Questionnaire - Patient empowerment Evaluation of the patient's online medical records

The purpose of this survey is to identify and understand why patients choose to read their medical records online, how they experience the eHealth service and which other eHealth and information sources you would like to have access to in the future.

The survey provides a basis for the evaluation of e-health service "Journalen" and provide opportunities for you to influence the improvement of the eHealth service. Your feedback is important as it can help in developing better eHealth services in the future. The survey is part of research on eHealth performed by a group of researchers from Uppsala University, Örebro University, Lund University and the University of Skövde. The research is coordinated by Åsa Cajander (Uppsala University).

The results will be reported publicly, and be the basis for scientific articles.

We are happy to answer questions regarding the research and survey. For questions regarding the questionnaire study, contact

Rose-Mharie Åhlfeldt rose-mharie.ahlfeldt@his.se 0730 - 67 72 67

For questions about the research project, please contact project manager

Åsa Cajander asa.cajander@it.uu.se 0704-425 07 86

All responses are anonymous and thus cannot be traced to the informant. The data will not be transferred to third parties or used for commercial purposes.

Your participation is completely voluntary and you can cancel at any time the survey

GENERAL QUESTIONS ON Journalen

1. I received information about the possibility to	use Journ	alen via:			
Medical professionals Media Information on the care unit Friends / Relatives □					
Other (specify):					
2. How often do you use Journalen?					
Several times a day Once a week Several times a week Once a month □					
3. What is your attitude towards <i>Journalen</i> ?					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I believe that access to medical records online is generally a good reform					
I believe that access to <i>Journalen</i> is good for me					
I would consider to change healthcare providers to get one that gives me access to <i>Journalen</i>					
4. Why do you use Journalen?					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Mostly general interest To get an overview of my medical history and treatment					
To get an overview of my relatives' medical history and treatment					
Because I am not sure if I got the right care To follow up what has been said during a healthcare visit					
Because I suspect inaccuracies To prepare for my healthcare visit To become more involved in my care					
Other (specify):					

5. How important is it for you to be able to access patient information?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree				
It improves communication between medical staff									
and me									
It leads to improvements in health and social care									
It improves the understanding of the condition									
It makes me feel safe									
It makes me feel informed									
It leads to that I can take care of my health better									
It leads to that I can take care of my relatives' health better									
It is essential that I am able to actively participate in									
decisions about my or my relatives' health									
For my own documentation									
It has no relevance									
Other (specify):									
have access to your medical records via Journalen? Same day (unsigned / uncertified information) After a day (unsigned / uncertified information) Two weeks (can be both signed / certified and unsigned / uncertified data) One month (can be both signed / certified and unsigned / uncertified data) Other (specify):									
7. To what extend do you agree with the following with healthcare?	g stateme	nts regard	ing your	relation	ship				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree				
To take part of the patient information via									
Journalen has affected the relationship with healthcare system positively									
Medical staff has informed me about the									
possibility to read <i>Journalen</i>									
Medical staff has encouraged me to use <i>Journalen</i>									
I discuss the content of <i>Journalen</i> with medical staff									

8. What do you think about the usability of *Journalen*?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I think I want to use <i>Journalen</i> regularly					
I think that <i>Journalen</i> is more complicated than it					
needs to be					
I think that <i>Journalen</i> is easy to use					
I think I would need personal technical support to					
use Journalen					
I think that the various functions in <i>Journalen</i> work					
well together					
I think there are many elements in <i>Journalen</i> that are	; <u> </u>				
not consistent					
I think that most people could learn to use <i>Journaler</i>	1 🗆				
fairly quickly					
I think that <i>Journalen</i> is difficult to use					
I feel very safe and secure (about what I do) when I					
use Journalen					
I need to learn quite a lot before I can start					
using Journalen					
I as a user of 1177.se find it difficult to find the					
link to Journalen					
Other (specify):					

INFORMATION CONTENT

9. How accurate are the following statements regarding your understanding of the content in *Journalen*?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I understand most of what is in the medical					
records I think that the medical records contain too much					
technical language I think that the medical records should be written					
more comprehensible I understand most of the test results					
I understand most of the log list					
I understand most of the referral function					

10. What would you do if you see something in *Journalen* you do not understand?

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	ct the current healthcare unit via phone					
	nedical staff at the next visit					
	medically trained person, e.g. via					
•	on 1177 n anonymous question via <u>www.1177.se</u>					
	omeone who I know personally, in family or					
	g acquaintances	Ш	Ш	Ш	Ш	Ш
	for information myself, e.g. via Internet					
Use so	ocial media, e.g. discussion forums					
Do no	thing					
Other	(specify):					
11. Ho	ow do you share information in <i>Journalen</i> y	with others	s?			
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I use t	he Share-function in <i>Journalen</i> to appoint					
	entatives and share information					
	ss it with relative					
Discus	ss it with medical staff					
Other	(specify):					
	If you use the Share-function in Journale	en, how do	you share	informat	ion?	
	I share all information in <i>Journalen</i> \square I share only selected parts in <i>Journalen</i> \square					
12. Ha	ave you read anything in Journalen that ma	ade you fee	el anxious?	•		
Yes No						
	If yes, what did you do?					
	Contacted healthcare via phone					
	Waited until the next visit					
	Contacted a friend with medical backgroun	d				
	Contacted patient association / patient com-	mittee				
	Tried to find information about it on the Int	ernet				
	Done nothing					
	Other (specify):					

13. Have you read anything in *Journalen* that has made you feel upset?

Y es No						
If you	like, specify why you felt upset:					
	If yes, what did you do?					
	Contacted healthcare via phone Waited until the next visit Contacted a friend who works in healthcare Contacted patient association / patient com Wrote about it on social media Done nothing					
	Other (specify):					
data?	ve you read anything in <i>Journalen</i> that w	vas wrong,	such as w	rong info	ormatio	n and/or
Yes No Do not	□ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □					
	If yes, what did you do?					
	Contacted healthcare via phone Waited until the next visit Contacted a friend with medical backgroun Contacted patient association / patient com Tried to find information about it on the Int Done nothing	mittee				
	Other (specify):					
15. Ho	ow accurate is the content of Journalen?					
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	ontent in the record reflects the information that healthcare has about me					
the rec	is information about me that is missing in ord which I think should be there and that ff should know					
If you is miss	consider that there is information missing the	at should be	e there, spec	cify what	type of i	information

16. How important is *Journalen* to make you feel that you are involved in your own care?

Multimedia Appendix 1: Questionnaire

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Information in <i>Journalen</i> has helped me in					
communication with medical staff Information in <i>Journalen</i> had a positive impact on the ability to work together with medical staff making decisions about care and treatment					
Information in <i>Journalen</i> had a positive impact on					
the ability to follow the prescription of treatment Information in <i>Journalen</i> had a positive impact on the ability to take own steps to improve health					
Other (specify):					
17. How important is it for you to have access to partly based on information contained in <i>Jou</i>		wing infor	mation w	which is	wholly
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Referral (content and how it is handled in care)					
List of all pharmaceuticals					
Overview of all vaccinations					
Results of tests					
Overview of all healthcare contacts					
Being able to read record entries from psychiatry					
Being able to read all types of record entries					
Ability to order and manage medical certificate and	I 🗆	Ш	Ц		Ш
other certificates Ability to point out errors I find in the record					
Ability to write own comments to text in <i>Journaler</i>	. 🗆				
Contribute with information on health, e.g. by	_				
providing Health declaration for next visit		Ш	Ц	Ш	Ш
Contribute with information of self-testing or					
monitoring at home Contribute information about expectations for the					
healthcare visit Ability to contact healthcare electronically and ask					
questions about medical record Ability to communicate electronically with other					
patients	_	_	_	_	_
Ability to block certain medical records from access by other medical staff	S 🗆				
See which care units and staff groups have been					
inside <i>Journalen</i> (see log data) Ability to access information and manage services for my children					

Other (specify):					
SECURITY					
18. How do you perceive the level of security in J	ournalen?	•			
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
As far as I can judge, I think that <i>Journalen</i> generally maintains a high level of security.					
I trust that only authorized medical staff is accessing my medical records in <i>Journalen</i> .	g 🗆				
It is good that I as a patient am able to take part in the log list and see who has accessed my patient					
Other (specify):					
GENERAL QUESTIONS ON INFORMATION					
19. How do you receive bad news about your hea	lth from y	our health	icare pro	vider?	
By Phone □ In connection with a healthcare visit □ Via mail □ Via other "web / eServices" □					
Other (specify):					
20. How would you want to receive bad news abo	out your h	ealth?			
By Phone In connection with a healthcare visit Via mail In connection with that I read alone about it in <i>Journ</i>	nalen				
Other (specify):					

21. How accurate are the following statements regarding access to health information?

	Strongly	Disagree	. Neutral	Agree	Strongly
	Disagree				Agree —
It is important (for me) to get information about health					Ш
I want to get health information from many different	t 🗇	П			П
sources					
I compare the health information I have received					
from various sources					
It is easy to determine in what situations I need					
health information I know where I can get health information					
-					
I can use the health information I have received or acquired in order to take care of my own or	ш				
other people's health					
I easily get hold of the health information I need					
a) in printed sources (magazines, books)					
b) on the internet					
c) on TV or radio					
d) from medical staff (e.g. doctors, nurses)e) from other people					
f) from healthcare information system etc.					
z) mon neument maximum of otem etc.	Ш				
It is difficult to know whom to trust regarding health issues / questions					
It is easy to determine whether the health informatio	n I				
received from the following sources are reliable or n					
a) in printed sources (magazines, books)					
b) on the internet					
c) on TV or radio					
d) from medical staff (e.g., doctors, nurses)					
e) from other people					
It is difficult to understand words or sentences used					
in health information It is easy to understand the drugs package inserts,					
labels, or prescription I get way too much information about health	П	П	П		П
I do not want to think about matters related to health	_				
	_	_	_	_	_
	Strongly	Disagree	Neutral	Agree	Strongly
I have avoided to read, listen to or watch health	Disagree				Agree
information					
a) in printed sources (magazines, books)					

Multimedia Appendix 1: Questionnaire

e) from other peop The health informatio a) helps me often to something new	n I receive to understand or learn				
	ny previous understanding				
-	ith my previous views				
I can affect my own h	eaitn				
22. What other source	es do you use to find health	informati	on?		
www.1177.se					
Internetmedicin.se					
Netdoktor.se					
Health magazines					
Books					
Peer-to-peer sources (e	.g., discussion forums, Faceb	ook)			
Other (specify):				_	
QUESTIONS ABOU	TYOURHEALTH				
23. I am part of one of	f the following disease grou	pings:			
Cancer					
Mental health					
Diabetic					
High blood pressure					
Other (specify):					

24. I consider myself

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My health is very good					
I am very worried about my health					
I often think about my health					
DEMOGRAPHIC QUESTIONS					
Age					
Year of Birth:					
Gender					
Female □ Male □ Other □					
Do you work (or have you worked) in healthcare	?				
Yes \square					
No \square					
Education? (Select the highest education/degree	you have r	eceived/co	mpleted)		
No formal education					
Compulsory education					
(e.g., elementary school, junior secondary school)					
High school, less than 3 years					
High school, 3 years or more					
Higher education, less than 3 years					
Higher education, 3 years or more					
Doctorate					
Other (specify):					

I belong to the following county council: Blekinge county council Dalarna county council Region Gotland Region Gävleborg Region Halland П Region Jämtland/Härjedalen Region Jönköpings Iän Kalmar county council Kronoberg county council Norrbotten county council Region Skåne Stockholm county council Sörmland county council Region Uppsala Värmland county council Västerbottens county council Västernorrland county council Västmanland county council Region Västra Götaland Region Örebro Region Östergötland П I have also received healthcare in another county council: Blekinge county council Dalarna county council Region Gotland Region Gävleborg Region Halland Region Jämtland/Härjedalen Region Jönköpings Iän Kalmar county council Kronoberg county council Norrbotten county council Region Skåne Stockholm county council Sörmland county council Region Uppsala Värmland county council Västerbottens county council Västernorrland county council Västmanland county council Region Västra Götaland Region Örebro

Region Östergötland