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Guided or factual computer support for kidney patients with different experience levels and medical health situations: Preferences and usage

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Abstract

Background Personalization of eHealth systems is a promising technique for improving patients' adherence. This paper explores the possibility of personalisation based on the patients' medical health situation and on their health literacy. The study is set within the context of a self-management support system (SMSS) for renal transplant patients.

Methods A SMSS is designed with layering, nudging, emphaticizing, and focusing principles. It has two communication styles: (1) a guided style that provided more interpretation support and addressed emotional needs; and (2) a factual style that showed only measurement history, medical information, and recommendations. To evaluate the design, 49 renal transplant patients with three different experience levels participated in a lab study, in which they used the system in imaginary scenarios to deal with three medical health situations (alright, mild concern, and concern).

Results A 96% understanding and 87% adherence rate was observed, with a significant interaction effect on adherence between patient group and health situation. Furthermore, compared to recently transplanted patients, not recently transplanted patients were relatively more positive towards the factual than the guided communication style in the "alright" condition. Furthermore, additional medical information was searched more often in health situations that causes mild concern and a majority of patients did not change the communication style to their preferred styles.

Conclusion By attuning the communication style to patient's experience and medical health situation according to the applied principles and acquired insights, SMSSs are expected to be better used.

Keywords self-management support system, user interface, renal transplant patient, adherence, health literacy, explainable artificial intelligence.

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Conflict of Interest
All Authors declare that they have no conflict of interest.

1. Introduction

Self-management has been proposed for chronic patients to increase compliance with medical standards, stimulate awareness of early physical changes, and facilitate patients' autonomy [1, 2]. To support such self-management, computer systems have been suggested [3]. These computer systems, referred to as self-management support systems (SMSSs), have shown beneficial effects for chronic diseases, such as heart diseases, chronic lung diseases, diabetes, and cardiovascular care [3-5]. Existing SMSSs provide various types of support, for example, providing a platform for patients to conduct self-monitoring of their health condition or daily life [4]

For such SMSSs, it is expected that personalisation would make them more effective and easier to accept [6]. Various aspects can be considered for personalisation when designing a SMSS, such as patient's age, education, interests, physical capabilities, familiarity, and access to technology [7]. For example, elderly patients with visual limitations might be more supported by a desktop app with large screens compared to small screen mobile apps. Besides the more stable trait-based personalisation aspects, work has also been done on more dynamic state-based personalization. For example, personalization of the timing for a mobile app reminders, by finding opportune moments during the day as people are engaged in less urgent online activities, or by detecting when people have been at the same location for a while [8]. Another example of research in this area is the personalisation of automatically generated motivational messages based on symptom progression and patients' trust in the case of home-therapy for post-traumatic stress disorder patients [9]. In this paper, we continue this research exploration by focusing on two less explored factors for personalisation: the patients' medical health situation and their health literacy. The study is set within the context of a SMSS for renal transplant patients. Although these patients can be positive towards the use of SMSS [10], their health literacy is likely to increase as they become more experienced over time with monitoring their kidney function after a renal transplant operation, and their health situation might also fluctuate over time. It is important to make sure kidney transplant patients adhere to the self-monitoring routine and follow the SMSS recommendations in order for self-monitoring to be safe. However, a decline in adherence over time has been reported [11]. Furthermore, an additional complicating factor in this specific study setting was the imprecision of single measurement by the portable blood creatinine measure device [12]. Therefore, the SMSS recommendation was based on trend monitoring. However, patients' unfamiliarity with such trend interpretation might hamper their trust in the device and recommendations [13]. Although

the device's characteristics might be unique in this case, the related problem is not. A lack of transparency and accessibility of the underlying recommendation algorithm challenges people's ability to make an informed decision. A more self-explaining SMSS, i.e. explainable artificial intelligence, seems therefore preferable. Still, such a solution should not cognitively overload a patient.

2. Communication style and hypotheses

2.1. Design rationale and principle of the system

Patients in different situations could have different needs, e.g., need for information, need for information presentation, and affective needs. As the model of self-regulation processes in disease prevention and management indicates, over time chronic patients learn strategies to manage their disease [14]. Their needs therefore may vary according to the patients' experience, i.e. their experience of being a renal transplant patient, their experience in using a SMSS, and their experience in coping with specific medical health situations, e.g. the SMSS warning about a medical concern and the recommendation to contact the hospital. This suggests that to accommodate these needs, the interaction design, i.e. the way in which information is presented to patients, needs to be personalised according to patients' needs. The proposed design here focuses on personalisation based on patients' experience and the medical health situation (i.e., the progress of renal function over time).

To design a SMSS for renal transplant patients, the following four design principles were established based on literature: layering, nudging, emphaticizing, and focusing. First, for *layering*, a key assumption is that, although the system is personalised, essential medical information should not be withheld from patients. However, medical information can initially (i.e. just after transplantation) be too complex for patients to understand. Reducing the complexity by simplifying the medical information could however lead to withholding information, which should be avoided. Instead, we propose a stepped approach, in which an additional interpretation layer is offered to less-experienced patients to support them to develop appropriate cognitive schemas to understand complex medical information provided by the system. The schema theory assumes that when people encounter new information, they tend to interpret it with their pre-existing knowledge patterns (called schemata), and use the interpretation to modify their beliefs [15]. According to this theory, when patients become more experienced, they will have internalised these cognitive schemas making the interpretation layer no longer desirable to present. Instead they might be directly presented with the factual medical information, such as analysis results from self-measurement data.

The second design principle, *nudging*, is based on the Nudge theory, which argues in favour of indirect suggestions instead of forced compliance as this could create resistance [16]. Nudging means offering a desirable default while leaving it still possible with some effort to deviate from this default. As people are likely to avoid making additional effort, most people will follow the default offering. For the design this means that patients can select another communication style, e.g. for recently transplanted patient the style with the interpretation

layer would be offered by default, but the patient could deselect this and use the style without the interpretation layer but only factual medical information.

The third design principle, *emphaticizing*, is to satisfy needs of different patients: for empathy or for conciseness. Empathy of physicians has a positive effects on patients' health, satisfaction, ability, and anxiety and distress reduction [17]. As people have shown to respond to computers in a similar manner as to other humans [18], Fogg hypothesizes that computer systems can use social cues to express empathy and achieve higher adherence [19]. Computer applications that include emotional responses are reported to result in better health outcomes, better adherence to self-management, and less decline in motivation [20]. Therefore, to satisfy patients' need for empathy or social communication, the system could use social cues, such as a virtual health agent (i.e. virtual coaches), with different facial expressions to express empathy. However, some patients would prefer a more straightforward instruction or explanation, instead of empathy, especially if they are already familiar with their medical situation [21]. As newly transplant patients are probably more anxious or worried [22], we assume therefore that less experienced patients will prefer more empathy, while more experienced patients prefer more conciseness.

The last design principle, *focusing*, centres on the severity of the medical condition (i.e. progress of renal function). The information about the medical health situation provided by the system determines patients' focus of attention and the amount of effort that they are willing to invest. According to the arousal theory, different levels of arousal are required for different tasks to achieve optimal performance [23]. For example, in an alarming situation, people's arousal levels are often high and therefore they lack the cognitive capability to process and obtain new information [23]. In addition, when there is reason for medical concern, it is important that patients take appropriate action immediately. They would probably not want to spend much effort on gaining new knowledge (e.g. why they need to take the action), but focus their attention on the actions they have to take instead. Therefore, information presented by the system aims at drawing patients' attention towards the current situation and providing information about appropriate patient actions. When there is no reason for alarm, a heightened arousal level is unlikely, and it can be an appropriate moment to gain knowledge. Therefore, the system should draw patients' attention towards consolidating procedural knowledge in case of less experienced patients, or extending existing knowledge in case of more experienced patients. When there is only reason for some medical concern without need for direct intervention, patients would probably be worried and eager to know the rationale of being provided with such feedback. The information presented here should focus on addressing patients' need for understanding the current situation.

2.2. Implementation of principles into prototype

Based on the four design principles, the proposed user interface design had two communication styles: a guided style especially for less experienced patients that provided the additional interpretation layer, and a factual style especially for more experienced patients that only showed factual medical information about the current renal status and corresponding recommendation of the patient. The guided style also included a virtual coach, which was a graphical presentation of a female dressed in a white doctor's coat. This

virtual coach addressed potential affective needs of less experienced patients, i.e. acknowledging patients' emotional state aiming for affective empathy. The virtual coach did this by expressing emotion with its face. Next, in verbal communication the coach made statements to reassure people. For example, in a situation that indicated concern it stated "It does not necessarily mean that there is something wrong. However, to be on the safe side, you are strongly advised to contact the hospital to discuss this with your doctor".

The prototype presentation was also different for three medical health situations and corresponding recommendation categories: (1) alright, i.e., creatinine level was stable or decreased, and therefore patients did not have to take extra action; (2) mild concern, i.e., creatinine level had increased a little, and therefore patients were requested to measure again the next day; and (3) concern, i.e., creatinine level had increased substantially, and therefore patients were advised to contact the hospital. The main presentation differences are listed in Table 1 and the screenshots are in Appendix A. The screenshots show the situation where a user has clicked on a link for additional information. Appendix B shows four screenshots that demonstrate the progression of providing more additional information in the guided style.

Table 1. Characteristic of guided and factual communication style in three different medical health situations.

		Communication style	
		Guided	Factual
Medical health situation	Alright	'Did you know' message to provide basic procedural self-management knowledge; a virtual coach to build an emotional connection with users; factual explanation with a link to detailed explanation	'Did you know' message to provide broader, lifestyle knowledge; factual explanation with a link to detailed explanation
	Mild concern	A pop-up with an action instruction; an interpretation layer and a virtual coach to offer empathic support; links to factual explanation	A pop-up with an action instruction; factual explanation with links to detailed explanation
	Concern	A pop-up with an action instruction; an interpretation layer and a virtual coach to offer empathic support; a link to factual explanation	A pop-up with an action instruction; factual explanation with a link to detailed explanation

When patients were in the alright situation, the system invited patients to read more about the procedure about conducting self-management at home in the guided style, whereas the factual style invited patients to read more about daily life after renal transplantation.

When patients were in the mild concern situation, interpretation layers with simplified information and links to factual explanation were added to help patients understand complex medical information easier in the guided style, or all the factual explanation of medical factors in the factual style. Figure 1 shows how the information was presented with and without the interpretation layer.

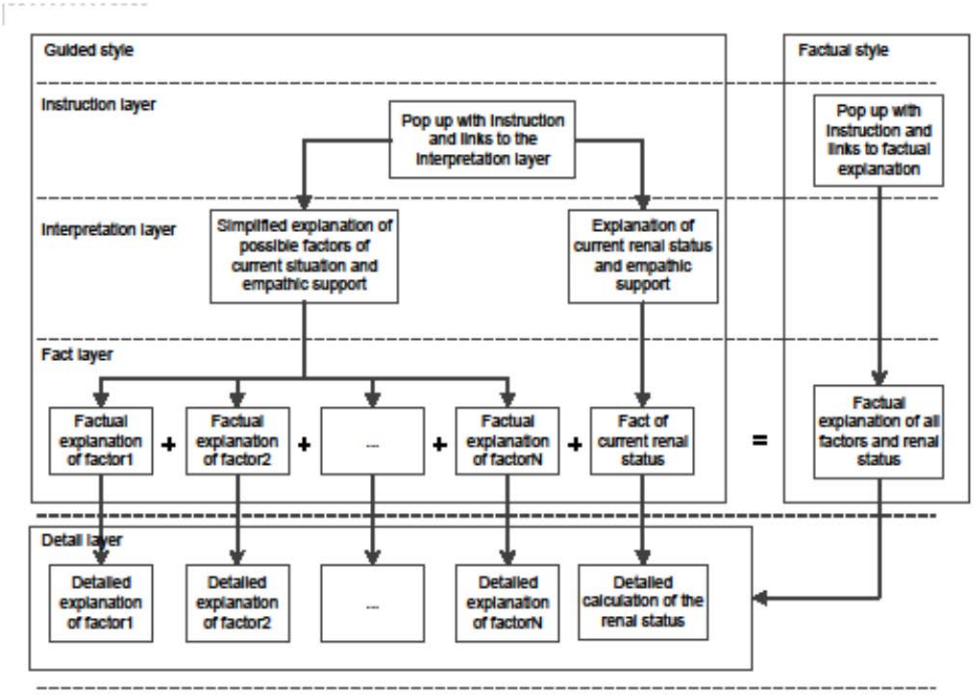


Fig. 1 The information presentation with (left) and without (right) the interpretation layer

When patients were in the concern situation, the system addressed patients' current renal situation, with information about appropriate actions. In this situation the interpretation layer conveyed a comforting message to patients in the guided style, but not in the factual style.

2.3. Hypotheses

The previous section presented the two communication styles in which the layering, nudging, emphaticizing, and focusing principles were instantiated. The general assumption is that this style should be attuned to patients' experience and medical health situation. Layered and empathic support is fitted for less experienced patients, focusing is important in more indefinite situations, and nudging leaves patients free in their style usage while expecting most people to stick to the default style. To investigate these three aspects of the general assumption, the following hypotheses were formulated:

H1: Less-experienced patients understand, prefer, and adhere to a guided communication style better than to a factual communication style, while this is the opposite for well-experienced patients.

H2: Patients try to obtain more information about their medical health situation in a mild concern situation than in an alright or concern situation.

H3: Instead of selecting their preferred communication style, a majority of patients do not change the default communication style.

3. Method

3.1. Experiment design

The experiment had both a within- and between-subjects design. The within-subject factors were 1) the two communication styles (guided versus factual style), 2) the three medical health situations based on the progress of the renal function over time (alright, mild concern, and concern), and 3) default communication style (default guided or default factual style in which the system starts). The between-subject factor examined in the study was patients' experience.

To reduce the complexity of the design, the three within-subject factors were compared in two separated phases. The first phase had six conditions in a two by three design, to study the effect for the two communication styles set within the three medical health situations, and the interaction effect of these two factors. The next phase only had two conditions to examine the effect for the default communication style set within a mild concern situation. Both phases allowed studying potential interaction effects with the between-subject factor patients' experience. Ethical approvals for the study were obtained both from the Human Research Ethics Committee of Delft University of Technology, and from the Medical Ethics Committee of Leiden University Medical Centre (addendum to P11.188), where the study was conducted and the participants were recruited following an opportunity sampling strategy.

3.2. Participants

Although 51 renal transplant patients participated in the experiment, two were excluded from the analyses. One quitted half way because she found the experiment too complex to finish, and another patient did not bring his reading glasses and could hardly see the content in the monitors. Patients were recruited for three roughly equally sized groups based on their level of experience, namely: 1) less experienced patients (n = 16), patients who had their first renal transplant surgery more than 2 months but no more than 7 months before participating the experiment, and had not used a SMSS for renal transplant patients; 2) full experienced patients (n = 18), patients that had their first renal transplant surgery more than 12 months ago, and who had used a SMSS for renal transplant patients for one year; and 3) the patient group labelled as intermediate experienced patients (n = 15), patients that had their first renal transplant surgery more than 12 month ago, and who had not used a SMSS for renal transplant patients. This classification is only a rough indication of patients' experiences, which was used to test the hypotheses. The profile of these participants is presented in Table 2.

Table 2. Participants profile

Participants	Less experienced	Intermediate experienced	Full experienced	Total
Number, n	16	15	18	49
Male, n (%)	12 (75.0)	5 (33.3)	10 (55.6)	27 (55.1)
Age				
Mean (SD)	52.8 (13.1)	55.6 (12.0)	58.1 (13.2)	55.6 (12.7)
Range	24 – 69	32 – 72	27 – 79	24 – 79
Educational level				
Median	Secondary	Secondary	Secondary	Secondary
Months since transplantation				
Mean (SD)	5.3 (1.1)	121.9 (154.7)	37.0 (55.0)	52.6 (101.9)
Range	3 – 7	16 – 444	14 – 255	3 – 444

3.3. Procedure

Each participant went through the following steps. First participants were told that the purpose of the study was to evaluate the user interface of a SMSS. They were introduced to the procedure of the experiment, after which they filled out a questionnaire about their personal information. This was followed by an introduction video on how to use the system. Next, participants had the opportunity to explore the system for 10 minutes. The default style setting (guided or factual) of the user interface was set randomly. During this step participants were allowed to change the communication style and experience both styles. In this step, participants were confronted with a recommendation by the system to do nothing extra.

In the main part of the experiment, participants were exposed to eight imaginary conditions. The first six conditions were the two different communication styles by three medical health situations. It was not possible for participants to change the communication style. The order of the six conditions was random and different for each participant. In condition seven and eight, participants could switch between the two styles, while the default style was different between the two conditions and the order was randomly assigned. Instructions given during these two conditions reminded the patients of the possibility to change the style. The medical health situation was mild concern in both conditions. To avoid potential learning effects, nine datasets with creatinine measurements were used, one for practise, two for alright, four for mild concern, and two for concern. Within each medical health situation, the datasets were randomly assigned to each participant.

In every condition, participants were asked to enter a pre-defined creatinine level in the SMSS, and receive the corresponding feedback. They could interact with the system for as long as they wanted to. Next to the SMSS, there was another monitor for them to indicate their understanding of the system's instructions, their planned actions, and their attitude towards the system.

After interacting with the system, the participants were asked which communication style they preferred for each of the medical health situation. They were also asked to discuss their opinions about the system at the end of the experiment in the debriefing. To standardize the information procedure, video clips were used to instruct participants during the various steps.

3.4. Measurements

Before the interaction with the prototypes, participants completed a questionnaire about personal information such as gender, age, and educational level. In the main part of each condition, they were asked to answer seven questions: 1) what the system asked them to do, 2) what they would do, 3) why they would do that, 4) how much they liked the way that the system had supported them, 5) how effectively or ineffectively the information was presented, 6) how worried or relaxed the information made them feel, and 7) with how much dignity they were treated by the system. All the questions were closed questions, except question 3. Questions 1 and 2 had the choices of a) to do nothing extra, b) to re-measure tomorrow, c) to contact the hospital, and d) other, with stating what that was. Question 4 was answered with a 7-point Likert scale ranging from 1 'not at all' to 7 'very much'. Patients were asked to respond to questions 5 to 7 by setting a slider from -10 for 'extremely negative' to 10 for 'extremely positive'. After the main part, participants were asked which communication style they preferred for each of the medical health situations with a slider, with -10 for extremely preferring the guided style to 10 for extremely preferring the factual style, or the other way around, as the direction was random for each participant. Self-report about experience and opinion was collected in the debriefing. Besides subjective data, behavioural data was also collected on whether or not patients clicked on the 'learn more' link, on the 'did you know' link, and on the button to switch communication styles.

3.5. Data preparation and data analyses

R, version 3.3.0, was used to conduct the statistical analyses, and SPSS version 22 to impute missing data values. The R markdown script is available online[1]. The first step was a reliability analysis on question 4 - 7. A Cronbach's alpha with a value of 0.73, showed an acceptable level of consistency between the questions. Therefore, the mean of these four questions was taken as an index for participants' attitude towards the system. For this question 4 was rescaled to a 21-point scale so that it had the same range as the other questions. One-sample *t*-tests were conducted to examine whether attitude and preference data deviated from zero, the neutral value. A relative attitude scale was calculated by subtracting a participant's attitude score towards the system in the guided style from the factual style. A negative score on this relative attitude scale indicated an attitude leaning more towards the guided style, while a positive score an attitude leaning more towards the factual style. To test whether patients had a more positive attitude towards one of the communication styles, one-sample t-tests were conducted on the relative attitude value of

[1] During review phase files can be accessed at https://surfdrive.surf.nl/files/index.php/s/1VQS56LwiPC8DGK

If the paper is accepted this link will be replaced by a link (doi) to national data repository hosted by 4TU Data Centre.

zero, a neutral attitude. This was also done for a single experienced patient group in which both intermediate and full experienced patient group were combined. Next, a multilevel analysis was conducted across the patient groups, taking participants as random intercept and medical health situations and patient experience, and two-way interaction between them as fixed factors. In addition, this analysis was repeated with the patient experience reduced to a two levels factor by combining the two experienced groups into a single group. Furthermore, a two-way interaction effect was examined with a simple effect analysis.

Exploration of the preference data revealed a W-shape distribution, with 19%, 17% and 27% of the measurements for -10, 0, and 10 score respectively. After removing the zero score from the data set, the preference variable was recoded in a dichotomous variable taking zero as the cut-off point to split the data set into a 0 for a preference for the guided style, and a 1 for the factual communication style. A similar analysis as for the relative attitude data was conducted on the preference data, however, fitting it as a dichotomous outcome variable.

The question about what the system asked the patient to do was recoded into a dichotomous variable, i.e., whether the patient understood it correct or not. Similarly, the question about what patients would do was recoded into whether patient would adhere to the desired action or not. Both variables and the data, whether or not a patient clicked on the 'learn more' link or the 'did you know' link, were analysed with a generalized linear mixed model with a binomial distribution. The analyses used communication style, medical health situation, patients' experience level, and their interactions as fixed factors, and participants' number as random intercept. Significant fixed factors were examined for differences between levels, and two-way interaction effects were examined with a simple effect analysis. Finally, a one-sample t-test was used to analyse if the majority of patients did not change the default communication styles to their preferred styles.

Potential confounding variables were examined by comparing age, education level, and gender ratio difference between the three patient groups. No significant (all *ps* > .05) difference was found by Kruskal-Wallis H tests. Furthermore, participants' age, gender, work hours, and internet use were considered as possible covariates. However, none of the variables correlated with the dependent variables, or in the case of internet use, were it did, there was only limited variations between patients.

4. Results

4.1. Understanding and adherence

Table 3 shows the number of patients that understood the action suggested by the system and that adhered to the advised action. With a 96% average for understanding and 87% adherence, a large majority of patients understood the suggested actions and indicated to also adhere to the actions. In the cell with the relative lowest understanding rate of 83%, the three full experienced patients thought the system instructed them to do nothing extra in the mild concern situation. In the cell with the relative lowest adherence rate 69%, the four less experienced patients wanted to take some action, re-measure or contact the hospital,

while not instructed by the system to do so. In total there were 35 non-adherent cases made by 21 different patients. While the multilevel analysis on understanding found no significant effects for patient group, health situation, or communication style, for the adherence results a significant two-way interaction between patient group and health situation was found, $\chi^2(5) = 13.49$, p. = 0.02. The less experienced group in the alright situation sometimes wanted to do more than recommended, for example, re-measuring or contacting the hospital. The full experience group, on the other hand, sometimes wanted to do less than the recommended hospital consultation in situations that causes concern (Table 4).

4.2. Preference and attitude

Table 5 shows the mean preference and attitude rating. Although the analysis on dichotomous preference variable did not find a significant effect for patient group ($\chi^2(2) = 0.82$, p. = 0.66) or medical health situation ($\chi^2(2) = 5.34$, p. = 0.069) separately, it did find a significant two-way interaction effect these two factors, $\chi^2(4) = 21.91$, p. < 0.001. A follow-up simple effect analysis showed no significant effect ($\chi^2(2) = 2.03$, p. = 0.362) for the health situation when only looking at the preferences of the less experienced group. However, a significant effect was found in the analysis for the two experienced patient groups combined, $\chi^2(2) = 12.06$, p. = 0.002. The preference of the less experienced group was roughly equally divided (52%-48%) for the two communication styles throughout the three health situations. This was similarly for the two experienced patient groups (50%-50%) in the situation that caused concern, but not for the other two situations. Here the experienced patients more often gave a preference for the factual style (37%-63%).

Table 3. Number of patients that understood and adhered to the requested action.

	Understand (%)			Adhere (%)		
Medical health situation / Style	Less (***n*** = 16)	Inter-mediate (***n*** = 15)	Full (***n*** = 18)	Less (***n*** = 16)	Inter-mediate (***n*** = 15)	Full (***n*** = 18)
Alright						
Guided	15 (94)	14 (93)	17 (94)	11 (69)	12 (80)	17 (94)
Factual	16 (100)	15 (100)	17 (94)	14 (88)	13 (87)	15 (83)
Mild concern						
Guided	16 (100)	15 (100)	15 (83)	16 (100)	14 (93)	15 (83)
Factual	15 (94)	14 (93)	17 (94)	13 (81)	14 (93)	16 (89)
Concern						
Guided	16 (100)	15 (100)	17 (94)	15 (94)	15 (100)	14 (78)
Factual	16 (100)	14 (93)	17 (94)	15 (94)	14 (93)	14 (78)

Table 4. Number of patients indicated to certain action in specific health situation.

	Actions			
	Other	Nothing extra	Re-measure	Hospital
Less experienced				
alright	0	25	3	3
mild concern	0	0	28	2
concern	0	0	2	30
Intermediate				
alright	0	25	4	1
mild concern	2	0	28	0
concern	0	0	1	29
Full experienced				
alright	0	31	4	0
mild concern	1	3	31	1
concern	3	1	4	28

Table 5 shows that on average all three patient groups in all medical health situations, had a significant positive attitude towards both communication styles. Overall, the experienced patients held a more positive attitude (M = 1.03 95% CI [0.33, 1.73]) towards the factual than towards the guided communication style as was found in medical health situations that gave no cause for concern, $t(32) = 3.01$, $p = 0.005$. This was also found back for the full experienced patients group separately, $t(17) = 2.25$, $p = 0.038$. The multilevel analyses on the relative attitude variable again found no significant effects for patient group ($\chi^2(2) = 3.84$, p. = 0.147) and medical health situation ($\chi^2(2) = 2.14$, p. = 0.343) separately, but a two-way interaction effect between these factors that approaches the significant threshold of 0.05 ($\chi^2(4)=9.33$, p. = 0.053), and reaches a significant ($\chi^2(2)=6.83$, p. = 0.033) level when the intermediate and full experience patients group were combined into a single group. As Figure 2 shows, in the medical health situation that gave no cause for concern, the relative attitude of the more experienced patients leaned more towards the factual style compared to less experienced patients. This was confirmed by a simple effect analysis that found a significant ($F(1,47) = 8.68$, p. = 0.005) difference between these two patient groups in this health situation, and not in the other health situations. The experienced patients' more positive attitude towards the factual style, however, declined when the health situation deteriorated. This was again confirmed by the simple effect analysis that only revealed a significant ($\chi^2(2)=8.30$, p. = 0.016) effect for health situation for the experienced group, and not for the less experienced group, $\chi^2(2)=1.63$, p. = 0.44.

Table 5. Mean (SD) preference and attitude of 3 patient groups for guided and factual communication style.

		Attitude / Preference, ***M*** (***SD***)		
Medical health situation	Style	Less	Intermediate	Full
Alright	Absolute Attitude			
	Guided	6.5** (3.3)	5.2** (3.8)	5.4** (3.3)
	Factual	5.7** (3.9)	6.3** (3.0)	6.4** (3.0)
	Relative attitude	-0.7 (2.0)	1.1 (2.2)	1.0* (1.8)
	Preference	0.5 (8.5)	2.5 (6.7)	1.4 (7.8)
Mild concern	Absolute Attitude			
	Guided	5.4** (3.3)	4.7** (3.6)	4.9** (2.5)
	Factual	5.0** (3.4)	5.3** (2.7)	4.5** (2.7)
	Relative attitude	-0.4 (3.2)	0.6 (1.6)	-0.3 (1.7)
	Preference	-0.9 (8.3)	1.5 (7.2)	2.7 (7.4)
Concern	Absolute Attitude			
	Guided	4.7** (3.4)	4.7** (2.7)	3.7** (1.9)
	Factual	5.0** (3.8)	4.3** (2.7)	3.8** (2.6)
	Relative attitude	0.3 (1.4)	-0.4 (1.4)	0.1 (1.5)
	Preference	0.3 (8.5)	-0.1 (8.0)	0.9 (7.7)

Note: *t*-test, H_0: $\mu = 0$; * p<.05, ** p <.01. The higher the preference or relative attitude was, the more they preferred (or hold a positive attitude towards) the factual style, and the lower it was, the more they preferred the guided style.

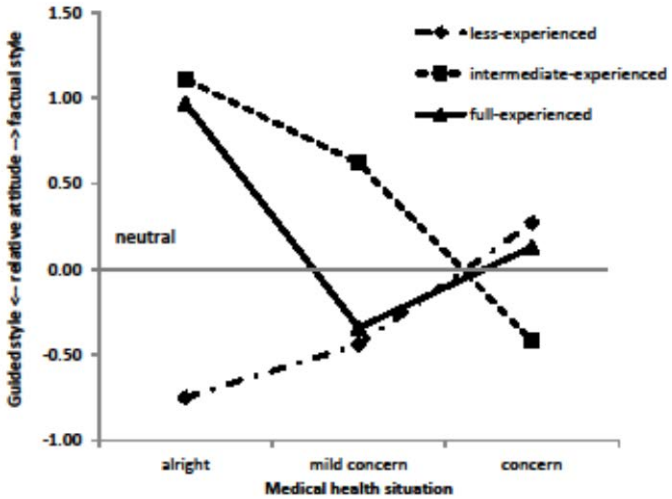


Fig. 2 Mean relative attitude for the guided and factual communication style by medical health situations and participants' experience group

4.3. Behaviour

During the two alright conditions, 27% of the patients clicked at least once on the 'did you know' link to broaden or to consolidate their knowledge, while 21% clicked on the 'learn more' link during one of the six conditions. While a multilevel analysis found no significant effect (all *p*s >.05) for factors on 'did you know' clicking behaviour, on the clicking 'learn

more' behaviour, the analysis did find significant main effects for the patient group ($\chi^2(6) = 17.46$, $p = 0.008$), for the medical health situation ($\chi^2(5) = 38.95$, $p < 0.001$), and for the communication style, $\chi^2(3) = 18.29$, $p < 0.001$. As shown in Table 6, patients especially clicked on this in the situation that causes mild concern. Also, fewer full experienced patients clicking on this link, and more clicks were made in the guided style (27%) than in the factual style (15%).

The analysis of the 'learn more' behaviour also revealed two-ways interaction effects: between the patient group and the health situation ($\chi^2(5) = 22.62$, $p < 0.001$), between the patient group and the communication style ($\chi^2(3) = 23.04$, $p < 0.001$), and between the health situation and the communication style ($\chi^2(3) = 15.8$, $p = 0.001$). Experienced patients tended not to click on 'learn more' link in situations that caused either no concern (3%) or concern (6%). This group and the intermediate group also clicked less on this link with the factual style (8%, 11%) than with the guided style (21%, 33%), whereas this was more similar for the less experienced group, where 27% clicked on the link with the factual style and 28% with the guided style. Finally, patients especially clicked on the link when working with the guided style when confronted with a situation that causes mild concern (49%).

Table 6. Percentage of patients that click on links for more information.

	Patient group			
Situation / style	Less	**Intermediate**	Full	Mean
Alright				12%
factual	27%	7%	0%	
guided	14%	20%	6%	
Mild concern				33%
factual	21%	13%	19%	
guided	43%	53%	50%	
Concern				18%
factual	33%	13%	6%	
guided	27%	27%	6%	
Mean	28%	22%	15%	21%

In the last two experimental conditions, patients could change the systems communication style when confronted with the medical health situation that caused some mild concern. Of the 42 patients who indicated to have a preference for one of the two communication styles in this specific medical health situation, only 36% changed the default style to the style they preferred when the styles did not match their preference. This was significantly less than 50% of the patients, $t(41) = -1.91$, $p = 0.03$, 1-sided hypothesis. For comparison, 31% of these patients changed the default style when it was already in their preferred style. No

significant (r = .02, *p* = .91) correlation was found between the strength of the preference, i.e. the preference value, and whether or not the patient had shifted to their preferred style.

5. Discussion and conclusions

To improve patients' understanding and adherence to a SMSS, a design rationale for developing of a web-based SMSS prototype was proposed. This included the principles of layering, nudging, emphaticizing, and focusing. It resulted in two communication styles: guided and factual. When interacting with the prototype, the patients showed on average a 96% understanding and an 87% adherence rate. Adherence did vary however, with less experienced patients wanted to do more than recommended in an alright situation, while full experienced patients wanted to do less than recommended in a situation that caused concern (i.e. not to contact the hospital while the SMSS advised to do so).

Overall, both communication styles were positively received, and findings provided partly support for the first hypothesis, i.e. the difference between more and less experienced patient groups across the communication styles. Though the results showed no understanding and adherence differences, the results showed preference and attitude differences between the two groups. Considering the groups in isolation, it was shown that experienced patients, specifically the fully experienced ones, had a more positive attitude and preference towards the factual communication style than the guided style in a medical health situation that gave no cause for concern. It was further shown that medical health situation had an impact on preferences and attitude, as preference and attitude differences between patient groups decreased in case of concern.

The overall 87% adherence rate observed was close to the upper limits of the 53%-85% adherence range to SMSS recommendation observed by renal transplant patients in the field [11]. Still, this is relative high compared to other adherence rates reported in the literature, for example 50% to physicians' medicine prescription for chronic diseases [24], 50% to treatment for chronic diseases in developed countries [25, 26], 25% - 59% to physicians' recommendations for colorectal cancer screening [27, 28], 19% - 96% in smoking cessation [29], 25% - 40% in self-monitoring blood glucose for diabetes [30, 31], and 52% for technology-mediated insomnia treatments [32]. However, the level of adherence studied in this experiment was just a snapshot in a lab setting, and did not look at adherence over time or considering other factors that influence adherence.

The second hypothesis, stating that medical health situation has an effect on patients search behaviour for additional information, was supported. As hypothesized, an increase in search behaviour was observed in case of a mild concern situation. For the alright situation, the system was designed to draw patients' attention towards accessing more information by using the "did you know" link, either to consolidate or to extent their knowledge. Patients, however, seemed to have mainly ignored that link and instead were more interested to learn about their current medical health situation. It was further observed that the guided style had an effect on search behaviour. It seemed that patients wanted to go beyond information initially offered in the interpretation layer and looked for more background information especially in case of mild concern situations. When given the advice to contact

the hospital, patients' priority might have shifted from information seeking to going to hospital. Also, they might have expected to receive information at the hospital anyway. For example, Medlock et al. found that senior patients searched for health information more frequently after than before an appointment with doctors [33].

The findings support the third hypothesis, which stated that a majority of patients do not change the default communication style to their preferred one. These results showed the importance of the default communication style setting. Only a minority of patients changed the default if it did not match their preference (support H3). Hence, future designers should consider this behaviour and not expect that patients will select an appropriate communication style spontaneously. Interesting was the finding that whether patients switched to their preferred styles was not correlated with the strength of their preference.

Further, about 31% patients switched to their non-preferred styles. A possible explanation is that patients might not know what they really preferred: what they rationally thought and what they actually selected could be different [34]. Still, these patients might simply have switched between the styles to explore them more in this experiment.

To the best of our knowledge, this is the first study that examines how patient experience and communication style of a SMSS could affect renal patients' preference, attitude, and behaviour. However, like in any empirical study, the results should be interpreted within the study's limits. The first limitation is the relatively small sample size, especially to study the between-subjects factor patient group. This has limited the statistical power of the analyses, and the confidence by which conclusions could be drawn. A second limitation is the controlled setting under which patients had to operate. The experiment only took one hour, and patients were asked to react to fictitious situations in the presence of an experimenter. All factors that would be different in a real-life situation. Still the setting allowed for systematic comparison between different medical health situations and provided insight into patients' understanding and adherence. The third related limitation is that this study did not consider other potential important factors such as attitude of health providers towards the SMSS, as this was found associated with patients' intentions to use a personal health tool [35]. The fourth limitation is the lack of experimental control on the assignment of a patient to one of the three patient groups. This means that variations between the groups could in theory be attributed to other factors besides the patients' experience. Still, examination of potential confounding factors ruled out factors such as age, education level, and gender ratio.

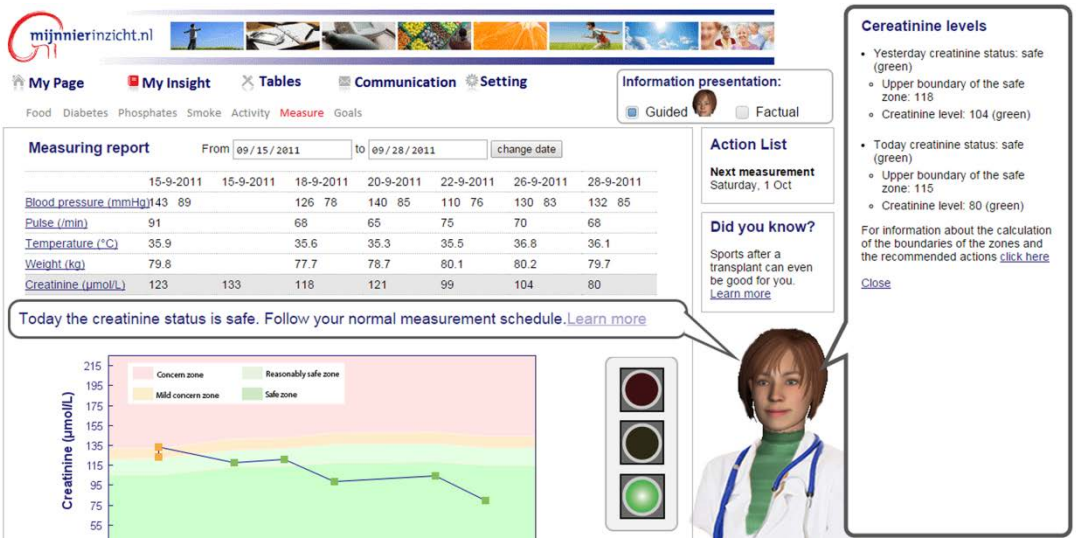
The work can be extended in several directions. First, it would be interesting to see if these findings can be generalized to SMSSs that target other chronic diseases such as diabetes or hypertension. Second, future research could explore the possibility for adapting communication style based on patients beliefs such as perceived susceptibility, severity, benefits, and barriers [36].

The main scientific contribution of the work presented in this paper is the insight of (1) the potential association between renal patients' experience and their preference and attitude towards a guided or factual communication style; (2) the inverted U shape association between the need for additional medical information and the possibility of a health situation that causes concern; and (3) patients' seemingly reluctance or ignorance to change the

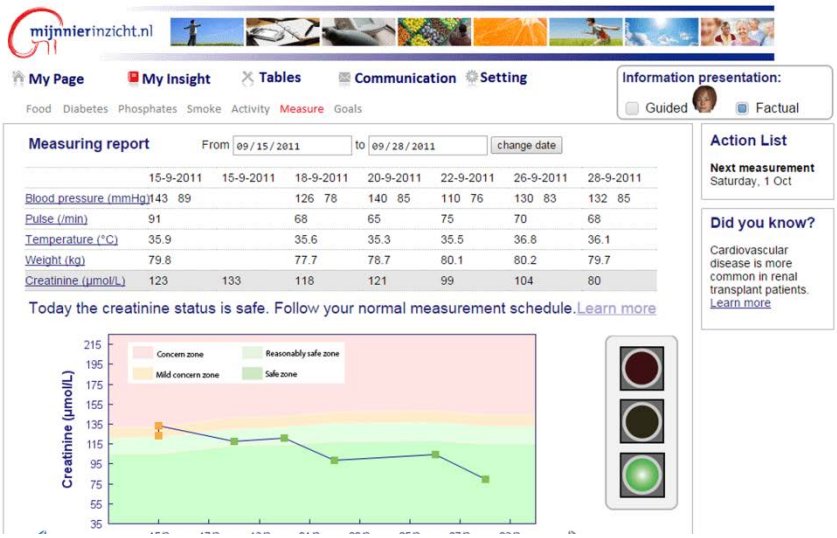
default communication style to their preferred style. Together this information suggests that when designing a SMSS, the communication style should be attuned to patient's experience and medical health situation.

Appendices

Appendix A. The two communication styles and the three medical health situations



a)



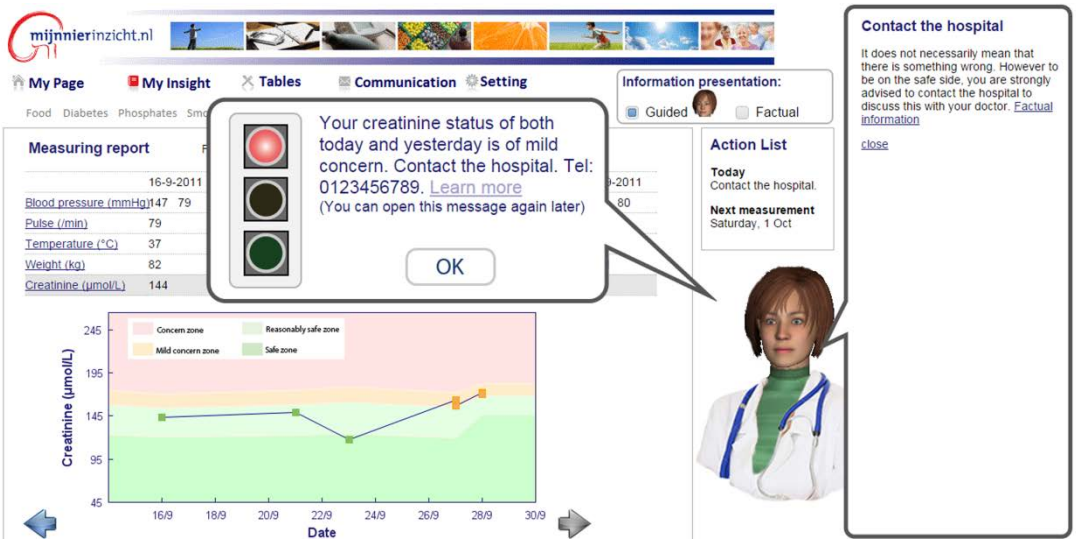
b)


mijnnierinzicht.nl
My Page
Your creatinine status is reasonably safe today, but yesterday the creatinine status was of mild concern. Measure again tomorrow.
- For information about going from mild concern to reasonably safe zone click here
- For information about factors that can influence the creatinine value click here
(You can open this message again later)
OK
Information presentation:
Guided
Factual
Action List
Next measurement
Tomorrow, Thursday, 29 Sep
Concern zone
Reasonably safe zone
Mild concern zone
Safe zone
Creatinine (µmol/L)
Date
From the mild concern (orange) to reasonably safe (light green) zone
The main focus underlying the monitoring of the renal functions is to look for sudden increases or slow but long-time increases in the creatinine level. Stabilities or reductions in the creatinine levels are common and not alarming. To detect potential problematic increases, the system works with zones that have boundaries that are based on the last 5 creatinine measurements. This means that the boundaries of the mild concern (orange) or reasonably safe (light green) zone can fluctuate on a daily bases as they adjust themselves to the last 5 measurements.
The boundaries for the reasonably safe (light green) zone for this day are 120 - 141. Your current creatinine level is 121, which is within the reasonably safe (light green) zone. The creatinine status is of reasonably safe.
Yesterday the boundaries for mild concern (orange) zone were 135 - 145. Your creatinine measurements from yesterday were 144 and 141, which felt therefore in the mild concern (orange) zone. Given these 2 measurements, yesterday's

c)


mijnnierinzicht.nl
My Page
My Insight
Tables
Communication
Setting
Your creatinine status is reasonably safe today, but yesterday the creatinine status was of mild concern. Measure again tomorrow. Learn more
(You can open this message again later)
OK
Information presentation:
Guided
Factual
Action List
Next measurement
Tomorrow, Thursday, 29 Sep
Measuring report
Blood pressure (mmHg)
Pulse (/min)
Temperature (°C)
Weight (kg)
Creatinine (µmol/L)
Concern zone
Reasonably safe zone
Mild concern zone
Safe zone
Creatinine (µmol/L)
Date
Facts
From the mild concern (orange) to reasonably safe (light green)
Yesterday creatinine status: mild concern (orange)
Boundaries of the mild concern zone: 135 - 145
Creatinine levels: 144 (orange) and 141 (orange)
Today creatinine status: reasonably safe (light green)
Boundaries of the reasonably safe zone: 120 - 141
Creatinine level: 121 (light green)
For information about the calculation of the boundaries of the zones and the recommended actions click here
Kidney Function
Kidneys filter waste from the blood. Creatinine is one of those wastes. An important indicator of the functioning of the kidney, the filter function is therefore the creatinine levels in the blood.
Performance of the StatSensor
The average variation or inaccuracy of the Stat Sensor is 10%. This means that two measurements made shortly after each other can differ 10% from

d)

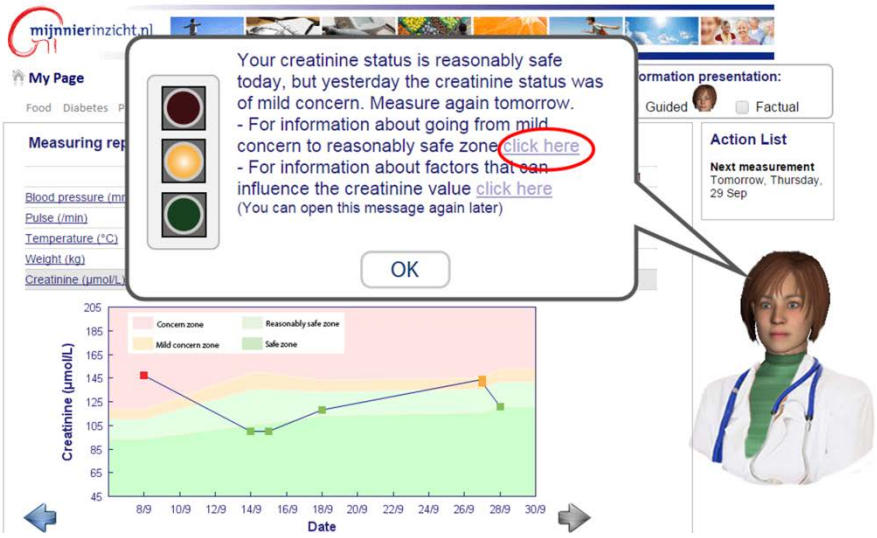

mijnnierinzicht.nl
My Page
My Insight
Tables
Communication
Setting
Your creatinine status of both today and yesterday is of mild concern. Contact the hospital. Tel: 0123456789. Learn more
(You can open this message again later)
OK
Information presentation:
Guided
Factual
Action List
Today
Contact the hospital.
Next measurement
Saturday, 1 Oct
Measuring report
Blood pressure (mmHg)
Pulse (/min)
Temperature (°C)
Weight (kg)
Creatinine (µmol/L)
Concern zone
Reasonably safe zone
Mild concern zone
Safe zone
Creatinine (µmol/L)
Date
Contact the hospital
It does not necessarily mean that there is something wrong. However to be on the safe side, you are strongly advised to contact the hospital to discuss this with your doctor. Factual information
close

e)

f)

Fig. 3 Screenshots of the two communication styles and the three medical health situation. a) Guided style of alright state b) Factual style of alright state c) Guided style of mild concern state d) Factual style of mild concern state e) Guided style of concern state f) Factual style of concern state

Appendix B. The progression of providing more information in guided style of mild concern situation



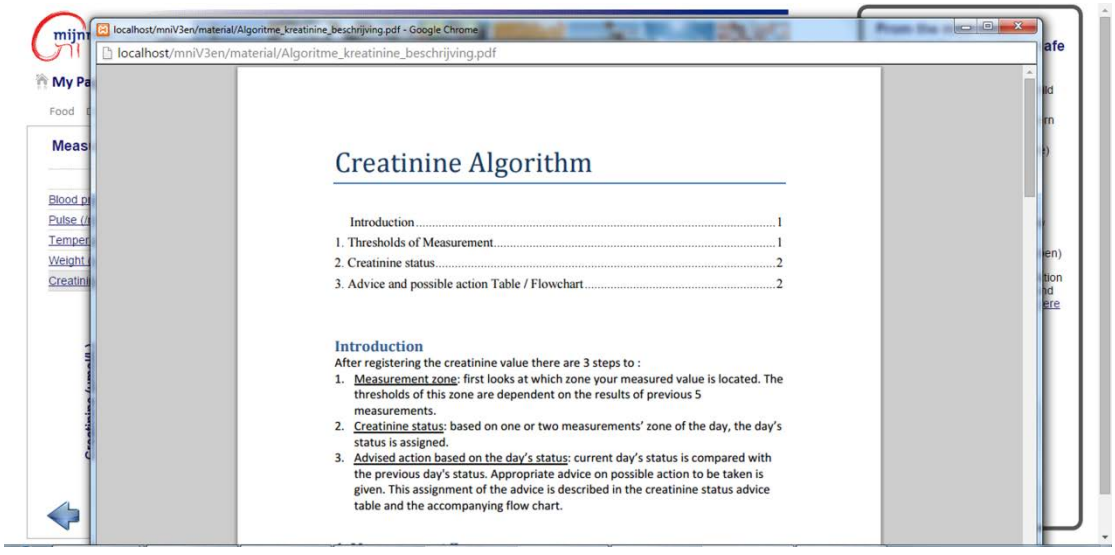
a)


mijnnierinzicht.nl
My Page
Food Diabetes
Measuring rep
Blood pressure (mn
Pulse (/min)
Temperature (°C)
Weight (kg)
Creatinine (µmol/L)
Your creatinine status is reasonably safe today, but yesterday the creatinine status was of mild concern. Measure again tomorrow.
- For information about going from mild concern to reasonably safe zone click here
- For information about factors that can influence the creatinine value click here
(You can open this message again later)
OK
ormation presentation:
Guided
Factual
Action List
Next measurement
Tomorrow, Thursday, 29 Sep
Concern zone
Reasonably safe zone
Mild concern zone
Safe zone
Creatinine (µmol/L)
205
185
165
145
125
105
85
65
45
8/9 10/9 12/9 14/9 16/9 18/9 20/9 22/9 24/9 26/9 28/9 30/9
Date
145. Your creatinine measurements from yesterday were 144 and 141, which felt therefore in the mild concern (orange) zone. Given these 2 measurements, yesterday's creatinine status was of mild concern.
To come to this status and recommended action, the system uses creatinine status table and recommendation flow chart, which are based on today's and yesterday's measurement zones.
For now it is important that you continue to monitor the creatinine level. If tomorrow's creatinine status stays safe, you will be able to continue again with your normal monitoring procedure. If on the other hand tomorrow's creatinine status becomes mild concern, you will need to continue with closely monitoring your creatinine level for another day, and if tomorrow it's concern, you will need to contact hospital.
But for now the advice is to measure again tomorrow.
A summary of the factual information is also available
(Facts)
Close

b)


mijnnierinzicht.nl
My Page
Food Diabetes
Measuring rep
Blood pressure (mn
Pulse (/min)
Temperature (°C)
Weight (kg)
Creatinine (µmol/L)
Your creatinine status is reasonably safe today, but yesterday the creatinine status was of mild concern. Measure again tomorrow.
- For information about going from mild concern to reasonably safe zone click here
- For information about factors that can influence the creatinine value click here
(You can open this message again later)
OK
ormation presentation:
Guided
Factual
Action List
Next measurement
Tomorrow, Thursday, 29 Sep
Concern zone
Reasonably safe zone
Mild concern zone
Safe zone
Creatinine (µmol/L)
205
185
165
145
125
105
85
65
45
8/9 10/9 12/9 14/9 16/9 18/9 20/9 22/9 24/9 26/9 28/9 30/9
Date
From the mild concern (orange) to reasonably safe (light green)
Yesterday creatinine status: mild concern (orange)
Boundaries of the mild concern zone: 135 - 145
Creatinine levels: 144 (orange) en 141 (orange)
Today creatinine status: reasonably safe (light green)
Boundaries of the reasonably safe zone: 120 - 141
Creatinine level: 121 (light green)
For information about the calculation of the boundaries of the zones and the recommended actions click here
Back
Close

c)


localhost/mniV3en/material/Algoritme_kreatinine_beschrijving.pdf - Google Chrome
localhost/mniV3en/material/Algoritme_kreatinine_beschrijving.pdf
Creatinine Algorithm
Introduction 1
1. Thresholds of Measurement 1
2. Creatinine status 2
3. Advice and possible action Table / Flowchart 2
Introduction
After registering the creatinine value there are 3 steps to :
1. Measurement zone: first looks at which zone your measured value is located. The thresholds of this zone are dependent on the results of previous 5 measurements.
2. Creatinine status: based on one or two measurements' zone of the day, the day's status is assigned.
3. Advised action based on the day's status: current day's status is compared with the previous day's status. Appropriate advice on possible action to be taken is given. This assignment of the advice is described in the creatinine status advice table and the accompanying flow chart.

d)

Fig. 4 Screenshots of the progression to provide more information a) Start point of action instruction b) An interpretation layer that explains current renal function course c) Facts of current renal function course d) Detailed algorithm that explains renal function course

Compliance with Ethical Standards

Disclosure of potential conflicts of interest

All Authors declare that they have no conflict of interest

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study."

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