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Measuring Community Participation Among Japanese with Serious Mental Illnesses

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Abstract Community participation is associated with physical, cognitive, and mental health benefits for people with serious mental illnesses (SMI) and is recognized as a critical component of health functioning. Developing reliable measurement of participation in different cultural contexts and languages is important to expanding knowledge in this area. The aim of this study was to translate a psychometrically sound English-language community participation measure into Japanese and examine its test-reliability with a

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population of Japanese people with SMI. Self-reported data were gathered twice from 253 individuals within 48 h using the Temple University Community Participation-Japanese version (TUCP-J) at Type-B Continuous Employment Support Centers in Japan between November 2020 and February 2021. Participant responses were similar on four of the five participation subscales. At the item-level, participants provided consistent responses on 26 out of 27 of the items about amount of participation and had high itemlevel concordance (77-93%) on their ratings of the importance (Yes; No) of each participation activity and their reported participation sufficiency (Enough; Not Enough; Too Much: 73-88%). Overall, the results demonstrated strong evidence of test-retest reliability of the TUCP-J and identified a number of areas that were important to respondents, but where they were reporting not doing enough.

Keywords Community inclusion · Participation · Measurement · Serious mental illness · Reliability

Introduction

The United Nations Convention on the Rights of People with Disabilities identified community inclusion, understood as the opportunity for full participation in meaningful activities, as a basic human right [1]. This declaration acknowledges the long-history of

Community inclusion, and the increased participation in society that results, such as greater employment, educational attainment, engagement in faith communities, and better relationships with friends and family, is also a medical necessity in the sense that such participation is associated with greater physical, cognitive, and mental health and wellness [2, 3]. The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health [4] has conceptualized participation as a key component of health. For example, people with serious mental illnesses who participate more experience greater levels of recovery and subjective well-being [5, 6], elevated levels of physical activity [7], and experience physical and cognitive health benefits, as well as reduced depression as a result [2, 8-10]. Moreover, participation can expand social networks and deepen social connectedness [11, 12], which are at the core of well-being [13–15]. Unfortunately, a report from the World Health Organization [16] concludes that few advances have been made in increasing community participation among people with SMI, which is consistent with research demonstrating that people with SMI lag well behind the general population in terms of amount, breadth, and sufficiency of participation [17].

Community participation of people with SMI is increasingly viewed as important in Japan. Unlike other developed countries, Japanese mental health systems have focused primarily on symptom reduction and maintenance, including heavy dependence on inpatient care, until relatively recently [18]. In 2004, the Japanese government initiated policies that emphasized deinstitutionalization and community living [19], which aligned with findings that Japanese citizens with SMI strongly desire opportunities for meaningful lives in their community [20, 21]. A number of participation-oriented intervention models have since been implemented in Japan and found to be effective, such as Individualized Placement and Support (IPS) [22, 23], assertive community treatment (ACT) [24, 25], and peer support [26].

Effective systems transformation requires robust measures of participation [27, 28] that are reliable in different cultural contexts. Such a measure in Japanese has not yet been established [19]. The aim of this study is to examine whether a measure of participation that was developed in the United States can reliably assess community participation among a Japanese psychiatric population. The Temple University Community Participation measure [29] was selected because it has a number of important characteristics. It involved input from individuals with significant mental health issues and examines a broad-range of participation areas (e.g., work, education, faith, leisure, social relationships, online activities, volunteering, etc.). It also incorporates a self-determination framework whereby participation is assessed within the context of an individual's desires [30], including an assessment of whether a person views each area of participation as important to them and the extent to which they believe they have engaged in the activity enough. The original English-language version also has good evidence of reliability [27, 29] and validity [5, 17] with an SMI population.

Method

Measures

Temple University Community Participation Measure

This study utilizes the Temple University Community Participation measure (TUCP) that was slightly modified to be more consistent with the WHO's International Classification of Functioning, Disability, and Health framework¹ and separately measure participation with family members versus friends, partly in order to be more sensitive to possible cultural differences in the roles these relationships play in the lives of people around the world. The TUCP examines participation in 27 areas of the participation-related life domains identified in the International Classification of Functioning, Disability, and Health [4]: major life areas (e.g., work, education), community, social,

¹ "Engaging in organized sport" and "socializing with people from work, school, neighborhood, or other acquaintances" were added because the ICF includes sport and informal social relationship as important participation areas.

and civic life (e.g., faith, leisure, volunteering), and interpersonal relationships (e.g., family, friends). A full list of items is presented in a later table. Participants report the number of days in the past 30 days they participated in each area without the help of mental health staff, whether they did the activity as much as they desired, with response options of "enough," "not enough," or "too much," and whether the activity was important to them. Five participation constructs were examined in the current study.

Participation Amount Sum of participation days reported across the 27 activity areas. The possible scores can range between 0 and 810 (27 areas of activities \times 30 days).

Number of Important Activity Areas Sum of the number of activities indicated as important to the participant. This construct assesses the breadth of interests the individuals has. The possible scores can range between 0 and 27.

Breadth of Participation Sum of the number of important areas the person identified where they participated at least one day. This construct indicates the variety of areas that a person is engaging in to some degree. The score of Breadth can range between 0 and 27.

Breadth Ratio Calculated as a ratio of the number of important areas identified by the person that were done at least one day over the total number of important areas identified by the person. For example, if a person had 12 important areas and engaged in six areas then their Breadth Ratio would be 0.50 or 50% (e.g., 6/12). Higher scores indicate broader engagement in important areas. Breadth Ratio can range between 0 and 1.00.

Participation Sufficiency Participation Sufficiency assesses the degree to which individuals report doing "enough" in areas identified as important to them. It is calculated as a ratio of the number of important areas they identify as being done enough over the total number of important areas they identify. For example, if a person indicated having 12 important areas and reported participating "enough" in four areas then their Sufficiency score is 0.33 or 33% (e.g., 4/12). Higher scores reflect a higher proportion of important areas where they feel they do enough.

Demographic Variables

Gender, age category (i.e., 20–29, 30–39, 40–49, etc.), how often they were involved in the CESC, and the amount of money they had to engage in community-based activities were included in the survey.

Translation Procedures

A two-step translation procedure involving backtranslation and assessment of cross-cultural equivalence was used. The back translation procedure [31] involved three individuals. First, a Japanese scholar who earned a Master's and Ph.D. degrees in the United States and had approximately ten years of work experience in the country translated the English version into Japanese. Second, a Japanese mental health professional who had studied and earned a master's degree in the United States translated the Japanese version back to English. Finally, an Englishspeaking scholar who was involved in the development of the measure verified the back-translated English-version. Cross-cultural equivalence was assessed by two individuals who had experience working with mental health service consumers in the United States and Japan who reviewed each item to ensure that the Japanese version was consistent with the intent of the English version. Finally, the five Japanese mental health service consumers reviewed the measure, which resulted in slight additional modifications.

Participants

Study participants were recruited from 17 Continuous Employment Support Centers in Japan between November 2020 and February 2021. Inclusion criteria included (a) using a service at a Type-B Continuous Employment Support Center (CESC: Ministry of Health, Labor, and Welfare, 2013 [32]), and either (b-1) possessing a psychiatric disability certificate endorsed by a psychiatrist and issued by a municipality or (b-2) having a diagnosis of psychiatric disorder. Those who use a Type-B CESC service have considered to have severe disability because its eligibility requirements include the use of an assistance for activities of daily living, or the identified critical problems for seeking employment confirmed by a transitional employment service provider. Those who are more able are typically be placed in a Type-A CESC or a transitional employment support service. Type-B CESCs are categorized as a social welfare service in the domain of employment. It is not a competitive employment, and there is no labor contract involved as the work is regarded as a job training service. Type-B CESCs are similar to sheltered employment programs and are often private companies and businesses that are certified by prefectures of Japan. Type-B CESCs provide entry-level, low intensity work experiences for those who have significant impairments. Service users work part-time and are paid for their labor.

Data Collection Procedures

Data were collected by staff mental health professional (e.g., a certified psychiatric social worker or a mental health counselor) at each Type-B CESC who had previously established rapport with their clients. Staff received written and verbal instructions for conducting the data collection. Program participants were informed about the opportunity to participate in the study by CESC staff and those who were interested in participating reviewed an informed consent form and provided written consent to participate and consent to publish. The participant then completed the TUCP (i.e., Time 1 survey) and demographic questions with staff support. They completed the TUCP a second time within 48 h (i.e., Time 2 survey) with the support of the same staff at Time 1. We chose to do the 48-h interval because it is a reasonable compromise between recall bias and unwanted change in behavior [33], considering the TUCP requires a 30-day recall. The research protocol was approved by the Institutional Review Board at the lead author's university (Protocol # East 2020-82).

A total of 358 individuals were informed about the study and 259 provided informed consent (72% of those approached) and completed the measures at Time 1. Six participants were absent due to sickness and could not make it to the Time 2 assessment. But the rest of the participants (n = 253) completed the TUCP at Time 2, which is the final sample for this study.

Data Analysis

Responses at both timepoints were inspected to identify potential outliers, resulting in the removal of one participant who reported participating 30 days in the past 30 days in all 27 participation areas, which was viewed as implausible. Paired sample *t*-test were conducted to examine the difference in continuous variables between Time 1 and Time 2. Cohen's Kappa and concordance rates were examined for categorical variables—responses regarding the perceived importance of the activity area and perceived sufficiency of their participation.

Results

Sample Characteristics

A total of 253 individuals completed the TUCP at both timepoints. Approximately two-thirds of the sample were men (67%, n = 82) and the median age category was 40 to 49. Additional sample characteristics are shown in Table 1.

Test-Retest Reliability Findings

Paired samples t-test results for scale scores and the amount of participation on individual items are presented in Table 2. No significant difference between Time 1 and Time 2 were detected on four out of five participation scales: Participation amount (t = -0.44, df = 209, p = 0.664); number of important activity areas (t = -0.62, df = 193, p = 0.538); breadth ratio (t = 0.11, df = 167, p = 0.912); and participation sufficiency (t = -1.79, df = 174,p = 0.076). Significant Time 1 to 2 differences were found for breadth of participation scale (t = -2.12, df = 194, p = 0.035), although the difference was small (Cohen's d = 0.113). At the individual item level for amount of participation, Time 1 to 2 differences were found on only one out of 27 items, visiting or inviting family (t = -2.19, df = 206,p = 0.030), which could have been due to chance.

The responses on the importance of each participation area (i.e., Item rated as "Important" or "Not important") between Time 1 and Time 2 were highly concordant, with a range of 77% and 93% (median = 84%) and acceptable Cohen's Kappa values

Table 1 Sample characteristics

	n		%	
Gender				
Female	82		32.4	
Male	170		67.2	
Missing	1		0.4	
Age category				
20 to 29	27		10.7	
30 to 39	54	21.3		
40 to 49	85	33.6		
50 to 59	60	23.7		
60 to 69	19	7.5		
70 or above	4	1.6		
Missing	4	1.6		
The frequency of CESC	use in the pas	st 30 days		
0 day	1	0.4		
1 to 3 days	14	5.5		
4 to 6 days	13	5.1		
7 to 9 days	21	8.3		
10 to 12 days	36	14.2		
13 to 15 days	27	10.7		
16 days or more	133		52.6	
		Mean	SD	
Monthly allowance for	16,593 yen	14,97		

(k = 0.402 - 0.811). Similarly, satisfactory concordance between the timepoints on participation sufficiency (i.e., participation in the area done enough, not enough, or too much) was also found (73–88%) along with satisfactory Cohen's Kappas (k = 0.404 - 0.757).

Additional Findings About Importance and Sufficiency of Participation

These results also provide insights about the participation interests and experiences of this population. Using Time 1 results, we found that more than 50% of respondents indicated that five areas were particularly important to them: shopping for leisure (n = 192, 85%), working for pay (n = 172, 80%), using public transportation (n = 149, 69%); going to a restaurant or coffee shop (n = 132, 60%), and going to a barber shop for leisure (n = 125, 58%). The bottom three areas of importance were going to watch sport event (n = 43, 20%), engaging in an organized sport (n = 39, 18%), and engaging in civic activities (n = 38, 18%). Overall, the percentage of individuals who viewed each area as important is generally much lower than what has been found in other research (e.g. [29]).

Among those who indicated the activity area as important, the percentage who reported that they participated enough was highest for shopping for leisure (87%), using public transportation (77%), working for pay (76%), and going to a barber shop (74%). There were a number of areas that were important to respondents, but where sufficiency of participation was only 50% or lower, including meeting with friends (48%), going to a gym (40%), volunteering (48%), hanging out and socializing with others (50%), and the lowest scores for watching a sport event (37%), going to school for degree (34%), and going to a zoo or botanical garden (34%) (Table 3).

Discussion

Study results demonstrated that the Temple University Community Participation could be successfully translated into Japanese and produce consistent test–retest responses. Despite concerns about cognitive impairments experienced by some with significant mental health issues [34], especially with episodic memory and meta-cognition, these results suggest that Japanese participants with significant mental health issues can provide reliable answers about their participation and interests on the scale scores and on individual items. These results for the TUCP-J are consistent with previous reliability findings on the English version [27, 29].

The successful translation of this measure and finding that it has good test-retest reliability is a major advance in fulfilling calls for increased attention to community participation in Japan [20, 21]. The TUCP-J could reasonably be used to develop a better understanding of an individual's current participation and interests, as well as assist in evaluating outcomes associated with programs like ACT [24, 25] and peer support programs [26]. The findings also suggest that the construct of community participation, at least as measured using the TUCP, may be similarly assessed

Table 2 Summary of paired t-tests, examining differences in scores between Time 1 and Time 2 administration

	Time 1			Time 2			Paired T-Test		
Variable	n	Mean	SD	n	Mean	SD	t	df	р
Number of participation days									
Go shopping for leisure	213	11.52	9.93	213	11.91	10.30	- 0.88	212	.3791
Work for pay		10.93	8.56	207	10.89	8.33	0.07	206	.9482
Use public transportation	210	6.71	8.78	210	6.32	8.53	1.06	209	.2919
Play game at their own home		4.10	9.18	211	3.42	8.65	1.7	210	.0907
Go to a restaurant or coffee shop		2.73	4.69	209	2.67	4.56	0.23	208	.8154
Go to a park or recreation center	209	1.40	3.84	209	1.84	4.87	- 1.88	208	.0614
Spending time with family at home	207	0.92	3.56	207	1.38	4.57	- 2.19	206	.0299
Socialize with people from work/school/etc	209	0.84	3.48	209	1.20	4.48	- 1.88	208	.0615
Play games outside the home		0.70	3.71	210	0.52	2.78	0.74	209	.4588
Spending time with friends at home		0.69	2.76	212	0.75	2.87	- 0.65	211	.5140
Go to a library		0.57	1.93	211	0.55	1.75	0.39	210	.6946
Go to a barber shop	209	0.57	1.62	209	0.60	1.42	- 0.23	208	.8157
Go to a gym		0.38	2.77	211	0.40	2.97	- 0.12	210	.9060
Engage in volunteering		0.34	2.28	210	0.53	2.59	- 1.01	209	.3117
Go to a movie	211	0.25	0.79	211	0.27	0.94	- 0.43	210	.6693
Go to a place of worship	214	0.24	1.03	214	0.26	1.13	- 0.54	213	.5912
Go to a social group in the community	210	0.24	1.49	210	0.14	0.63	0.97	209	.3337
Engage in civic activities		0.22	2.13	207	0.10	0.59	0.81	206	.4214
Go to a community event	209	0.14	0.86	209	0.16	0.88	- 0.67	208	.5063
Go to a theater or cultural event	211	0.11	0.55	211	0.15	0.60	- 0.9	210	.3714
Attend a community event with family		0.06	0.30	211	0.12	0.79	- 1.07	210	.2847
Attend a community event with friends		0.06	0.32	210	0.11	0.75	- 0.95	209	.3450
Go to a zoo or botanical garden		0.06	0.32	210	0.04	0.23	0.77	209	.4399
Go to watch a sport event		0.06	0.45	211	0.04	0.38	1.42	210	.1578
Take a class for leisure	211	0.03	0.24	211	0.05	0.30	- 1	210	.3185
Engage in an organized sport	210	0.02	0.19	210	0.04	0.44	-0.78	209	.4362
Go to school for degree		0.02	0.23	211	0.13	1.11	- 1.43	210	.1550
Participation scales									
Participation amount	210	42.95	29.39	210	43.54	29.32	- 0.44	209	.6636
Number of important activities	194	9.98	7.09	194	10.19	7.08	- 0.62	193	.5376
Breadth of participation	195	4.18	3.02	195	4.52	2.98	- 2.12	194	.0349
Breadth ratio	168	0.56	0.32	168	0.56	0.32	0.11	167	.9117
Sufficiency	175	0.56	0.34	175	0.60	0.33	- 1.79	174	.0760

in both Western and non-Western countries (e.g., Japan). Most current research on community participation among individuals with mental illnesses have been conducted in Western countries.

While evidence of test-retest reliability was observed in nearly all areas, there was a difference

on one scale—breadth of participation, and on the item about number of days they visited family. The five consumers who provided feedback on the measure during the translation process indicated that they had never been asked about their community participation interests in such a thorough way before and that the

Table 3	Importance	and sufficienc	y of communit	y participation	at Time 1

	Out of those who say area is important report engaging in area								
	Important		Not enough		Enough		Too much		
Variable	N	%	N	%	N	%	N	%	
Go shopping for leisure	192	84.96	20	10.58	164	86.77	5	2.65	
Work for pay	172	80.00	37	22.84	123	75.93	2	1.23	
Use public transportation	149	68.98	30	21.28	109	77.30	2	1.42	
Go to a restaurant or coffee shop	132	60.27	44	34.38	83	64.84	1	0.78	
Go to a barber shop	125	57.87	32	26.45	89	73.55	0	0.00	
Spend time with friends at home	92	43.60	45	51.14	42	47.73	1	1.14	
Go to a library		42.99	50	54.35	42	45.65	0	0.00	
Spend time with family at home	89	42.18	31	36.90	51	60.71	2	2.38	
Go to a park or recreation center	86	40.19	31	36.90	52	61.90	1	1.19	
Socialize with people from work/school/etc	81	38.03	36	47.37	38	50.00	2	2.63	
Engage in volunteering	76	36.02	36	49.32	35	47.95	2	2.74	
Go to a movie	78	35.94	38	51.35	36	48.65	0	0.00	
Go to a theater or cultural event	72	33.49	38	53.52	33	46.48	0	0.00	
Play game at their own home	71	32.87	19	28.36	44	65.67	4	5.97	
Go to a gym	67	31.16	38	58.46	26	40.00	1	1.54	
Go to a zoo or botanical garden	65	30.23	42	65.63	22	34.38	0	0.00	
Go to school for degree	62	28.70	40	65.57	21	34.43	0	0.00	
Attend a community event with friends	60	28.44	28	48.28	30	51.72	0	0.00	
Attend a community event with family	59	27.70	25	43.86	32	56.14	0	0.00	
Go to a social group in the community	58	27.49	25	45.45	30	54.55	0	0.00	
Go to a place of worship	56	26.17	19	35.19	34	62.96	1	1.85	
Play games outside the home	55	25.70	21	39.62	32	60.38	0	0.00	
Go to a community event	54	25.23	19	36.54	33	63.46	0	0.00	
Take a class for leisure	47	22.07	24	52.17	22	47.83	0	0.00	
Go to watch a sport event	43	20.00	26	63.41	15	36.59	0	0.00	
Engage in an organized sport	39	18.14	21	56.76	16	43.24	0	0.00	
Engage in civic activities	38	18.01	13	36.11	23	63.89	0	0.00	

questions made them reflect on it much more than they had previously. It is plausible that the difference on breadth of participation resulted from their paying increased attention to what they are doing between Time 1 and Time 2, although no differences were found on the other scales where such attention might also make a difference. The inconsistent finding on visiting with family could simply be due to chance (i.e., one out of 27 tests was statistically significant).

The results also provide insights on the current community participation among a sub-group of Japanese with serious mental illnesses (SMI). Study results indicate that only five areas were rated as important by more than 50% of respondents, which is strikingly low compared to one study conducted in the United States, where more than 50% of respondents rated 16 areas as important [29]. This could have been an indicator of cross-cultural incompatibility of the items, but the Japanese translators, program staff, and advisory group of consumers all believed the participation items covered on the TUCP-J were important to Japanese people. It is possible that respondents in this study had more severe impairments, including negative symptoms, based on the type of program they were recruited from compared to the fairly heterogenous sample of individuals in the U.S. study, resulting in their reporting of fewer interests. The relative lack of important areas could also reflect adaptive preferences [35], whereby respondents may not indicate some areas as important because they have been discouraged from participating in them or had failure experiences while previously participating [36]. For example, they may receive messages, both implicit and explicit, about challenges they will face in obtaining competitive employment and possibly engagement in other participation areas [37]. Limited participation opportunities while receiving institutional care [38] may have also led some to never develop a broad-range of interests.

Japanese respondents had similar level of interests in certain activities such as shopping, and working for pay, as was found in the U.S. sample. However, they differed significantly in other areas. For example, only 26% of the Japanese participants reported interests in activities related to worshipping, but most (78%) participants showed interests in worshipping in the US sample [29]. This might reflect different spiritual practices, as Americans go to places like churches or other places of worship while many Japanese engage in unchurched spiritual practices such as meditation [39]. It may be that the Shinto ban following World War II and cult terrorism in 1995 led Japanese people to avoid explicit religious practices [40]. Similarly, many respondents in this study did not consider civic and political activities as important, possibly because it has been observed that political participation and civic engagement among Japanese has been inactive for decades [41], possibly due to their unwillingness to get involved in the activities that might express their political stance [42].

Sufficiency of participation was relatively high in some important areas, such as shopping, use of public transportation, and work for pay, the latter not being surprising because all participants were recruited from employment programs. There were also a number of areas that were important to respondents, but where they believed they did not participate enough. This includes spending time with friends or others, where about 50% of participants indicated not doing enough, as well as leisure activities, such as going to a move or cultural activity, watching a sports event, or taking a class for leisure, as well as volunteering.

There are a number of implications from this study. The results suggest that the TUCP-J is a reliable measure with a very impaired SMI subgroup and could be used with broader group in future research. The limited number of highly important areas that were reported point to a number of possible directions, including addressing barriers people may face in their attempts to participate in the community, such as reducing prejudice and discrimination and providing community-based participation supports, to reduce possible adaptive preferences. Type-B CESCs could also spend more time speaking with program participants about their interests and encouraging participation in a broad-range of areas. Finally, efforts could be made to also address individual skills required for successful participation in areas that are important to them and addressing environmental barriers they may face (e.g., stigma, costs, transportation, lack of social support) in those areas. It should be noted, however, that the data were gathered during the COVID-19 pandemic, which could have impacted results. It is plausible that ratings about importance and sufficiency could have been impacted by the closure of an activity venue or because of not wanting to leave the home due to fear of infection.

Limitations

While the current study was quite informative, there are a few limitations to be acknowledged. First, although all the participants were recruited from the same type of program (i.e., Type-B CESCs) that has fairly prescriptive requirements for enrollment of those with among the most impairments, individual diagnostic information was not collected. While the level of functioning should be quite homogeneous, this limited our ability to fully describe the diagnostic composition of the sample, which may or may not have impact on participation results. Another limitation is some degree of selection bias. Program staff encouraged all the service users to participate, and 72% did participate, but it is unclear whether the other 28% differed in some important way from the others. Finally, as mentioned above, data collection took place during public health measures associated with the COVID-19 pandemic and some community activities such as sporting events, festivals, and social gathering were restricted. This will serve as an interesting point of comparison for future research when restrictions are lessened.

Conclusion

This study found good evidence of test-retest reliability for the Japanese version of the Temple University Community Participation measure (TUCP-J). Such a measure can be useful in Japan as policies and services continue to advance in the promotion of community inclusion of individuals with SMI and move away from institutional care. The results also suggest a possible need to attend to the relatively few areas that are viewed as important to these respondents and possible reasons for that. It also draws attention to the notion of sufficient participation—doing enough in important areas, and structuring future supports and services to assisting Japanese citizens with SMI to engage fully in areas that are important to them as a rights issue and a matter of health promotion.

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Declarations

Conflict of interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Ethical approval This study was approved by the University of Tsukuba, Faculty of Human Science IRB: Protocol # East 2020–82.

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