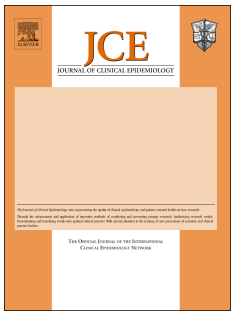

Are we measuring what matters? Exploring the alignment between the ICHOM-set for schizophrenia and online patient stories

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Are we measuring what matters? Exploring the alignment between the ICHOM-set for schizophrenia and online patient stories

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Abstract

Background

In recent years, the use of standardized sets of outcome measures has grown in popularity, particularly through initiatives like the International Consortium for Health Outcome Measurement (ICHOM). While these sets use Patient Reported Outcome Measures (PROMs) to reflect what matters to patients, it is unclear if they accurately capture patients' lived experiences and contribute to Value-Based Health Care (VBHC).

Objectives

This study seeks to explore the usage of online patient stories to assess the patient-relevance of the outcomes measured in the ICHOM-set for schizophrenia. The aim is to show to what extent these align with outcomes that schizophrenia patients describe in online patient stories.

Methods

First, a qualitative, cross-sectional analysis of 28 online stories of patients with schizophrenia was performed in the ATLAS.ti software. Second, the item and definition section of the outcome measures used in ICHOM-set for schizophrenia were systematically compared to the underlying codes resulting from the qualitative analysis of the patient stories.

Results

The findings reveal significant overlap especially in clinical areas such as symptoms, functioning and treatment. However, the study also reveals that patients frequently write about topics that are missing or underrepresented in the ICHOM standard set, such as coping strategies and the value of social support. A notable gap is the issue of stigma and social identity, which appeared prominently in the patient stories but is not addressed in the current ICHOM standard set.

Conclusions

While the ICHOM set reflects many clinical and functional outcomes, it falls short in capturing the full scope of patient experiences. Online patient stories allow for a deeper exploration of dimensions that are sometimes missed in standardized outcome sets like

ICHOM. Considering such perspectives can help to improve VBHC by ensuring outcome measures reflect on what truly matters to schizophrenia patients.

Highlights

- Online patient stories were used to assess patient relevance of outcomes in the ICHOM standard set for schizophrenia
- Alignment was found for symptoms, functioning and treatment outcomes
- Key patient priorities such as coping and social support were underrepresented
- Stigma and social identity were present in patient stories but absent in the outcome set
- Considering these perspectives in the development or adaptation of core outcome sets can help to ensure outcome measures reflect what matters to schizophrenia patients.

Keywords

- Schizophrenia
- PROMs
- ICHOM
- Patient narratives
- Content validity
- Qualitative analysis

1. Introduction

In recent years, there has been a greater emphasis on creating value for patients [1]. In healthcare, value is defined as the improvement in a person's health outcome versus the expense of making that improvement [2]. To measure these improvements, the International Consortium for Health Outcome Measurement (ICHOM) has been developing standardized outcome sets for specific medical conditions, including one for psychotic disorders [3] (schizophrenia and bipolar disorder). Instead of focusing exclusively on clinically relevant measures, ICHOM prioritizes outcomes important to patients, such as recovery, quality of life and long-term health benefits. To capture these, ICHOM incorporates Patient-Reported Outcome Measures (PROMs) into their sets [3]. The US Food and Drug Administration (FDA) defines a patient reported outcome (PRO) as: "A measurement based on a report that comes directly from the patient (i.e., study subject) about the status of a patient's health condition without amendment or interpretation of the patient's response by a clinician or anyone else". [4, p.32] However, these measures only support VBHC when their content is genuinely relevant to patients' lived experiences. Therefore, patient involvement is essential for ensuring that PROMs address outcomes relevant to patients [5,6].

In the development of the ICHOM psychotic disorders set, patients participated through literature review, focus groups and Delphi rounds. Recruitment occurred via clinicians and patient organisations, making representativeness uncertain [7]. Participating in research can be challenging for people with psychotic disorders. Therefore, although patients who blog about their experiences probably do not represent the average schizophrenia patient [8, 9], online patient stories are proposed as an additional source of patient input [10,11].

With schizophrenia patients increasingly sharing their experiences online [12], such stories offer a valuable opportunity to compare lived experiences with outcomes recommended in the ICHOM-set. Therefore, we aimed to show to what extent the outcomes used in the ICHOM-set for schizophrenia align with outcomes that schizophrenia patients describe in online patient stories. First, we explore how patients with schizophrenia describe their health-related quality of life and outcomes of care in online patient stories. Subsequently, we analyse which overlap and/or gaps exist between the outcomes mentioned in online patient stories and the outcomes recommended in the ICHOM-set.

2. Research methods

This study was designed as a cross-sectional comparative analysis, in which the outcomes that schizophrenia patients described in their online patient stories were compared with the outcomes recommended in the ICHOM-set for schizophrenia.

2.1 Data sources

Online patient stories were included when written by adults with schizophrenia or when narrated by patients and transcribed by others (e.g., mental health staff). Stories not written in English or not told from the patient's perspective (e.g., by relatives) were excluded. Nationality was not a criterion. Patient stories were retrieved via Google using search terms such as "schizophrenia patient blog," "living with schizophrenia," and "my experience with schizophrenia." Only publicly accessible sources requiring no login or interaction were used. Data were collected between February and May 2025, and URLs were recorded for traceability.

Outcome measures for psychotic disorders were obtained from the ICHOM website, including the Data Dictionary [3]. According to McKenzie et al. [6], nine measures are grouped into four domains:

1. Symptoms: Patient Health Questionnaire-9 (PHQ-9), Modified Colorado Symptom Index (MCSI), Altman Self-Rating Mania Scale (ASRM) and Patient-Reported Outcomes Measurement Information System – Sleep Disturbance (PROMIS-Sleep).
2. Recovery: Recovering Quality of Life Questionnaire (REQOL-20),
3. Functioning: World Health Organization Disability Assessment Schedule 2.0 (WHODAS-20), KIDSCREEN-10 and Patient Health Questionnaire-15 (PHQ-15).
4. Treatment: Glasgow Antipsychotic Side-Effect Scale (GASS).

ASRM was excluded because it only applies to bipolar disorder.

All these measures are based on reports that come directly from the patients and therefore qualify as a PROM.

2.2 Text analysis

Patient stories were analysed qualitatively in ATLAS.ti through open and axial coding. Data saturation was reached after 28 stories. The codebook resulting from the text analysis was then systematically applied to the PROM items and definitions from the ICHOM data dictionary. If no existing code could be assigned to an item in the PROM, additional codes were generated.

2.3 Ethics statement

This study used publicly available online patient stories. If contact information of the patient was available, they were contacted for informed consent and permission to use direct quotes. If explicit permission was granted, quotes were used. If permission to quote was denied, the stories were still included in the overall thematic analysis, but without quotations. In cases of no response or no contact information, the stories were also included in the analysis and quoted as 'anonymous patient number x'. The study did not require formal ethical approval under Dutch regulations.

3. Results

3.1 How do patients with schizophrenia describe their health-related quality of life and outcomes of care in online patient stories?

A total of 28 patient stories written or narrated by patients with schizophrenia were analysed. This resulted in 135 individual codes, which were grouped into a wide range of eight overarching subthemes, see Appendix 1.

1. Symptoms

Patients most frequently discussed symptoms, describing symptoms such as hallucinations and delusions. These experiences often dominate their narratives and profoundly affect their sense of stability. As Misty [13] explains, *"My main symptoms of schizophrenia were depression, hearing voices and having delusions."*

2. Coping & Self-development

A second major theme concerns coping and self-development, where patients describe the ongoing effort to manage their condition through routines, self-management strategies, acceptance and personal growth. One patient states: *"Living with schizophrenia is not about erasing the illness, but about weaving resilience, acceptance, and growth into everyday life."* (Anonymous patient 1). Many emphasize the continuous process of learning to live with the illness.

3. Functioning & Daily life

Schizophrenia also significantly influences functioning and daily life, particularly in relation to work, education, and the ability to maintain everyday routines. Some patients describe meaningful engagement in work or study, while others recount how symptoms disrupt these activities. Stuart Baker-Brown [14] reflects on this impact: *"As the weeks passed and pressure took its toll, I had to take time off work."*

4. Social relationships & Support

The theme of social relationships and support highlights the importance of interpersonal connections. Family, friends and peers often play a crucial role in emotional and practical support, though social interaction can also be exhausting or challenging.

5. Treatment & Recovery

Patients also describe varied experiences with treatment and recovery, including diagnosis, medication, therapy, and the broader recovery process. For some, receiving a diagnosis brings clarity and relief. Others describe misdiagnoses, side effects, or difficulties engaging with treatment.

6. Stigma & Social identity

A prominent theme across the stories is stigma and social identity. Patients frequently report facing stereotypes, discrimination, and misunderstanding, which shape both how others perceive them and how they perceive themselves. A patient reflects on this fear-based stigma: "*People hear the word schizophrenia and immediately think you are dangerous, unpredictable, or violent, even though that is not who I am.*" (Anonymous patient 2)

7. Trauma & Emotional experience

In addition, many narratives include trauma and emotional experiences**,** ranging from past traumatic events to emotional suffering linked to the illness itself. Feelings of fear, guilt, sadness, and distress are common. A patient describes coping with overwhelming emotions: *"My trauma is not only from what happened before, but also from the daily battles with my illness."* (Anonymous patient 3)

8. Side effects

Finally, patients discuss side effects of medication and treatment, including weight changes, fatigue, and metabolic issues. These physical consequences can significantly affect quality of life. As Greg Ralls [15] writes, *"It seems to reduce the symptoms but also resulted in metabolic syndrome, insulin resistance, and type 2 diabetes."*

3.2 Which overlap and/or gaps exist between the outcomes mentioned in online patient stories and the outcomes recommended in the ICHOM-set for schizophrenia?

The ICHOM-set identifies four key outcome domains: symptoms, recovery, functioning and treatment. The difference between these domains is not clear-cut. For example, both the PROM in the domain symptoms as well as the one in the domain recovery ask how often the patient felt lonely. Eight validated PROMs are used to assess the most important patient experience components. See Appendix 2 for an overview of the outcomes identified in the

PROMs. Table 1 shows the codes in the PROMs compared to those identified in the patient stories and those identified in the PROMs.

For a detailed overview of which codes derived from the patient stories were mapped to which PROM codes, Appendix 3 column H ('codes') provides this information.

Table 1: A comparison of codes in patient stories and in PROMs

PROMs	
PHQ-9	1. Codes matching: • (not) able to function in normal life • depression / mood changes • difficulty with speaking • eating (problems) / gaining weight / losing weight • feeling guilty • feeling low • hopeless • no energy • problems concentrating • sleeping (problems) • suicidal 2. Codes in PROM but not in patient stories: • Symptom OTHER: Little pleasure in doing things
MCSI	1. Codes matching: • (not) be alone • being scared • confusion • could not focus • decision making (difficulties) • delusions • depression / mood changes • hallucinations • hearing voices • paranoia • problems concentrating • seeing things • suicidal • weird / different behaviour • worrying 2. Codes in PROM but not in patient stories: • Symptoms OTHER: not fitting in, hurting someone else
PROMIS-Sleep	1. Codes matching: • no energy • sleeping (problems)

ReQoL-20	1. Codes matching: • (not) able to function in normal life • (not) be alone • (not) feeling confident • anxiety • being happy • being scared • coping with illness • doing things I enjoy • no control • not being able to do things • not wanting to do things • positive future • problems concentrating • recovery • sleeping (problems) • suicidal • trust issues 2. Codes in PROM but not in patient stories: • Functioning & daily life OTHER: avoiding things, being calm • Symptoms OTHER: feeling irritated • Trauma & emotional experience OTHER: feeling like a failure
WHODAS 2.0	1. Codes matching: • (not) able to function in normal life • (not) socialising • community activities • decline cognitive function • emotional pain • friendships • going outside • not able to work • not being able to do things • physical activity • problems concentrating • taking drugs • work / getting a job 2. Codes in PROM but not in patient stories: • Functioning & daily life OTHER: washing body, getting dressed • Coping & self-development OTHER: learning a new task
KIDSCREEN-10	1. Codes matching: • (not) able to function in normal life • (not) be alone • doing things I enjoy • education • family relations • friendships • no energy

	• problems concentrating • quality of life • sad / crying 2. Codes in PROM but not in patient stories: • Functioning & daily life OTHER: have enough time for yourself
PHQ-15	1. Codes matching: • black out • heart pounding • no energy • physical illness • sleeping (problems) • tiredness
GASS	1. Codes matching: • black out • eating (problems) / gaining weight / losing weight • medications • sleeping (problems) 2. Codes in PROM but not in patient stories: • Side effects OTHER (tense muscles, shaky arms and legs, restless legs, drooling, slower movements, uncontrollable movements, blurry vision, dry mouth, difficulty passing urine, vomiting, opening bowels, wetting the bed, very thirsty, pain with nipples, problems with sex, change in period)

3. Codes in patient stories but missing in all PROMs of the ICHOM-set

Symptoms: angry, burnout, catatonic, finding myself in darkness, freezing, having stress, hysterical, irrational thoughts, isolation, losing motivation, neglecting self-care, overwhelmed, panic (attack), pass out, psychotic, screaming, smelling things
Coping & self-development: (creating) awareness, (no) insight in illness, (not) telling family, acceptance of illness, aspiration, be aware of triggers, being positive, denial, developing yourself, distract yourself, hope, independent, keeping routine, making meaning of illness, not talking about illness, pretending to feel good, religion, self-compassion, self-management
Functioning & daily life: financial problems, getting back into society, homelessness, life disruption, moving / want to move, not getting up / out of house, staying in bed
Social relationships & support: being understood, bad home situation, community support, in contact with / helping other patients, relationships, support doctors, support from friends / family
Treatment & recovery: diagnosis, injections, lack of care, mindfulness, misdiagnosis, non-compliance, shared decision making, therapy, treatment
Stigma & social identity: being ashamed, being misunderstood, discrimination, inequity, misconception, negative self-identity, not one size fits all, stigma / stereotypes
Trauma & emotional experience: assaulted, bad home situation, being bullied, criminality, hard to talk about illness, ignoring symptoms, schizophrenia in family, self-loathing, self-worth, traumas
Side effects: diabetes, high cholesterol, metabolic syndrome, tooth problems, twitching

Table 1 demonstrates that many definitions of the PROMs match with the codes generated from the patient stories, particularly in the areas relating to Symptoms, Functioning & daily

Life and Treatment & recovery. However, several issues raised by patients are not captured in any of the PROMs. PROMs do not go into depth about insight in illness and self-management, even though patients frequently emphasize this when discussing how to cope with schizophrenia. PROMs hardly capture the issues related to the stigma and social identity, which is prominently discussed in the patient stories. Similarly, social relationships and support, as well as trauma and emotional experience receive less emphasis, despite being a common theme in patients' stories.

4. Conclusion and discussion

4.1 Main findings

The aim of this study was to explore the usage of online patient stories to evaluate the patient-relevance of the ICHOM-set for schizophrenia. The analysis shows that schizophrenia affects multiple areas of life. Beyond symptoms, patients emphasise coping strategies, personal development, routines, social relationships, family support, stigma and social identity as key factors shaping daily life and recovery. There is overlap between PROMs and patient stories, but patients often highlight coping, growth, social support and stigma. ICHOM does not capture these concepts. The concepts were not prioritized by the service users who participated in the construction of the ICHOM-set, which is aimed to serve as a core outcome set. For this core set, service users particularly valued "positive and negative symptoms, physical health, medication side effects, personal recovery, and prevention of relapse" [7, p. 251]. However, McKenzie et al. [7] point to the low number of service users in the ICHOM working group.

Patient-reported outcomes cover a wide range of concepts varying from specific symptoms to health behaviours, satisfaction with treatment, and health-related quality of life [16]. Topics such as social support or stigma do not directly capture functioning, health status or health-related quality of life and would therefore not fit in PROMs. Whether it would still make sense to broaden the schizophrenia standard set, depends on the purpose of measurement [17]. PROMs may support shared decision-making, monitor individual progress, evaluate quality of care or assess treatment effectiveness in research.

4.3 Limitations & strengths

Using inductive, qualitative methods to assess the patient relevance of outcomes recommended in the ICHOM-set is a key strength, as it reveals that several patient-relevant themes are underrepresented or missing. However, in future research, it may be useful to map the outcomes identified in both patient stories as well as in the ICHOM-set to a predefined conceptual model, e.g. the Wilson & Cleary model of health [18]. This would enable a more systematic comparison.

A limitation of using online stories is the issue of representation: social media users tend to be younger [19], more educated [19,20] and more often female [21], while schizophrenia is more

prevalent among men [22]. Another limitation is the difficulty of verifying the accuracy of patient stories [23]. Additionally, relying on Google to collect stories may exclude patients who are less digitally active [11]. Finally, analyses of patient stories may miss rare or sensitive outcomes. Complementary methods such as interviews or surveys may be necessary [24].

In conclusion, this study shows that while the ICHOM standard set for schizophrenia effectively captures many clinically relevant and functional outcomes, it tends to fall short in addressing the broader psychosocial and experiential dimensions which are emphasized in online patient stories. These narratives offer valuable insight into how patients experience their health-related quality of life. Incorporating such perspectives can help clinicians and researchers avoid missing essential patient-relevant outcomes.

Appendices

Appendix 1: Codebook generated from the analysis of the patient stories

	A	B	C
1	**Codes**	**Code group:**	**Frequency of occurance in blogs**
2	stigma / stereotypes	Stigma & Social Identity	50
3	coping with illness	Coping & self-development	48
4	delusions	Symptoms	46
5	hearing voices / seeing things	Symptoms	43
6	paranoia	Symptoms	40
7	support from friends / family	Social relationships & support	39
8	in contact with / helping other patients	Social relationships & support	37
9	(no) insight in illness	Coping & Self-development	34
10	work / getting a job	Functioning & daily life	30
11	being positive	Coping & Self-development	29
12	depression / mood changes	Symptoms	29
13	isolation	Symptoms	29
14	diagnosis	Treatment & Recovery	29
15	medication	Treatment & recovery	27
16	recovery	Treatment & recovery	27
17	(not) socialising	Social relationships & support	26
18	hospitalization	Treatment & recovery	25
19	treatment	Treatment & Recovery	25
20	being misunderstood	Stigma & Social Identity	24
21	family relations	Social relationships & support	23
22	suicidal	Symptoms	23
23	being scared	Trauma & emotional experience	23
24	psychotic	Symptoms	22
25	selfmanagement	Coping & Self-development	21
26	(not) able to function in normal life	Functioning & daily life	19
27	hallucinations	Symptoms	18
28	education	Functioning & daily life	17
29	community support	Social relationships & support	17
30	relationships	Social relationships & support	17
31	therapy	Treatment & Recovery	17
32	(creating) awareness	Coping & Self-development	16
33	doing things I enjoy	Functioning & daily life	16
34	anxiety	Symptoms	16
35	having stress	Symptoms	16
36	developing yourself	Coping & Self-development	15
37	support doctors	Social relationships & support	15
38	(not) be alone	Functioning & daily life	14
39	decline cognitive function	Functioning & daily life	14
40	eating (problems)/ gaining weight / losing weight	Side effects	14

41	hobbies	Coping & self-development	13
42	hope	Coping & Self-development	13
43	life disruption	Functioning & daily life	12
44	misconception	Stigma & Social Identity	12
45	confusion	Symptoms	12
46	acceptance of illness	Coping & Self-development	11
47	aspiration	Coping & Self-development	11
48	sleeping (problems)	Functioning & daily life	11
49	denial	Coping & Self-development	10
50	religion	Coping & Self-development	10
51	physical activities	Functioning & daily life	10
52	friendships	Social relationships & support	10
53	discrimination	Stigma & Social Identity	10
54	non-compliance	Treatment & Recovery	10
55	being happy	Coping & self-development	9
56	getting back into society	Functioning & daily life	9
57	being understood	Social relationships & support	9
58	not one size fits all	Stigma & Social Identity	9
59	finding myself in darkness	Symptoms	9
60	irrational thoughts	Symptoms	9
61	emotional pain	Trauma & emotional experience	9
62	moving / want to move	Functioning & daily life	8
63	negative self-identity	Stigma & Social Identity	8
64	feeling low	Symptoms	8
65	(not) feeling confident	Coping & self-development	7
66	not talking about illness	Coping & Self-development	7
67	community activities	Functioning & daily life	7
68	losing motivation	Symptoms	7
69	shared decision making	Treatment & Recovery	7
70	independent	Coping & Self-development	6
71	financial problems	Functioning & daily life	6
72	going outside	Functioning & daily life	6
73	diabetes	Side effects	6
74	Sad/crying	Trauma & emotional experience	6
75	decision making (difficulties)	Coping & self-development	5
76	criminality	Trauma & emotional experience	5
77	lack of care	Treatment & Recovery	5
78	keeping routine	Coping & Self-development	4
79	homelessness	Functioning & daily life	4

80	not able to work	Functioning & daily life	4
81	staying in bed	Functioning & daily life	4
82	hopeless	Symptoms	4
83	weird / different behaviour	Symptoms	4
84	angry	Symptoms	4
85	misdiagnosis	Treatment & Recovery	4
86	making meaning of illness	Coping & Self-development	3
87	self-compassion	Coping & Self-development	3
88	no control	Functioning & daily life	3
89	not being able to do things	Functioning & daily life	3
90	no energy	Side effects	3
91	trust issues	Social relationships & support	3
92	panic (attack)	Symptoms	3
93	bad home situation	Trauma & emotional experience	3
94	being bullied	Trauma & emotional experience	3
95	feeling guilty	Trauma & emotional experience	3
96	hard to talk about illness	Trauma & emotional experience	3
97	ignoring symptoms	Trauma & emotional experience	3
98	taking drugs	Trauma & emotional experience	3
99	traumas	Trauma & emotional experience	3
100	injections	Treatment & Recovery	3
101	(not) telling family	Coping & Self-development	2
102	distract yourself	Coping & Self-development	2
103	not getting up / out of house	Functioning & daily life	2
104	quality of life	Functioning & daily life	2
105	high cholesterol	Side effects	2
106	being ashamed	Stigma & Social Identity	2
107	inequity	Stigma & Social Identity	2
108	burnout	Symptoms	2
109	physical illness	Symptoms	2
110	worrying	Symptoms	2
111	freezing	Symptoms	2
112	overwhelmed	Symptoms	2
113	assaulted	Trauma & emotional experience	2
114	selfworth	Trauma & emotional experience	2
115	mindfullness	Treatment & Recovery	2
116	be aware of triggers	Coping & Self-development	1
117	pretending to feel good	Coping & Self-development	1
118	heart problems	Side effects	1
119	metabolic syndrome	Side effects	1
120	tiredness	Side effects	1
121	tooth problems	Side effects	1
122	twitching	Side effects	1
123	black out	Symptoms	1
124	catatonic	Symptoms	1
125	could not focus	Symptoms	1
126	difficulty with speaking	Symptoms	1
127	heart pounding	Symptoms	1
128	not wanting to do things	Symptoms	1
129	problems concentrating	Symptoms	1
130	hysterical	Symptoms	1
131	neglecting self-care	Symptoms	1
132	pass out	Symptoms	1
133	screaming	Symptoms	1
134	smelling things	Symptoms	1
135	schizophrenia in family	Trauma & emotional experience	1
136	self-loathing	Trauma & emotional experience	1

Code Groups	Frequency of occurance in blogs
Symptoms	364
Coping & self-development	281
Functioning & daily life	201
Social relationships & support	196
Treatment & Recovery	181
Stigma & Social identity	117
Trauma & Emotional experience	70
Side-effects	30

Appendix 2: Coded ICHOM data-dictionary[1]

	A	B	D	E	H
1	CATEGORY/I	CATEGORY	ITEM	DEFINITION	CODES
65	OUTCOMES	Symptoms	Question 1 of PHQ9	Over the last 2 weeks, how often have you been bothered by any of the following: A. Little interest or pleasure in doing things?	Symtoms OTHER
66			Question 2 of PHQ9	following: B. Feeling down, depressed, or hopeless	Depression / mood changes, hopeless, feeling low
67			Question 3 of PHQ9	following: C. Trouble falling or staying asleep, or sleeping too much?	Sleeping (problems)
68			Question 4 of PHQ9	following: D. Feeling tired or having little energy?	No energy
69			Question 5 of PHQ9	following: E. Poor appetite or overeating?	Eating (problems), gaining weight / losing weight
70			Question 6 of PHQ9	following: F. Feeling bad about yourself - or that you are a failure or have let	Feeling guilty
71			Question 7 of PHQ9	following: G. Trouble concentrating on things, such as reading the newspaper	Problems concentrating
72			Question 8 of PHQ9	following: H. Moving or speaking so slowly that other people could have	Difficulty with speaking
73			Question 9 of PHQ9	following: I. Thoughts that you would be better off dead or of hurting yourself	Suicidal
74			Question 10 of PHQ9	If you checked off any problems, how difficult have these problems made it for	(Not) able to function in normal life
75			Question 1 of Modified Colorado Symptom Index	Please think about how often you experienced certain problems and how much	Being scared
76			Question 2 of Modified Colorado Symptom Index	How often have you felt depressed?	Depression / mood changes
77			Question 3 of Modified Colorado Symptom Index	How often have you felt lonely?	(not) be alone
78			Question 4 of Modified Colorado Symptom Index	How often have others told you that you acted "paranoid" or "suspicious"?	Paranoia
79			Question 5 of Modified Colorado Symptom Index	How often did you hear voices, or hear and see things that other people didn't	hearing voices, Seeing things, hallucinations, delusions
80			Question 6 of Modified Colorado Symptom Index	How often did you have trouble making up your mind about something, like	Decision making (difficulties)
81			Question 7 of Modified Colorado Symptom Index	How often did you have trouble thinking straight or concentrating on	Worrying, problems concentrating
82			Question 8 of Modified Colorado Symptom Index	How often did you feel that your behavior or actions were strange or different	weird / different behaviour
83			Question 9 of Modified Colorado Symptom Index	How often did you feel out of place or like you did not fit in?	Symptoms OTHER
84			Question 10 of Modified Colorado Symptom Index	How often did you forget important things?	Confusion
85			Question 11 of Modified Colorado Symptom Index	How often did you have problems with thinking too fast (thoughts racing)?	Could not focus
86			Question 12 of Modified Colorado Symptom Index	How often did you feel suspicious or paranoid?	Paranoia
87			Question 13 of Modified Colorado Symptom Index	How often did you feel like hurting or killing yourself?	Suicidal
88			Question 14 of Modified Colorado Symptom Index	How often have you felt like seriously hurting someone else?	Symptoms OTHER
89			Question 1 of Altman Self-Rating Mania Scale	statements carefully. You should choose the statement in each group that best	
90			Question 2 of Altman Self-Rating Mania Scale	Self-confidence	
91			Question 3 of Altman Self-Rating Mania Scale	Sleep Patterns	
92			Question 4 of Altman Self-Rating Mania Scale	Speech	
93			Question 5 of Altman Self-Rating Mania Scale	Activity Level	
94			**PROMIS-29 - Sleep109**	Please respond to each question or statement by marking one box per row.	Sleeping (problems)
95			PROMIS-29 - Sleep116	In the past 7 days...	Sleeping (problems)
96			PROMIS-29 - Sleep20	In the past 7 days...	Sleeping (problems)
97			PROMIS-29 - Sleep44	In the past 7 days...	Sleeping (problems)
98			Hospitalisations- 12 months	Number of hospitalisations related to the target condition in the past 12	Hospitalization
1	CATEGORY/I	CATEGORY	ITEM	DEFINITION	CODES
99		Recovery	Question 1 of the Recovering Quality of Life – 20-item version	I found it difficult to get started with everyday tasks.	not being able to do things, (not) able to function in normal life
100			Question 2 of the Recovering Quality of Life – 20-	I felt able to trust others.	Trust issues
101			Question 3 of the Recovering Quality of Life – 20-	I felt unable to cope.	Coping with illness, recovery
102			Question 4 of the Recovering Quality of Life – 20-	I could do the things I wanted to do.	not wanting to do things
103			Question 5 of the Recovering Quality of Life – 20-	I felt happy.	Being happy
104			Question 6 of the Recovering Quality of Life – 20-	I thought my life was not worth living.	Suicidal
105			Question 7 of the Recovering Quality of Life – 20-	I enjoyed what I did.	Doing things I enjoy
106			Question 8 of the Recovering Quality of Life – 20-	I felt hopeful about my future.	Positive future
107			Question 9 of the Recovering Quality of Life – 20-	I felt lonely.	(not) be alone
108			Question 10 of the Recovering Quality of Life – 20-	I felt confident in myself.	(not) feeling confident
109			Question 11 of the Recovering Quality of Life – 20-	I did the things I found rewarding.	Doing things I enjoy
110			Question 12 of the Recovering Quality of Life – 20-	I avoided things I needed to do.	Functioning & daily life OTHER
111			Question 13 of the Recovering Quality of Life – 20-	I felt irritated.	Symptoms OTHER
112			Question 14 of the Recovering Quality of Life – 20-	I felt like a failure.	Trauma & emotional experience OTHER
113			Question 15 of the Recovering Quality of Life – 20-	I felt in control of my life.	no control, recovery
114			Question 16 of the Recovering Quality of Life – 20-	I felt terrified.	being scared
115			Question 17 of the Recovering Quality of Life – 20-	I felt anxious.	anxiety
116			Question 18 of the Recovering Quality of Life – 20-	I had problems with my sleep.	Sleeping (problems)
117			Question 19 of the Recovering Quality of Life – 20-	I felt calm.	Functioning & daily life OTHER
118			Question 20 of the Recovering Quality of Life – 20-	I found it hard to concentrate.	Problems concentrating
119			Question 21 of the Recovering Quality of Life – 20-	Please describe your physical health (problems with pain, mobility, difficulties	physical illness

[1] It is important to note that in some cases, the definition of the PROM could not be linked to a code that was generated out of the patient stories but did correspond with an overarching theme. These are indicated as '... OTHER' and are grouped under the category 'Codes not matching' in Table 2.

	A	B	D	E	H
1	CATEGORY/I	CATEGORY	ITEM	DEFINITION	CODES
120		Functioning	Question 1 of WHODAS 2.0	This questionnaire asks about difficulties due to health conditions. Health	taking drugs, decline cognitive function
121			Question 2 of WHODAS 2.0	S2: Taking care of your household responsibilities?	(Not) able to function in normal life
122			Question 3 of WHODAS 2.0	S3: Learning a new task, for example, learning how to get to a new place?	Coping & self-development OTHER
123			Question 4 of WHODAS 2.0	[illegible] example, festivities, religious or other activities) in the same way as anyone else	communitiy activities
124			Question 5 of WHODAS 2.0	S5: How much have you been emotionally affected by your health problems?	emotional pain
125			Question 6 of WHODAS 2.0	S6: Concentrating on doing something for ten minutes?	problems concentrating
126			Question 7 of WHODAS 2.0	S7: Walking a long distance such as a kilometer [or equivalent]?	Physical activity, going outside
127			Question 8 of WHODAS 2.0	S8: Washing your whole body?	Functioning & daily life OTHER
128			Question 9 of WHODAS 2.0	S9: Getting dressed?	Functioning & daily life OTHER
129			Question 10 of WHODAS 2.0	S10: Dealing with people you do not know?	(not) socialising, friendships
130			Question 11 of WHODAS 2.0	S11: Maintaining a friendship	friendships
131			Question 12 of WHODAS 2.0	S12: Your day-to-day work?	work / getting a job, not able to work
132			Question 13 of WHODAS 2.1	S13: Overall, in the past 30 days, how many days were these difficulties present?	not being able to do things
133			Question 14 of WHODAS 2.2	S14: In the past 30 days, for how many days were you totally unable to carry out	not able to work
134			Question 15 of WHODAS 2.3	S15: In the past 30 days, not counting the days that you were totally unable, for	(Not) able to function in normal life
135			Question 1 of the KIDSCREEN-10 Index	Have you felt fit and well?	(Not) able to function in normal life
136			Question 2 of the KIDSCREEN-10 Index	Have you felt full of energy?	no energy
137			Question 3 of the KIDSCREEN-10 Index	Have you felt sad?	sad / crying
138			Question 4 of the KIDSCREEN-10 Index	Have you felt lonely?	(not) be alone
139			Question 5 of the KIDSCREEN-10 Index	Have you had enough time for yourself?	Functioning & daily life OTHER
140			Question 6 of the KIDSCREEN-10 Index	Have you been able to do the things that you want to do in your free time?	Doing things I enjoy
141			Question 7 of the KIDSCREEN-10 Index	Have your parent(s) treated you fairly?	family relations
142			Question 8 of the KIDSCREEN-10 Index	Have you had fun with your friends?	friendships
143			Question 9 of the KIDSCREEN-10 Index	Have you got on well at school?	education
144			Question 10 of the KIDSCREEN-10 Index	Have you been able to pay attention?	problems concentrating
145			Question 11 of the KIDSCREEN-10 Index	In general, how would you say your health is?	quality of life
146			Question 1 of Patient Health Questionnaire 15-item	During the past 7 days, how much have you been bothered by any of the	physical illness
147			Question 2 of Patient Health Questionnaire 15-item	Back pain.	physical illness
148			Question 3 of Patient Health Questionnaire 15-item	Pain in your arms, legs, or joints (knees, hips, etc).	physical illness
149			Question 4 of Patient Health Questionnaire 15-item	Menstrual cramps or other problems with your periods.	physical illness
150			Question 5 of Patient Health Questionnaire 15-item	Headaches.	physical illness
151			Question 6 of Patient Health Questionnaire 15-item	Chest pain.	physical illness
152			Question 7 of Patient Health Questionnaire 15-item	Dizziness.	physical illness
153			Question 8 of Patient Health Questionnaire 15-item	Fainting spells.	black out
154			Question 9 of Patient Health Questionnaire 15-item	Feeling your heart pound or race.	heart pounding
155			Question 10 of Patient Health Questionnaire 15-item	Shortness of breath.	physical illness
156			Question 11 of Patient Health Questionnaire 15-item	Pain or problems during sexual intercourse.	physical illness
157			Question 12 of Patient Health Questionnaire 15-item	Constipation, loose bowels, or diarrhoea.	physical illness
158			Question 13 of Patient Health Questionnaire 15-item	Nausea, gas, or indigestion.	physical illness
159			Question 14 of Patient Health Questionnaire 15-item	Feeling tired or having low energy.	no energy, tiredness
160			Question 15 of Patient Health Questionnaire 15-item	Trouble sleeping.	Sleeping (problems)
1	CATEGORY/I	CATEGORY	ITEM	DEFINITION	CODES
161		Treatment	Question 1 of Glasgow Antipsychotic Side-Effect Sc	Over the past week:	Sleeping (problems)
162			Question 2 of Glasgow Antipsychotic Side-Effect Sc	I felt drugged or like a zombie.	medications
163			Question 3 of Glasgow Antipsychotic Side-Effect Sc	I felt dizzy when I stood up and/or have fainted.	black out
164			Question 4 of Glasgow Antipsychotic Side-Effect Sc	I have felt my heart beating irregularly or unusually fast.	heart pounding, heart problems
165			Question 5 of Glasgow Antipsychotic Side-Effect Sc	My muscles have been tense or jerky.	Side effects OTHER
166			Question 6 of Glasgow Antipsychotic Side-Effect Sc	My hand or arms have been shaky.	Side effects OTHER
167			Question 7 of Glasgow Antipsychotic Side-Effect Sc	My legs have felt restless and/or I couldn't sit still.	Side effects OTHER
168			Question 8 of Glasgow Antipsychotic Side-Effect Sc	I have been drooling.	Side effects OTHER
169			Question 9 of Glasgow Antipsychotic Side-Effect Sc	My movements or walking have been slower than usual.	Side effects OTHER
170			Question 10 of Glasgow Antipsychotic Side-Effect S	I have had uncontrollable movements of my face or body.	Side effects OTHER
171			Question 11 of Glasgow Antipsychotic Side-Effect S	My vision has been blurry.	Side effects OTHER
172			Question 12 of Glasgow Antipsychotic Side-Effect S	My mouth has been dry.	Side effects OTHER
173			Question 13 of Glasgow Antipsychotic Side-Effect S	I have had difficulty passing urine.	Side effects OTHER
174			Question 14 (a) of Glasgow Antipsychotic Side-Effe	I have felt like I am going to be sick or have vomited.	Side effects OTHER
175			Question 14 (b) of Glasgow Antipsychotic Side-Effe	I have had problems opening my bowels (constipation).	Side effects OTHER
176			Question 15 of Glasgow Antipsychotic Side-Effect S	I have wet the bed.	Side effects OTHER
177			Question 16 of Glasgow Antipsychotic Side-Effect S	I have been very thirsty and/or passing urine frequently.	Side effects OTHER
178			Question 17 of Glasgow Antipsychotic Side-Effect S	The areas around my nipples have been sore and swollen.	Side effects OTHER
179			Question 18 of Glasgow Antipsychotic Side-Effect S	I have noticed fluid coming from my nipples.	Side effects OTHER
180			Question 19 of Glasgow Antipsychotic Side-Effect S	I have had problems enjoying sex.	Side effects OTHER
181			Question 20 of Glasgow Antipsychotic Side-Effect S	I have had problems getting an erection.	Side effects OTHER
182			Question 21 of Glasgow Antipsychotic Side-Effect S	Tick yes or no for the last three months:	Side effects OTHER
183			Question 22 of Glasgow Antipsychotic Side-Effect S	I have been gaining weight.	Eating (problems), gaining weight / losing weight

Appendix 3: Comparison of codes used in the ICHOM data-dictionary and codes only used in patient stories

Codes that could be linked to the PROMs	Group
(not) able to function in normal life	Functioning & daily life
(not) be alone	Functioning & daily life
(not) feeling confident	Coping & self-development
(not) socialising	Social relationships & support
anxiety	Symptoms
being happy	Coping & self-development
being scared	Trauma & emotional experience
black out	Symptoms
communitiy activities	Functioning & daily life
confusion	Symptoms
coping with illness	Coping & self-development
could not focus	Symptoms
decision making (difficulties)	Coping & self-development
delusions	Symptoms
depression / mood changes	Symptoms
difficulty with speaking	Symptoms
doing things I enjoy	Functioning & daily life
eating(problems) / gaining weight / losing weight	Side effects
education	Functioning & daily life
emotional pain	Trauma & emotional experience
family relations	Social relationships & support
feeling guilty	Trauma & emotional experience
feeling low	Symptoms
friendships	Social relationships & support
going outside	Functioning & daily life
hallucinations	Symptoms
hearing voices / seeing things	Symptoms
heart pounding	Symptoms
heart problems	Side effects
hopeless	Symptoms
hospitalization	Treatment & recovery
medication	Treatment & recovery
no control	Functioning & daily life
no energy	Side effects
not able to work	Functioning & daily life
not being able to do things	Functioning & daily life
not wanting to do things	Symptoms
paranoia	Symptoms
physical activity	Functioning & daily life
physical illness	Symptoms
problems concentrating	Symptoms
quality of life	Functioning & daily life
recovery	Treatment & recovery
sad / crying	Trauma & emotional experience
sleeping (problems)	Functioning & daily life
suicidal	Symptoms
tiredness	Side effects
trust issues	Social relationships & support
weird / different behaviour	Symptoms
work / getting a job	Functioning & daily life
worrying	Symptoms

Codes that could NOT be linked to the PROMs (only used in patient stories)	Group
(creating) awareness	Coping & Self-development
(no) insight in illness	Coping & Self-development
(not) telling family	Coping & Self-development
acceptance of illness	Coping & Self-development
angry	Symptoms
aspiration	Coping & Self-development
assaulted	Trauma & emotional experience
bad home situation	Trauma & emotional experience
be aware of triggers	Coping & Self-development
being ashamed	Stigma & Social Identity
being bullied	Trauma & emotional experience
being misunderstood	Stigma & Social Identity
being positive	Coping & Self-development
being understood	Social relationships & support
burnout	Symptoms
catatonic	Symptoms
community support	Social relationships & support
criminality	Trauma & emotional experience
denial	Coping & Self-development
developing yourself	Coping & Self-development
diabetes	Side effects
diagnosis	Treatment & Recovery
discrimination	Stigma & Social Identity
distract yourself	Coping & Self-development
financial problems	Functioning & daily life
finding myself in darkness	Symptoms
freezing	Symptoms
getting back into society	Functioning & daily life
hard to talk about illness	Trauma & emotional experience
having stress	Symptoms
high cholesterol	Side effects
homelessness	Functioning & daily life
hope	Coping & Self-development
hysterical	Symptoms
ignoring symptoms	Trauma & emotional experience
in contact with / helping other patients	Social relationships & support
independent	Coping & Self-development
inequity	Stigma & Social Identity
injections	Treatment & Recovery
irrational thoughts	Symptoms
isolation	Symptoms
keeping routine	Coping & Self-development
lack of care	Treatment & Recovery
life disruption	Functioning & daily life
losing motivation	Symptoms
making meaning of illness	Coping & Self-development
metabolic syndrome	Side effects
mindfulness	Treatment & Recovery
misconception	Stigma & Social Identity
misdiagnosis	Treatment & Recovery
moving / want to move	Functioning & daily life
negative self-identity	Stigma & Social Identity
neglecting self-care	Symptoms
non-compliance	Treatment & Recovery
not getting up / out of house	Functioning & daily life
not one size fits all	Stigma & Social Identity

not talking about illness	Coping & Self-development
overwhelmed	Symptoms
panic (attack)	Symptoms
pass out	Symptoms
pretending to feel good	Coping & Self-development
psychotic	Symptoms
relationships	Social relationships & support
religion	Coping & Self-development
schizophrenia in family	Trauma & emotional experience
screaming	Symptoms
self-compassion	Coping & Self-development
self-loathing	Trauma & emotional experience
selfmanagement	Coping & Self-development
selfworth	Trauma & emotional experience
shared decision making	Treatment & Recovery
smelling things	Symptoms
staying in bed	Functioning & daily life
stigma / stereotypes	Stigma & Social Identity
support doctors	Social relationships & support
support from friends / family	Social relationships & support
taking drugs	Trauma & emotional experience
therapy	Treatment & Recovery
tooth problems	Side effects
traumas	Trauma & emotional experience
treatment	Treatment & Recovery
twitching	Side effects

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Highlights

- Online patient stories were used to assess patient relevance of PROMs
- Alignment was found for symptoms, functioning and treatment outcomes
- Key patient priorities such as coping and social support were underrepresented
- Stigma and social identity were present in patient stories but absent in PROMs
- Considering these perspectives in PROM development or adaptation can help to ensure outcome measures reflect what matters to schizophrenic patients.

Competing interests

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