value in using the system [31], the present study aimed to evaluate parents' experiences regarding the system's contribution to their communication with involved professionals during the six-months pilot. Hereto, we focused on those aspects of parent-professional communication in which we previously identified gaps and hence were targets of improvement for the web-based system, being sufficiency of contact, timeliness of information exchange, accessibility of professionals, consistency of information and the extent to which parents felt they had to act as care coordinator or messenger of information between professionals. In addition, we aimed to gain insight into factors related to parents' system use and non-use, by comparing parents who had used the system (n=21) with those who had not used the system (n=9) with respect to their baseline experiences with parent-professional communication and the complexity of their child's care network, hypothesizing that users would have less positive baseline experiences and a more complex care network.

Theory and methods

System aims

Following the Chronic Care Model [29], productive interactions between the patient('s family) and involved practice teams arise from essential system changes at the health care organization level, such as self-management support, delivery system design, decision support and clinical information systems [6].

Although eHealth technology has the potential to contribute to each of these system changes [36], changes with respect to self-management support (how to help patients live with their conditions) and delivery system design (who's on the health care team and in what ways they interact with patients) will relatively be most visible to the patient('s family) [6]. As the identified gaps in our study (Box 2) particularly reflected improvement needs in these domains, the primary aims of the web-based system were to increase patient-centeredness, facilitate inter-professional contact and enhance network transparency. In the Appendix, an overview is given of these aims and the corresponding design features. In the present study, we focused on the system's aim to increase patient-centeredness and hereto evaluated parents' experiences regarding the system's contribution to their communication with involved professionals during the six-months pilot.

Study population

In order to obtain data representative for the integrated care setting of cerebral palsy, three Dutch care regions were included ranging from urban to more rural settings. The selection of patients was carried out by a rehabilitation physician, based on files of patients with annual supervision and the following selection criteria: (1) diagnosis cerebral palsy (confirmed by neurologist) and (2) age between 4–8 years [from the age of four years diagnosis is mostly clear and (special) education becomes an additional communication partner in the

Box 2. Improving communication in cerebral palsy care

To identify experienced gaps in communication across the integrated care setting of cerebral palsy, we searched the literature for appropriate research methodology. Existing methods though were often restricted to only one aspect of communication (e.g. discharge- or referral communication), one communication link (e.g. general practitioner—hospital specialist) or one evaluation perspective (e.g. the perspective of primary care physicians), or relied solely on quantitative-resp. qualitative methods, thus obtaining either general/population based data or in-depth qualitative data derived from small samples [28]. In view of these shortcomings, we developed a mixed method evaluation approach [28], based on key elements of the Chronic Care Model [6, 29], quality of care aspects formulated by the Institute of Medicine [4] and essential quality dimensions of information(-exchange) [30]. Application of this approach in three Dutch cerebral palsy care regions [21] showed that parents primarily experienced gaps in inter-professional communication, particularly between the (rehabilitation) hospital and primary care physiotherapy resp. (special) education/day care centre. Subsequent in-depth interviews with a subset of parents showed that the experienced gaps were primarily related to inadequate cooperation of professionals and an experienced lack of patient-centeredness, as well as insufficient inter-professional information-exchange and consistency of information, which often necessitated parents to take up the role of messenger of information or even that of care coordinator [21]. Confronting professionals with these findings yielded further understanding of underlying factors, such as capacity problems and a lack of interdisciplinary guidelines and clear definition of roles, tasks and responsibilities [21].

Based on these gaps in communication, we developed an asynchronous secure web-based system for parent-professional and inter-professional communication, aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency [31]. For each of these aims, functional specifications were formulated, which were subsequently translated into technical requirements (see Appendix). Based on the findings of a six-month pilot-evaluation in three Dutch care regions, the system proved to be technically robust and reliable [31]. Approximately two-thirds of the parents and half of the professionals had used the system, of which most parents and some professionals reported to have experienced added value in its use [31], comprising each of the three system aims: patient-centeredness (parents could ask questions at the moment they arose and the whole network could be reached at once, avoiding fruitless phone calls), inter-professional contact (lower threshold for consultation, contact with disciplines which previously were not actively involved in decision making) and network transparency (professionals were being kept up to date between visits, obtaining insight about other professionals' advice; parents could re-view their communication with professionals) [31].

care network]. Parents needed to have (1) sufficient Dutch language skills (as judged by the rehabilitation physician) in order to be able to use the communication system and complete questionnaires and (2) access to the internet as well as basic knowledge how to use it. Finally, minimal three involved professionals [i.e. the child's rehabilitation physician, (primary care) physiotherapist and professional of (special) education/day care centre] needed to participate in the study in order to have a sufficient network for communication. On the basis of these criteria, the parents of 30 cerebral palsy patients were included in the study. After completion of informed consent they received log-in data for access to the system. The study was conducted in keeping with the protocol of the WMA Declaration of Helsinki. According to Dutch legislation (WMO Medical Research Involving Human Subjects Act) a medical ethics review was not required.

System use and non-use

System use was on a voluntary basis, i.e. parents were free in their choice to use the system in a given situation or apply their usual modes of communication (face-to-face, telephone etc.). The system comprised an open access part (a generally accessible website with project related information) and a personalized secured access part with various consultation options. Parents could contact professionals in their child's care network, while professionals could contact both parents as well as colleague-professionals involved in the patient's care network. For each submitted question parents had to mark one feedback-responsible professional, an automatic copy was sent to other involved professionals (parents could remove this option if preferred, see Appendix). Information about parents' system use was extracted from the system's database. Of the 30 participating parents, 21 had actually used the system during the six-months pilot by submitting one or more questions and/or responses to professionals, whereas nine parents had only logged into the system without submitting a question/response. Considering the system's aim to improve parent-professional and inter-professional communication, system use was defined in terms of submitting a question/response on the system more than once. Consequently, trying out the system only once or logging-in without submitting a question/response was not considered actual system use.

Study design

Baseline questionnaire (T0)
In order to describe the study population and to evaluate parents' experiences with parent-professional communi-

cation before the pilot, parents completed a baseline questionnaire, including parent/patient characteristics, frequency and modes of contact with involved professionals in the child's care network and parents' experiences regarding their communication with these professionals, focusing on sufficiency of contact, timeliness of information exchange, accessibility of professionals, consistency of information and the extent to which parents felt they had to act as care coordinator and/or messenger of information between professionals. For each of these aspects a scoring table was used in which parents could indicate for each involved professional the extent to which they had experienced sufficient contact/timely information exchange etc. during the preceding six months (3-point Likert scale *'usually'*, *'occasionally'* or *'rarely'*, see Appendix).

Questionnaire after six-month pilot (T1)
After the pilot parents completed a questionnaire on the experienced contribution of the system to each of these aspects of parent-professional communication. In addition, parents were asked whether they less often needed face-to-face/telephone contact with involved professionals as a result of using the system. For the items sufficiency of contact, timeliness of information exchange and accessibility of professionals, the experienced contribution was evaluated by means of scoring tables in which parents could indicate for each involved professional the extent to which they had experienced a contribution of the system (3-point Likert scale *'considerably'*, *'to some extent'* or *'(hardly) not'*, see Appendix). For the items consistency of information and the coordinator/messenger role, detailed evaluation per professional was considered less appropriate given the inter-dependency among professionals that is inherent to these aspects of parent-professional communication. Therefore instead of using scoring tables, the experienced contribution for these items was evaluated by means of a 5-point Likert-scale (ranging from *'yes, definitely'* to *'no, not at all'*, see Appendix).

Data analysis

Parents' questionnaire responses T0/T1
Parents' T0 questionnaire responses were listed in an overall table, indicating for each parent the proportion of professionals that were scored with a positive/intermediate/negative response (respectively *'usually'/'occasionally'/'rarely'*, see Table 1). As such, the intermediate and negative responses represented experienced shortcomings in parent-professional communication and thus targets for improvement of the communication system.

Parents' T1 questionnaire responses on the items sufficiency of contact, timeliness of information exchange

Table 1. Parents' baseline experiences regarding parent-professional communication

		Sufficiency			Timeliness			Accessibility			Consistency			Coordinator			Messenger		
		With this professional I [.....] had sufficient contact			*With this professional I [.....] had timely information exchange*			*This professional was [.....] accessible for consultation*			*Of this professional I [.....] received consistent information*			*With this professional I [.....] felt I had to act as care coordinator*			*With this professional I [.....] felt I had to act as messenger of information*		
Parent		N$_{professionals}$			N$_{professionals}$			N$_{professionals}$			N$_{professionals}$			N$_{professionals}$			N$_{professionals}$		
Use (n=21)	1	5	1		4	2		3	1	1	5	1		3		2	1		5
	2	7	2		9			9			8			5	3		4	3	
	3	10	2		12			12			12			7	5		6	6	
	4	4			4			4			4			4			3		
	5	1	4		5			2	3		5			5			1		
	6	9	3		10	1		7	1		4			7			3		
	7	8	4	1	9	1		2	7		4			3	4		10		
	8	6	3		5	2		6			6			3	2	1	1		
	9	4	3		3	2		5	2		6			4	3		3	1	
	10	3	2		1	1		3	1		4			3	1	1	2		
	11	5	3	3	1	7	3	1	9	2	10	1		11			11		
	12	14			14	1		14	1		15			10	1		14		
	13	8	1		9			7	1		9			8		1	5	2	
	14	6	2	1	3	3		2	3		X			2	2		5		
	15	6	1		7			4	2		7			7			6		
	16	2	2		2			3	2		1			1		1	X		
	17	6			6			3	1		X			X			2		
	18	11	1		12			3	9		12			12			10	1	
	19	4		3	3	1		4			4			4	1		2	1	1
	20	4	2		4	1		4	1		X			1	1	2	1	1	1
	21	6			5			3	1		3	1		1	4		5		
Non-use (n=9)	22	7			5			6			6			6			2		
	23	8	3		5	5		8	3		4	4		5	2		4	2	
	24	5			3	1		5			5			5			5		
	25	5			5			4	1		4	1		5			3	1	
	26	3	3		4	1	1	3	3		4	1		2			1	4	
	27	4	2		8			8			X			4	4		X		
	28	8			7	1		5			8			5	3		5	1	
	29	4	6	2	6	4		10			6	1	1	2			6		
	30	7	1		6	2		8			3	2		3	3		3		
Total	N$_{professionals}$	176	55	10	177	31	9	158	48	7	151	19	2	126	42	17	88	47	19
	%	73%	23%	4%	82%	14%	4%	74%	23%	3%	88%	11%	1%	68%	23%	9%	57%	31%	12%
	%$_{parents}$	73% (n=22)			57% (n=17)			63% (n=19)			38% (n=10)			72% (n=21)			79% (n=22)		

	= 'Usually'
	= 'Occasionally'
	= 'Rarely'
X	= Missing value

	= 'Rarely'
	= 'Occasionally'
	= 'Usually'
X	= Missing value

and accessibility of professionals were listed in an overall table, indicating parent's responses regarding the experienced contribution of the system for each involved professional that participated in the study ['considerably', 'to some extent'/'(hardly) not', see Table 3].

Factors associated with parents' system use and non-use

To evaluate whether parents' system use was associated with their baseline experiences regarding parent-professional communication, the T0-questionnaire responses of parents who had used the system (use-group, n=21) were compared with the responses of parents who had not used the system (non-use group, n=9), focusing on the proportion of professionals that were scored with a positive experience on the concerning aspect of parent-professional communication. Given the skewed distribution of these proportions, non-parametric tests for independent samples were applied (Mann-Whitney, a=0.05), using one-sided p-values in line with our hypothesis that the use-group would have less positive baseline experiences with parent-professional communication and thus the proportion of professionals that were scored with a positive experience would be lower than in the non-use group. In addition, we evaluated whether the complexity of their child's care network was associated with parents' system use, by comparing the amount of involved professionals and institutions between the use and non-use group. For this comparison independent-sample t-tests were applied (a=0.05), using one-sided p-values in line with our hypothesis that the amount of involved professionals and institutions would be higher in the use-group than in the non-use-group.

Results

Parents' baseline experiences (T0)

Table 1 summarises parents' responses at baseline, both for the parents who had used the system (use,

n=21) and the parents who had not used it during the six-month pilot (non-use, n=9). The numbers represent the number of professionals that were marked with a positive (white label), intermediate (grey label) or negative response (black label). As can be seen in the vertical total scores, the majority of professionals were marked with a positive response, although the proportion of positive responses differed between the items, ranging from 88% for consistency of information to 57% for parents as messenger of information. However, looking horizontally at the individual parent level, each parent had scored intermediate or negative responses on one or more items. A relatively high proportion of parents indicated that they had to act as care coordinator or messenger of information: resp. 21 out of 29 parents (72%) and 22 out of 28 parents (79%) had scored one or more professionals with an intermediate and/or negative response. Of the professionals that were marked with a negative response (n=26), the majority were medical specialists (n=14) and paramedical therapists in (special) education-/day care centres (n=8).

Parents' system use during the six-month pilot

Of the 30 participating parents, 21 parents had actually used the system, submitting n=111 questions and n=59 responses, with a mean of five questions (range 1–17) and three responses (range 1–9) per parent. As can be seen in Table 2, the rehabilitation physician was most frequently marked as feedback-responsible professional (41% of the 111 submitted questions), next to the physiotherapist and occupational therapist (respectively 20% and 14% of the 111 submitted questions). Overall, (para-)medical professionals were feedback-responsible for the far majority of parents' questions (90%), whereas education professionals were addressed for feedback in only 10% of the submitted questions.

Experienced contribution of the system (T1)

Of the 21 parents that had used the system, 20 completed the T1-questionnaire. Table 3 shows their responses regarding the experienced contribution of the system to respectively sufficiency of contact (s), accessibility of professionals (a) and timelinesss of information exchange (t) for each involved professional that participated in the system's pilot. As can be seen in the overall scores at the bottom of the the table, all 20 parents that completed the T1-questionnaire indicated that for one or more involved professionals the system had to a greater or lesser extent-contributed to sufficient contact, accessibility and/or timely

Table 2. Overview of feedback-responsible professionals in parents' submitted questions (n=111).

		Questions	
		n	%
Care region	Region A (urban)	34	31
	Region B (urban/rural)	16	14
	Region C (rural)	61	55
Institution	Hospital	27	24
	Rehabilitation centre	48	43
	(Special) education/day care centre	19	17
	Primary care centre	17	15
Discipline	Medical	49	44
	Paramedical	51	46
	Educational	11	10
Medical	Rehabilitation physician	45	41
	Paediatrician	3	3
	Paediatric neurologist	1	1
Paramedical	Physiotherapist	22	20
	Occupational therapist	15	14
	Manufacturer rehabilitation aids	5	5
	Speech therapist	2	2
	Social work	2	2
	Orthoptist	2	2
	Pedagogue	1	1
	Dietician	1	1
	Creative therapist	1	1
Educational	Teacher	8	7
	(Ambulant) supervisor	2	2
	Group leader (day care)	1	1

information exchange. In total 14 parents indicated that the system had 'considerably' contributed to sufficient contact with one or more involved professionals, particularly the rehabilitation physician (indicated by 10 parents) and the physiotherapist (five parents). With respect to accessibility and timely information exchange, in total 13 parents indicated a considerable contribution of the system, again particularly for the rehabilitation physician (indicated by resp. 8/9 parents) and the physiotherapist (indicated by resp. 9/10 parents). As can be further seen in the table, the number of times that professionals were marked as feedback-responsible for a submitted question (total n=111) was related to the experienced contribution of the system. For those professionals that had not been marked as feedback-responsible for a submitted question (n=0), parents mostly did not experience a contribution of the system. On the other hand, the table shows that even when a professional was only marked once as feedback-responsible for a submitted question (n=1), various parents indicated that they had experienced a considerable contribution of the system for that particular professional.

Considering parents' responses regarding the experienced contribution of the system to consistency of

Table 3. Parents' responses regarding the experienced contribution of the system to sufficiency of contact (s), accessibility of professionals (a) and timelinesss of information exchange (t)

T1	Region A						Region B						Region C								
	Parent 1	Parent 2	Parent 3	Parent 4	Parent 5	Parent 6	Parent 7	Parent 8	Parent 9	Parent 10	Parent 11	Parent 12	Parent 13	Parent 14	Parent 15	Parent 16	Parent 17	Parent 18	Parent 19	Parent 20	Parent 21
Hospital	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n
Rehabilitation physician	8	1	0	4	0	2		2 0			4 0				0	1 0				0	0
Paediatrician								2						0	1 0				1		0
Paediatric neurologist			0																1 0		0
Orthopaedic surgeon																				0	0
Physiotherapist					0																
Occupational therapist					0																
Orthoptist						0	0							2				0			
Other															1						
Rehabilitation center	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n
Rehabilitation physician		2	0			0	2				0	0	6	6	1	1	2	1	0	3	0
Physiotherapist			4			0					0		2	0			2	2			
Occupational therapist			2									1	0	1	3	1	0	0			
Speech therapist												0									
Social work														0			2				
Creative therapist													1					0			
School/day care center	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n
Physiotherapist							0	1				0			2				0		
Occupational therapist					2										0						
Speech therapist					0		2														
Pedagogue					0			0		X 1	0		0		0		7				0
Teacher	0			1			0				0			0	0						
Ambulant supervisor	0	0							0				0								
Interval supervisor	0			1			0							1							
Group leader (day care)								0						1							
Other	0			0	0		0	0			0										
Primary care center	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n	s a t n
Physiotherapist	1	0			0	3			1					2				0		0	2
Occupational therapist								0						5							
Manufacturer rehab. aids	0	0	0	0		3			0		0	0	2	0						0	0
Other														0							
Overall	9	3	6	6	2	8	4	5	1	X 1	4	1	11	17	9	2	6	10	1	3	2

s Parents' responses regarding the experienced contribution of the system to **sufficiency** of contact
a Parents' responses regarding the experienced contribution of the system to **accessibility** of professionals
t Parents' responses regarding the experienced contribution of the system to **timeliness** of information exchange
■ *System use **considerably** contributed to sufficiency of contact/accessibility of professionals/timeliness of information exchange*
▨ *System use **to some extent** contributed to sufficiency of contact/accessibility of professionals/timeliness of information exchange*
▧ *System use **(hardly) not** contributed to sufficiency of contact/accessibility of professionals/timeliness of information exchange*
n Number of times that the parent marked this professional as feedback-responsible for a submitted question

information and parents' messenger/coordinator role, less than half of the 20 parents (n=9) indicated a positive response on these items (10%–25% did not know and 25%–35% indicated a negative response).

Factors associated with parents' system use and non-use

Comparing the 21 parents who used the system with the nine parents who had not used the system, the non-users scored relatively higher at baseline on accessibility of professionals: 89% of the professionals were marked with a positive experience on this item, compared to 68% for the users, a statistically significant difference (p=0.023). With respect to parents' baseline experiences regarding sufficiency of contact, both groups scored nearly the same (in the non-use group 75% of the professionals were marked with a positive response on this item, compared to 72% in the use-group). For the remainder of the items, the use-group scored higher than the non-use group, although no significant differences were found.

Comparing the complexity of the child's care network between both groups, the mean number of involved professionals in the use-group was 8.3 (range 5–14) compared to 5.7 (range 3–10) in the non-use group, a statistically significant difference (p=0.006). The mean number of involved institutions was higher in the use group (mean 4.1, range 2–7) compared to the non-use group (mean 3.7, range 2–5), although this was not a significant difference.

Discussion

Although the rationale for integrated care is often approached from a system/-organisational perspective in terms of efficiency and cost-effectiveness, the patient-centered imperative and meaning is of increasing importance [37]. In order to improve parent-professional and inter-professional communication in the integrated care setting of children with cerebral palsy, we developed a web-based communication system aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency. The aim of this study was to

evaluate parents' experiences regarding the system's contribution to their communication with involved professionals. Based on previous findings [21], the system was expected to contribute to sufficient contact, timely information exchange, accessibility of professionals and consistency of information, as well as to decrease the need for parents to act as care coordinator and messenger of information between professionals. Of the 30 parents that participated in the six-months pilot, 21 had used the system. At baseline, all of them generally experienced good communication with the majority of professionals, but each parent also experienced gaps on one or more aspects, especially sufficiency of contact, accessibility of professionals and the coordinator/messenger role. This corresponds with findings in literature, in which parents reported being the only coordinators of care for their children or the primary method of communication between physicians [7, 11]. Of the 20 users that completed the T1 questionnaire, all had experienced a contribution of the system on one or more aspects. The majority of parents indicated to have experienced a contribution of the system on sufficiency of contact, timely information exchange and accessibility of professionals, whereas consistency of information and the extent to which parents feel care coordinator or messenger of information seemed less influenced by the system. The higher experienced contribution on sufficiency, timeliness and accessibility could be due to a more direct impact of the system on these items, whereas the other aspects might be more dependent on other modes of communication (face-to-face/telephone contact) as well, each affecting consistency of information and the extent to which parents feel care coordinator/messenger of information. Improvement of these aspects might be stimulated through parent-professional discussion of these issues, in which parents are given choices about their role in communicating information between professionals [11]. From a methodological point of view, the differences in experienced contribution could also be due to the fact that the items sufficiency, timeliness and accessibility were assessed by means of a scoring table (in which experienced contribution was operationalized on the level of individual professionals), whereas the system's contribution to the other items were assessed in more general terms by means of a 5-point Likert scale in which parents could only give overall scores. The choice for a more generic evaluation for these items was made after analysis of parents' responses in the baseline questionnaire, in which detailed evaluation per professional turned out to be less appropriate considering the inter-dependent nature inherent to these aspects of parent-professional communication.

Although all users had experienced a contribution of the system on one or more aspects, the extent of the experienced contribution varied considerably: some parents experienced a contribution on only one aspect and for just one or two involved professionals, while other parents experienced a contribution on more aspects and for various professionals. This might be partly explained by parents' differing baseline experiences, but another factor might be the broad variation in frequency of system use (with a mean of n=8 questions/responses per parent, standard deviation 6 and range 2–20). Parents who used the system more frequently might be more likely to have experienced a contribution of the system, although our findings showed that just one submitted question could also positively contribute to parent-professional communication.

Considering the applied methodology to evaluate parents' experiences, the choice for detailed scoring tables was made in order to evaluate parents' experiences for each involved professional, and thereby to detect potential disciplines for whom the web-based system might have particular added value. Based on the findings in the present study, this seemed to be the case for the rehabilitation physician and the physiotherapist, whom parents frequently marked as feedback-responsible professionals in submitted questions, and for whom parents experienced a considerable system contribution to sufficient contact, accessibility and/or timely information exchange. However, the reliability of parents' responses was suboptimal, as could be seen in the total number of marked professionals in the baseline questionnaire question item. A more overall quantitative measure or qualitative evaluation might have additional value, although the possibility to detect changes per professional would be lost.

Of the participating parents, almost one-third had not used the system. At baseline, these parents scored significantly higher on accessibility of professionals, which might partly explain their non-use of the system: they already could reach their professionals relatively easily. In these situations of good accessibility of professionals, a web-based system might therefore be less indicated. In line with this, we found that the complexity of the care network (measured by means of the amount of involved professionals and institutions) was higher in the use-group than in the non-use group. Based on the differences found between the use- and non-use group, we hypothesize that the system may be especially valuable in patient populations with complex care networks involving multiple professionals and institutions, and less positive experiences with accessibility of professionals.

Conclusions

All users experienced a contribution of the system to parent-professional communication, although the extent of the experienced contribution varied considerably. The strength of the system appears to lie in its contribution to sufficient contact, timely information exchange and accessibility of professionals, whereas consistency of information and the coordinator/messenger role seemed less influenced by the system. In line with a staged approach of telemedicine evaluation, these findings can be taken into account in the further development of the system, ranging from optimization of the system by expanding consultation possibilities and providing insight into the consultation process, to a more specific definition of the system's target population, focusing on patient populations with complex care networks and problematic access to professionals. In addition, innovative methods such as social network analysis might be applied to gain insight into the strength of parent-professional and inter-professional relationships as a proxy for success in integrated care [38].

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Appendix

Table X1. System aims and corresponding functional specifications and technical requirements [31]

Aims	Functional specifications	Technical requirements
Patient centeredness	– Enable parents to consult the professionals involved in their child's care when necessary – Enable professionals to consult parents when necessary – Enable consistency of information in the response provided to parents	– Overview of the child's care network in which parents can tick mark one or more professionals for consultation – Overview of the child's care network in which professionals can tick mark the child's parents for consultation – Parents' assignment of one feedback-responsible professional for the consultation question
Inter-professional contact	– Enable professionals to consult other professionals involved in the child's care – Notify professionals as soon as they are consulted or responded to – Enable inter-professional conference prior to feedback to parents	– Overview of the child's care network in which professionals can tick mark one or more professionals for consultation – Automatic email-alerts with a hyperlink to the submitted question or response – Submitted reactions from professionals only visible among involved professionals
Network transparency	– Stimulate network contact over one-to-one interactions – Enable network-wide insight in the consultations conducted – Provide an up to date overview of which professionals are involved in the child's care network	– Automatic copy of submitted question to other professionals in the child's network (if preferred, parents can remove these automatic copies) – Up to date overview of the child's care network, specifying names specialities and affiliations of the professionals involved
General aims	– Provide open access information about system aims and procedures – Warrant safe information exchange – Enable independent system administration and assistance to system users when needed – Up to date information regarding personal details	– Generally accessible website with project related information – Secure log-in with SSL-encryption and retyping an alphanumerical code – Administrator menu for registration of system users and helpdesk function – Personal menu in which parents and professionals can edit their personal details

Table X2. Questionnaire items at baseline (T0) and after the pilot (T1). Items marked with * were assessed by means of a scoring table in which parents could indicate their response for each involved professional

	T0	T1
Sufficiency of contact	With this professional* I *[rarely] [occasionally] [usually]* had sufficient contact during the past 6 months	For this professional* system use had *[scarcely] [to some extent] [considerably]* contributed to sufficient contact
Timeliness of information exchange	With this professional I *[rarely] [occasionally] [usually]* had timely information exchange during the past 6 months	For this professional system use had *[scarcely] [to some extent] [considerably]* contributed to timely information exchange
Accessibility of professionals	This professional* was *[rarely] [occasionally] [usually]* accessible for consultation during the past 6 months	For this professional* system use had *[scarcely] [to some extent] [considerably]* contributed to better accessibility for consultation
Consistency of information	Of this professional* I *[rarely] [occasionally] [usually]* received consistent information about my child's care	According to your experience, did system use contribute to obtaining consistent information?*[5-point Likert-scale, ranging from 'no, not at all' to 'yes, definitely']*
Parents as care coordinator	With this professional* I *[rarely] [occasionally] [usually]* had to act as care coordinator in order to manage my child's care during the past 6 months	Did you, as a result of using the system, less often have to act as care coordinator in order to manage your child's care? *[5-point Likert-scale, ranging from 'no, not at all' to 'yes, definitely']*
Parents as messenger of information	In the communication among the rehabilitation physician and this professional* I *[rarely] [occasionally] [usually]* had to act as messenger of information during the past 6 months	Did you, as a result of using the system, less often have to act as messenger of information among involved professionals? *[5-point Likert-scale, ranging from 'no, not at all' to 'yes, definitely']*

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