

## Supplemental Appendix 1 Terminologies

We further improved the clarifications based on the input from the validation study and updated the clarifications with the latest version of the PFRS. To minimize the errors and clarifications considered to be unacceptable that we had identified in our validation study, we made 219 modifications in the patient-friendly extension, thus resulting in a local extension that included the modifications. We excluded 13 concepts and 22 descriptions from the extension, and excluded 20 diagnoses from the Diagnosethesaurus (DT), accepted 2 descriptions, preferred 23 descriptions, added 20 synonyms and 73 text definitions, and replaced 8 synonyms and 38 text definitions. Additionally, we decided to

provide the same general clarification for all metastases (based on the September 2021 edition), to prevent problems with metastases clarifications. The coverage of clarifications by supertypes had dropped from 86.79 to 83.13% because of the modifications (e.g., excluding the clarification “a type of disease”) and dropped further to 65.99%, because of newly introduced concepts in DT. We used these modified supertype clarifications from the April 2020 DT version and the descriptions from the February 2022 DT version. The coverage of the diagnoses by clarifications was 9.4 times higher with generalization compared with the coverage of diagnoses by clarifications based on descriptions from the PFRS only. See [Table S1](#).

### Supplementary Appendix Table S1 Diagnosethesaurus coverage

Statistic	<i>n</i>	% of DT	% of SCT
Diagnoses	25,199	100.0	
Diagnoses with SNOMED CT id	22,762	90.3	100.0
Diagnoses with clarifications by synonyms and definitions	1,576	6.3	6.9
Diagnoses with clarifications by generalization	13,304	52.8	58.5
Total diagnoses with clarifications	14,880	59.1	65.4

Abbreviations: CT, computed tomography; DT, Diagnosethesaurus; SCT, SNOMED CT.

## Supplementary Appendix 4

Differences in conversion per user characteristic and diagnosis.

**Supplementary Table S2** *p*-Values of the Fisher exact test and adjusted *p*-values after Benjamini–Yekutieli correction for the false discovery rate, testing whether the differences in proportions of users that viewed their problem list and that clicked on an info button are different

Level	Variable	Viewed differences		Clicked differences	
		<i>p</i> -Value	Adjusted <i>p</i>	<i>p</i> -Value	Adjusted <i>p</i>
Patient	Age group	0.0062	0.0560	0.4739	1
	Age subgroup	0.5652	1	0.8596	1
	Gender	0.0002	0.0037	0.7965	1
	User type	0.6249	1	0.2561	1
	Latest diagnosis year	0.0002	0.0037	<0.0001	0.0003
	Number of diagnoses	0.0097	0.0746	0.0468	0.2811
Diagnosis	Diagnosis concept	0.5231	1	0.0051	0.0547
	Medical specialty	0.0431	0.2811	0.0003	0.0037

## Conversion per User Characteristic

**Supplementary Table S3** Logins and problem list views per user characteristic with number of users that logged in “l,” the percentage of total number of patients for whom users logged in (19,961), the number of users that viewed their problem list “v,” with the percentage of users that logged in that viewed their problem list, the odds ratio of viewing the problem list after logging in, with 95% confidence intervals, *p*-value of the Fisher exact test, and \* indicating whether the odds the direction of the odds (+ or -) or whether the category was the reference category (indicated with “ref”)

Characteristic	Category	Logged in		Viewed problem list						
		l	% l	v	% v	OR	(95% CI)	<i>p</i> -Value	*	ref
Age	00–09	373	1.9	130	34.9	1.25	(0.99, 1.57)	0.0587		
	10–19	492	2.5	166	33.7	1.19	(0.96, 1.45)	0.0951		
	20–29	2,280	11.4	764	33.5	1.17	(1.05, 1.32)	0.0057	+	
	30–39	3,612	18.1	1,085	30.1	–	–	–	–	ref
	40–49	2,807	14.1	929	33.1	1.15	(1.03, 1.28)	0.0092	+	
	50–59	3,284	16.5	1,110	33.8	1.19	(1.07, 1.32)	0.0008	+	
	60–69	3,478	17.4	1,193	34.3	1.22	(1.10, 1.35)	0.0001	+	
	70–79	2,861	14.3	923	32.3	1.11	(1.00, 1.23)	0.0583		
	80–89	711	3.6	211	29.7	0.98	(0.82, 1.18)	0.8580		
≥90	63	0.3	19	30.2	1.01	(0.55, 1.77)	1			
Age subgroups	00	17	0.1	7	41.2	1.32	(0.42, 3.97)	0.6072		
	01–09	356	1.8	123	34.6	–	–	–	–	ref
	10–11	54	0.3	14	25.9	0.66	(0.32, 1.30)	0.2782		
	12–15	131	0.7	51	38.9	1.21	(0.78, 1.86)	0.3944		
	16–17	94	0.5	33	35.1	1.02	(0.61, 1.69)	0.9038		
	18–19	213	1.1	68	31.9	0.89	(0.61, 1.29)	0.5822		
Gender	Male	7,629	38.2	2,375	31.1	0.89	(0.84, 0.95)	0.0002	–	
	Female	12,332	61.8	4,155	33.7	–	–	–	–	ref
Account	Proxy	42	0.2	12	28.6	0.82	(0.38, 1.66)	0.6249		
	Patient	19,923	99.8	6,519	32.7	–	–	–	–	ref
Diagnoses	≥2	3,288	16.5	1,124	34.2	1.11	(1.02, 1.20)	0.0139	+	
	1	4,638	23.2	1,567	33.8	1.09	(1.01, 1.17)	0.0210	+	
	0	12,032	60.3	3,839	31.9	–	–	–	–	ref
Latest diagnosis year	2022	1,275	6.4	495	38.8	1.35	(1.20, 1.53)	< 0.0001	+	
	2021	1,457	7.3	490	33.6	1.08	(0.96, 1.22)	0.1814		
	2020	1,599	8.0	517	32.3	1.02	(0.91, 1.14)	0.7107		
	2019	1,421	7.1	477	33.6	1.08	(0.96, 1.22)	0.1961		
	2018	984	4.9	328	33.3	1.07	(0.93, 1.23)	0.3745		
	≤2017	1,193	6.0	384	32.2	1.01	(0.89, 1.15)	0.8452		
	No diagnosis	12,032	60.3	3,839	31.9	–	–	–	–	ref
Total		19,961	100.0	6,530	32.7					

**Supplementary Table S4** Number of users with certain user characteristics that viewed info buttons and clicked on info buttons, with percentages and 95% confidence intervals (Cis)

Characteristic	Value	Viewed info button		Clicked on info button						
		v	% v	c	% c	OR	(95% CI)	p-Value	*	ref
Age	00–09	54	41.54	32	59.26	1.23	(0.67, 2.29)	0.5649		
	10–19	58	34.94	33	56.90	1.11	(0.62, 2.02)	0.7807		
	20–29	181	23.69	95	52.49	0.93	(0.65, 1.33)	0.7272		
	30–39	265	24.42	138	52.08	0.92	(0.67, 1.25)	0.5927		
	40–49	333	35.84	191	57.36	1.14	(0.85, 1.52)	0.3910		
	50–59	442	39.82	259	58.60	1.20	(0.91, 1.56)	0.1858		
	60–69	487	40.82	264	54.21	–	–	–		ref
	70–79	417	45.18	218	52.28	0.93	(0.71, 1.21)	0.5928		
	80–89	114	54.03	56	49.12	0.82	(0.53, 1.25)	0.3489		
≥90	12	63.16	5	41.67	0.60	(0.15, 2.25)	0.5597			
Age subgroups	00	2	28.57	1	50.00	0.68	(0.01, 55.66)	1		
	01–09	52	42.28	31	59.62	–	–	–		ref
	10–11	3	21.43	1	33.33	0.35	(0.01, 7.03)	0.5652		
	12–15	24	47.06	15	62.50	1.13	(0.38, 3.50)	1		
	16–17	13	39.39	6	46.15	0.59	(0.14, 2.36)	0.5327		
	18–19	18	26.47	11	61.11	1.06	(0.31, 3.80)	1		
Gender	Male	856	36.04	471	55.02	1.02	(0.86, 1.22)	0.7965		
	Female	1,507	36.27	820	54.41	–	–	–		ref
Account	Proxy	7	58.33	2	28.57	0.33	(0.03, 2.03)	0.2561		
	Patient	2,357	36.16	1,289	54.69	–	–	–		ref
Diagnoses	≥2	1,094	97.33	622	56.86	1.18	(1.00, 1.40)	0.0467	+	
	1	1,269	80.98	669	52.72	–	–	–		ref
Latest diagnosis year	2022	426	86.06	323	75.82	3.08	(2.30, 4.15)	< 0.0001	+	
	2021	449	91.63	258	57.46	1.33	(1.02, 1.74)	0.0348	+	
	2020	476	92.07	240	50.42	–	–	–		ref
	2019	420	88.05	205	48.81	0.94	(0.71, 1.23)	0.6399		
	2018	276	84.15	120	43.48	0.76	(0.55, 1.03)	0.0695		
	≤2017	316	82.29	145	45.89	0.83	(0.62, 1.12)	0.2179		
Total		2,363	36.19	1,291	54.63					

Abbreviation: OR, odds ratio.

Note: The percentages and CIs concern the number of users that viewed info buttons compared with the number that viewed the problem list, the number of users that clicked on an info button compared with the number of users that viewed an info button, and the number of users that provided a rating (answer) compared with the number of users that clicked on an info button. The columns with the asterisks \* show whether the CI is significantly differs from (whether it is lower or higher than) the CI of the total number of info button views, clicks, or answers.

## Conversion per Medical Specialty

**Supplementary Table S5** Logins and problem list views of patients with one or more diagnoses per medical specialty with number of users that logged in or viewed their problem list with percentages and 95% confidence intervals (CIs)

Specialty	Logged in		Viewed problem list							
	l	% l	v	% v	OR	(95% CI)		p-Value	*	ref
Orthopedics	2,033	100.0	701	34.5						ref
Ear, nose, and throat surgery	1,636	16.8	570	34.8	1.02	(0.88,	1.17)	0.8342		
Ophthalmology	1,359	13.5	433	31.9	0.89	(0.77,	1.03)	0.1188		
Surgery	1,086	11.2	358	33.0	0.93	(0.80,	1.10)	0.4048		
Dermatology	1,037	9.0	370	35.7	1.05	(0.90,	1.24)	0.5219		
Neurology	777	8.6	260	33.5	0.96	(0.80,	1.14)	0.6250		
Internal medicine	541	6.4	161	29.8	0.81	(0.65,	0.99)	0.0404	-	
Rheumatology	511	4.5	172	33.7	0.96	(0.78,	1.19)	0.7546		
Cardiology	501	4.2	161	32.1	0.90	(0.73,	1.11)	0.3434		
Urology	486	4.1	147	30.2	0.82	(0.66,	1.03)	0.0781		
Plastic surgery	363	4.0	107	29.5	0.79	(0.62,	1.02)	0.0705		
Pulmonary medicine	356	3.0	133	37.4	1.13	(0.89,	1.44)	0.3057		
Gastrointestinal and liver diseases	271	2.9	99	36.5	1.09	(0.83,	1.43)	0.4980		
Pediatrics	265	2.2	94	35.5	1.04	(0.79,	1.37)	0.7837		
Gynecology	169	2.2	59	34.9	1.02	(0.72,	1.43)	0.9330		
Revalidation	160	1.4	66	41.2	1.33	(0.95,	1.87)	0.0857		
Psychiatry	153	1.3	53	34.6	1.01	(0.70,	1.44)	1		
Pain medicine	146	1.3	61	41.8	1.36	(0.95,	1.94)	0.0875		
Anesthesiology	132	1.2	37	28.0	0.74	(0.49,	1.11)	0.1549		
Geriatrics	109	1.1	31	28.4	0.76	(0.48,	1.17)	0.2143		
Intensive care	5	0.9	3	60.0	2.85	(0.33,	34.18)	0.3477		
Neurosurgery	2	0.0	1	50.0	1.90	(0.02,	149.09)	1		
Nephrology	1	0.0	0	0.0				-		
Obstetrics	1	0.0	0	0.0				-		

Abbreviation: OR, odds ratio.

Note: The percentage of logins concerns the percentage of the sum of the total number patients with one or more diagnoses per specialty (12,100), while the percentage of views concerns the percentage of users that viewed their problem list of the total number of users with that characteristic that logged in. The column with an asterisk \* shows whether the CI is significantly lower or higher than the CI of the total number of views.

**Supplementary Table S6** Number, percentage, and confidence interval (CI) of patient account users that viewed info buttons, clicked on info buttons, and answered the questionnaire per medical specialty of the diagnoses registered

Specialty	Viewed info button		Clicked on info button							
	v	% v	c	% c	OR	(95% CI)		p-Value	*	ref
Orthopedics	637	90.9	343	53.8	–	–	–	–		ref
Ear, nose, and throat surgery	527	92.5	251	47.6	0.78	(0.61,	0.99)	0.0392	–	
Dermatology	318	85.9	125	39.3	0.56	(0.42,	0.74)	< 0.0001	–	
Surgery	305	85.2	142	46.6	0.75	(0.56,	0.99)	0.0369	–	
Ophthalmology	300	69.3	128	42.7	0.64	(0.48,	0.85)	0.0016	–	
Neurology	220	84.6	101	45.9	0.73	(0.53,	1.00)	0.0503		
Rheumatology	156	90.7	73	46.8	0.75	(0.52,	1.09)	0.1284		
Internal Medicine	139	86.3	70	50.4	0.87	(0.59,	1.28)	0.5115		
Urology	127	86.4	48	37.8	0.52	(0.34,	0.78)	0.0013	–	
Cardiology	117	72.7	66	56.4	1.11	(0.73,	1.69)	0.6156		
Pulmonary medicine	115	86.5	53	46.1	0.73	(0.48,	1.11)	0.1293		
Gastrointestinal and liver diseases	97	98.0	47	48.5	0.81	(0.51,	1.26)	0.3280		
Pediatrics	73	77.7	32	43.8	0.67	(0.40,	1.12)	0.1092		
Revalidation	60	90.9	36	60.0	1.29	(0.73,	2.31)	0.4166		
Plastic surgery	56	52.3	21	37.5	0.51	(0.28,	0.93)	0.0249	–	
Gynecology	48	81.4	18	37.5	0.51	(0.26,	0.98)	0.0353	–	
Pain medicine	43	70.5	25	58.1	1.19	(0.61,	2.37)	0.6373		
Anesthesiology	31	83.8	11	35.5	0.47	(0.20,	1.05)	0.0639		
Geriatrics	18	58.1	13	72.2	2.23	(0.73,	8.07)	0.1523		
Psychiatry	6	11.3	3	50.0	0.86	(0.11,	6.45)	1		
Intensive care	3	100.0	2	66.7	1.71	(0.09,	101.42)	1		
Neurosurgery	1	100.0	1	100.0						
Nephrology	0	0.0	0	0						
Obstetrics	0	0.0	0	0						

Abbreviation: OR, odds ratio.

Note: The percentages and CIs concern the number of users that viewed info buttons compared with the number that viewed the problem list, the number of users that clicked on an info button compared with the number of users that viewed an info button, and the number of users that provided a rating (answer) compared with the number of users that clicked on an info button. The columns with the asterisks \* show whether the CI is significantly differs from (whether it is lower or higher than) the CI of the total number of info button views, clicks, or answers.

### Conversion per Diagnosis

**Supplementary Table S7** Top 20 of patient account users with a certain diagnosis that logged in, with the SNOMED CT concept Id, diagnosis description (SNOMED CT preferred term) and clarification, the number of diagnoses for which patients logged in, percentage of the sum of the number of patients that logged per diagnosis (13,939), and 95% confidence intervals

Id	Diagnosis	Clarification	Logged in		Viewed problem list							
			I	%	v	%	OR	(95% CI)	p-Value	*	ref	
239873007	Osteoarthritis of knee	Osteoarthritis: this is a chronic joint disease in which alteration of the cartilage in the joints leads to pain and stiffness.	214	1.5	61	28.5	-	-	-	-	-	ref
442520000	Inflammation of rotator cuff tendon	A condition of tendon and shoulder.	185	1.3	71	38.4	1.56	(1.00, 2.43)	0.0427	+		
267103008	Feeling of lump in throat (globus feeling in Dutch)	Another word for "globus feeling" is lump in the throat: feeling that there is a slimy plug in the throat that cannot be swallowed.	139	1.0	58	41.7	1.79	(1.12, 2.88)	0.0114	+		
21522001	Abdominal pain	Nagging, cramping, or stabbing pain in the abdominal area.	133	0.9	58	43.6	1.94	(1.20, 3.13)	0.0052	+		
239872002	Osteoarthritis of hip	Osteoarthritis: this is a chronic joint disease in which alteration of the cartilage in the joints leads to pain and stiffness.	133	0.9	45	33.8	1.28	(0.78, 2.10)	0.3378			
57406009	Carpal tunnel syndrome	Disease in the wrist that results from putting too much pressure on a major nerve that runs through the wrist canal.	121	0.9	42	34.7	1.33	(0.80, 2.21)	0.2677			
39450006	Senile cataract	Another word for "senile cataract" is elderly cataract: lens clouding, caused by aging.	119	0.8	33	27.7	0.96	(0.56, 1.63)	0.8997			
16491000146102	Injury of medial meniscus structure	A disease of cartilage and joint.	104	0.7	44	42.3	1.84	(1.09, 3.08)	0.016	+		
72866009	Varicose veins of lower extremity	A type of varicose veins.	91	0.6	35	38.5	1.57	(0.90, 2.70)	0.1057			
25071000146105	Osteoarthritis of medial compartment of knee	Osteoarthritis: this is a chronic joint disease in which alteration of the cartilage in the joints leads to pain and stiffness.	84	0.6	28	33.3	1.25	(0.70, 2.22)	0.4819			
254837009	Malignant neoplasm of breast	Another word for "malignant neoplasm of breast" is breast cancer: a malignant tumor in the breast.	80	0.6	23	28.7	1.01	(0.55, 1.84)	1			
78275009	Obstructive sleep apnea syndrome	Another word for "obstructive sleep apnea syndrome" is OSA or OSAS: temporary stop of breathing during sleep caused by the airway becoming blocked by the tongue, the soft part of the palate, or the wall of the pharynx.	79	0.6	27	34.2	1.3	(0.72, 2.33)	0.3894			
239865003			78	0.6	26	33.3	1.25	(0.69, 2.26)	0.4702			

(Continued)

Id	Diagnosis	Clarification	Logged in		Viewed problem list						
			I	%	v	%	OR	(95% CI)	p-Value	*	ref
195967001	Osteoarthritis of acromioclavicular joint	A disease of the shoulder. Osteoarthritis: this is a chronic joint disease in which alteration of the cartilage in the joints leads to pain and stiffness.	74	0.5	31	41.9	1.8	(1.00, 3.24)	0.0426	+	
39898005	Asthma	Attacks of breathlessness and shortness of breath, caused by narrowing of the smaller airways.	74	0.5	21	28.4	0.99	(0.52, 1.84)	1		
202842005	Sleep disorder	Collective term for disorders in which sleep is disturbed or in which abnormal behavior occurs during sleep.	72	0.5	18	25.0	0.84	(0.43, 1.59)	0.6485		
49526009	Partial thickness rotator cuff tear	A disease of the shoulder.	72	0.5	19	26.4	0.9	(0.46, 1.70)	0.7639		
254701007	Presbycusis	A type of hearing loss.	71	0.5	18	25.4	0.85	(0.43, 1.62)	0.6491		
26241000146104	Basal cell carcinoma of skin	Another word for "basal cell carcinoma of skin" is basal cell cancer: form of skin cancer, usually in areas of the skin exposed to the sun; rarely metastasizes.	71	0.5	22	31.0	1.13	(0.60, 2.09)	0.7633		
430725003	Primary osteoarthritis of knee	Osteoarthritis: his is a chronic joint disease in which alteration of the cartilage in the joints leads to pain and stiffness.	69	0.5	22	31.9	1.17	(0.62, 2.18)	0.6487		
60862001	Patellofemoral stress syndrome	Irritation that can occur between the kneecap and the knee joint because the kneecap slides over the joint when bending and stretching; gives pain at the kneecap, especially when squatting, climbing stairs, or cycling; mainly occurs in teenagers and young adults.	69	0.5	23		1.25	(0.67, 2.32)	0.452		
	Tinnitus	Another word for "tinnitus" is ringing in the ears: hearing sounds (such as humming, whistling, and wind noise) that do not come from outside.									

Abbreviations: CI, confidence interval; OR, odds ratio.

**Supplementary Table S8** Patient account users with a certain diagnosis that viewed a diagnosis with an info button, clicked on it and answered the questionnaire, with the numbers. The columns with the asterisks \* show whether the CI is significantly differs from (whether it is lower or higher than) the CI of the total number of info button views, clicks or answers.

Id	Diagnosis	Viewed info button		Clicked on info button												
		v	% v	c	% c	OR	(95% CI)		p-Value	*	ref					
							lower	upper								
442520000	Inflammation of rotator cuff tendon	71	38.4	26	36.6	-	-	-	-	-	-	-	-	-	ref	
239873007	Osteoarthritis of knee	61	28.5	35	57.4	2.31	(1.09, 4.98)		.0228							ref
21522001	Abdominal pain	58	43.6	19	32.8	0.84	(0.38, 1.86)		.7121							
267103008	Feeling of lump in throat	58	41.7	22	37.9	1.06	(0.48, 2.30)		1							
239872002	Osteoarthritis of hip	45	33.8	26	57.8	2.35	(1.03, 5.46)		.0350							+
16491000146102	Injury of medial meniscus structure	44	42.3	26	59.1	2.48	(1.08, 5.82)		.0218							+
57406009	Carpal tunnel syndrome	42	34.7	9	21.4	0.48	(0.17, 1.22)		.0984							
72866009	Varicose veins of lower extremity	35	38.5	13	37.1	1.02	(0.40, 2.55)		1							
39450006	Senile cataract	33	27.7	15	45.5	1.44	(0.57, 3.61)		.3988							
195967001	Asthma	31	41.9	11	35.5	0.95	(0.35, 2.48)		1							
25071000146105	Osteoarthritis of medial compartment of knee	28	33.3	13	46.4	1.49	(0.56, 3.98)		.3733							
78275009	Obstructive sleep apnea syndrome	27	34.2	11	40.7	1.19	(0.43, 3.22)		.8163							
239865003	Osteoarthritis of acromioclavicular joint	26	33.3	11	42.3	1.27	(0.45, 3.47)		.6424							
399114005	Adhesive capsulitis of shoulder	23	42.6	11	47.8	1.58	(0.55, 4.55)		.4618							
254837009	Malignant neoplasm of breast	23	28.7	9	39.1	1.11	(0.37, 3.22)		1							
111360009	Obstipation	23	43.4	5	21.7	0.48	(0.13, 1.57)		.2133							
60862001	Tinnitus	23	33.3	7	30.4	0.76	(0.23, 2.27)		.6264							
247081001	Posterior vitreous detachment	22	34.4	8	36.4	0.99	(0.31, 2.94)		1							
430725003	Patellofemoral stress syndrome	22	31.9	11	50.0	1.72	(0.59, 5.08)		.3215							
26241000146104	Primary osteoarthritis of knee	22	31.0	10	45.5	1.44	(0.48, 4.22)		.4649							