consent form (mean number of returned forms per practice 44, range 6-80).

Participating patients and non-participants did not differ in age (68.5 ± 10.8 years and 68.5 ± 13.2 years (p=0.95), respectively), but significantly more males participated (57.9% versus 47.8% (p<0.001)).

At one year follow-up complete data from 1348 (95.2%) patients in the intervention group and 1297 (95.2%) patients in the control group were available (Figure 1).

At baseline 599 (42.3%) patients in the intervention group and 598 (43.9%) patients in the control group were treated in the correct setting (Table 1). After one year 175 out of

1416 (12.4%) patients in the intervention group and 144 out of 1362 (10.6%) patients in the control group (p=0.30) had shifted to the correct setting; 642 (45.3%) patients in the intervention group and 620 (45.5%) in the control group remained in the incorrect setting (p=0.67). Most patients remained in the setting they started, which was incorrect for most patients in primary care and correct for those in secondary care (Table 2). No intervention effect for change in treatment setting after one year was found (adjusted odds ratio 0.99 (95% CI 0.77-1.28)).

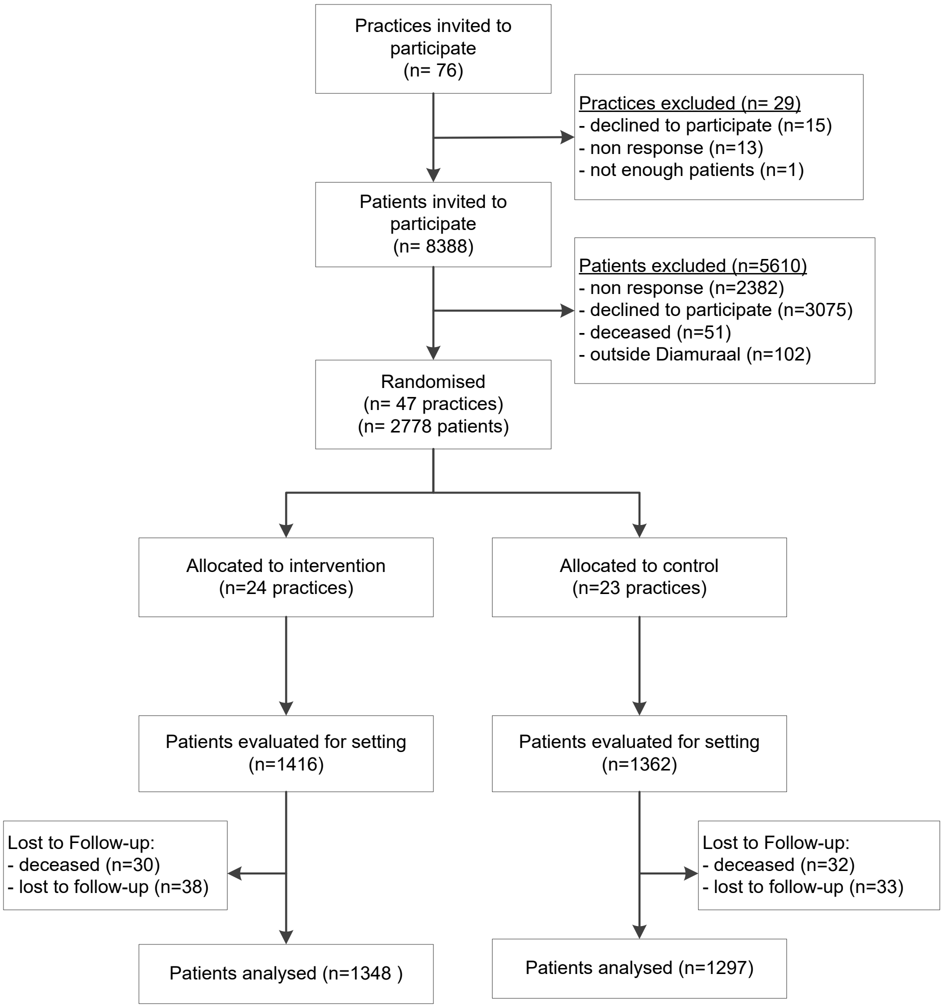

Figure 1: *Flowchart*

Table 1. *Baseline characteristics of practices and patients*

	Intervention	Control
Practices (N = 47)	**24**	**23**
Primary Care	20	18
Secondary Care	4	5
Primary care practices		
Location (city / rural)	12/8	11/7
Practice (group / single handed)	12/8	10/8
Size (≤ 150 patients / > 150 patients	10/10	9/9
Secondary care practices		
Size (≤ 100 patients / > 100 patients)	1/3	2/3
Patients (N = 2778)	**1416**	**1362**
Age, years	63.8 ± 10.8	68.8 ± 10.8
Gender, male	811 (57.3)	798 (58.6)
HbA1c, % (mmol/mol)	6.8 ± 0.9 (51.3 ± 9.7)	6.9 ± 0.9 (51.7 ± 10.1)
BP systolic, mmHg	134.1 ± 15.6	132.5 ± 15.0
LDL-cholesterol, mmol/l	2.3 ± 0.9	2.3 ± 0.8
Patients in primary care (number)	1235	1147
Correct setting	447 (36.2)	422 (36.8)
Incorrect setting	788 (63.8)	725 (63.2)
Patients in secondary care (number)	181	215
Correct setting	152 (84.0)	176 (81.9)
Incorrect setting	29 (16.0)	39 (18.1)

Patients: categorical variables are total number (percentage); continuous variables are mean ± SD

Table 2. *Shift in setting within groups after one year*

	Intervention group (N = 1416)			Control group (N = 1362)		
Baseline		***Follow-up***			***Follow-up***	
Total Group (N=2778)	**Correct**	**Incorrect**	**Total**	**Correct**	**Incorrect**	**Total**
Correct	419 (29.6)	180 (12.7)	599	438 (32.2)	160 (11.7)	598
Incorrect	175 (12.4)	642 (45.3)	817	144 (10.6)	620 (45.5)	764
Total	594	822	1416 (100)	582	780	1362 (100)
*P-value**		*0.83*			*0.39*	
Secondary Care (N = 396)	**Correct**	**Incorrect**	**Total**	**Correct**	**Incorrect**	**Total**
Correct	123 (68.0)	29 (16.0)	152	151 (70.2)	25 (11.6)	176
Incorrect	11 (6.1)	18 (9.9)	29	21 (9.8)	18 (8.4)	39
Total	134	47	181 (100)	172	42	215 (100)
*P-value**		*0.01*			*0.66*	
Primary Care (N = 2382)	**Correct**	**Incorrect**	**Total**	**Correct**	**Incorrect**	**Total**
Correct	296 (24.0)	151 (12.2)	447	287 (25.0)	135 (11.8)	422
Incorrect	164 (13.3)	624 (50.5)	788	123 (10.7)	602 (52.5)	725
Total	460	775	1235 (100)	410	737	1147 (100)
*P-value**		*0.50*			*0.49*	

Data are numbers (percentages); * McNemar

Advice to change treatment setting was applicable to 817 (57.7%) persons in the intervention group with an incorrect setting at baseline (Table 2). In 559 persons, the general practitioner was advised to consult an internist (292 patients with sole advice for consultation and 267 patients with both an advice for consultation and advice for referral), most frequently based on HbA1c values above target (n=220) or signs of kidney complications (n=195). In 451 patients, the general practitioner was advised to refer to an internist (184 patients with sole advice for referral and 267 patients in combination with a consultation advice), mainly based on a SBP above target or the presence of a high BMI (Table 3).

Advice for consultation of a medical specialist was intentionally followed in only 5.9% of the concerning advices, the advice to refer the patient in only 8.2% and the advice for self-monitoring in 24.4%. In about one in three (34.5%) cases the internists followed the advice to refer people back to the general practitioner. If general practitioners did not follow the advice to consult an internist, most frequently they reported not to do so because they wanted to make treatment adjustments themselves. If patients were not referred by the general practitioner, this was hardly (6.7%) the result of a patient's request. In contrast, internists reported that if they did not refer a patient back, in 40% this was because of patients' request (Table 4).

Table 3. *Number and frequency of different markers leading to advice at baseline*

Markers for consultation of an internist (n=559 patients)	
Diabetes mellitus other than type 2	6 (0.9)
Probability of diabetes other than type 2	5 (0.7)
High HbA1c	220 (31.1)
Known with high systolic blood pressure for a short period	110 (15.5)
Inadequate lipid profile	140 (19.8)
Presence of moderate kidney complications	195 (27.5)
Presence of diabetic ulcer	24 (3.4)
Presence of macroangiopathy	8 (1.1)
Markers for referral (n=451 patients)	
Known with high systolic blood pressure since long time	151 (26.8)
Probability of familial hyperlipidemia	114 (20.2)
High triglyceride level	2 (0.4)
Presence of severe kidney complications	32 (5.7)
Presence of retinopathy	119 (21.1)
Presence of body mass index above 35 kg/m2	145 (25.8)
Markers for instructing patients for self-monitoring (n=45 patients)	
Stable disease with good cardiometabolic control	45 (100)
Markers for advice for back referral (n=29 patients)	
Reaching personal treatment goals in secondary care	29 (100)

Advice for change in treatment setting could be based on one or more markers, for definition of the markers see Appendix 1. Data are numbers (percentages).

Table 4. *Physician response to advice given and main reasons for not following the advice*

	Consultation	Referral	Self-monitoring	Back referral
Response physician after receiving advice	**N = 559**	**N = 451**	**N = 45**	**N = 29**
Will follow advice	33 (5.9)	37 (8.2)	11 (24.4)	10 (34.5)
Will not follow advice	390 (69.8)	369 (81.8)	31 (68.9)	18 (62.1)
No response	136 (24.3)	45 (10.0)	3 (6.7)	1 (3.4)
Main reasons for not following advice*	**N = 541**	**N = 492**	**N = 53**	**N = 15**
Physician wants to make treatment adjustments first	182 (33.6)	98 (19.9)		
Doubt about compliance/lifestyle/therapy adherence by patient	56 (10.4)	40 (8.1)		
At patient's request	57 (10.5)	33 (6.7)	11 (20.8)	6 (40.0)
No retinopathy present *(specific for referral)*		57 (11.6)		
Referral in the past, not documented in the electronic medical record		45 (9.1)		
Patient has no glucose and/or blood pressure monitor at home			10 (18.9)	
Other comorbid conditions / recent complication			11 (20.8)	6 (40.0)

Data are total number (percentage).

* physicians could provide more than one reason for not following the advice

DISCUSSION

This study shows that over 50 percent of patients with type 2 diabetes were not treated in the correct setting according to nationally agreed guidelines. This percentage was twice as high as expected. Sending a computerised prompt to raise physicians' awareness of the situation, combined with advice for the preferred treatment setting did not result in a shift of the patient flow in the desired direction. Most general practitioners did not adhere to the advice, mostly because they preferred adjustments of the therapy first. Also patient preference was an important reason for non-adherence.

Several reasons are known from literature why physicians do not follow clinical practice guidelines, e.g. because they are not aware of them or do not agree with,[8–10] or recommendations are controversial, non-specific or not evidence based.[11] In the Netherlands the diagnostic and therapeutic guidelines on type 2 diabetes in primary care are developed by the Dutch College of General Practitioners, they are highly evidence-based, firmly embedded in primary care and with a high adherence rate. All general practitioners are considered to have experience to follow these guidelines, which provide a stepwise approach for blood glucose lowering therapy. If an adequate diabetes control is not achieved (for whatever reason), the patient should be referred to secondary care.[2,3] The national management guideline on type 2 diabetes, defining the collaboration between internists / endocrinologists and general practitioners had been published less than 2 years prior to this study and is consensus-based.[3] Both types of guidelines pass an agreement procedure among physicians from the Dutch College of General Practitioners and the Dutch Society of Internal Medicine. Nevertheless, it must be kept in mind that limited evidence is available to support the (cost-) effectiveness of shared care programs for chronic diseases in general and type 2 diabetes in particular.[12–14] Maybe physicians do not agree with some advice, e.g. it seems questionable whether all physicians agree with advice for referral in case of high BMI. We would like to recommend that collaboration agreements and guidelines about collaboration between primary and secondary care undergo an extensive testing in the field. Furthermore, the management guideline is consensus based instead of evidence-based which lowers the compliance with the agreement.[11] We feel it needs a more extensive agreement procedure even before implementation, with testing and feedback from more physicians in order to gain support.

Notably, advice for consultation because of high values of HbA1c was based on at least 2 measurements above target and the prerequisite that this situation had existed for over one year. However, it is possible that general practitioners could have adjusted the diabetes treatment resulting in a better fasting glucose level, and this could be a reason for the physician not to follow the advice to consult an internist immediately. Nevertheless, even after having been made aware of the situation, during the follow-up of another whole year, on average 79% of primary care patients (624 out of 788) incorrectly remained treated in solely the primary care setting.

Furthermore, attitudes and preferences from both physicians and patients can be a reason for non-adherence.[15–19] A national survey showed that Dutch general practitioners felt that guideline adherence in general leads to improved patient care and that they have a high perceived adherence to guidelines especially with respect to recommendations for referral.[16] However, during a face-to-face consultation with an individual patient, there are reasons for non-adherence. Physicians may feel that guidelines are no more than suggestions and do not fit individual patients.[20] This might also be true for the physicians in our study, as we found that the main reasons for not following the advice were the physician's wish to make treatment adjustments first as well as patients' preferences to remain in the current treatment setting. These preferences could be the results of a long-term relationship in which they have built trust upon each other, and therefore hesitate to change setting. Another aspect may be their view on cost aspects. First of all, in the Dutch health care system, primary care (general practitioner) appointments are completely covered by the national health insurance system, whereas patients have a personal liability scheme on medication and secondary care treatment. By denying secondary care referral and choosing for basic, cheap medication, patients can save costs. Cost aspects may also drive the general practitioner to try and prevent referral, to save on the national health budget for secondary diabetes care. However, in our opinion an alternative explanation is likely more relevant, namely that primary care nurses and physicians were confident in their ability to achieve the same results as in secondary care by adjusting treatment regimens, as they had learned from a long time of intense collaboration with the internal medicine specialists. Should this be true, then referral guidelines should be loosened, e.g. advisory prompts for consultation less strict and advisory prompts for referral replaced more widely by prompts for consultation. Whether such self-confidence is justified, may become clear from studying treatment outcomes in the intervention versus the control group. Finally, the fact that patient's preferences also accounted for a small percentage of the reasons not to refer or refer back, implies that an EMR should contain smart digital information on patient preferences. Patient preference is an often reported reason for guideline non-adherence, which might be valid and not compromising quality of care.[18] The adherence of the internists to our advice to refer back patients to primary care after targets are met or in case of stable disease might reassure general practitioners and their patients that intensifying treatment setting could indeed be temporarily.

Strength of the current study is a large population of patients with type 2 diabetes both from primary and secondary care physicians. To the best of our knowledge this is the first study on the effect of advice to health care providers by using the EMR to change treatment setting. However, there are also limitations. Our interpretation of guideline items that were imprecisely formulated, in order to run the algorithm, could have led to more patients in the wrong treatment setting at baseline, although it was done and agreed upon by a team of different diabetes care providers. In daily practice physicians may interpret "persistent high level" loosely and this could lead to clinical inertia. As a result the patient is likely to be worse off. With respect to physician characteristics, although almost 60% of the general practices an almost all internists participated we cannot rule out selection bias. It is possible that the composition of practices who are agreed to participate had more physicians with interest in diabetes. We cannot rule out that physicians who participated are more interested in diabetes than those who did not. Assuming that they are more interested, they might have been more confident in their ability to adjust treatment, without the need for consultation or referral. In this way, selection bias would result in a higher non-adherence to the advice message. Furthermore, Literature shows that female physicians prefer to prescribe different types of antihypertensive medication to patients with type 2 diabetes with hypertension compared to male physicians.[21] Overall reasons for referral to secondary care are different for female physicians.[22] We do not have any information about age and gender of the physicians and nurse practitioners, so we are unable to explore the impact of this on our findings. With regard to patient characteristics, a second selection round took place when patients were invited, with 35.3% (primary care) and 24.2 % (secondary care) participants. There was a difference in gender but not in age with more males in the participating group. A previous study showed that the odds of referral in a general practice increase with age and especially with the presence of morbidity, but that the effect of gender was very small and most of the variation in referrals remain unexplained.[23] In that study there were slightly more females referred compared to males. In our study there was an overrepresentation of males. It is possible that this could have led to less referrals in our study due to males seemingly being referred less compared to females but as the effect of age and gender combined only explain 5% of the variation in referrals we feel that this did not affected our results. In the Netherlands a patient needs a referral in order to consult an intern medicine specialist. This might be considered a limitation with regard to the generalisability of the results of this study. However, in our opinion also for health care systems with direct access to medical specialists our study is relevant both for physicians as well as for policy makers. Both general practitioners and specialists worldwide are working with EMR based systems are able to incorporate a computerised message, prompt or pop-up to remind the physician to adjust treatment. Our study shows that their effectiveness will depend on human decisions during consultation and local collaboration agreement.

In conclusion, we could not find evidence that a consultation-linked electronic advice to physicians that was based upon nationally agreed guidelines to consult an internal medicine specialist or to refer the patient with type 2 diabetes (general practitioner) or to refer patients back (specialist) resulted in a shift of patients. Both patient and physician related factors play a role in not following the advice. The content of the guidelines may be discussed.

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APPENDIX 1. **Four different types of advice and algorithm on which the advice is based**

Advice 1 based on:	**This patient should receive a consultation by an internist using the EMR**
Diabetes Mellitus other than type 2	One of the following: • Diabetes type 1 • Latent Auto-immune Diabetes in Adults (LADA) • Maturity-Onset Diabetes of the Young (MODY)
Probability of diabetes other than type 2	One of the following: • Age <25 years • The first glucose value >25 mmol/l in combination with a first BMI <27 kg/cm2
High HbA1c (in mmol/mol)	Duration of diabetes mellitus more than 1 year and one of the following (at least two values above target and for more than one year): • HbA1c > 53 and no medication • HbA1c > 53 and age < 70 years • HbA1c > 58 and age ≥ 70 years and duration of diabetes less than 10 years • HbA1c > 64 and age ≥ 70 years and duration of diabetes more than 10 years Duration of diabetes mellitus between 6 months to 1 year and one of the following: • HbA1c > 58 and age < 70 years • HbA1c > 64 and age ≥ 70 years • HbA1c > 69
High systolic blood pressure	• If age <80 years: the last two values were > 140mmHg (within the last 6 months) • If age ≥80 years: the last two values were > 160mmHg (within the last 6 months)
High Lipid profile	One of the following: • LDL-cholesterol > 2.5 mmol/l (for at least one year) and SCORE ≥ 20% • Triglyceride > 6 mmol/l (within the last six months) and SCORE = Systematic COronary Risk Evaluation (10 year risk of fatal CVD in Europe)
Presence of kidney complications	One or more of the following (the most recent value): • If age ≥65 years: eGFR value between 30 and 45 ml/min • If age <65 years: eGFR value between 45 and 60 ml/min • If male: albumin/creatinine ratio between 2.5 and 25 mg/mmol • If female: albumin/creatinine ratio between 3.5 and 35 mg/mmol • Most recent blood creatinine value is at least 25% higher than the second to last

Presence of diabetic ulcer	Presence of diabetes ulcer
Presence of macroangiopathy	One or more of the following within the last year: • Myocardial infarction • Coronary artery disease • Angina pectoris • Heart failure • Cerebrovascular accident • Transient ischemic accident • Peripheral artery disease
Advice 2 based on:	**This patient should be referred to secondary care**
High systolic blood pressure	• If age <80 years: the last two values were > 140mmHg (for more than 6 months) • If age ≥80 years: the last two values were > 160mmHg (for more than 6 months)
Probability of familial hyperlipidemia	One of the following (one measure once): • Total cholesterol of 8 mmol/l or higher • Total cholesterol/LDL-cholesterol ratio of 8 or higher • LDL-cholesterol of 5 mmol/l or higher
High triglyceride	Triglyceride 6 mmol/l or higher for at least 6 months
Presence of kidney complications	One or more of the following (the most recent value): • If age ≥65 years: eGFR value below 30 ml/min • If age <65 years: eGFR value below 45 ml/min • If age <40 years: eGFR value below 90 ml/min • Albuminuria ≥200 mg/ml • If male: albumin/creatinin ratio ≥25 g/mol • If female: albumin/creatinin ratio ≥35 g/mol
Presence of retinopathy	• Presence of retinopathy
Presence of high Body Mass Index	• Value ≥ 35 kg/m2
Advice 3	**This patient should substitute one or more clinic visits by self-monitoring using the patient portal**

Stable disease with good cardiometabolic control	All of the following:
	• HbA1c ≤ 53 mmol/mol
	• Systolic blood pressure
	  o If age < 80 years: value below 140 mmHg
	  o If age ≥ 80 years: value below 160 mmHg
	• LDL-cholesterol ≤ 2.5 mmol/l

	• Total cholesterol ≤ 4.5 mmol/l • Total cholesterol / HDL-ratio < 8 • Kidney function: o If age ≥65 years: eGFR value above 40 ml/min o If age 40-65 years: eGFR value above 60 ml/min o If age < 40 year: eGFR value above 90 ml/min • Body Mass index < 35 kg/cm2 • In the last 2 years no new: o Myocardial infarction o Coronary artery disease o Angina pectoris o Heart failure o Cerebrovascular accident o Transient ischemic accident o Peripheral artery disease o Retinopathy o Diabetes ulcer o Amputation
Advice 4	**This patient should be referred back to the primary care**
Reaching personal treatment goals	All of the following: • No insulin pump • Medication classes have not been changed the last six months (concerning oral diabetes medication, insulin, lipid lowering medication, blood pressure lowering medication and blood thinning agent) • No new dietitian advice in the last six months • In the last 12 months no proteinuria or macroalbuminuria defined as: o Albumin in urine ≥ 200 mg/ml o If male: albumin/creatinine ratio ≥25 mg/mmol o If female: albumin/creatinine ratio ≥35 mg/mmol • In the previous years no new: o Myocardial infarction o Coronary artery disease o Angina pectoris o Heart failure o Cerebrovascular accident o Transient ischemic accident o Peripheral artery disease o Retinopathy

    - Diabetes ulcer
    - Amputation

Furthermore, if treatment in secondary care has only recently started, between 3 and 12 months before, all of the following:

- Good glycemic control (in mmol/mol):
    - HbA1c ≤ 53 and age < 70 years
    - HbA1c ≤ 58 and age ≥ 70 years and duration of diabetes less than 10 years
    - HbA1c ≤ 64 and age ≥ 70 years and duration of diabetes more than 10 years
- Good systolic blood pressure:
    - If age < 80 years: value below 140 mmHg
    - If age ≥ 80 years: value below 160 mmHg
- LDL-cholesterol ≤ 2.5 mmol/l
- Total cholesterol ≤ 4.5 mmol/l
- Total cholesterol / HDL-ratio ≤ 3.5
- Triglyceride value < 2 mmol/l
- eGFR > 45 ml/min

Or, if treatment in secondary care has already been lasting more than 12 months, all of the following:

- Kidney function stable:
    - If age < 65 years: eGFR above 45 ml/min for all values in the last six months
    - If age ≥ 65 years: eGFR above 30 ml/min for all values in the last six months
- Improvement of most recent HbA1c value < 11 mmol/mol compared to the second to last value
- Systolic blood pressure below 180 mmHg for the last 2 recent values

APPENDIX 2. **Reasons for not following advice**

	General reasons (applicable in response of all four advice messages)
*	At patient’s request
*	Life expectancy of this patient is less than one year
*	There is reasonable doubt about compliance, lifestyle and adherence to therapy
*	After consideration there were missing values in the EMR and we have added the missing values, this advice should probably not reappear again

	Reasons applicable in advice for consultation and in advice for referral
*	The situation has already been discussed with the internist and no further improvement is expected
*	This patient is already evaluated by the internist for this complication without using the EMR of Diamuraal
	The current treatment team has room for treatment adjustments
*	This patient is treated by the cardiologist (in case of blood pressure, high lipids or macroangiopathy)
†	There is another comorbid condition
	Due to age or social situation
†	I disagree with the advice [‡]
†	There is no high blood pressure but there is white coat hypertension
†	I doubt that consulting an internist has added value [§]
†	We have already started taking steps in agreement with your advice
†	The patient doesn’t want a change in medication
	We believe that this is not needed with this patient (values are marginaly high or stable high)

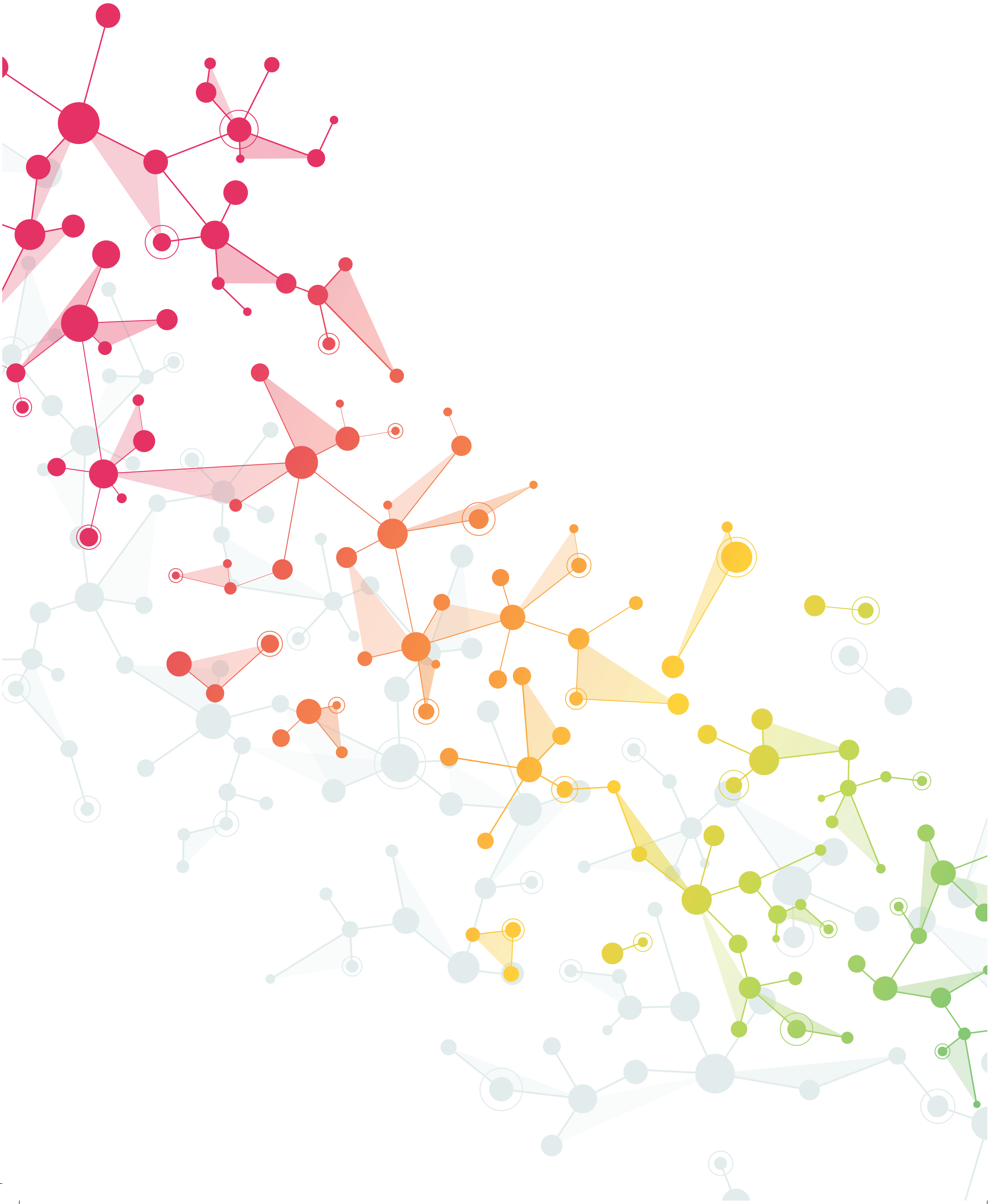
	Reasons applicable only in advice for consultation
*	In hindsight this is not a diabetes type 1, LADA or MODY but indeed a diabetes mellitus type 2
*	There is a temporary metabolic complication due to infection / surgery / prednisone
*	There is alcohol abuses
*	The ulcer is superficial, existing less than 2 weeks and there are no signs of peripheral artery disease

	Reasons applicable only in advice for referral
*	There is no progressive retinopathy
*	BMI is above 35 but primary care treatment is still continuing

	Reasons applicable only in advice for self-monitoring
*	Medication has been adjusted within the last 8 weeks
*	This patient does not have a glucose and/or blood pressure monitor at home
*	This patient is not interested in access to his personal health record (patient portal)
*	This patient does not have access to the internet

†	Glucose treatment still needs adjustments (newly diagnosed or hypoglycemic episodes)
†	Other comorbid disease or expected problems that make self-monitoring undesirable
†	Due to age or social situation
†	This practice doesn’t have the resources for self-control by patients
†	I believe this patient is not suited for self-control (unspecified)
Reasons applicable only in advice for referral back	
*	This patient is using or will be using an insulin pump
*	Medication is recently adjusted, the effect needs to be evaluated first
*	There is a severe comorbid condition
*	There is severe or progressive micro-albuminuria or decline in kidney function
*	This patient receives dialysis
*	This patient has a recent (in the last 12 months) complication
*	This patient is currently under counselling by a psychologist
*	The primary care practice of this patient doesn’t provide intensive insulin treatment
*	The primary care practice of this patient doesn’t accept the referral back of this patient

* Predefined reasons at baseline; † Reasons added after evaluating free text; ‡ We checked all these responses: every case the physician provided this as an answer he was neglecting the specific content of the management guidelines at this point; § i.e. added value of the internist in case of already long term treatment by surgeon (diabetes ulcer), ophthalmologist diabetes retinopathy) and cardiologist (wrongfully believes that cardiologist takes care of diabetes treatment), or in case of options of discussion new/different medication when there wer previous side-effects.



CHAPTER 7

Quality of primary type 2 diabetes care after prompting general practitioners to consult an internal medicine specialist or refer the patient

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Submitted

ABSTRACT

Background If a patient with type 2 diabetes needs treatment intensification, the electronic medical record can prompt his general practitioner to do so. We evaluated the effect of an electronic medical record alert to a general practitioner to consult an internal medicine specialist or refer the patient.

Methods Cluster randomised controlled trial, follow-up 12 months. Intervention: a prompt in the electronic medical record to consult a specialist or refer patients if that patient was treated in the incorrect setting according to national diabetes management guidelines. Data collected from the electronic medical record and the Diabetes Treatment Satisfaction Questionnaire (DTSQ). Quality of diabetes care measured with QuED (range 0-40) a combination of process and outcome measures.
Outcomes: between groups difference in QuED at follow-up, percentage of patients meeting targets; and DTSQ. A Generalised Linear Mixed Model was used to determine the effect, adjusted for clustering, baseline values, age, sex, and patient's access to the web portal.

Results 2382 primary care diabetes patients were included. Incorrect treatment allocation was observed in 1357 (57%) cases (653 control, 704 prompting intervention group). After twelve months QuED had improved and was higher in the intervention group (26.1 ± 0.5 versus 25.1 ± 0.5, p=0.04). In both groups about 50% patients met two treatment targets, but HbA1c, blood pressure (SBP) and LDL-cholesterol did not change differently between groups (at follow-up: HbA1c intervention 49.9 ± 0.7, control 51.0 ± 0.8 mmol/mol; SBP 135.4 ± 0.8 mmHg and 135.8 ± 0.6 mmHg resp.; LDL 2.5 ± 0.0 mmol/l and 2.6 ± 0.0 mmol/l respectively). Patient satisfaction remained stable (intervention 30.7 ± 0.2, control 30.7 ± 0.2, p=0.29).

Conclusions Prompting general practitioners resulted in a better quality of diabetes care, despite a high starting level.

INTRODUCTION

Type 2 diabetes mellitus is a chronic disease with severe complications, increased mortality risk and high cost. The number of adults worldwide with T2DM is steadily increasing.[1] Despite extensive guidelines, treatment targets are often not met.[2–8]

To improve the management of type 2 diabetes mellitus, quality measures are of interest, including both intermediate outcome measures like HbA1c, blood pressure and lipids as well as so-called process of care items, reflecting how often the values of interest have been measured and whether medication is prescribed when necessary. Adherence with process of care seems associated with fewer diabetes complications and improvements in patient health outcomes.[9–11] In the QuED study, process and outcome measures were combined in a sum score, ranging from 0-40; people with an overall QuED score below 10 have a higher risk to develop a cardiovascular event than patients with a score above 20.[12] In The Netherlands about 85% of the people with type 2 diabetes mellitus are treated by general practitioners collaborating with practice nurses, dieticians and podiatrists, all in the primary care setting and with overall good results. Against that background, only a minority of patients that are in need of complex diabetes care should be referred to an internist or endocrinologist, according to a 'referral guideline'.[13] That guideline includes the option of electronic consultation ("e-consult") between general practitioner and medical specialist without the need for actual referral. Sharing and correct allocation of diabetes care may lead to a significant reduction of HbA1c[14–16] and improvement of the process of care.[14]

However, information is lacking on how to optimise the allocation of patients to specific settings of care and how a suggested allocation shift effects patient satisfaction. Knowledge in this respect is important because due to increasing numbers of patients with type 2 diabetes mellitus and the accompanying costs, organising diabetes care as (cost-)effective as possible is relevant.

We conducted a cluster randomised controlled trial in which we alerted general practitioners to consult an internal medicine specialist / endocrinologist (via e-consult) or to refer the patient according to the mutually agreed national diabetes guidelines. Less than 50% of patients proved to be treated in the correct setting. After twelve months around 10% of individuals in the intervention group had shifted to the correct treatment setting. The main reasons given by general practitioners for not adhering to the guideline-based advice was that they preferred to consider other treatment options first as well as patients' preference to stay in the current setting.[17] In this paper we evaluate the effect of the trial on quality of care and patient satisfaction. More specifically, we studied these effects in those patients that at the start of the trial were in primary care and whose general practitioner received a prompt to consult an internal medicine specialist or to refer the patient.

METHODS

Design and setting

A cluster randomised controlled trial was performed in a so-called care group ("Diamuraal") with 66 primary care practices and an outpatient clinic with ten internist practices. The care group provides diabetes care to over 12.000 patients with type 1 and type 2 diabetes mellitus and all healthcare providers work with the same electronic medical record. Patients can request access to their medical record through a patient web portal. General practitioners can use the electronic medical record to consult an internal medicine specialist/endocrinologist ("e-consult").

All physicians were invited to participate, practices were only included if all physicians consented. When a practice was included, all their adult patients with type 2 diabetes mellitus were invited to participate. Practices were first randomised to intervention and control group. We then assessed all patients whether they were treated in the correct treatment setting, i.e. primary or secondary care. This paper contains the analysis of the patients in primary care who were not treated in the guideline-stipulated setting at baseline. To assess if patients were treated in the correct setting, we created an algorithm (Appendix Chapter 6), making use of the database of Diamuraal. We used cut-off values based on the above mentioned guideline.[13] We (MR and LTDO) manually performed such an assessment for each patient both at the start and end of study. Detailed information about the randomisation process, assessment of setting, and data collection has been published previously.[17] This study was conducted between March 2013 and October 2014 and approved by the Medical Ethics Committee of the University of Utrecht and registered at Clinicaltrials.gov (NCT02229110).

Intervention

If a patient in the intervention group was treated in the incorrect setting according to the algorithm, a message was sent to the treating physician, using the electronic medical record. This message prompted the general practitioner to consult the internist using the message function in the electronic medical record (e-consult) or to refer the patient to the internist. In case of a double advice (both consultation and referral, based on separate parameters) the GP received two messages. The advice was accompanied by an explanation on which diabetes treatment variables it was based. Some of the patients in the intervention group had a login to the patient portal at the time of the study; we sent the advice to these patients as well. Notably, the physician and the individual with diabetes had to make a shared decision to follow the advice or not.

Patients in the control group received care as usual, without any messages sent to their physician nor to the patients themselves.

Outcomes and measures

To measure quality of diabetes care we used the Quality of Care and Outcomes in Type 2 Diabetes scoring system (QuED). It is based on readily available process and outcome measures, has a proved relationship with the incidence of cardiovascular events[12] and has previously been adapted to the cut-off values used for diabetes care in The Netherlands.[18] It consists of four parts regarding: 1.HbA1c; 2.systolic blood pressure (SBP); 3.LDL-cholesterol and 4. the combination of micro-albuminuria and an angiotensin converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) prescription. Each part includes both process and outcome measures. A yearly measurement of the above mentioned four variables is considered a quality indicator for process of care. The lowest score (0 points) is given when the outcome is above target or microalbuminuria is not treated with ACE inhibitor or ARB. An intermediate score (5 points) means that treatment goals are met, but measurements have not been performed within the last 12 months. The highest score (10 points) is given when both the outcome values and measurement frequency are according to the guidelines. This leads to a sum score of 0-40 with a higher score reflecting better quality of care (Box).

Because the current targets in the Dutch guidelines on T2DM19 are stricter than those used in the original and adapted QuED,[12,18] we made slight modifications to the original summary score. With respect to the HbA1c target value, the Dutch guidelines follow an algorithm depending on age (in patients <70 years the target is ≤53mmol/mol), use of medication (in patients ≥70 years with no medication or only metformin the target is also

BOX. Quality of Diabetes Care Scoring System (QuED)

Quality of Care Indicator	**Score**
HbA1c above target	0
HbA1c below target but measurement less than once per year	5
HbA1c below target and measurement at least once per year	10
Systolic blood pressure above target	0
Systolic blood pressure below target but measurement less than once per year	5
Systolic blood pressure below target and measurement at least once per year	10
LDL-cholesterol above target	0
LDL-cholesterol below target but measurement less than once per year	5
LDL-cholesterol below target and measurement at least once per year	10
Not treated with ACE inhibitor or ARB in the presence of microalbuminuria	0
Treated with ACE inhibitor or ARB in the presence of microalbuminuria, or microalbuminuria absent, but measurement less than once a year	5
Treated with ACE inhibitor or ARB in the presence of microalbuminuria, or microalbuminuria absent, and measurement at least once a year	10
Score range	**0 - 40**

HbA1c = haemoglobin A1c; LDL=Low-density lipoprotein; ACE=angiotensin converting enzyme; ARB=angiotensin receptor blocker

≤53 mmol/mol) and duration of diabetes (in patients ≥70 years with two oral glucose lowering drugs or insulin and a diabetes duration less than 10 years the target is ≤58 mmol/mol, while in the same patients but with a diabetes duration over 10 years, the target is ≤64mmol/mol).[19] The target of SBP treatment is depending on age: in patients <80 years ≤140mmHg; in patients ≥80 years≤ 160 mmHg.[20] The target of LDL-cholesterol is ≤2.5mmol/l.

Diabetes treatment satisfaction was measured with the Diabetes Treatment Satisfaction Questionnaire (DTSQ).[21] It measures satisfaction with treatment regimen (six items) and perceived frequency of hyperglycaemia (one item) and hypoglycaemia (one item). The total item score ranges from 0 (very dissatisfied) to 36 (very satisfied). This questionnaire was sent to the patient's homes together with a stamped envelope, both at the start of study and after twelve months.

Data on patients' age, sex, treatment setting (primary or secondary care), HbA1c (mmol/mol), SBP (mmHg), LDL-cholesterol (mmol/l), albumin (mg/l). eGFR and medication (ACE inhibitor or ARB) were all collected from the electronic medical record. As the medication module of the database was introduced around the start of the trial, data on medication were missing (100% at the start and 48.7% at end of study). After checking which patients were in need of medication due to the presence of micro-albuminuria and with apparently missing medication, we sent the general practitioners a medication case report form to fill in and return.

Statistical Analysis

Primary care patients whose general practitioners were prompted to consult an internal medicine specialist or to refer the patient were compared to patients with the same advice in the control group. Categorial variables were expressed as percentages and continuous variables as means with standard deviation (SD). Chi-square tests were used for all categorial variables and paired t-tests for all continuous variables.

The QuED score is a summary score. The single values needed for this score were missing in some cases (at start and endpoint: HbA1c 5.8% and 3.2%; blood pressure 1.0% and 1.5%; LDL-cholesterol 12.5% and 6.4%; micro-albuminuria 28.2% and 24.9%). Missing answers on the eight questions of the DTSQ were between 1.6 - 5.8% at start and 21.7 – 22.% at endpoint. Excluding these participants may lead to loss of power and biased results.[22,23] We therefore created ten datasets with imputed data using SPSS version 25. A generalised linear mixed model was used to determine the effectiveness of the intervention. In the crude model we adjusted for the cluster design. In the full model, we additionally adjusted for baseline value, age, sex and patients' access to the patient portal. Data were analysed using SPSS version 25 (SPSS Inc, Chicago, IL, USA).

RESULTS

Of the 6755 patients invited in primary care 2382 (35.3%) agreed to participate. After randomisation at practice level there were 1235 (51.8%) patients in the intervention and 1147 (48.2%) in the control group. At baseline the general practitioner of 704 (57.0%) patients in the intervention group was prompted to consult an internal medicine specialist or to refer the patient. In the control group 653 (56.9%) patients received the same label; however, neither their general practitioner nor the patients themselves were informed in this respect. Baseline characteristics of participants whose general practitioner should consult an internist or should be referred were comparable between groups; however, in the intervention group more patients had a login to the patient web portal (Table 1).

Table 1. *Baseline characteristics of participants with GP advice for consultation or referral (N = 1357)*

	N	Intervention (N=704)	Control (N=653)
Age, years	1357	68.3±10.7	68.4±10.9
Gender, male	1357	391 (55.5%)	371 (56.8%)
Login to patient web portal, yes	1357	202 (28.7%)	145 (22.2%)
Duration of Diabetes , years	1347	8.5±5.9	8.3±5.7
Complications			
Amputation, yes	1092	4 (0.7%)	5 (1.0%)
Retinopathy, yes	889	44 (9.2%)	42 (10.2%)
Comorbidities			
Myocardial infarction or angina pectoris	1357	38 (5.4%)	16 (2.5%)
Stroke or Transient Ischemic Attack	1357	14 (2.0%)	5 (0.8%)
Peripheral Arterial Disease	1357	8 (1.1%)	6 (0.9%)
Smoking	1111		
Never		231 (40.7%)	231 (42.5%)
Current		75 (13.2%)	80 (14.7%)
Previous		262 (46.1%)	232 (42.7%)
Body Mass Index, kg/cm2	1286	29.9±5.2	30.2±5.5
Kidney function, eGFR	1096	77.9±28.1	74.8±26.5
Diabetes Medication	1294		
No blood glucose lowering medication		100 (14.9%)	75 (12.1%)
Oral blood glucose lowering medication		425 (63.2%)	423 (68.1%)
Insulin plus oral BG lowering medication		119 (17.7%)	84 (13.5%)
Insulin monotherapy		29 (4.3%)	39 (6.3%)
Types of advice	1357		
Only consultation		277 (39.3%)	257 (39.4%)
Both consultation and referral		255 (36.2%)	218 (33.4%)
Only referral		172 (24.4%)	178 (27.3%)

Normally distributed data are mean±SD values. Continuous variables are total number (percentages).

Table 2. *Measures and targets reached at baseline and after twelve months in patients with the GP advised at baseline (intervention) to consult a specialist or refer the patient (N = 1357)*

	Intervention (N=704)		Control (N=653)		Unadjusted Model *		Full Model **	
	Baseline	**Follow-up**	**Baseline**	**Follow-up**	**Mean Difference ±**	***P***	**Mean Difference ±**	***P***
QuED sumscore	24.1±0.6	26.1±0.5	24.6±0.6	25.1±0.5	1.0 (-0.4 – 2.4)	0.15	1.2 (0.0 – 2.4)	0.04
Process of Care	**Baseline**	**Follow-up**	**Baseline**	**Follow-up**	**Odds Ratio**	***P***	**Odds Ratio**	***P***
HbA1c test, %	94.6	97.3	93.7	96.3	2.0 (0.4 – 8.6)	0.38	1.9 (0.4 – 8.0)	0.40
SBP test, %	98.9	98.9	99.1	98.0	2.3 (0.5 – 9.7)	0.27	2.5 (0.5 – 11.6)	0.25
LDL-cholesterol test, %	89.6	95.3	85.3	91.7	1.3 (0.5 – 3.3)	0.60	1.3 (0.5 – 3.2)	0.61
Microalbuminuria test, %	70.0	76.1	73.7	74.0	1.2 (0.7 – 1.9)	0.57	1.2 (0.7 – 2.0)	0.44
ARB prescription, %	57.3	63.2	55.6	59.6	1.3 (0.9 – 1.7)	0.14	1.3 (0.9 – 1.7)	0.12
On Target	**Baseline**	**Follow-up**	**Baseline**	**Follow-up**	**Odds Ratio**	***P***	**Odds Ratio**	***P***
HbA1c, %	63.4	74.6	63.6	71.5	1.2 (0.7 – 2.1)	0.50	1.3 (0.8 – 2.1)	0.31
SBP, %	69.2	78.9	74.9	77.4	1.2 (0.8 – 1.9)	0.40	1.3 (0.9 – 1.9)	0.17
LDL-cholesterol, %	40.3	34.5	38.2	32.6	1.1 (0.8 – 1.5)	0.56	1.1 (0.8 – 1.5)	0.70

Categorial data are percentages (%), continuous variables are mean±standard error (SE).

HbA1c = haemoglobin A1c; SBP = systolic blood pressure; LDL = Low-Density Lipoprotein; ARB = angiotensin receptor blocker.

* Adjusted for clustering. ** Adjusted for cluster, baseline value, age, gender and login to patient portal

± At follow-up

baseline, around 63% of patients were on target for HbA1c, 70-75% for blood pressure and 40% for LDL-cholesterol. The proportion of patients on target for HbA1c or SBP improved, but decreased with regard to LDL-cholesterol (Table 2).

Adherence to yearly measurements for HbA1c, SBP and LDL-cholesterol was high at baseline. The QuED score in both groups was equal and about 24 points at baseline. At follow-up, the QuED score in both the intervention and control group improved with a larger improvement in the intervention group, resulting in a statistical significant difference due to the adjustment of the baseline QuED value which was lower at baseline in the intervention group.

After twelve months, most people in both groups met two out of three treatment targets, mostly the combination of HbA1c and SBP (Table 3).

There were no significant differences between both groups in outcome measures. Treatment satisfaction was already high at start in both groups and did not change (Table 4).

Table 3. *Number and type of targets reached after twelve months in patients with the GP at baseline advised to consult a specialist or refer the patient (N = 1357)*

Targets	HbA1c	SBP	LDL	Intervention (N=704)		Control (N=653)	
n=3	■	■	■	20.8%	20.8%	17.6	17.6%
n=2	■	■		38.4%	50.2%	38.1	50.1%
n=2	■		■	4.3%		5.4	
n=2		■	■	7.5%		6.6	
n=1	■			11.1%	25.2%	10.3	28.4%
n=1		■		12.4%		15.1	
n=1			■	1.7%		3.0	
n=0				3.8%	3.8%	3.9	3.9%

HbA1c = haemoglobin A1c; SBP = systolic blood pressure; LDL=Low-Density Lipoprotein- Cholesterol

Table 4. *Outcomes at baseline and after twelve months in primary care patients with advice for consultation or referral to an internist at baseline (N = 1357)*

	Intervention (N=704)		Control (N=653)		Unadjusted Model *		Full Model **	
Outcomes	**Baseline**	**Follow-up**	**Baseline**	**Follow-up**	**Mean Difference ‡**	***P***	**Mean Difference ‡**	***P***
HbA1c, mmol/mol	52.1±0.6	49.9±0.7	52.7±0.6	51.0±0.8	-1.1 (-3.1 – 1.0)	0.32	-0.7 (-2.0 – 0.6)	0.28
SBP, mmHg	136.6±1.0	135.4±0.8	135.5±1.1	135.8±0.6	-0.4 (-2.6 – 1.9)	0.76	-1.0 (-2.6 – 0.6)	0.24
LDL, mmol/l	2.4±0.0	2.5±0.0	2.4±0.0	2.6±0.0	-0.1 (-0.2 – 0.1)	0.32	-0.0 (-0.2 – 0.1)	0.38
Albuminuria, mg/l	27.8±1.8	37.4±2.7	29.4±1.9	34.9±2.8	2.5 (-5.1 – 10.1)	0.52	3.7 (-3.3 – 10.6)	0.31
DTSQ sumscore	30.5±0.3	30.7±0.2	31.0±0.3	30.7±0.2	0.1 (-0.5 – 0.6)	0.80	0.2 (-0.2 – 0.7)	0.29
DTSQ hyperglycemia	1.8±0.1	1.8±0.1	1.5±0.1	1.7±0.1	0.1 (-0.2 – 0.3)	0.52	-0.0 (-0.3 – 0.2)	0.82
DTSQ hypoglycaemia	1.1±0.1	1.2±0.1	1.0±0.1	1.1±0.1	0.1 (-0.0 – 0.3)	0.15	0.1 (-0.1 – 0.2)	0.30

Data are continuous with mean±standard error (SE)

HbA1c = haemoglobin A1c; SBP = systolic blood pressure; LDL = Low-Density Lipoprotein; DTSQ = Diabetes Treatment Satisfaction Questionnaire.

* Adjusted for clustering. ** Adjusted for cluster, baseline value, age, gender and login to patient portal. ‡ At follow-up.

DISCUSSION

We evaluated if prompting the general practitioner to consult an internal medicine specialist or to refer a patient who needs intensified treatment would lead to improvement in quality of diabetes care, diabetes outcomes and patient satisfaction. We found a significant improvement in the QuED-score in general practitioners who received an alert message, even in this group of general practitioners with a mean QUED score above 20 points at start of the trial. Notably, in the present study we analysed QuED in a subpopulation of primary care type 2 diabetes patients that did not have adequate metabolic control. However, in single process of care or outcome indicators the intervention did not result in any significant difference compared to the control group nor did it influence treatment satisfaction.

Studies have demonstrated that the use of reminders in the electronic medical record about recommended care to the physician is associated with better performance with regard to testing HbA1c, LDL-cholesterol, and nephropathy screening in patients with diabetes mellitus.[24,25] The lack of effectiveness in our study may be caused by the fact that in the Netherlands, the adherence to yearly measurements is already very high, especially for HbA1c and SBP measurements, with hardly any room for improvement.[6,7,26] It is possible that in countries with lower percentages of adherence, the improvement in process of care indicators would be larger when prompting the care provider.

Despite this overall excellent process of care, many patients do not meet their treatment targets. The percentage of patients on target for HbA1c, systolic blood pressure and LDL-cholesterol at the start of the study was comparable or higher than found elsewhere.[6,27,28] In the present study, we made modifications to the adapted QuED score correcting for the targets in the Dutch guidelines. Although in all patients the medical specialist should at least be consulted according to the management guidelines, the overall QUED score in the participating general practices was already quite high.[18] However, there is still room for improvement, especially in increasing the number of patients who meet all three targets, which is associated with less macrovascular complications, myocardial infarction, cerebrovascular accidents and death compared to patients who achieve only two or one target(s).[29] Patients with type 2 diabetes in which both HbA1c, systolic blood pressures and lipid levels are within the target ranges, in addition to not smoking and no albuminuria, appear to have no increased risk of stroke, myocardial infarction or death compared to the general population.[30]

Our findings demonstrate a missing link between adherence to process measures and diabetes outcomes despite evidence that adherence with process of care seems associated with fewer diabetes complications, improvements in patient outcomes and decreased probability of hospitalisation.[9–11,31] It reflects clinical inertia, defined by failure of healthcare providers to initiate or intensify therapy when indicated[32] a worldwide

problem leading to poorer diabetes outcomes.[29,33]
Physician-, patient-, and healthcare-related factors all play a role in clinical inertia.[32,34–38] Physician factors, e.g. failure to initiate or intensify treatment and underestimation of patient's need, probably play a role in our study. We did not evaluate if adjustments in treatment (e.g. intensification of medication) were performed by general practitioners after they received the alert, but we surmise that adjustments were made. General practitioners already reported that they had room for improvement before involving an internal medicine specialist or endocrinologist,[17] but it is possible that after a first step in treatment intensification had been taken, monitoring and a next step in treatment adjustments were delayed.[39] Also, providers might be reluctant to modify treatment after a single elevated measure especially in blood glucose lowering and antihypertensive medication.[40] However, after twelve months with obviously more measurements many patients had hardly or not improved, and as a result their general practitioner should be prompted again to consult an internist or refer the patient. A shared care approach between primary care physicians and diabetes specialists is not a quick remedy to improve diabetes care,[16] but it might improve diabetes control.[15,16,41] The majority of the prompts were a consequence of insufficient cardiometabolic control. We already showed that health care providers did not adhere to this advice and we speculated that guidelines about collaboration between primary and secondary care should undergo more testing and feedback from the practicing physicians in order to gain more support and adherence.[17] Although an e-consultation in the electronic medical record between primary and secondary care physicians could provide easy access to specialist care, reduce waiting times, avoid unnecessary specialist visits and have high levels of satisfaction,[42–44] this option was not utilised much by the general practitioners in our study. Also 'alert fatigue' in the physicians in this study may be the cause of our findings. In a recent study ignoring reminders was caused more by 'cognitive overload' than by declining responsiveness from repeated exposure to the same alert over time, resulting in a lack of cognitive resources to distinguish relevant from irrelevant information.[45] Therefore, consensus over which electronic medical record alerts have priority and diminishing the number of different alerts might be a way to enhance the quality of diabetes care.

What about the patients' role? Their treatment satisfaction was quite high and not influenced by the prompt. We do not know whether the general practitioner discussed the prompt he received with the concerning patient, but assuming he did and they took a shared decision, it is unsure whether treatment intensification or referral would have influenced satisfaction, because patients can have negative perceptions about treatment intensification[46] but patients also expressed more treatment satisfaction after intensification.[47,48] And if the general practitioner did not discuss the prompt with the patient at all, nothing will change indeed. Our results are independent of whether patients had a login to the patient web portal, which increases their generalisability.

Strength of this study is a large population of patients with T2DM in a care group setting in which patients can request access to their own electronic medical record. To the best of our knowledge this is the first study that evaluates the effectiveness of an alert message in the electronic medical record on quality of diabetes care. We used a summary score that includes both process and outcome measures and has shown to be related to cardiovascular events. We also evaluated patient satisfaction with a validated questionnaire. However, there are also limitations. Most of the prompts were not adhered to by general practitioners, which limits the reliability of the results. Besides, there were more patients in the intervention group with access to their own medical record. This is probably due to randomisation at practice level. Patients in the intervention group with a portal login also received the alert message that advice or referral was in order. This 'patient prompt' may have led to improved outcomes due to patient activation. However, we corrected for this in the adjusted model. Finally, we adapted the QuED score to the target values in the Dutch guidelines, as stated earlier. Our adjustments could have altered the validity to predict risk on cardiovascular events.

In conclusion, prompting the general practitioner in patients with suboptimal diabetes care led to an improvement in quality of care, even when general practitioners did not actually consult an internal medicine specialist or refer the patient. Adding such a prompt, based on management guidelines, to the electronic medical record seems beneficial.

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PART III

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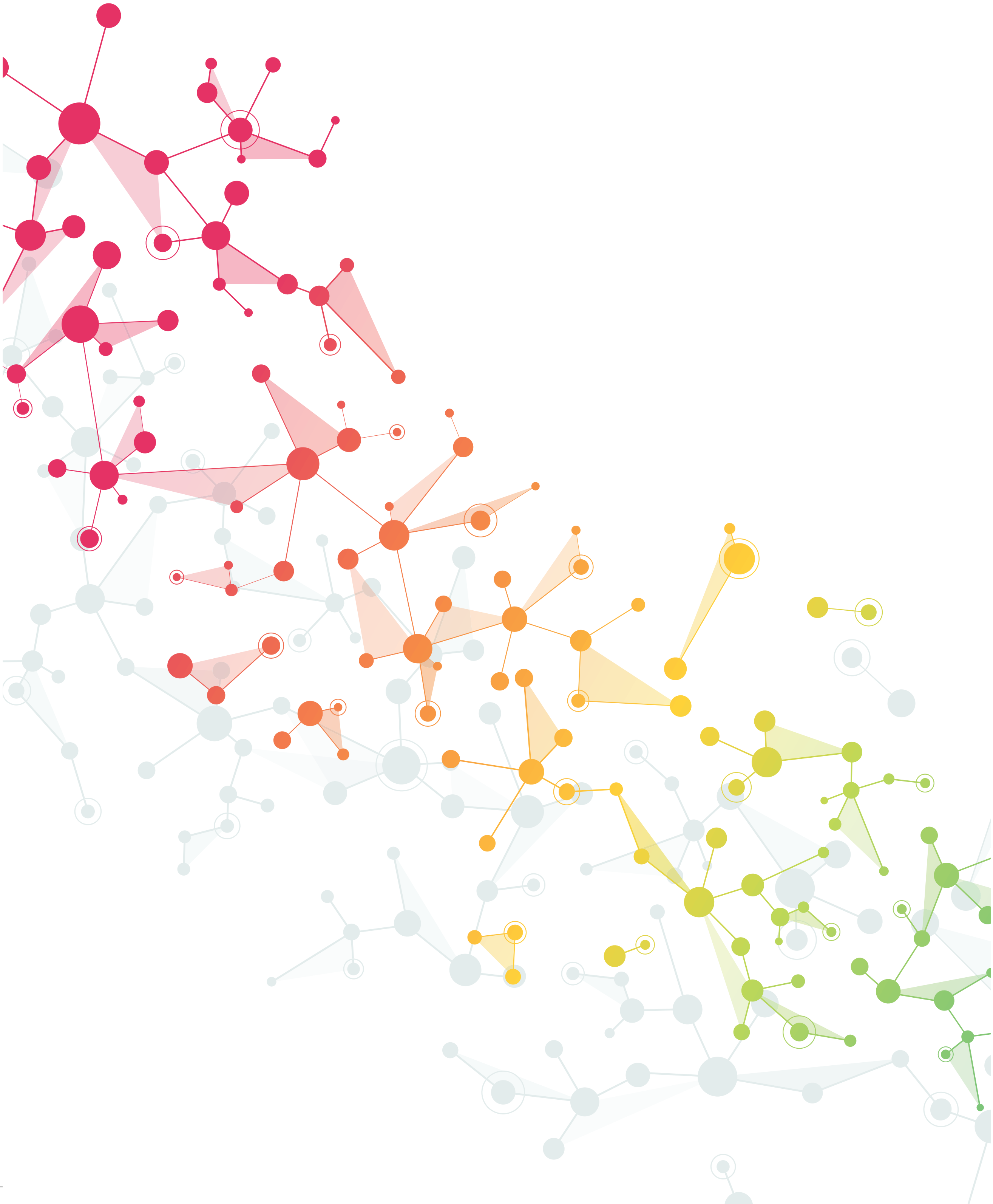

CHAPTER 8

General Discussion

This thesis provides an overview of two eHealth examples that can be used in the management of diabetes: a patient web portal and an alert message in the electronic medical record (EMR). First, we examined which patients use the diabetes web portal and which don't; the reason for their (des)interest; their experiences and opinions. Furthermore, we examined the experiences and working methods of the health care providers as well. Secondly, we designed a cluster randomised trial in which we tested an electronic message that alerts the health care provider if a patient is not treated in the correct setting according to national management guidelines. We evaluated the effect on changes in the treatment setting, the reasons why physicians do not adhere to the guideline, changes in diabetes outcomes and patient satisfaction.

PART 1: THE DIABETES PATIENT WEB PORTAL

In recent years, patient portals became more and more available.[1]. In 2017, the Dutch centre of expertise of eHealth (Nictiz) published their eHealth monitor that, amongst other information, rapports the current state of online portal access for patients in The Netherlands. In a sample of 290 primary care physicians and 253 medical specialists, online access to the clinic notes was possible in 3% of primary care physicians and 18% of medical specialists. Access to test results and prescribed medication is better (test results: 11% of primary care physicians and 30% of specialists; prescribed medication: 24% of primary care physicians and 26% of specialists). There were intentions to open a portal in 2018 (6% of primary care physicians; 15% of specialists).[2]

A recent review and meta-analysis demonstrated a mean adoption rate of 52%, but also found that rates differed between study types: in controlled experiments, adoption rates were around 71% (CI 64-79%) while in real-life experiments the rate was 23% (CI 13-33%).[3] In diabetes-specific portals the rates are comparable or even lower without a good explanation.[4,5]

So despite good intentions, regulations and an increasing body of research about portals there still is a lot of work to be done to provide all patients with access to a patient web portal. Among other things, we need a better understanding of barriers and facilitators in requesting access and using the portal, both from patients' perspective and from physicians' perspective and we need to learn from experiences from both.

Who uses a patient web portal?

Our first interest was to examine the differences between patients with diabetes mellitus who are interested in using the portal and patients who are not. Before the start of our study, there were some worries in the literature, that patients with lower education, patients with limitations in health literacy and patients with no access to the internet were less likely to sign on, as were older patients.[6–8] Apart from confirming these findings, we demonstrated several other determinants of using a web portal. Because the Diamuraal portal is in use in the primary care practice as well in the outpatient clinic, we had the unique opportunity to assess the relationship between portal use and treatment setting. Other studies focussed on primary care[9] or hospital-based portals.[10,11] We examined patients with type 1 and patients with type 2 diabetes separately. We showed that patients with type 1 diabetes mellitus request a login more frequently than patients with type 2 diabetes mellitus and that there are many differences between patients with a login and patients without **(Chapter 2)**. Patients with type 1 diabetes mellitus with a login were younger and had better diabetes knowledge. Patients with type 2 diabetes and a login were also younger, were more often male and had a higher education , but we also demonstrated that having a login was independently associated with treatment by an internist, the use of insulin and polypharmacy.

Furthermore, we looked in more detail into the patients with a login and found that not all patients who request a login actually use it to gain access to their medical record. Two-thirds of people who request the login never logged in or only once and then abandoned it ("early quitters"). These individuals differ from regular or persistent users: insulin use, experiencing more frequently hyperglycaemic episodes, and better diabetes knowledge, do increase the odds of becoming a persistent user **(Chapter 4)**. Of note: first, we called the group patients who continue to login "regular users" but during the progression of this study we felt that the word regular did not fit well and we changed it into "persistent users". The discrepancy between requesting a login and being an actual user has been demonstrated more often[11–13] and underpins that not all users are comparable, with possible different experiences and wishes for portal use.

Our study confirms and highlights the differences between patients previously reported in the literature. It also shows that providers and treatment setting play a role in requesting a login and that people with diabetes mellitus who use insulin or have a more complex disease and/or treatment regimen have more interest in the portal compared to patients who do not. The association between requesting a login and treatment by an internist in the outpatient clinic might be due to greater enthusiasm of the specialists and secondary care nurses about the patient portal, better implementation of patient education on the web poral in the outpatient diabetes clinic and/or the fact that patients with a more complex disease are more often treated in specialist care. At the moment, diabetes web portals have a one-for-all design and ignore the fact that there are different types of patients with diabetes who have different needs and preferences. A recent meta-analysis showed that telemedicine resulted in a significantly higher reduction in HbA1c in patients with type 2 diabetes compared to patients with type 1 diabetes; and that older patients benefited more than younger ones.[14] A difference between patients with type 1 and 2 diabetes with respect to the effectiveness of telemedicine to lower HbA1c was also demonstrated in an earlier meta-analysis with fewer trials included, but the effect was the other way around.[15] Type 1 and type 2 diabetes have different pathophysiological backgrounds with different management strategies and portals need to accommodate these differences. One might question whether separate patient web portals for people with type 1 diabetes and with type 2 diabetes are preferable. This also holds true within the group of patients with type 2 diabetes, because patient with type

2 diabetes have a large diversity in the medication regimens and they additionally need to focus on several lifestyle changes. Ignoring the differences will result in increasing disparities and the patients who could benefit the most might be left behind.

The interest in using a patient portal

After knowing which patients are using the portal (or not), it is important to gain insight into the reason for this (des)interest. The main two reasons for requesting a login among the persistent users were (1) to reread the information of the consultation at home and (2) the feeling that portal use gave them influence on their disease and treatment. The group of patients without a login stated that the main two reasons for not requesting a login were (1) unawareness of the portal's existence and (2) that they preferred to leave disease management to the physician **(Chapter 3)**.

It seems that whether or not someone is interested in having an active role in managing his or her disease can be either a facilitator or a barrier for requesting a login. In this respect we should keep in mind that in a study in 2011 only 62% of Dutch patients with type 2 diabetes agreed to take responsibility for their diabetes.[16] Such a difference between people also exists with regard to the use of the Internet: more patients with a login already used the internet on a daily basis and were longer online, and half of them had searched on the Internet for information about diabetes compared to only a quarter of patients without login. Patients who prefer to leave disease management to the physician are likely not to be interested in requesting a login to a web portal, and we need a different approach to interest those patients, e.g. giving a caretaker or family member access who in turn can help to navigate the portal and support the disease management.

Indeed it seems that having another person who could access the portal (e.g. partner or children) could lead to increased web portal use, as one-fifth of patients without login declared they would request a login if someone would help **(Chapter 3)**.

A study with lower educated persons showed that these people consider the proxy access to the electronic records of their children or their parents valuable, especially if the family members are dealing and helping with their diabetes care. They felt somewhat more hesitant to provide access of their own medical record to family members, but understood it could be useful on the condition that this proxy access is voluntary and patients can self-determine who receive access codes.[17] During our study we noticed that many family members (mainly children or partners of the participants) responded to our home sent questionnaire by telephone, mail or a note on the returned questionnaire mentioning the proxy access, showing an already active participation in healthcare of parents and family. Indeed, patients are quite often escorted by a family member to medical consultations. This access can be accomplished without undermining a patient's privacy, e.g. using distinct authorisation for care partners in combination with restricted access to medical information in which some details of diabetes management could be shared but other (sensitive) information not.[18] Such a policy might ensure that also patients who are less inclined to request a login, the elderly and those with lower education levels, could benefit from a diabetes web portal. There have been many concerns about privacy and confidentiality surrounding the use of portals,[19] although in our study only 6% of patients without a login mentioned such concern as the main reason for not requesting a login. However, good security measures are important, while making sure that the security itself will not become a barrier to log in.

The role of the healthcare provider

Of the patients without a login, 72% declared they were unaware of the portal's existence. This unawareness was the main barrier for enrolling, a finding which is in line with other studies.[20,21] We showed that in becoming aware of the portal, the diabetes health care provider plays a role. It seems that the healthcare providers (especially in the primary care setting) did not communicate the possibility of using the shared electronic medical record clearly enough. Almost all patients with a login learned about the existence of the portal from their diabetes healthcare provider, whereas less than half of patients without a login but aware of its existence stated that they learned about it because their healthcare provider told them **(Chapter 3)**. Against that background, it is interesting that diabetes healthcare providers feel that the portal could improve diabetes patients' knowledge and quality of care and that they emphasised the importance of patients uploading glucose levels and patients having access to clinic notes and laboratory values **(Chapter 5)**. The feeling that patient portal use leads to improved quality of care was also demonstrated in a recent review on chronic diseases.[19]

In the 2017 Dutch eHealth-Monitor, 34% of primary care physicians and 53% of specialists support online access of medical records by patients, while others are feeling neutral (25% of primary care physicians; 17% of specialists) or are against it (41% of primary care physicians; 30% of specialists).[2] This is somewhat in contrast with the positive attitudes toward a portal by the participants of our study and may indicate selection bias. However, the participating diabetes care providers still do not recommend the portal to all patients; it is especially recommended to patients with type 1 diabetes, type 2 diabetes patients on insulin use and to younger patients. This might partially explain the differences in characteristics between patients with and without a login, displayed in **chapter 2**. No studies have been performed on healthcare providers' opinions about the suitability of patient portals to specific patient groups. In general, healthcare providers are somewhat reluctant to encourage patients to gain access to medical notes and laboratory results, e.g. because they fear to create anxiety by patients,[22,23] worry that patients are able to conceal information,[24] think that patients will disagree with clinical note content,[25] fear a change in patient-provider communication, [19,26] or view it more as a resource for physicians rather than a tool for patients.[27,28] With increased portal use and positive responses from patients who read their clinical notes, these worries may decrease.[29,30]

A second important step to take is the way providers communicate about the portal with their patients and support them in requesting a login. Despite many patients declaring being unaware of the portal, the majority of the providers reported that they informed their patients about the portal, most often face-to-face. However, they rarely provided additional information (e.g. informational leaflet, a web-address or registration form) and rarely enquired about patients' interest nor addressed it during the next consultation. Physicians and nurses can feel conflicted over whose responsibility it is to promote the patient portal and can perceive the portal as extra work to an already long list of clinical responsibilities.[21] We proposed in **chapter 5** that additional training might be necessary to support the physicians and nurses in discussing the benefits of the portal with patients, in helping their patients to navigate the portal and in checking the patient's understanding of information. Since most care providers stated that they did not repeatedly address the issue, extra support could also consist of adding an item in the EMR to remind physicians and nurses to promote portal use, e.g. a checkbox. Healthcare provider endorsement strongly influences a patient's interest and ability to use the patient portal,[31] and primary care practices with a more active strategy to promote portal use achieve more patients gaining access.[13] The help of support staff, e.g, a diabetes nurse who takes time to help a patient learn and navigate the portal, may ensure the continued use by patients.[21] The more a clinician is able to motivate people with diabetes mellitus with regard to adequate self-management behaviour, the higher their engagement and activation in eHealth is.[32]

The usability of the portal and further wishes for improvement

If one tries to increase the adoption of portals by certain patients, it is important to understand how the portal is used, which parts do work well for patients, which parts need improvement. Earliest portals were designed for trials or by policymakers without input from the targeted users, namely patients.

The persistent users in our study were of opinion that the portal is easy to use, were satisfied with regard to its lay-out and assessed the overall information to be comprehensible. They had no problems with understanding the laboratory values, the medical abbreviations and phrasings used, and understood the need for appointments and check-ups **(Chapter 4)**. On the contrary, early quitters experienced more troubles with the comprehensibility of portal features, e.g. understanding of the medical phrasings and abbreviations. Portals need to be user-friendly to enhance uptake.19 Interface challenges, navigational problems and medical language have proven to be the main barriers in optimal patient portal enrolment and use.[21] This could have played a role in the abandonment by some of the users in our study and both redesign and training and support of patients on digital basics and portal use might be necessary.

The best scoring features of the portal as mentioned both by persistent users and by early quitters were rereading the information discussed at consultations and the access to laboratory and treatment goals, while the access to general diabetes information scored least. This was also demonstrated in a diabetes patient portal in Canada: one of the two most useful features of that patient portal was data graphs, which were helpful for diabetes tracking (leading patients to self-awareness of their health status). The other one was reporting and feedback on glucose (leading to medication adjustment and behavioural changes). Thirdly, that access to information was valued but not much used.[33] Furthermore, others demonstrated that less educated patients, women, and older patients considered the reading of the consultation notes extremely important to get engaged in care.[34] As already stated, we should think about tailoring a diabetes web portal to specific patient needs. Patients have different needs and wishes for diabetes information, e.g. links to information about diet and medication[35] and wish that portals are able to customise information content.[36] Some people have continuous blood glucose sensors, activity trackers and food diaries and those could be connected to the portal, on the condition that they have good connectivity with the portal.[35]

Telemedicine may result in a significant decrease of HbA1c compared to usual care,[14] but it is uncertain which portal features contribute most. Studies to specific portal features are scarce, most studied is the e-message function of the patient portal. Patients with T2DM with a more active e-message communication via a patient portal appeared to have a greater likelihood of HbA1c control,[37–40] however many patients do not take advantage of portal features such as messaging.[39,41] Healthcare providers have been worrying about secure e-messaging with patients,[19,42] but even older patients and caregivers seem to prefer communication with providers via email instead of via the phone;[41,43] they find the message function of the portal easy to use.[43] Interestingly, in our study, among the patients, half of the early quitters and three-quarters of the persistent users declared e-messaging a very useful feature of the portal, and 65% of the participating diabetes care providers feel very positive about patients sending an e-message **(Chapter 5)**. Furthermore, uploading pre-visit notes, in which patients set a visit agenda and problems they wish to discuss with their healthcare provider, is likely to lead to improved clinicians' understanding of patients concerns, to make the visit more efficient and to improve patient-provider communication.[44] This feature is currently not yet an option in the portal used in this study. However about three-quarters of healthcare providers in our study strongly agreed that a positive effect of the portal is that patients can prepare themselves for the consultation at home by using the portal as it is. Adding a pre-visit agenda might improve the communication between physicians and patients about patients' worries regarding diabetes, but also about patient portal use.

Besides, the users of this portal, but also the persons who abandoned it at an early stage had several wishes for improvement **(Chapter 4)**. The glucose diary could be improved by adding the injected insulin units and by an automatic upload from glucose meters. A scheduling function for planning a consultation and also sending reminders for upcoming visits would be appreciated. And the information about diabetes could be improved by providing updates on current medical diabetes information and by offering more information about medication and its adverse effects.

In the design of the patient portal in this study, the patients did play a role. However, it is necessary that patient involvement is not a one-time-only activity. Portals need to be easy to use, easy to understand and easy to navigate. Patient's wishes need to be taken into account. Based on the results of this study, we suggest a redesign of the patient portal, creating one more suited for patients who inject insulin and another for patients who do not **(Chapter 4)**. And after every change, users need to be involved again in testing. Multiple rounds of usability testing and user feedback have proven to achieve greater success in patient adoption and use.[21]

Methodological Considerations

In this study, we used postal questionnaires, which are widely used and are an efficient way to gather large quantities of data. However, there are several challenges in developing a questionnaire and to minimise non-response. Questionnaire surveys have several sources of bias.[45] At the start of our study, not much knowledge was available about diabetes portals and we based our questions on the variables demonstrated previously to be relevant for the use of eHealth.[46,47] Besides, we asked questions about the usability of specific Diamuraal portal features . We used several response formats and had also free text item(s). The questionnaire was pretested and we used the feedback to make improvements. Our questionnaire contained many questions and this could have hampered response. We discussed to send patients with portal login an electronic questionnaire but decided not to do so; we sent all participants a postal questionnaire. We took into account that patients without login would probably be less interested to participate and therefore we sent twice as many invitations to participate to patients without a login. We sent twice a reminder letter to increase response. Response rates of both patients and healthcare providers were comparable to others with a postal questionnaire.[48] As common in questionnaire studies, not all patients filled in all items of the questionnaire, therefore we used multiple imputation.[49] This study was cross-sectional, therefore we cannot distinguish cause and effect. Distinguishing determinants would require a longitudinal design with a baseline situation. It is uncertain if we can generalise our results to diabetes populations in other countries, because we found an association between treatment setting and requesting a login, and whereas in The Netherlands there is a distinct separation between primary care and specialist diabetes care, such a separation might play a different role in other countries. Moreover, we found that and insulin use was a determinant of requesting a login in patients with type 2 diabetes, and the proportion of patients with type 2 diabetes using insulin considerably differs between countries.[50]

However, the issues raised in our papers about barriers, usability, and additional wishes are important in designing diabetes web portals, irrespective of the specific location or region or national population.

Future research

It would be interesting to measure the effect of a diabetes web portal use by patients whose care providers have been educated in the use of eHealth in diabetes treatment, e.g. after training on how to discuss the portal, helping and checking the patients understanding of the information and how to incorporate the portal in their workflow.

And finally, the effects of portal redesign (e.g. usability of a portal specially designed for patients with type 1 diabetes, or for those with type 2 diabetes using insulin, or the effects on different self-management education sections of the portal on diabetes outcomes) should be evaluated in order to overcome barriers and optimise a portal's usability and maybe effectiveness.

PART 2: ALERT MESSAGES IN THE ELECTRONIC MEDICAL RECORD

Recently, a systematic review on global achievement of guideline targets recommended by the ADA (American Diabetes Association), the EASD (European Association for the Study of Diabetes) and NICE (National Institute of Health Care Excellence) for type 2 diabetes was performed in which the authors studied target attainment between 2006 and 2017. They found pooled target achievements of 42.8% (95%CI 38.1 – 47.5%) for glycaemic control, 29% (95% CI 22.9 – 35.9%) for blood pressure and 49.2% (39.0 – 59.4%) for LDL-cholesterol, with no improvement in rates by year for any target.[51] In the Netherlands, in 2014, 94.6% of patients with type 2 diabetes treated in the primary care setting had a measurement of HbA1c in the previous year, more than 95.0% had a measurement of blood pressure and 89.9% had a screening for lipid profile.[52] Two out of three patients <70 years had an HbA1c <53 mmol/mol and 5.6% had an HbA1c >69 mmol/mol; 68.0% of patients <80 years had a systolic blood pressure ≤140 mmHg; and 60.7% of patients <80 years had a LDL-cholesterol ≤2.5 mmol/l.52 So, overall the process of diabetes primary care in The Netherlands seems excellent, but still many patients do not meet their treatment targets. The setting in which diabetes care should take place is described in The National Management Guideline on type 2 Diabetes, a so-called LTA.[53] When designing our study protocol, we estimated roughly that one quarter of patients was not treated in the correct setting, and we performed an intervention which, we hypothesised, would result in better treatment allocation and improved quality of care.

The effect of the intervention on shift to the correct setting

The intervention we performed was to send an alert in the EMR to raise physicians' awareness that a patient was not treated in the recommended setting according to the above mentioned LTA , explaining on which patient variable(s) the alert was based. The alert was combined with advice for the preferred treatment setting. More than 50 percent of patients with type 2 diabetes were not treated in the correct setting, which was higher than expected. However, at the end of our study, most patients had not switched to the LTA stipulated setting. Advice for consulting an internist or advice for referral was intentionally followed in less than 10%, advice for self-monitoring was followed in 24%. Specialists performed better, the advice for referral back to the general practitioner was followed in 35% of cases **(Chapter 6)**.

Dutch general practitioners have a positive attitude towards NHG guidelines in general and report high adherence rates, although adherence can vary across recommendations.[54] Still, physicians can have several reasons for not following (parts of) clinical practice guidelines (Box 1).

Box 1. Barriers to Guideline Adherence

Lack of Awareness or Familiarity
- Guideline accessibility
- Time needed to stay informed
- Volume of information
- Falsely not indicated
    - Knowledge gap by physician
    - Specialist forgot initiation and general practitioner did not pick-up on it

Lack of agreement with specific guideline
- Interpretation of evidence
- Applicability to patients, e.g. in multimorbid patients
- Not cost-effective
- Lack of confidence in guideline developer

Ambiguity of the guideline
- Unclear who is supposed to do what, where, when or how
- Information is not prioritised in most important therapies

Lack of agreement with guidelines in general
- Too 'cookbook', e.g. not catering patient needs and capabilities
- Too rigid to apply or unpractical
- Biased synthesis
- Challenge to autonomy

Physician Attitudes
- Lack of outcome expectancy, e.g. expected compliance problem, short life expectancy
- Lack of self-efficacy, e.g. the physician believes that he/she cannot perform guideline recommendation because they lack the appropriate medical training or experience
- Lack of physicians' motivation
    - Difficulty of changing habits and routines
    - Feels it's not his/her responsibility
- Priorities, e.g. patient has another disease and the physician decides to focus on that first
- Feels it is unnecessary because the patient is at near goal levels

Patient Barriers
- Patient agrees but does not act on it, e.g. treatment discontinuation
- Patient does not agree, e.g. expected/perceived side-effects, preference for alternative medication

External Barriers
- Primary secondary interface, e.g. no or late outpatient letters to general practitioners
- Guideline factors
    - Multiple contradictory guidelines
    - Guideline format
- Environmental factors
    - Lack of time
    - Lack of office resources/materials
    - Lack of reimbursement
    - Increase in liability
    - Change in practice routine needed
    - Organisational constraints, e.g. in arrangements with practice assistants, pharmacies or medical specialists

Based on the literature [54–62]

Recommendations that are non-controversial, clear, evidence-based and do not demand a change in existing practice routine are better followed.[56] The NHG guideline on type 2 diabetes[63] contains recommendations that are highly-evidence based and general practitioners are familiar and used to work with this guideline. On the other hand, the national management guideline (LTA Diabetes Mellitus Type 2)[53] is a consensus between physicians from the Dutch College of General Practitioners (NHG) and the Dutch Society of Internal Medicine (NIV). The advice is based on several guidelines, both from primary care (i.e. NHG guideline Diabetes Mellitus Type 2) and secondary care (internal medicine). Local adaptions can be made into a working agreement between general practitioners and internal medicine specialists. Because it is consensus-based it may be obvious that not all general practitioners nor all internal medicine specialists will agree with all its aspects and / or advice. However, in our study we used the LTA and the local agreement of the Diamuraal care group as a starting point. The target values used in the QuED sumscore (of HbA1c, blood pressure and LDL-cholesterol) were the same as used in the Diamuraal care group and described in the evidence-based NHG guidelines.[63,64] It might even be possible that the primary care providers in our study had a lack of awareness of the LTA or at least are not familiar with using it, because they were used to working solely with the NHG guideline Type 2 diabetes itself. Indeed, specialists and general practitioners support the use of a joint treatment guideline, but are used to the guidelines of their own discipline.[65]

In our study, healthcare professionals reported several reasons for non-adherence to the advice in the electronic alert, namely room for treatment adjustment, patient's request and doubts about patient's compliance, lifestyle or therapy adherence. We did not specifically ask about awareness and agreement with the guideline. General practitioners feel more often that NHG guidelines do not always incorporate patient preferences, needs and capabilities[54] or may have low expectations of their patients.[66,67] Internal medicine specialists had a much better adherence to our advice, but still 65% of patients were not referred back to primary care. Their main reasons for non-adherence were: (1) other co-morbid conditions or recent complications and (2) at patient's request. These reasons reflect the well-known weak sides of guidelines. Indeed, non-adherence to guidelines and also to the electronic alert can be intentional and does not necessarily impact quality of care, e.g. when the reasons are related to contra-indications or patient preferences.[62]

First, we should mention that lack of agreement with some of the advice messages could have played a role in the low shift in care allocation in our study population. In order to perform a computerised prompt we used information available in the EMR. One fifth of advice for referral was due to presence of retinopathy. We could not distinguish the severity of retinopathy in order to run our algorithm. In some of these cases physicians mentioned that they did not adhere to our advice for referral because there was no progressive retinopathy, in which case indeed referral was not needed, and correctly ignored. In the trial setting we had to standardise the method to determine whether a patients was in the correct setting both in the intervention and the control group, the latter not being able to comment at baseline. Therefore such feedback information from intervention group physicians was not taken into account in the analyses. But the amount of patients who were treated in the incorrect setting is slightly overestimated. The EMR is currently not advanced enough to consider such specific situations. It needs to be redesigned with check-boxes that can specify certain situations that should be taken into account.

Furthermore, not all targets and advice might be deemed equally important. Physicians might be more interested in guideline advice for targets such as HbA1c, blood pressure and kidney problems, and less in advice for targets such as high BMI. Indeed, in our study around 25% of advice for referral was due to presence of BMI ≥35 kg/m2 **(Chapter 6)**. The LTA consensus board had proposed 'consultation of referral' for this condition because prescription of the novel antidiabetic injection therapy with GLP-1 agonists, which can be highly effective in the very obese type 2 diabetic patient, could at that time, until 2018, only be started by an internist and not by a general practitioner. Further restrictions also applied: insurance only covered the costs of this medication at the BMI ≥35 kg/m2. The Diamuraal care group experts, consisting of primary and secondary care providers, locally agreed on 'referral' for practical reasons and based on witnessing success of this treatment, thus solely available in secondary care, in the weight management of patients.

The main three reasons mentioned for not adhering to the advice for referral of these patients were: (1) at patient's request; (2) doubts about patient's compliance and lifestyle; and (3) BMI too high but primary care options (e.g. dietitian, exercise program) are still continuing. In our opinion this result reflects the desirability of a less strict referral advice. Prioritising guideline items, taking patient preferences into account and reaching an agreement on cut-off values is important. Physicians feel that when patient preferences and capabilities contrast with guideline recommendation, patient preferences and capabilities are prioritised over guideline adherence.[68] Furthermore, as we discussed in **chapter 6**, the LTA on type 2 diabetes needs a more extensive agreement procedure before implementation. Conversation between developer and end user of a guideline is important to prevent lack of agreement with a guideline.[69] General practitioners have been reluctant to fully adhering to guidelines because of their perception that physicians have little input during guideline development.[70]

Irrespective of these mitigating circumstances for non-adherence to some advices, the majority of advice for consultation and referral in our study were due to high HbA1c, high blood pressure and inadequate lipid profile **(Chapter 6)**. With regard to advice for consultation or referral regarding these targets, the main reason for non-adherence in these cases was that the primary care providers declared they still had room for treatment adjustments. In diabetes, physicians can be hesitant to intensify treatment in fear of a high medication burden resulting in lower treatment adherence. Nevertheless, medication prescription according to the Dutch guidelines on diabetes type 2 is not related to decreased health related quality of life.[71]

Non-adherence could also have been due to other factors. Most alerts to general practitioners concerned the advice to consult an internal medicine specialist **(Chapter 6)**. This easily could have been done by sending an e-message using the EMR, but was strongly underutilised. E-consultation provides easy access to specialist care, reduces waiting times, avoids unnecessary specialist visits and has high levels of satisfaction.[72–74] It is unclear why this option was not better utilised by the primary care providers in our study. This might have to do with the physicians feeling there was room for improvement before consulting, which in the literature is referred to as physician autonomy.[75] Other studies also revealed privacy concerns, or the fact that healthcare providers were not aware of the option in the EMR.[76] However, even after they explicitly were made aware of the option, still few healthcare providers in the intervention group made use of e-consultation. Not much information about the effectiveness on diabetes outcomes of e-consultation between physicians is available. When implementing e-consultation by primary care providers for diabetes, gastrointestinal and neurosurgical inquiries at the same time, e-consultation was used in a much higher percentage for the latter two specialties, in particular for preprocedural questions. The authors speculated that primary care providers felt more confident in treating diabetes without the advice of the internal medicine specialists.[77] Similar assumptions could have withheld the primary care providers in our study from using e-consultation However, whereas general practitioners may have gained enough experience over the years to treat hyperglycaemia quite well, many new blood glucose lowering agents could still make e-consultation of a specialist in this field valuable. Many physicians are positive about the added clinical and educational value of a dialogue with specialists, but also feel that e-consulting shifts some of the specialist's work to them.[78]

Advice for substituting a visit for self-monitoring in our study was followed better than advice for consultation and referral, but still 76% did not adhere to the advice **(Chapter 6)**. Six-monthly monitoring does not compromise outcome[79] and the use of the patient portal can lead to a decrease in HbA1c.[14,80] The patients who were eligible for substituting care were patients already with good cardiometabolic control. However, these patients could use the patient portal to support them with their self-management (e.g. monitoring with the glucose diary and getting feedback). When problems arise, the portal might be useful to adjust treatment in a more early stage, e.g. using the e-message function. It is unclear why this option was not used. Earlier, many healthcare providers in our study population declared to believe that in a cardiometabolically well-controlled patient with portal access, one of the quarterly monitoring visits can be substituted by self-monitoring **(Chapter 5)**. Maybe it is a matter of time, as patients need to request a login to the patient portal before self-monitoring can take place; and to get familiar with the portal before substitution of care can take place. Furthermore, substituting visits by self-monitoring is a relatively new way of diabetes care. Patients might need the time to feel they are able to do the required actions needed for self-monitoring and might need reassurance from their healthcare provider.[80] Healthcare providers might underestimate the capabilities of their patients and need time to experience this different way of monitoring as well.[26] In addition, a few healthcare providers mentioned they had decreased monitoring visits without asking patients to perform self-monitoring through the web portal.

Many physicians mentioned patient preference as reason for not adhering to advice for consultation or referral. The patients in the Netherlands have a longstanding relationship with their primary healthcare providers and might be hesitant to change treatment setting. However, it is uncertain whether the primary care providers discussed the options clearly enough and if patients were able to consider the consequences. Furthermore, while physicians focus on attaining targets for HbA1c, blood pressure and LDL-cholesterol, patients might be more focussed on avoiding hypoglycaemia. There are large differences in the views between patients and physicians concerning health status and diabetes management and treatment, e.g. physicians overestimate the satisfaction of patients about given diabetes information, their health status, and that the current treatment suited patient preferences.[81] Therefore, it is important that patients and physicians establish shared goals. Improved communication could reverse clinical inertia[82] A structured diabetes consultation model, with more focus on patient related factors, shared goal setting and decision making about for example the required care may result in more patient involvement.[83] In addition, if and when more patients will use the patient portal, advice messages need not only to be sent to physicians but their patients as well to include the patient in the decision making in an earlier stage. Doing so, patients might become more aware of the suboptimal diabetes management situation and hopefully can get stimulated to discuss the need for letting their general practitioner consult a medical specialist or to be referred to a specialist. Due to the low numbers of patients in our study with access to the portal we could not determine the effect of patients receiving this message.

The effect of the intervention on quality of care

Our intervention did not create a shift in treatment setting, but it did improve the combined score on process and outcome measures (QuED) **(Chapter 7)**. In two studies the use of physician reminders was associated with improved testing of diabetes measures, but not with intermediate outcomes.[84,85] In another study, healthcare providers who received computerized reminders alone did not show a tendency to intensify treatment, but when performance feedback was added, healthcare provider behaviour improved, and after three years proved to be sustainable. Intensification contributed independently to decrease of HbA1c.[86] The most recent study showed that an automated pop-up message in a diabetes EMR (a reminder of performing screening tests; a prompt to initiate treatment intensification; or an alert to potential adverse reaction), improved HbA1c and had no negative effect on workflow, and no (negative) impact on patient satisfaction.[87] However, 'alert fatigue' might become an issue and consensus over which EMR alerts have priority and diminishing the number of different alerts is necessary.[88]

Despite improvement of the QuED measure, most patients still did not meet their three target goals (HbA1c, blood pressure and LDL-cholesterol) **(Chapter 7)**. In two cohorts of type 2 diabetes patients in the Netherlands around 21-35%, 37-45% and 25-32% of patients with type 2 diabetes achieved 1, 2 or 3 targets respectively.[89,90] Another large cohort of type 2 diabetes patients found comparable numbers: 26% achieved single goal, 41% achieved dual goal and only 25% achieved triple goal.[91] The alert and advice that was given as a message at baseline to the healthcare professionals still applied to most patients after one year **(Chapter 6)**. This means that therapy in at least a proportion of the patients has not been successfully adjusted, which suggests clinical inertia, defined by the failure of healthcare professionals to initiate, intensify or de-intensify therapy when appropriate.[92,93]

In patients with diabetes clinical inertia is a worldwide problem. In the Netherlands, in 1283 patients with type 2 diabetes treated in general practice and with HbA1c >8%, blood pressure ≥140/85 mmHg or total cholesterol >5mmol/l, clinical inertia was present in about 45%, 68%, and 90% of patents respectively.[94] In Belgium, in patients with non-insulin treated type 2 diabetes in general practice, 59% had an HbA1c >7% for over one year without any treatment intensification.[95] A large cohort study in the UK in patients with type 2 diabetes and HbA1c >7.0% found that the median time to intensification with an additional oral antidiabetic drug (OAD) was 2.9 years for patients taking one OAD, and >7.2 years for those taking two OADs. For patients using one to three OADs the median time to start insulin treatment was > 6years.[96] In another large retrospective cohort in the UK, in patients with type 2 diabetes and HbA1c >7%, 26% of patients did not receive treatment intensification within 2 years.[97] Furthermore, studies in the UK, Croatia, the US, in Colombia and in a large hospital of Bahrain, all demonstrated considerable proportions of patients whose therapy had not been intensified for several years despite not achieving recommended treatment targets.[98–102] The consequences of clinical inertia in type 2 diabetes are serious. It is associated with significantly increased risks of myocardial infarction, stroke, cardiovascular events[97] and triple goal achievement is associated with a risk reduction of those complications and mortality.[91]

We did not evaluate whether the participating general practitioners in our study intensified therapy after they stated they had room for improvement within the primary care setting instead of consulting an internal medicine specialist or referring a patient. However, it is possible that after the first step in treatment intensification had been taken, further adjustments were delayed again.[103] Physicians are often willing to tolerate extended periods of mild hyperglycaemia.[67] Still, during follow-up of a whole year, most primary care patients showed insufficient improvement in targets met and remained incorrectly treated in solely primary care. General practitioners in both low target achievement and high target achievement UK practices felt the main reasons for clinical inertia were patient or system related. However, they had an inaccurate perception of the achievement of their own practice, thinking they scored better than they actually did.[104]

We must bear in mind that the alert in the EMR of patients not on treatment targets was aimed at shifting treatment allocation, which did not happen. Perhaps within the borders of the NHG guidelines no better intermediate outcomes could be achieved. Yet, according to the local management guideline, not achieving adequate glycaemic, blood pressure and lipid control are all reasons for e-consultation. It would be interesting to know whether the primary care providers in this study agree that the choice not to use e-consultation as a form of therapy intensification when targets are not met can be considered as clinical inertia. Sharing and allocating of diabetes care seems to result in a significant reduction of HbA1c.[105–107] However, a Cochrane review that included data from seven different studies, showed no net effect of shared care on glycaemic control. Importantly, this result was mainly based on studies in primary care populations with on average an already low HbA1c. On the contrary, hypertension, also in diabetes, was better controlled in shared versus usual care.[108] Therefore, the use of e-consultation can be an important step in improving diabetes care and this option might need more attention. In our study we did not interview general practitioners why this option was not used. It could have been because they were uncertain about the steps to take in the EMR or there could have been other reasons. At least, information or education about the possible benefits, and support in using the EMR system, are relatively easy to arrange.

Methodological considerations

We performed a cluster Randomised Controlled Trial to evaluate our intervention. We cannot rule out selection bias, even if over half of general practices and almost all internal medicine specialists participated. To evaluate if patients were treated at the correct setting we made an algorithm, based on specific items of the diabetes management guideline.[53] Most cut-off values were clear; however, we had to quantify several imprecisely formulated items (e.g. “persistent high level”) and this could have led to more patients in the wrong treatment setting at baseline, although it was done and agreed upon by a team of different diabetes care professionals. Also we could not take specifics into account to run the algorithm, e.g. whether there was progressive retinopathy or if a patient was already treated by specialist outside of the Diamuraal care group. Because we did not take mitigating circumstances into account when running the algorithm, the total percentage of patients in need for consultation or referral was somewhat overestimated.

The participating practices of this study are part of a care group that already has a long history of experience with improving the quality of diabetes care. Even before start of the care group in 2007, the primary care physicians and the internal medicine specialists of the outpatient clinic were working together to improve diabetes care. It is possible that this long time collaboration has given primary care providers the feeling that they are able to adjust treatment regimens without the need for consulting/referring to a specialist and hence, that adherence to our advice was not needed. Therefore, the high level of non-adherence in our study might not reflect the situation elsewhere. In order to built-in this advice message in practices in other places, it might need some adjustments, taking type of EMR and local working agreements into account.

Clinical implications and future studies

Our aim to create a better treatment allocation of patients with diabetes, with improvements in quality of diabetes care has not completely been achieved. Both guideline adherence and clinical inertia are a large problem worldwide and a solution has not yet been found due to the many factors that play a role. A meta-analysis on the effectiveness of quality improvement projects on diabetes care showed that many of them reduce HbA1c, both in strategies targeting patients (promotion of self-management, patient education and patient reminders) and in strategies targeting health systems (case management, team changes, electronic patient registry, facilitated relay of information to clinician). In improvement strategies targeting physicians this was only true in clinician reminders.[109]

Our intervention did not lead to guideline adherence for consultation and referral, but it did improve quality of care. Other studies have shown that physician reminders were associated with better process of diabetes care.[84,85] Furthermore, adding an electronic decision support tool in a EMR concerning the management of cardiovascular risk factors has been associated with improved guideline recommended prescribing in undertreated patients with type 2 diabetes at high risk.[110] In the Netherlands, delegation of diabetes care combined with computerized decision support and feedback did not improve HbA1c but reduced cardiovascular risk in type 2 diabetes patients.[111] This program was only cost effective in diabetes patients with cardiovascular disease.[112] It seems that adding a reminder in a EMR can play a role in supporting physicians in diabetes care. However, only a reminder is not enough; more (e.g. patient and physician education, adding decision aids) is needed to take the next step for consultation and referral.

Regarding the management guideline on consultation and (back)referral itself, several things need to be considered. First, lack of knowledge needs to be addressed. General practitioners are used to work with the NHG guideline, but less used to consult the LTA. The general practitioners might need to be reminded about the content of the LTA. The NHG-guideline itself provides only a small paragraph at the end of the guideline about criteria for consultation and referral, while the LTA is much more detailed. An option might be that this detailed information can be added to the current NHG guideline, instead of maintaining two different guidelines. Furthermore, the time it takes to reach consensus about local agreement and time for implementation needs to be taken into account. Secondly, lack of agreement needs to be addressed. All physicians working with the guideline need to be in agreement about the content. This means a more extensive agreement procedure and feedback from the field. Also, prioritising which goals need to be met, and making consultation or referral advices on other goals less strict might be in order, e.g. acceptance of higher values or replacing the advice to refer to a specialist into the advice to consult a specialist.

Thirdly, the guideline content needs to be clear and easy to use. Optimise guideline language and format might influence uptake, e.g. more clear definitions replacing phrases such as “not being achieved”, “periodic measurements” and “infrequent”.[113] And the possibility of the easy to use e-consultation needs to receive more attention.

eHealth Supported Diabetes Management

In this thesis two types of eHealth have been examined that could be useful in the support of diabetes management.

The first study addressed the patient portal, and we discussed the barriers and facilitators of its use. We proposed redesign of the portal in which experiences and wishes of patients are taken into account, and secondly, creating different types of portals. Not all patients might be interested, but many patients are and are willing to use the portal but need some support. To enhance this support, the diabetes care providers should be educated and stimulated. The interest in new types of eHealth will probably increase in the future, with the current younger generation already living in a more digital world. We should respond to this and see how their attitude will support diabetes care.

The second study showed in a cluster randomised design that adding an alert in the EMR to warn a physician did not result in patients shifting to the correct treatment setting. Awareness of the guideline, agreement about the content and the use of e-consultation need to be improved. Despite the non-adherence, the overall quality of care as measured with the QuED slightly improved, so adding the alert seems to diminish clinical inertia. In this way eHealth may help not only patients, but also healthcare providers.

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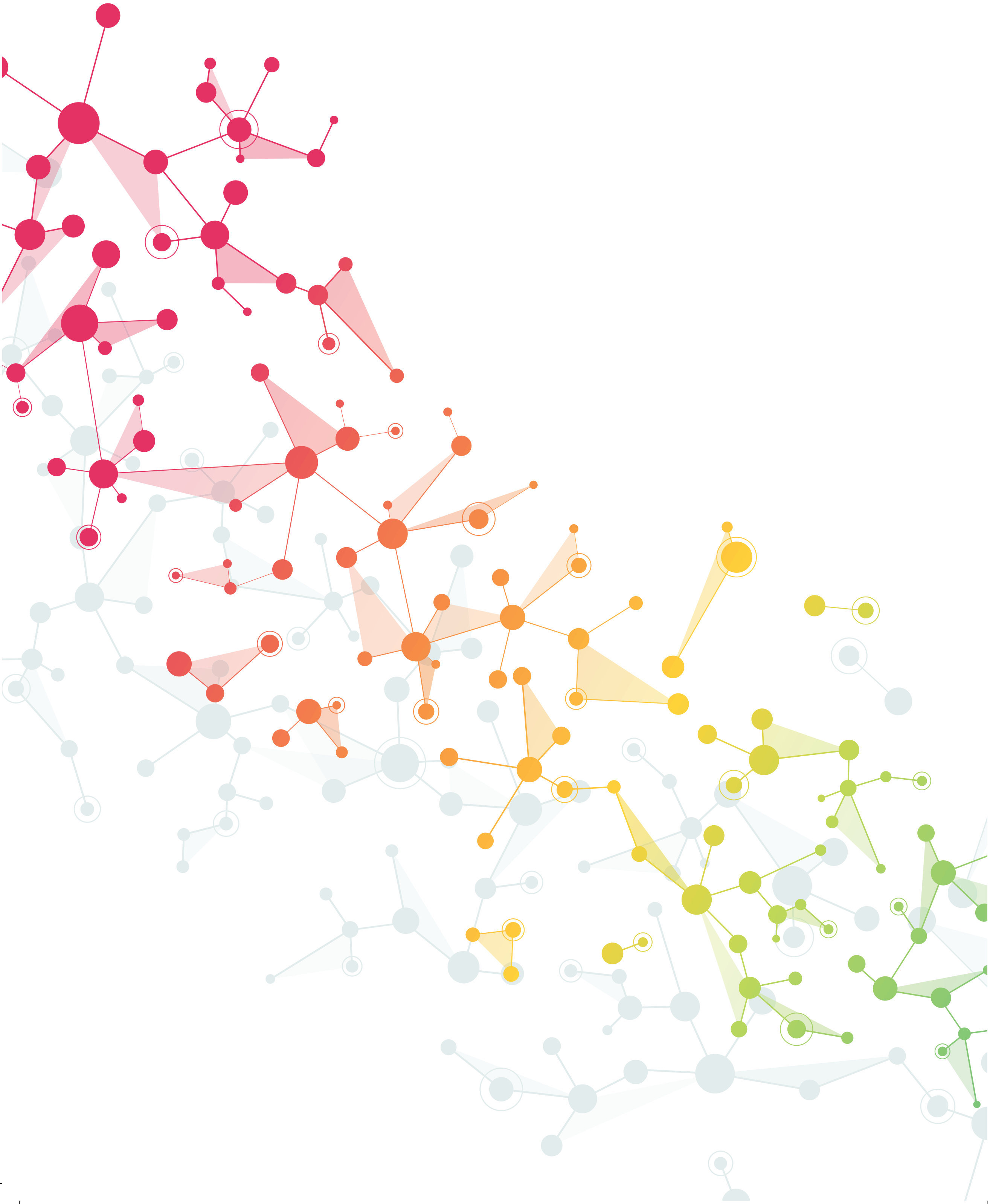


SUMMARY

Diabetes mellitus is a chronic metabolic disease, leading to severe complications, with an increasing worldwide prevalence of currently about 8.5% at the adults age (≥ 18 years). Type 1 diabetes is caused by an auto-immune reaction with destruction of beta cells in the pancreas. Patients with type 1 diabetes are insulin dependent and treatment takes place in the outpatient clinic. In type 2 diabetes there is both insulin resistance and inadequate insulin secretion, which causes high blood glucose levels, often in combination with elevated blood pressure and elevated cholesterol. Patients with type 2 diabetes are mostly treated with lifestyle advices and also often oral blood glucose lowering drugs, and if necessary insulin; in combination with blood pressure lowering drugs and cholesterol lowering drugs. With appropriate treatment and recommended lifestyle changes, the onset of complications can be delayed or prevented. In order to gain and / or maintain good cardiometabolic control, patients visit their healthcare provider four times a year. Most patients with type 2 diabetes are treated in primary care, and only patients in need of more complex care are referred to the outpatient clinic. To anticipate the rising number of patients with diabetes, the costs and the increasing workload of healthcare professionals, the organisation of diabetes care may need to change. Electronic healthcare (eHealth) is a technology that can be used to support patients and healthcare professionals in the management of diabetes care. In this thesis we assess two eHealth applications that can be used in the management of diabetes: a diabetes patient portal and a prompt in the medical record that alerts the healthcare professional if a patient with diabetes is not treated in the correct treatment setting. The studies were conducted among patients and healthcare providers within the care group of Diamuraal (in 2017 the name was changed into Huisartsen Eemland Zorg). In this care group the physicians of general practices and an outpatient clinic work together in the same diabetes electronic medical record (EMR) and patients can request access to the EMR using a patient portal (“Digitaal Logboek”).

PART 1: THE PATIENT PORTAL

We have conducted a survey among patients with type 1 and type 2 diabetes treated in the care group. In 2011 we sent 1500 patients with a login and 4500 patients without a login a questionnaire. It contained questions about patient characteristics and we added several validated questionnaires: the Diabetes Treatment Satisfaction Questionnaire (DTSQ) which measures satisfaction with diabetes treatment; the Problem Areas in Diabetes questionnaire (PAID) which measures diabetes-specific distress; the European Quality of Life scale (EQ-5D) which measures health status; and the Diabetes Management Self-Efficacy Scale (DMSES) which measures self-efficacy in patients with diabetes mellitus; and the validated diabetes Brief Diabetes Knowledge Test (BDKT). Furthermore, we designed two additional questionnaires: one for patients with a login and one for patients without a login. They were based on characteristics on the use of eHealth previously found in literature and there were also specific items about content from the "Digitaal Logboek".

In **Chapter 2** we describe the difference between patients with and without a login of the patient portal. There were 1390 patients who returned the questionnaire (response rate 31.6%). Patients with type 1 and type 2 were evaluated separately. 128 patients with type 1 diabetes returned our questionnaire and 89,9% had requested a login. Patients with a login were younger and more frequently treated by an internist and scored better on the insulin related questions of the BDKT. Of the 1262 patients with type 2 diabetes, only 41% had a login. The multivariable logistic regression analysis showed that the likelihood of having a login in patients with type 2 diabetes mellitus was independently associated with younger age, male gender, higher educational level, fluency in Dutch language, treatment by an internal medicine specialist, and the use of insulin and polypharmacy (insulin use $p<0.01$, all others $p<0.001$). We concluded that patients with type 1 diabetes request a login more frequently than patients with type 2 diabetes, and that there are many differences between patients with and without a login to the patient portal. Because of the difference in patients with a login in primary care and in the outpatient clinic, we speculate that healthcare professionals play an important role in their patients' decision to request a login. This study was of cross-sectional design, therefore we cannot be certain. We advised to study the differences between the groups in further detail before promoting eHealth for all. This way we can prevent losing a group of patients who could benefit from portal use.

In **Chapter 3** we explore both the reasons for using the patient portal and the barriers for starting to use it. Of the 1390 participants who returned the questionnaires 632 (45.5%) had a login and 758 (54.5%) did not ("non-users"). Of the patients with a login, 413 (65.3%) persons had accessed the patient portal 2 or more times; the "persistent users". Persistent users are using the Internet more often than non-users and use it also for searching information about their disease. Furthermore, 79.4% of the persistent users declared that they are the main user of the portal and 19.1% declared that someone else had access. Of the non-users, 21.4% declared that they would consider using the portal if someone could help, while 38.7% would not consider using the portal even if someone could help.

The main reasons for requesting a login was to reread information at home (75.5%), and the feeling that portal use would give them influence on their disease and treatment (32.0%).

The main reasons for not requesting a login were that patients were not aware of the portal (72.4%), and that they preferred to leave disease management to the physician (28.5%).

Of the patients without a login who were aware of the existence of the portal, 48.8% knew about the portal because their healthcare provider informed them. In comparison, 94.9% of the patients with a login were informed about the portal by their healthcare provider (p<0.001).

Regarding the usability of specific portal items, the non-users and the persistent users had different opinions. Persistent users perceived as most useful: (1) access to laboratory values with treatment target, and (2) rereading information at home; while the non-users speculated that most useful features would be: (1) summary of upcoming consultations, and (2) summary of their medications.

We concluded that unawareness of its existence is the main barrier of portal enrolment and that users and non-users perceive the usefulness of a portal differently. Thus, not only its existence but also the possible benefits of the portal for specific patients needs to be addressed by the physician to increase patient participation.

In **Chapter 4** we look in closer detail to the 632 patients who requested a login to the patient portal. We compared the 413 (65.3%) persistent users with the 219 (34.7%) patients who requested a login but never or once logged in (we named them "early quitters"). The multivariable logistic regression showed that the use of insulin (OR 2.07; 95%CI 1.18-3.62), more hyperglycaemic episodes (OR 1.30; 95%CI 1.14-1.49) and better diabetes knowledge (OR 1.02; 95%CI 1.01-1.03) increase the odds of becoming a persistent user.

All patients with a login appreciated most that they could reread information at home, the access to laboratory values and the treatment goals, but persistent users rated the usefulness of these items significantly higher than early quitters (rereading information at home: 89.6% versus 72.6%, p<0.001; access to laboratory values and treatment goals: 92.5% versus 72.1%, p<0.001).

Furthermore, the early quitters found the specific portal items less comprehensible compared to persistent users: the meaning of laboratory values (92.0% of the persistent users versus 77.1% of the early quitters found this comprehensible), the abbreviations used (75.8% versus 54.9%) and the medical phrasings used (69.4% versus 49.0%) (all p<0.001).

There were different recommendations for improvement: persistent users wanted to be

able to add their insulin units to the glucose diary and use the portal for supportive care (e.g. scheduling an appointment and receiving reminders), while early quitters felt that a diabetes portal could benefit from more information about medication and its adverse effects and functions that enable automatic uploading from glucose meters and also a request for medication-refills functionality.
We concluded that one uniform portal is not suitable for all patients and we proposed creating separate portal features for patients on insulin or not. Designing different portal features will meet the need of different patients and can take their wishes into account. Furthermore, when designing new portals or improve existing portals, the portal content needs to be understandable for all users..

In **Chapter 5** we look at the diabetes portal from the perspective of the healthcare professional. All physicians and nurses from the general practices and the outpatient clinic in the care group received a questionnaire in order to gain insight in their opinions on the diabetes patient portal and their working methods regarding the portal. One hundred and twenty-eight questionnaires could be analysed (response rate 56.6%). The majority of the respondents was of opinion that a portal improves patients' diabetes knowledge (91%) and the quality of care (73%). A clear majority of the professionals are of opinion that uploading glucose diary (94%) and patients access to laboratory values and clinical notes (91% and 71%) are important, however only 72%, 30% and 20% respectively of healthcare professionals recommended these features to patients. The healthcare professionals recommended the portal especially to patients with type 1 diabetes, to patients on insulin and patients younger than 65 years of age.
Regarding communication with patients about the possible use of the portal, the results showed that 65% of professionals inform their patients about the portal and only 45% of healthcare professionals handed-out the information leaflet and website address. Linear regression showed no association between number of patients with a login and time the practice had been using the portal, and there was also no association found between the opinions of the healthcare professionals about the portal and the number of patients with access to the patient portal in their practices. We concluded that physicians and nurses are positive about patients portals but that there is room for improvement in their working methods.

PART 2: ALERT MESSAGE IN THE EMR

The majority of patients with type 2 diabetes are treated in a primary care setting and only patients that are in need of more complex care are referred to a hospital-based internal medicine specialist. There is a national agreement (LTA) between primary and secondary care with clear indications for consultation of and referral to an internal medicine specialist, and, referral back to primary care. Correct treatment allocation is important to improve quality and cost-effectiveness of diabetes care. We designed an intervention in which either the general practitioner or the internal medicine specialist received an electronic advisory message in the EMR of the patients who were not treated to the correct setting according the national agreement. In order to assess the correctness of treatment setting, we created an algorithm using the LTA cut-off values of e.g. HbA1c, the systolic blood pressure, and LDL-cholesterol; but also the presence of complications was taken into account). Healthcare professionals did not receive a message in the records of patients who were assessed to be in the correct treatment setting (for example, patients in primary care with values on target and no complications whose records showed that at least one office visits was replaced by a self-monitoring report).

There were different types of advice: the general practitioner could receive one or more of the following advices: (1) to consult with an internal medicine specialist; (2) to refer to the internal medicine specialist; or (3) to instruct the patient to use the patient portal for self-monitoring instead of office visits. The internal medicine specialist could only receive one type of advice: referral back to the general practice, which was sent to the record of patients who had met their treatment targets and to the record of patients who were treated in the outpatient clinic and who had not met their target but who were stable for over one year.

We tested the intervention in a cluster randomised trial; i.e. the practices (including the patients within that practice) were randomised in either the intervention or the control group. The physicians in the control group were not alerted if their patient was not treated in the correct setting and the patients in the control group received care as usual.

In **Chapter 6** we evaluate the effectiveness of the intervention. We invited the healthcare providers of 66 primary care practices and of the 10 internal medicine practices. There were 47 practices (38 primary care and 9 internal medicine) included (response rate 61.8%). After inclusion of the practice, we invited the patients of the practice. There were 8388 patients invited and 2778 patients could be included (response rate 33.1%). At baseline we found that 57.7% of patients in the intervention and 56.0% of patients in the control group were not treated in the correct setting as stipulated in the LTA. After one year 12.4% of patients in the intervention and 10.6% of patients in the control group had shifted to the correct setting (p=0.30).

Advice to consult a specialist and advice to refer to a specialist could be sent simultaneously regarding the same patient. Advice most often (in 559 patients) regarded a consult with an internal medicine specialist, most frequently based on HbA1c values above target (31.1%) or signs of kidney complications (27.5%). In 451 patients there was advice for referral, mainly based on a systolic blood pressure above target (26.8%).

The advice to the internal medicine specialist on back-referral was followed more often than the advices to the general practitioners on consultation and referral (advice for consultation and referral were followed in 5.9% and 8.2% respectively, advice for self-monitoring was followed in 24.4%, and advice for back referral was followed in 34.5% of cases). Physicians were able to provide a reason in the EMR using a return message, if they decided not to follow the advice. The main reasons were the physicians preference to consider other treatment options first before consultation/referral (33.6% and 19.9% respectively) and not following the advice for back referral due to patients' preferences (10.5% and 8.1% respectively). We concluded that we could not find evidence that using the EMR to send advice on correct setting according to national agreement results in a shift of patients. We recommended that the content of the guideline needs to be discussed and that a more extensive agreement procedure is necessary before implementation.

In **Chapter 7** we evaluate the effect of the intervention on quality of care and patient satisfaction of the patients in primary care who were at start not treated in the correct setting. To evaluate quality of care we used the Quality of Care and Outcomes in Diabetes Type 2 scoring system (QuED), which is a combination of process and outcome measures and has a score range of 0 - 40 points. Furthermore, we analysed the number of targets met. For HbA1c the targets are:HbA1c ≤ 53 mmol/mol in age < 70 years or ≥ 70 year and no medication or only metformin; HbA1c ≤ 58 mmol/mol in age ≥ 70 years with two or more oral glucose lowering drugs or insulin and duration of diabetes < 10 years; and HbA1c ≤ 64 mmol/mol in age ≥ 70 years with two or more oral glucose lowering drugs or insulin with duration of diabetes ≥ 10 years). The target of the systolic blood pressure is: ≤ 140mmHg for age < 80 years, and ≤ 160 mmHg for age ≥80 years. The target of LDL-cholesterol is ≤2.5 mmol/l in all patients.

To measure patient satisfaction we sent participants the DTSQ. We used a generalised linear mixed model to determine the effect of the intervention and we adjusted for clustering, age, sex, baseline value and having a login of the patient portal.

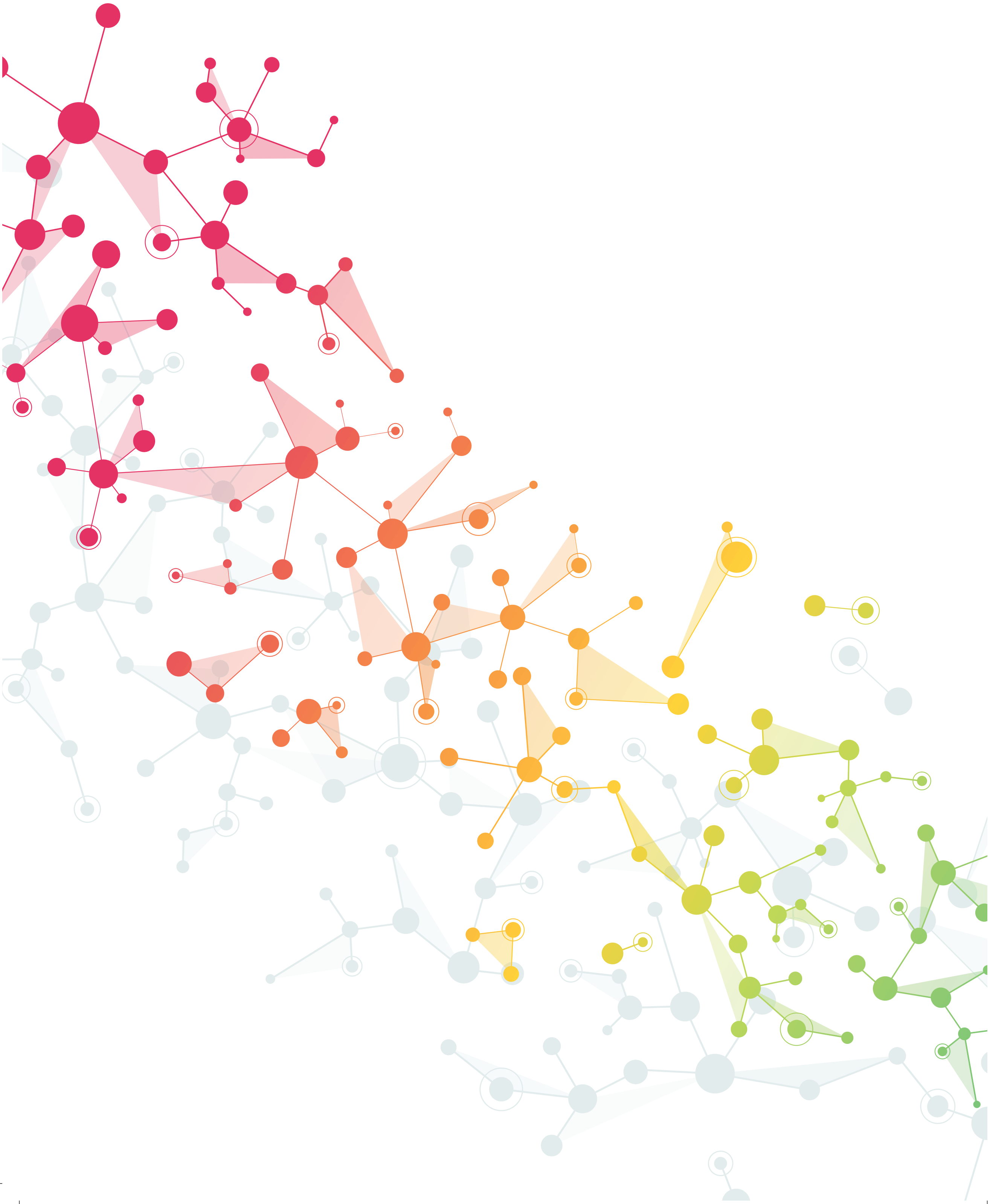
After one year, the QuED in the intervention group had improved from 24.1 to 26.1, thus a slight but statistically significant (p=0.04) better improvement than in the control group, where QuED went from 24.6 to 25.1. In 50.2% of the patients in the intervention group and in 50.1% of the control group two out of three targets were met, mainly the combination of HbA1c and blood pressure (38.4% in the intervention- and 38.1% in the control group). There were no differences between groups in outcome measures. Patient satisfaction was already high at start in both groups, with mean scores of 30.5 and 31.0 (out of 36) and this did not change. We concluded that prompting the general practitioner resulted in a small improvement in quality of diabetes care in patients that did not have adequate metabolic control, even when general practitioners did not actually consult an internal medicine specialist or refer the patient. However, we feel there remains room for improvement in meeting the three treatment targets.

In **Chapter 8** we discuss the implications of our findings in the context of more recent research work. Increasing evidence that not just organisation of care but also diabetes control may benefit from similar eHealth support, both for type 1 and type 2. In addition to better control, by offering functionalities like e-messaging and the being able to reread the reports of monitoring visits, the EMD meets the of many others than higher educated younger men. Healthcare institutions increasingly offer their patients access to their EMD. Patients however do not adopt these tools as often as desirable and notably diabetes patients may stay behind. Healthcare professionals in The Netherlands even seem more reluctant to give all patients access to the portal than the physicians and diabetes nurses.

So what needs to be done – bearing all these good reasons found in literature in mind as well as the positive attitude among the diabetes healthcare professionals – to motivate more patients to start using the diabetes patient portal? In the first part of chapter 8 we discuss that not all patients might be interested in using a patient portal, although many patients are willing but need some support, e.g. explanation of medical content or another appointed person having access to the portal. We proposed a portal redesign in which understandability of content and patients preferences are taken into account. Literature supports the relevance of zooming in on early quitters. Having identified differences between this category and the persistent users, we advised creating different types of portal features for specific subgroups, such as for patients who use insulin. The effects of redesign should be evaluated to optimise a portal's usability and effectiveness. Furthermore, we discuss the role of the healthcare provider in the use of a patient portal by patients. We advise additional training to help healthcare providers to discuss the portal and support the patient in using it. Additionally the assistance of a nurse practitioner or diabetes nurse who can spent some time navigating the portal together with the patient could be invaluable in supporting the patient's, e.g. in understanding of information. And finally, an item in the EMR to remind physicians and nurses to promote portal use can be added.

In the second part of **Chapter 8** we discuss that adding an alert to the EMR does not result in patients shifting to the correct treatment setting. Healthcare providers might not agree with the advice messages, probably partly due to the fact the algorithm could not take some of the nuances into account (e.g. we could not differentiate between retinopathy and progressive retinopathy, only the latter being a reason for referral) and partly due disagreement with some of the criteria for consultation or referral (e.g. referral in case of BMI ≥ 35 mg/m2). However, most advices were sent due to high HbA1c, systolic blood pressure and LDL-cholesterol. Digital consultation advices were hardly followed and this was motivated by the fact that the primary care professionals felt they still had room to make adjustments In treatment regimen themselves. Scarce literature in this field suggested that specifically on diabetes – as compared to other conditions or medical specialties - primary care physicians did not feel as much need for consultation of medical specialists, possibly because they felt confident in their own knowledge on diabetes treatment. However, notwithstanding the fact that the quality of diabetes care in The Netherlands is scoring very well among international statistics, we could still do better in helping patients to achieve their treatment targets.

Several issues regarding the LTA need improvement: from awareness of the LTA by reminding physicians, to local and regional agreement about the content with feedback from the field. Otherwise adherence remains low. Furthermore, we advised to prioritise which goals need to be met, and making consultation or referral advices on other goals less strict. We also recommend that the detailed information from the LTA can be added to the Dutch guidelines of General Practitioners, which is used more often (the so called NHG guideline). Furthermore, we also discuss that despite the non-adherence of physicians to the LTA-based advice in the EMD, the overall quality of care improved, so adding the alert seems beneficial.



SAMENVATTING

Diabetes mellitus is een chronische stofwisselingsziekte die kan leiden tot ernstige complicaties. Type 1 diabetes ontstaat door een auto-immuun reactie waarbij de insulineproducerende cellen in de alvleesklier worden aangevallen en mensen met dit type zijn afhankelijk van insulinegebruik. De behandeling vindt voornamelijk op de polikliniek in het ziekenhuis plaats. Bij type 2 diabetes is de insulineproductie verminderd en is het lichaam minder gevoelig voor insuline geworden, waardoor bloedglucosewaarden te hoog zijn, vaak in combinatie met een verhoogde bloeddruk en een verhoogd cholesterol. Mensen met type 2 diabetes worden in beginsel behandeld met adviezen voor een gezonde leefstijl, maar ook vaak met orale bloedglucose verlagende medicijnen en zo nodig insuline, alsmede met bloeddruk- en cholesterolverlagende medicatie. Met de juiste behandeling en de juiste veranderingen in de leefstijl kan het optreden van complicaties worden vertraagd of voorkomen. Patiënten komen daarvoor meestal vier keer per jaar op controle bij hun zorgverlener. Het merendeel van hen wordt in de huisartsenpraktijk behandeld, en alleen mensen met problemen worden naar de tweede lijn verwezen. Wereldwijd is ongeveer 8.5% van de mensen van 18 jaar of ouder bekend met diabetes en het aantal patiënten met type 2 diabetes zal de komende jaren sterk stijgen. Hierdoor zullen de kosten van de zorg en de werkdruk van zorgverleners toenemen. Om de juiste zorg op de juiste plaats te kunnen bieden aan het stijgende aantal patiënten met diabetes is het nodig dat de organisatie van de diabeteszorg kritisch wordt beoordeeld en zo nodig veranderd. Het bevorderen van beoogde veranderingen kan mogelijk worden ondersteund door het inzetten van digitale toepassingen in de zorg (‘eHealth’). Wij onderzochten twee eHealth toepassingen in de diabeteszorg. Eerst evalueerden we een diabetes patiëntenportaal. Vervolgens onderzochten we de effecten van een adviesbericht in het elektronisch medisch dossier, dat de zorgverlener erop attendeerde dat een patiënt met diabetes niet werd behandeld in de juiste behandelsetting, dat wil zeggen in de huisartsenpraktijk als dat volgens de Landelijke Transmurale Afspraken (LTA) bij de internist zou moeten, of andersom, bij de internist terwijl dat volgens de LTA in de huisartsenpraktijk zou moeten. De onderzoeken werden uitgevoerd onder patiënten en zorgverleners van de zorggroep Diamuraal (in 2017 is de naam veranderd in Huisartsen Eemland Zorg). In deze zorggroep werken huisartsen en de internisten van het Meander Medisch Centrum in Amersfoort samen in hetzelfde elektronisch diabetesdossier (EMD) en kunnen patiënten via een patiëntenportaal ("Digitaal Logboek") toegang tot het EMD aanvragen. Om dat te kunnen doen moeten patiënten wel eerst een ‘login’ aanvragen.

DEEL 1: HET PATIËNTENPORTAAL

Om te bestuderen hoe mensen met diabetes omgaan met het aanbod om gebruik te maken van een patiëntenportaal, hebben we een enquête verzonden onder patiënten met type 1 en type 2 diabetes die werden behandeld in de zorggroep. Eind 2011 verstuurden we een vragenlijst naar 1500 patiënten met een login en 4500 patiënten zonder login van dit Digitaal Logboek. De vragenlijst bevatte onder andere een aantal gevalideerde vragenlijsten: de Diabetes Treatment Satisfaction Questionnaire (DTSQ), die de tevredenheid over de behandeling van diabetes meet; de Problem Areas in Diabetes-vragenlijst (PAID) die specifiek de stress die samenhangt met diabetes meet; de Europese Quality of Life scale (EQ-5D) die de gezondheidsstatus meet, en de Diabetes Management Self-Efficacy Scale (DMSES) die meet hoeveel vertrouwen iemand heeft in de eigen bekwaamheid om invloed uit te oefenen op de behandeling van de diabetes. We voegden nog een gevalideerde beknopte diabetes-kennistest (BDKT) toe met algemene diabetes- en insuline-gerelateerde vragen. Naast bovengenoemde vragenlijsten hadden we twee vragenlijsten zelf ontworpen: één voor patiënten met een login en één voor patiënten zonder login. De items waren gebaseerd op in de literatuur bekende aspecten die van belang zijn bij het gebruik van eHealth, aangevuld met specifieke items over de inhoud van het "Digitaal Logboek".

In **hoofdstuk 2** wordt het verschil beschreven tussen patiënten met en zonder een login van het portaal. Dertienhonderdnegentig mensen reageerden op onze vragenlijst (antwoordpercentage 31.6%). Patiënten met type 1 en type 2 diabetes werden apart geëvalueerd. Er waren 128 mensen met type 1 diabetes, 89.9% had een login. Degenen met een login waren jonger en werden vaker behandeld door een internist. Ook scoorden ze beter op de insuline gerelateerde vragen van de BDKT. Er reageerden 1262 patiënten met type 2 diabetes, hiervan had slechts 41.0% een login. Uit de multivariabele regressie analyse bleek dat de mensen met een login jonger waren, vaker mannen waren, een hoger opleidingsniveau hadden, vaker vloeiend Nederlands spraken, vaker behandeld werden door een internist, en dat ze vaker insuline gebruikten en ook vaker vijf of meer verschillende soorten medicijnen (insuline gebruik $p<0.01$, de rest $p<0.001$).
We concludeerden dat patiënten met type 1 diabetes vaker om een login vragen dan patiënten met type 2 diabetes, en dat er veel verschillen zijn tussen patiënten met en zonder aanmelding bij het patiëntenportaal. Aangezien patiënten over een patiëntenportaal geïnformeerd worden door hun zorgverlener, vermoeden wij dat deze een grote rol speelt bij het aanvragen van een login door de patiënt, gezien de verschillen tussen aanvraag in eerste en tweede lijn. Aangezien dit een dwarsdoorsnedeonderzoek is, kunnen we dit echter niet zeker zeggen. Verder inzicht in de verschillen en de oorzaak/gevolgrelatie moet ons uiteindelijk ertoe in staat stellen dat we de gehele doelgroep voor innovatieve eHealth toepassingen bereiken. Zodoende kunnen we proberen te voorkomen dat een groep patiënten voor wat betreft eHealth de boot mist, terwijl ze juist baat zouden kunnen hebben bij het gebruik van een digitaal patiëntenportaal,

bijvoorbeeld de patiënten die hun behandeldoelen niet halen of patiënten die minder van het vereiste gezondheidsgedrag vertonen.

In **hoofdstuk 3** onderzoeken we zowel wat de redenen voor het gebruik van het patiëntenportaal zijn, als wat de barrières zijn om er een te gaan gebruiken. Het aantal mensen dat zich aanmeldt voor het diabetes patiëntenportaal neemt maar langzaam toe; theoretisch kan dit worden veroorzaakt door persoonskenmerken van de patiënt zelf (zoals leeftijd, geslacht en mate van complicaties), maar ook door het ontwerp van het portaal, de inhoud en de promotie ervan.
Van de totaal 1390 deelnemers die de vragenlijsten terug hadden gestuurd, hadden 632 (45.5%) personen een login en 758 (54.5%) personen niet ("niet-gebruikers"). Van de mensen met een login hadden 413 (65.3%) personen twee of meer keer ingelogd. We noemden die groep "terugkerende gebruikers". In dit hoofdstuk zijn de terugkerende gebruikers met de niet-gebruikers vergeleken. De terugkerende gebruikers bleken meer vertrouwd te zijn met internet in vergelijking met de niet-gebruikers: ze gebruikten het dagelijks en gebruikten internet ook vaker om informatie over hun diabetes op te zoeken. Bovendien verklaarde 79.4% van de terugkerende gebruikers dat zij de hoofdgebruiker van het Digitaal Logboek waren en 19.1% dat iemand anders ook toegang had. Van de niet-gebruikers gaf 21.4% aan dat ze zouden overwegen om het portaal te gebruiken als iemand zou kunnen helpen, terwijl 38.7% dit ook dan niet zou overwegen.
De belangrijkste redenen voor het aanvragen van een login (deelnemers konden meerdere antwoorden aankruisen) waren om thuis informatie opnieuw te lezen (75.5%) en het gevoel te hebben dat portaalgebruik de gebruiker invloed zou geven op zijn of haar ziekte en behandeling (32.0%). De belangrijkste redenen om juist geen login aan te vragen waren dat patiënten niet op de hoogte waren dat ze gebruik konden maken van het patiëntenportaal (72.4%), en/of dat zij er de voorkeur aan gaven de behandeling volledig aan de arts over te laten (28.5%).
Er was een opvallend verschil tussen terugkerende gebruikers en niet-gebruikers over hoe zij het Digitaal Logboek hadden ontdekt: slechts 48.8% van de niet-gebruikers kon zich herinneren de mogelijkheid van hun zorgverlener gehoord te hebben, terwijl 94.9% van de patiënten met een login erover had gehoord van hun arts of verpleegkundige ($p<0.001$).
Met betrekking tot het nut van verschillende onderdelen van het portaal waren er ook verschillen tussen de terugkerende gebruikers en de niet-gebruikers. Terugkerende gebruikers vonden de toegang tot laboratoriumwaarden met daarbij vermeld het behandeldoel en het herlezen van informatie thuis het meest nuttige onderdeel. Ook aan de niet-gebruikers was gevraagd welke onderdelen van het portaal voor hen van nut zouden kunnen zijn; zij gaven aan dat een overzicht van de benodigde controles en een overzicht van het medicijngebruik belangrijk zijn.
We concludeerden dat de meeste mensen die geen login hebben aangevraagd niet wisten dat het patiëntenportaal überhaupt bestaat. Verder beoordeelden de terugkerende gebruikers en niet-gebruikers het nut van een portaal verschillend. Zowel het bestaan

als de mogelijkheden van het portaal voor specifieke patiënten moeten door de behandelend zorgverlener worden besproken om de patiëntenparticipatie te vergroten.

In **hoofdstuk 4** kijken we in detail naar de 632 patiënten die een login voor het patiëntenportaal hadden aangevraagd. We vergeleken de 413 (65.3%) terugkerende gebruikers met de 219 (34.7%) patiënten die na het verkrijgen van het login nooit of maar één keer ingelogd hadden ("vroegtijdige verlaters"). Hoewel beide groepen patiënten een login bij het Digitaal Logboek hadden aangevraagd, hadden ze verschillende persoonskenmerken en zagen ze het nut van het portaal anders. In de multivariabele logistische regressie analyse bleek dat gebruik van insuline (OR 2.07; 95%CI 1.18-3.62), meer hyperglykemische episodes (OR 1.30; 95%CI 1.14-1.49) en een betere diabeteskennis (OR 1.02; 95%CI 1.01-1.03) de kans verhoogden om een terugkerende gebruiker te worden, terwijl een hoger HbA1c deze kans juist verlaagde (OR 0.97; 95%CI 0.95-0.99).

Alle patiënten waardeerden dat ze thuis informatie konden nalezen en dat ze toegang hadden tot hun laboratoriumwaarden en de behandeldoelen. De terugkerende gebruikers beoordeelden het nut hiervan echter aanzienlijk beter dan de vroegtijdige verlaters (informatie nalezen: 89.6% versus 72.6%, $p<0.001$; toegang tot laboratoriumwaarden en behandeldoelen: 92.5% versus 72.1%, $p<0.001$). De vroegtijdige verlaters vonden daarnaast de informatie die ze terug konden vinden in het Digitaal Logboek minder begrijpelijk, zoals de betekenis van laboratoriumwaarden (92.0% van de terugkerende gebruikers versus 77.1% van de vroegtijdige verlaters vond het duidelijk; $p<0.001$), de betekenis van de gebruikte afkortingen (75.8% versus 54.9%, $p<0.001$) en de medische uitdrukkingen (69.4% versus 49.0%, $p<0.001$).

Er waren ook verschillende aanbevelingen voor verbetering van het Digitaal Logboek: terugkerende gebruikers wilden de door hen gespoten insuline-eenheden aan het glucosedagboek kunnen toevoegen en daarnaast het Logboek kunnen gebruiken voor ondersteunende zorg, bijvoorbeeld het plannen van een afspraak en het ontvangen van herinneringen. De vroegtijdige verlaters waren echter van mening dat een diabetesportaal beter wordt met meer informatie over medicatie en bijwerkingen en wanneer automatische upload van gegevens uit de glucosemeters naar het Logboek mogelijk wordt.

We concludeerden dat één en hetzelfde patiëntenportaal niet geschikt is voor iedereen. We stelden voor om aparte portalen te ontwerpen, één voor patiënten met insuline en één voor patiënten die geen insuline nodig hebben. Bij het ontwerpen van verschillende soorten portalen moet met de verschillende wensen rekening worden gehouden. Verder moet bij het ontwerpen van nieuwe patiëntenportalen of bij het aanpassen van bestaande portalen de inhoud ook zodanig duidelijk worden aangeboden dat iedereen begrijpt wat de afkortingen en medische termen betekenen.

In **hoofdstuk 5** bekijken we het diabetesportaal vanuit het perspectief van de zorgverlener. We hebben een enquête verzonden aan alle artsen, praktijkondersteuners en diabetesverpleegkundigen van de huisartsenpraktijken en de polikliniek van het ziekenhuis in de zorggroep. Hiermee wilden we zicht krijgen op hun mening over het patiëntenportaal en inzicht in hun werkwijze met betrekking tot het portaal. Honderdachtentwintig vragenlijsten konden worden geanalyseerd (responspercentage 56.6%).

Een ruime meerderheid van de respondenten was van mening dat door het portaal de diabeteskennis van patiënten en de kwaliteit van de zorg verbeteren, respectievelijk 91% en 73%.

Er was een discrepantie tussen wat zorgverleners belangrijk vonden en wat ze aan de patiënt aanraadden om te raadplegen of te gebruiken. Het uploaden van een glucosedagboek was volgens 94% van de zorgverleners belangrijk, maar slechts 72% raadde het patiënten aan. Net als het bekijken door patiënten van laboratoriumwaarden (volgens 91% belangrijk, door 30% werd het aangeraden) en het nalezen van klinische notities (volgens 71% belangrijk, door 20% aangeraden). Het patiëntenportaal werd met name aangeraden aan patiënten met type 1 diabetes, aan patiënten die insuline gebruiken en aan patiënten onder de 65 jaar.

Met betrekking tot communicatie met patiënten over het mogelijke gebruik van de portaal bleek dat 65% van de zorgverleners hun patiënten informeerde over het Logboek, 45% gaf de informatiefolder en het webadres mee, 30% vroeg waarom een patiënt geïnteresseerd is of niet en 22% kwam op dit onderwerp terug in een volgend consult. Lineaire regressie liet geen associatie zien tussen het aantal patiënten met een login en het aantal jaren dat de praktijk gebruik maakt van het portaal en er was ook geen correlatie tussen de mening van de zorgverlener over het nut van het portaal en het aantal patiënten met een login in hun praktijk.

We concludeerden dat zorgverleners positief zijn over het patiëntenportaal, maar dat er verbetering mogelijk is in de manier waarop ze het met een patiënt bespreken en het gebruik ervan stimuleren.

DEEL 2: ADVIESBERICHT IN HET ELEKTRONISCH MEDISCH DOSSIER

Het merendeel van de patiënten met type 2 diabetes wordt behandeld binnen de huisartsenpraktijk, meestal drie maal per jaar door de praktijkondersteuner en eenmaal door de huisarts. Alleen patiënten die complexere zorg nodig hebben worden doorverwezen naar de internist in het ziekenhuis. Er bestaat een landelijke transmurale afspraak (LTA) tussen huisarts en internist met duidelijke indicaties voor consultatie en verwijzing naar de internist. Daarnaast zijn er duidelijke indicaties voor terugverwijzing door de internist van de polikliniek naar de eerste lijn. In verband met de kwaliteit van de zorg en met kostenbeheersing is het belangrijk de verschillende patiënten op de juiste plaats te behandelen.

We hebben een interventie ontworpen waarbij de huisarts of de internist bij het openen van het elektronisch medisch dossier van een patiënt die niet volgens de LTA werd behandeld een advies kreeg over het behandelteam waarbinnen de behandeling plaats zou moeten vinden. Hiervoor hebben we per persoon gekeken of ze volgens de criteria van de LTA terecht in de eerste of tweede lijn behandeld werden (gebaseerd op o.a. HbA1c, systolische bloeddruk, LDL-cholesterol, maar ook de aanwezigheid van complicaties). Hiervoor hebben we een algoritme gemaakt waarin alle variabelen werden vergeleken met de waarden van de geïncludeerde patiënten. Als de patiënt "op de juiste plaats" behandeld werd, volgde geen advies in het EMD. Bijvoorbeeld: bij een 62-jarige man, die behandeld werd in de huisartsenpraktijk en gedurende meer dan een jaar minstens twee waardes van HbA1c >53 mmol/mol had, werd een automatisch advies in het EMD verzonden, gericht op consultatie van de internist.

De huisarts kon één of meer van de volgende adviezen ontvangen: (1) overleggen met een internist (= consultatie), de huisarts blijft hoofdbehandelaar; (2) verwijzen naar de internist, de specialist wordt in dit geval hoofdbehandelaar; of (3) om de patiënt te instrueren het Digitaal Logboek te gebruiken voor zelfcontrole in plaats van controle op de praktijk. De internist kon slechts één advies ontvangen: terugverwijzing naar de huisartsenpraktijk. Het betrof hier patiënten bij wie de streefwaarden inmiddels waren gehaald, of mensen die meer dan een jaar in de tweede lijn werden behandeld en bij wie de streefwaarden nog niet gehaald waren maar wel stabiel waren gebleven het voorgaande jaar en bij wie geen nieuwe complicaties waren opgetreden.

We testten de effectiviteit van deze interventie in een cluster gerandomiseerde trial. Hierbij worden praktijken door loting in een interventie- en een controlegroep verdeeld. Dus alle zorgverleners én alle patiënten van een bepaalde praktijk werden als geheel gerandomiseerd in een van beide groepen. Alleen de artsen van de interventiegroep kregen zo nodig een advies via het EMD. De artsen van de controlegroep kregen geen waarschuwing als hun patiënt niet in de juiste setting werd behandeld.

In **hoofdstuk 6** evalueren we de effectiviteit van deze interventie. Er waren 66 huisartsenpraktijken en de tien internisten uit het diabetesteam van het Meander Medisch Centrum uitgenodigd om mee te doen. Er konden 47 praktijken (61.8%) (38 huisartsenpraktijken en 9 internistenpraktijken) geïncludeerd worden. Vervolgens werden 8388 patiënten uitgenodigd, hiervan wilden 2778 (33.1%) patiënten meedoen. Bij het begin van de studie vonden we dat meer dan de helft (57.7% van de patiënten in de interventie en 56.0% van de patiënten in de controlegroep) niet in de juiste setting werden behandeld zoals afgesproken in de LTA. Aan het eind van de studie, na één jaar, waren 12.4% van de patiënten in de interventie- en 10.6% van de patiënten in de controlegroep verschoven naar het volgens de LTA wél geschikte behandelteam en kregen de praktijken van huisartsen en internisten bij het openen van het dossier van deze patiënten geen advies meer. Dit verschil tussen beide groepen was niet significant (p = 0.30).

Het advies bij 559 personen om een internist te consulteren bleek vooral gebaseerd op te hoge HbA1c waarden (31.1%) of op aanwijzingen voor nierproblemen (27.5%). Het advies bij 451 personen om hen naar de internist te verwijzen was in 26.8% van de gevallen gebaseerd op een langdurig te hoge systolische bloeddruk.

De adviezen aan de internist werden vaker opgevolgd dan de adviezen aan de huisartsen (advies om te consulteren werd in 5.9% van de gevallen opgevolgd, advies om te verwijzen in 8.2%, advies voor zelf-monitoring in 24.4% en advies om terug te verwijzen in 34.5%). Als praktijken besloten om het advies niet op te volgen konden ze daar in het EMD middels een bericht retour een reden voor opgeven. De belangrijkste redenen voor het niet opvolgen van het advies waren dat de praktijken de voorkeur gaven om eerst zelf nog andere behandelingsopties te overwegen vóórdat ze zouden consulteren / verwijzen (33.6% resp. 19.9%). Daarnaast werd in 10.5% resp. 8.1% van de gevallen als reden opgegeven dat het advies niet opgevolgd was vanwege de voorkeur van de patiënt.

We concludeerden dat het toevoegen van een advies in het EMD niet tot gevolg had dat de patiënt verschoof naar de volgens de LTA juiste behandelsetting. We vermoeden dat met name de huisartsen het vaak niet eens zijn met consult- en verwijscriteria van de LTA. We adviseerden om de inhoud van de LTA uitgebreider te bespreken met alle huisartsen en dat er eerst breder draagvlak gevonden moet worden alvorens de LTA te implementeren.

In **hoofdstuk 7** evalueren we het effect van de interventie op de kwaliteit van zorg voor en de tevredenheid van patiënten. Dit betrof uitsluitend de patiënten in de eerste lijn die aan het begin niet behandeld waren in de juiste setting. Om de kwaliteit van de zorg te evalueren, gebruikten we namelijk de Quality of Care and Outcomes in Diabetes Type 2 score(QuED). Deze score bestaat uit een combinatie van uitkomst- (HbA1c, bloeddruk en LDL-cholesterol) en procesindicatoren (hoe vaak zijn deze waarden gemeten en is er adequaat medicatie voorgeschreven indien nodig). De score varieert van 0 tot 40. Verder hebben we het aantal behaalde behandeldoelen geanalyseerd. Die behandeldoelen zijn met betrekking tot HbAc1: ≤53mmol/mol bij leeftijd < 70 jaar, of ≥ 70 jaar met ten hoogste alleen metforminegebruik; streefwaarde ≤58mmol/mol bij leeftijd > 70 jaar met gebruik van twee orale middelen of insuline en diabetesduur korten dan 10 jaar; streefwaarde ≤64mmol/mol bij dezelfde patiënt maar dan met een diabetesduur meer dan 10 jaar). Voor de systolische bloeddruk gelden de volgende streefwaarden: bij leeftijd < 80 jaar ≤140 mmHg en bij een leeftijd ≥ 80 jaar ≤160 mmHg); voor het LDL-cholesterol geldt een streefwaarde ≤2.5mmol/l. Om de tevredenheid van de patiënt te meten hebben we de deelnemers de DTSQ gestuurd. We hebben een generalised linear mixed model gebruikt om de effectiviteit van de interventie te bepalen, waarbij we hebben gecorrigeerd voor clustering, leeftijd, geslacht, baselinewaarde en inloggen op het patiëntenportaal.

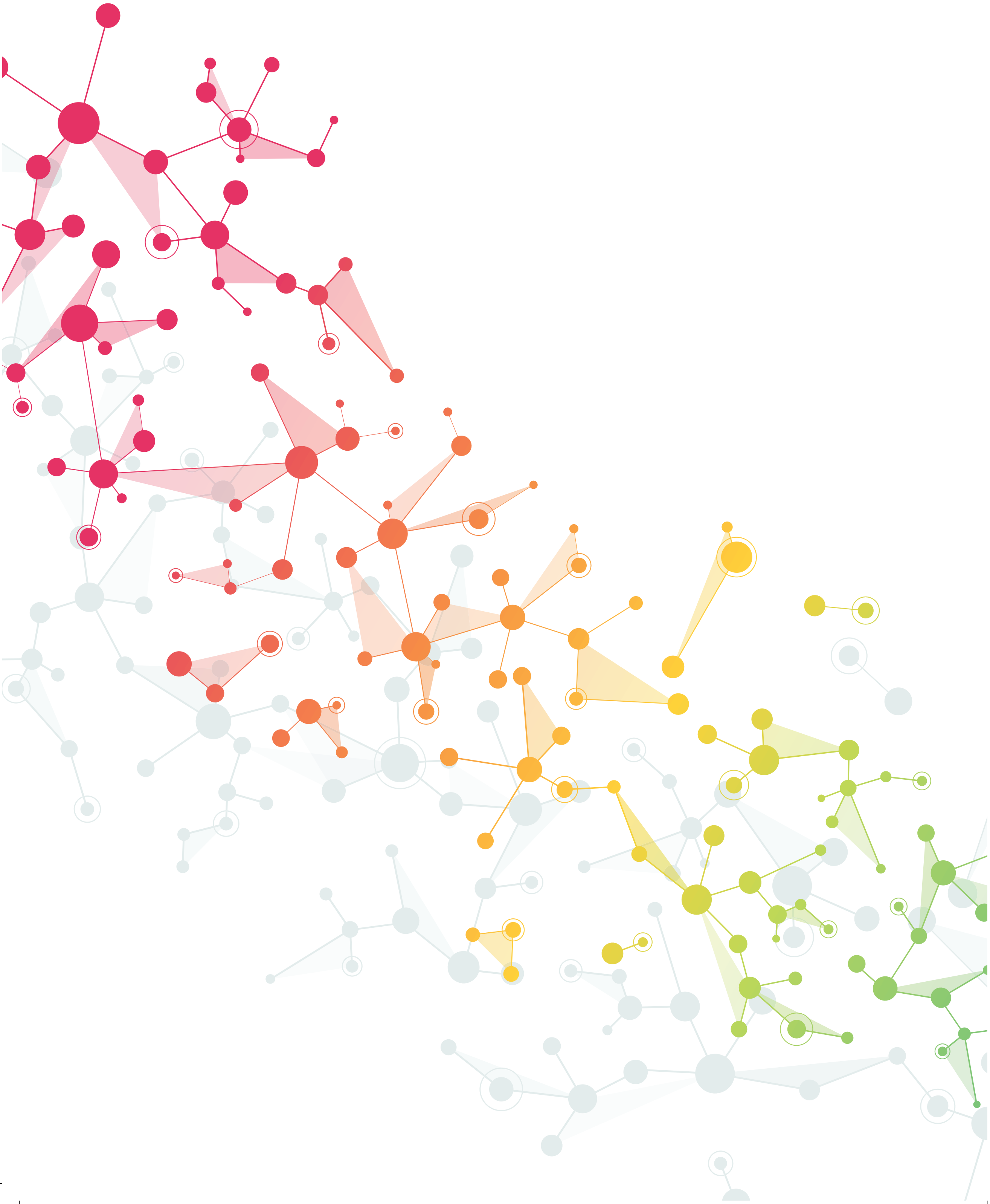
Na een jaar was de QuED in de interventiegroep verbeterd van 24.1 naar 26.1. Deze verbetering was sterker dan de verbetering in de controlegroep (die liep van 24.6 naar 25.1) en het verschil was klein maar wel significant (p = 0.04). In zowel de interventie- als de controlegroep behaalde de helft van de patiënten (50.2% van de interventie en 50.1% van de controlegroep) twee van de drie doelen, voornamelijk de combinatie van HbA1c en bloeddruk (38.4% van de interventie- en 38.1% van de controlegroep). Er waren geen verschillen tussen beide groepen in de gemiddelden van de uitkomstmaten. De tevredenheid van de patiënten over de diabeteszorg was bij de start van de studie al hoog in beide groepen met een gemiddelde score van 30.5 resp. 31.0 (bij een maximumscore 36) en dit veranderde niet.

We concludeerden dat het adviseren aan de huisarts om de behandelsetting te veranderen resulteerde in een geringe verbetering van diabeteszorg, ook al werd dat advies maar in een klein deel van de gevallen opgevolgd, zoals we in het vorige hoofdstuk lieten zien. We zijn echter van mening dat er nog ruimte voor verbetering is zodat alle drie behandeldoelen worden gehaald.

In **hoofdstuk 8** staan we stil bij de implicaties van onze bevindingen, in de context van gegevens uit onderzoek van anderen op het gebied van eHealth. Er is toenemend bewijs dat niet alleen de organisatie van zorg maar ook het bereiken van een betere regulatie zoals lager HbA1c bevorderd kan worden door vergelijkbare eHealth ondersteuning. Dit geldt voor zowel type 1 als type 2 diabetes. Naast de bijdrage in betere regulatie voorzien functionaliteiten als elektronisch berichtenverkeer en het kunnen nalezen van consulten over de diabetesbehandeling ook in een behoefte van veel andere patiënten dan hoger opgeleide jongere mannen. Steeds meer instellingen bieden hun patiënten de mogelijkheid tot gebruik van een portaal. De patiënten maken daar echter niet ruimschoots gebruik van en er is vergelijkend onderzoek waar de diabetespatiënten hierin notabene nog achter blijven op andere patiënten. Buiten de diabeteszorg lijkt er in Nederland bovendien meer terughoudendheid bij zorgverleners te bestaan over het bieden van toegang tot het patiëntendossier dan in de door ons bevraagde groep.

Wat moet er dan gebeuren om - met al deze goede redenen ondersteund door literatuur én positieve overtuigingen bij de zorgverleners - meer patiënten gebruik te laten maken van het portaal voor hun diabeteszorg? Niet alle patiënten zijn geïnteresseerd in het gebruik van een patiëntenportaal. Daar staat tegenover dat patiënten wel bereid zijn gebruik te maken van het portaal, maar zij hebben ondersteuning nodig, bijvoorbeeld door uitleg van de medische termen of door een door de patiënt toegewezen familielid ook (gedeeltelijk) toegang tot het portaal te geven. We hebben voorgesteld dat er nog eens goed gekeken moet worden naar de inhoud en vormgeving van het patiëntenportaal, waarbij rekening wordt gehouden met de ervaringen en wensen van patiënten. De literatuur ondersteunt dat de 'vroege verlaters' een interessante doelgroep is. Na deze groep te hebben vergeleken met de terugkerende gebruikers hebben wij geadviseerd om verschillende soorten patiëntenportalen te ontwerpen waarbij de behoeften van verschillende categorieën patiënten centraal komen te staan (bijvoorbeeld een portaal voor mensen die insuline gebruiken en een andere voor mensen die hun aandoening behandelen met dieet en/of orale medicatie). Dit vernieuwde portaal moet wel steeds opnieuw worden geëvalueerd en aangepast om de bruikbaarheid en effectiviteit ervan te optimaliseren. Om te leren hoe het portaal met de patiënt besproken kan worden en de patiënt verder kan worden ondersteund, zouden zorgverleners een training kunnen volgen. Ook kan de hulp worden ingeroepen van een diabetesverpleegkundige of praktijkondersteuner die meer tijd heeft om met de patiënt mee te kijken tijdens het gebruik van het portaal. Een derde optie is het inbouwen van bijvoorbeeld een checkbox in het EMD die de zorgverlener helpt herinneren om het portaal met een patiënt te bespreken.

Met betrekking tot de LTA kwamen we in het tweede deel van **hoofstuk 8** tot de conclusie dat zorgverleners het niet eens zijn met (een deel van) de berichten die wij verzonden. Dit kan komen doordat ons algoritme en het EMR niet in staat zijn om nuances mee te nemen (zoals niet verwijzen in geval van aanwezigheid van retinopathie maar wel verwijzen in geval van progressieve retinopathie), maar ook doordat zorgverleners het niet eens lijken te zijn met bepaalde verwijscriteria (zoals verwijzen bij een BMI ≥35kg/m2). De meeste adviezen waren gegeven op basis van te hoge waarden van HbA1c, systolische bloeddruk en LDL-cholesterol. De adviezen, veelal om de internist digitaal te consulteren, werden weinig gevolgd en als redenen werd aangevoerd dat de huisartsenpraktijken nog ruimte zagen om zelf de waarden te verbeteren. In de literatuur zijn voorzichtige aanwijzingen dat ook internationaal de eerste lijn met name voor diabeteszorg minder urgentie voelt om digitaal de tweede lijn te consulteren, mogelijk omdat er voldoende vertrouwen in eigen kunnen is. Hoewel de diabeteszorg in Nederland zeer positief afsteekt bij internationale statistieken, is echter ook in ons land nog verbetering wenselijk als het gaat om het behalen van behandeldoelen uit de richtlijnen. We adviseerden om de LTA beter onder de aandacht te brengen van de zorgverleners en menen dat op plaatselijk / regionaal niveau op brede schaal overeenstemming bereikt moet worden over de inhoud van de LTA. Verder adviseerden we om duidelijk te maken welke behandeldoelen prioriteit hebben, zodat de overige behandeldoelen met minder strikte consultatie- / verwijscriteria af kunnen. Mogelijk helpt het als gedetailleerde informatie van de LTA wordt toegevoegd aan de meer gebruikte klinische richtlijn over type 2 diabetes van de huisartsen (de NHG-standaard). We bespreken ook dat, ondanks dat de adviezen van de LTA niet zijn opgevolgd, de kwaliteit van diabeteszorg wel verbeterd is, al is het verschil niet groot. Blijkbaar hebben zorgverleners hun zorg toch enigszins aangepast naar aanleiding van het advies in het EMD. Het toevoegen van zo’n signaal lijkt dus toch nuttig.



DANKWOORD

"Wisdom comes from experience. Experience is often a result of lack of wisdom.”
Terry Pratchett

Mijn promotietraject heeft ongeveer zevenenhalf jaar geduurd. Toen ik begon had ik geen idee hoe lang deze reis zou duren en wat er allemaal zou gebeuren in die tijd. Ik heb twee mooie dochters gekregen, de huisartsopleiding doorlopen en prachtige landen bezocht. Ik heb ook veel nieuwe mensen leren kennen, waaronder een aantal vrienden voor het leven. De tijd is voorbij gevlogen.

Dit proefschrift zou niet tot stand zijn gekomen zonder de hulp van veel heel mensen. Ik kan niet iedereen noemen, daarom beperk ik mij tot de mensen die het meest hebben bijgedragen aan deze promotie die ik hierbij graag wil bedanken.

Allereerst mijn promotor prof.dr. G.E.H.M. Rutten. Beste Guy, bedankt voor de kans die je mij hebt gegeven om met dit onderzoek aan de slag te gaan. Je visie en perspectief hebben ervoor gezorgd dat we steeds weer verder kwamen. Ik heb veel van je geleerd. Bedankt voor je geduld.

Dr. L.T. Dijkhorst-Oei, beste Lioe-Ting. Met dank aan jou ben ik bij dit project betrokken geraakt. Je scherpe inzicht en oog voor zowel context als detail hebben mij meer dan eens goed verder geholpen. Het maakte niet uit of ik je diep in de nacht of (erg) vroeg in de ochtend mailde, je had altijd aandacht en tijd om mijn vragen te beantwoorden, mijn zinnen te verbeteren en het helpen mijn gedachten te verhelderen. Dank je voor inzet en steun.

Dr. R.C. Vos, beste Rimke. Halverwege tijdens dit traject ben jij mijn co-promotor geworden. Samen met jou heb ik naar (voor mij) lastige analysen gekeken en nagedacht over onze bevindingen. Je kan ingewikkelde dingen vaak helder en duidelijk uitleggen, en ik kon altijd bij je terecht met nog meer vragen. Dat heb ik erg gewaardeerd, dank daarvoor.

Er zijn ook andere onderzoekers wil ik bedanken voor hun bijdrage: dr. J.W.J. Beulens en P. Westers voor hun bijdrage aan het onderzoek en de artikelen. En dr. K.J. Gorter, beste Kees, jij was in de eerste jaren van mijn onderzoek als co-promotor betrokken bij dit project, dank je wel voor je begeleiding.

Prof. dr. Verheij, prof. dr. Moons, dr. Westerink, prof. dr. Tack en prof. dr. Chavannes, bedankt dat jullie bereid waren om dit proefschrift te lezen en kritisch te beoordelen.

Dit project was nooit gelukt zonder alle mensen die wilden deelnemen aan het onderzoek. Allereerst wil ik alle patiënten bedanken voor het invullen en terugsturen van de vragenlijsten. Zonder jullie allen was er geen onderzoek mogelijk geweest. Daarnaast alle huisartsen, praktijkondersteuners, internisten en diabetesverpleegkundigen: bedankt dat jullie wilden meedoen aan het onderzoek, de tijd die is gaan zitten in het beantwoorden en retour sturen van de vragenlijsten en elektronische berichten.

Dit onderzoek was er ook niet geweest zonder de hulp vanuit Diamuraal. Marian en Monique, bedankt voor het beantwoorden van al mijn vragen, de hulp bij de logistiek, het aannemen van telefoontjes van deelnemers, en het aanleveren van informatie. Leo, dank je voor hulp om de informatie over dit onderzoek onder de huisartsen te verspreiden. Verder wil ik de mensen bij Portavita bedanken voor het mogelijk maken van het alert naar de zorgverleners, en met name Jaco, omdat je telkens mijn vragen geduldig beantwoorde en geen enkele irritatie hebt laten blijken als ik weer wat in het algoritme wilde aanpassen.

De 6.101-club! Anoukh, Maarten, Manon, Noor, Sara, Sophie, Willemijn, en uiteraard ook Stavros, Julien en Floriaan. In onze kamer was het altijd gezellig, met gesprekken over de meest uiteenlopende onderwerpen. Ik herinner mij vooral lekker samen koffie drinken, soms met heerlijke chocolade (bedankt Martina!), diverse uitjes, etentjes en borrels, pasta maken, crêpes eten, Bob Ross, de kerstmarkt in Duitsland en BBQ in Nijmegen. En natuurlijk jullie hulp bij het inpakken van de vragenlijsten voor de deelnemers. Wat waren het er veel! Het spijt me van de telefoon. Als laatste van ons groepje promoveer ik nu eindelijk ook. Maarten, naast de gezelligheid in de kamer, ook dank voor al je hulp en je (geduldige) uitleg en antwoorden op alle statistische vragen waarmee ik je heb lastig gevallen. Bedankt dat je paranimf wil zijn.

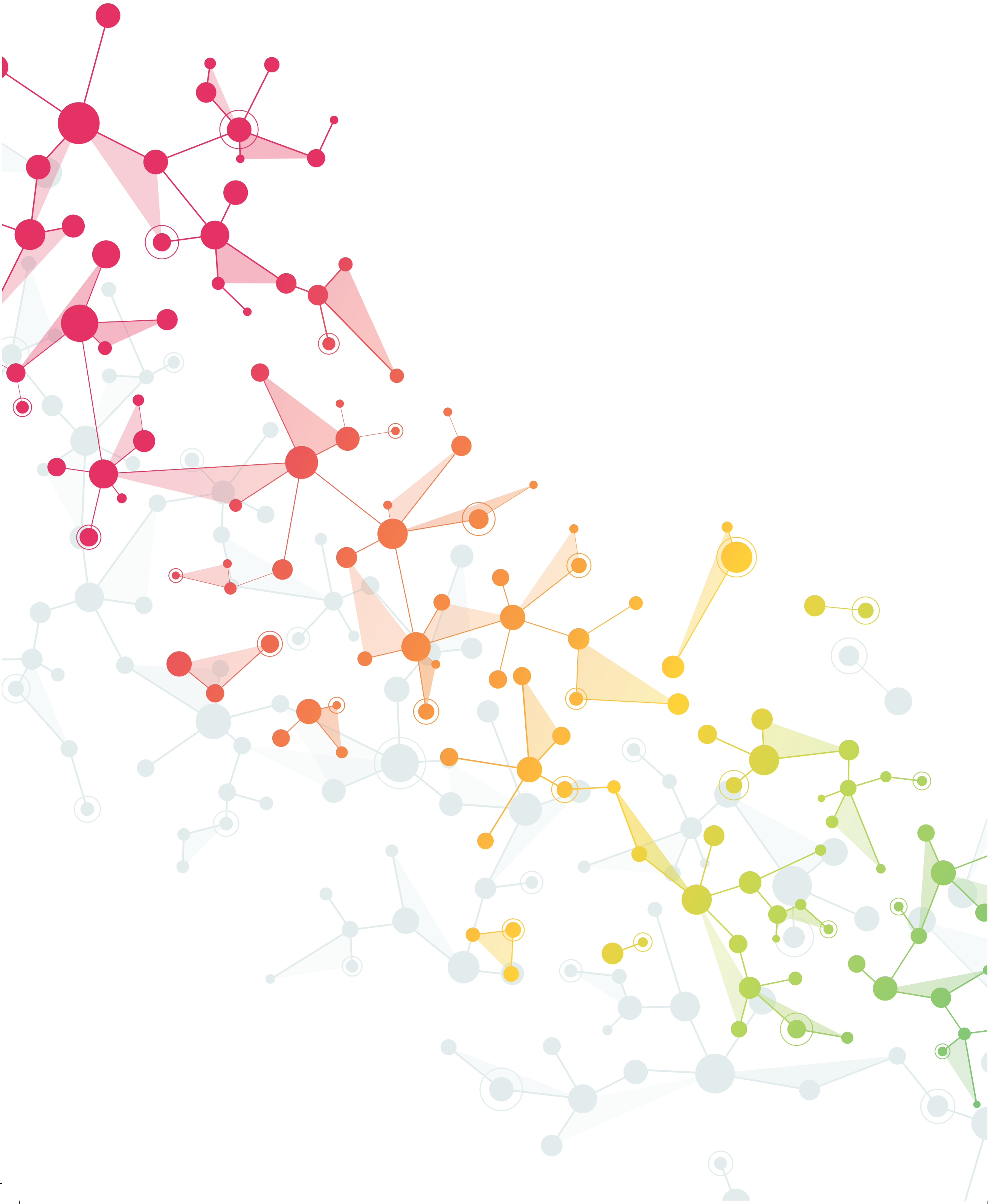
Corine, Marise, Paula, Paulien, Marjo, Anne-Meike en Henk, Jolien, Carla, Hanneke, Jacqueline en Boon-How, voor jullie inbreng tijden de diabetes werkgroepen, de gezelligheid op congressen en de koffies. Irene, bedankt dat je ‘mentormama’ wilde zijn, en dank je voor de gezellige tijd. Coby van Rijn en Henk ter Keurs, bedankt voor jullie hulp bij de meest uiteenlopende zaken. Coby, wat fijn dat ik mijn blijdschap met je kon delen toen de eerste enveloppen met vragenlijsten retour kwamen. Je enthousiaste mailtjes met “jaaa, er zijn weer enveloppen binnen” hebben mij goed gedaan.

Mijn ouders Tonny en Cor, en mijn schoonouders Aatje en John. Dank voor alle steun. Zes jaar geleden vroegen wij of jullie tijdens mijn eerste opleidingsjaar één dag per week de opvang voor Anika op jullie wilden nemen toen ik tijdens mijn opleiding aan het onderzoek doorwerkte. Jullie zijn na dat eerste jaar altijd blijven komen, ook wel eens vaker dan die ene dag omdat ik aan mijn promotie moest werken. De meiden vragen regelmatig naar “opa en oma” als ik een dag met ze thuis ben en ik ben blij dat jullie zo een belangrijke plek in hun leven hebben.

En natuurlijk wil ik alle (schoon)zussen en zwagers niet vergeten: Celine en Martijn, Alexia en Jan, Raïssa en Mark, Ralph en Kitty, en Jiska en Marten. Bedankt voor jullie interesse die jullie altijd in mij hebben getoond. En Kitty, je bent een life-saver! Zonder jou was ik nog 4 maanden langer bezig geweest.

Lieve Anika en Madouc. Tijdens het traject van opleiding en onderzoek zijn jullie in ons leven gekomen. Dat heeft veel extra uitdagingen meegebracht, maar jullie hebben mij ook geleerd het een en ander in perspectief te zien. Ik geniet van de manier waarop jullie de wereld aan het ontdekken zijn. Jullie hebben aanvankelijk op schoot geslapen en later aan de keukentafel naast mij veel zitten knutselen en tekenen terwijl ik op de laptop aan het werk was. Terwijl ik dit schrijf, aan de keukentafel, zijn jullie gezellig naast mij bezig om met behulp van de keukenstoelen een tent te bouwen. Het leven is met jullie erbij een stuk levendiger geworden. Ik ben zo trots op jullie en ik hou van jullie.

Lieve Karik, wat een reis is dit geweest. Je bent mijn rots in de branding en je hebt mij ongelooflijk veel steun gegeven tijdens mijn project. Zonder jouw humor en nuchterheid was ik niet zo ver gekomen. Zeker als ik weer eens liep te stressen of in de avond of weekend dan wel met mijn opleiding of onderzoek bezig was stond je altijd voor mij klaar. Samen hebben we de afgelopen jaren twee mooie meiden gekregen en een aantal prachtige reizen gemaakt. Ik kijk er naar uit meer tijd voor je te hebben. Bedankt dat je al die jaren met me uit hebt gehouden, ook als ik minder gezellig was omdat ik hetzelfde artikel weer helemaal moest ombouwen voor een ander tijdschrift. En ontzettend fijn dat je straks als paranimf ook tijdens de promotie mij wil bijstaan. Ik hou van je.



CURRICULUM VITAE

Maaike Cecilia Maria Ronda was born on Februari 7th 1979, in Amsterdam, the Netherlands. In 1998 she started studying Medical Biology at the University of Amsterdam, and a year later she stared her medical training at the University of Amsterdam. She obtaned her medical degree in 2007, after which she worked as a resident at the pediatrics department of the Tergooi Ziekenhuis in Blaricum, followed by a recidency at the pediatrics department of the Leiden University Medical Center in Leiden. In 2010 she worked as a resident at the internal medicine department of Meander Medical Center in Amersfoort. In 2011 she started her research described in this thesis under the supervision of prof. dr. G.E.H.M. Rutten, dr. L.T. Dijkhoest-Oei, dr. K.J. Gorter and dr. R.C. Vos. Since 2013, she combined this with her general practitoner vocational training at the University Medical Center Utrecht. As of december 2017 she is a general practitioner and since 2019 she combined this with a speciality training in diabetes mellitus.