

Original Article

Barriers to equitable use of patient-reported outcomes in diabetes management

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ABSTRACT

INTRODUCTION. Inequity in diabetes-related health due to socioeconomic status is a recognised challenge. A patient-centred approach tailors care to individual needs, and patient-reported outcome (PRO) measures can be a valuable tool in this process. In Denmark, a new diabetes-specific PRO questionnaire has been developed to enable a systematic assessment of patients' experiences and potential barriers to care. This study examined participation in the PRO diabetes questionnaire and its relation to socioeconomic status and severe psychiatric comorbidity.

METHODS. This register study included people with diabetes who were invited to complete the questionnaire. Participation status was analysed using multiple logistic regression models, incorporating variables related to socioeconomic status.

RESULTS. Socioeconomic status was a significant overall predictor of questionnaire participation, with non-Western immigration showing the strongest association. Additionally, Western immigration, low educational attainment and severe psychiatric comorbidity were significant predictors in subsets of the regression models.

CONCLUSIONS. This study highlights disparities in participation in the PRO diabetes questionnaire related to socioeconomic status and severe psychiatric comorbidity. To promote equitable access and reduce diabetes-related health inequalities, targeted efforts are needed to support vulnerable groups in engaging with patient-centred interventions.

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Diabetes mellitus (DM) is one of the most burdensome chronic diseases of our time [1, 2]. Inequities in diabetes-related health stemming from differences in socioeconomic status (SES) represent a considerable challenge. SES encompasses educational level, income and occupation, whereas other related components include ethnic heritage and civil status [3]. Among people with diabetes (PWD), low SES is associated with lower treatment adherence [4, 5], a higher prevalence of diabetes complications [2, 6] and increased mortality [1, 2, 6]. Furthermore, individuals with schizophrenia or bipolar disorder carry an elevated risk of diabetes-related mortality [7, 8].

As part of a patient-centred approach, a diabetes-specific questionnaire has been developed to facilitate the assessment of patient-reported outcomes (PRO). PRO reflect the subjective experiences of daily life and care among PWD and serve as a tool to identify their needs, preferences and potential psychosocial barriers. Furthermore, the use of PRO is expected to contribute positively to patient-clinician communication, symptom management and clinical decision-making [9]. Among individuals with heart failure, PRO have been used to

identify those at risk of medication non-adherence, thereby providing essential knowledge to help reduce the risk of adverse outcomes and mortality [10].

The Centre for Diabetes and Heart Diseases in the Municipality of Copenhagen (CfDH) and the Endocrinological Outpatient Clinic at Bispebjerg Hospital in Copenhagen (ICamb) participated in a national multi-centre pilot test of the PRO diabetes questionnaire. It is essential to examine whether the PRO diabetes questionnaire benefits all PWD regardless of their SES. This register study investigated the relationship between participation in the PRO diabetes questionnaire and factors related to SES, including severe psychiatric comorbidity.

Methods

Study setting

The PRO diabetes questionnaire was co-developed by PWD and healthcare professionals (HCP). The electronic Danish-language questionnaire covers health, daily life, diabetes-related concerns, self-management, treatment, care experiences and personal care priorities [11].

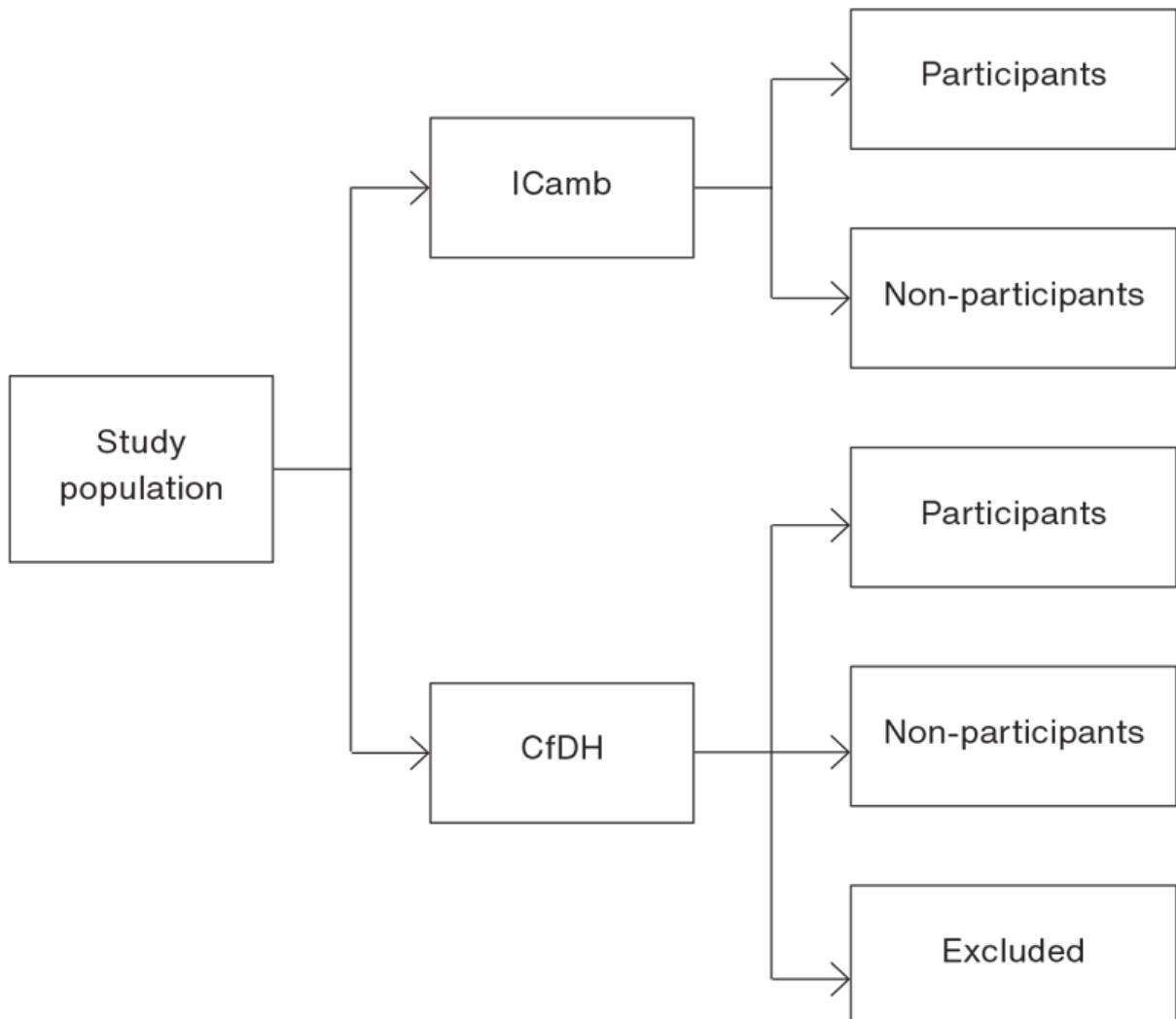
The CfDH provides municipal rehabilitation for adults with type 2 DM, including education and lifestyle support, typically in short-term programmes. The ICamb delivers specialist care for patients with type 1- and complex type 2 DM, often involving prolonged treatment due to poor glycaemic control.

The data were collected as part of a national multi-centre pilot research programme for the national PRO diabetes solution in 2020, involving multiple diabetes centres and regions in Denmark. The primary aim was to estimate the odds of questionnaire participation based on SES, including severe psychiatric comorbidity. It was not a primary goal to test the effectiveness of necessary strategies to optimise equal access for vulnerable populations.

Research design and study cohort

This register-based study included PWD with scheduled consultations at the ICamb (March-October 2020) or the CfDH (April-October 2020; January-April 2022).

The CfDH excluded PWD with psychiatric illness, language barriers or limited technical skills, as these groups required different care (Figure 1). While language versions, outreach and culturally adapted staff training were considered important, they were beyond the scope of the 2020 pilot.

FIGURE 1 Study cohort overview.

CfDH = Center for Diabetes and Heart diseases in the Municipality of Copenhagen, Denmark; ICamb = Endocrinological Outpatient Clinic at Bispebjerg Hospital, Denmark.

Danish hospitals use the electronic health record system Sundhedsplatformen, which is integrated with the patient app minSP, enabling access to questionnaires, among other features. At the ICamb, the PRO diabetes questionnaire was accessed from the patients' home via the app MinSP or using a computer/tablet. At the CfDH, it was accessed from home using a computer/tablet, or using a tablet at the reception. At both sites, the PWD received two reminders to complete the PRO diabetes questionnaire.

Data collection

Personal identification numbers (CPR) and PRO diabetes participation status were retrieved from Sundhedsplatformen and Diaprofil – the IT systems used at the ICamb and the CfDH, respectively. Relevant variables were then extracted from Statistics Denmark registries and linked via the patient's CPR. Demographic

data (sex, age, ethnicity and civil status) were retrieved from the Danish Central Person Register, whereas the highest attained educational level was collected from the Education Registers. Additionally, psychiatric diagnoses and psychotropic medication use were obtained from the Psychiatric and Prescription Registers; and HbA_{1c} values, from the Laboratory Results Register.

For analysis, age was grouped into ≤ 49 , 50-69 or ≥ 70 years. Ethnic heritage followed Statistics Denmark's categories ("Danish origin", "immigrant" or "descendant", subdivided into "western"/"non-Western"). Education was classified as "primary school", "high school or vocational school" or "further education", and civil status as either "cohabitant or registered partner" or "single". Severe psychiatric comorbidity was defined as schizophrenia or bipolar disorder (International Classification of diseases, tenth version (ICD-10) F20-22, F25, F28-29, F31) or by redeeming ≥ 2 antipsychotic prescriptions (ATC N05) within 12 months. HbA_{1c} values (Jan 2019-Mar 2020) were based on the most recent result available.

Statistics

Statistical analyses were conducted in R-Studio (version 4.2.1). Data were obtained from the ICamb and the CfDH separately. Participants and non-participants at the ICamb were pooled into one multiple logistic regression model, whereas participants and non-participants at the CfDH were pooled in another multiple logistic regression model. The excluded CfDH population was fitted to the ICamb model to estimate their expected responses.

By iteratively removing insignificant variables, we ended up with a regression model that used only significant predictors. Observations with missing data were omitted from the model estimation.

The same dataset was used for both model selection and estimation, potentially introducing selection bias. However, given the number of observations and the limited number of predictors, the sample size is considered sufficient to yield robust conclusions.

For all analyses, $p < 0.05$ was considered statistically significant.

Study registration and approval

The study was approved by the Regional Ethics Committee and registered with the Knowledge Center for Data Reporting (Pactius), Capital Region of Denmark.

Trial registration: Pactius.

Results

Descriptive data

The study population consisted of 1,082 PWD in total (Table 1), including 383 individuals at the ICamb and 699 at the CfDH, of whom 368 were excluded from receiving the PRO diabetes questionnaire at the CfDH. Among the included population, 77% at the CfDH and 19% at the ICamb participated in the PRO diabetes questionnaire.

TABLE 1 Descriptive statistics.

	ICAMB			CfDH			Total			HbA _{1c}							
	non-participants, n (%)	participants, n (%)	total, n (%)	mean (SD)	(%)	non-participants, n (%)	participants, n (%)	excluded, n (%)	total, n (%)	mean (SD)	(%)	non-participants, n (%)	participants, n (%)	excluded, n (%)	total, n (%)	mean (SD)	(%)
Total	310 (81)	73 (19)	383			4 (11)	257 (37)	368 (53)	699			384 (35)	330 (30)	368 (34)	1.082		
Sex																	
Male	192 (62)	47 (64)	239 (62)			36 (49)	150 (58)	164 (45)	350 (50)			228 (59)	197 (60)	164 (45)	589 (54)		
Female	118 (38)	26 (36)	144 (38)			37 (50)	107 (42)	202 (55)	346 (49)			155 (40)	133 (40)	202 (55)	490 (45)		
Not available	< 5 (0)	< 5 (0)	< 5 (0)			< 5 (1)	< 5 (0)	< 5 (1)	< 5 (0)			< 5 (0)	< 5 (0)	< 5 (1)	< 5 (0)		
Age																	
≤ 49 yrs	62 (20)	16 (22)	78 (20)			11 (15)	37 (14)	57 (15)	105 (15)			73 (19)	53 (16)	57 (15)	183 (17)		
50-69 yrs	147 (47)	35 (48)	182 (48)			42 (57)	150 (58)	227 (62)	419 (60)			189 (49)	185 (56)	227 (62)	601 (56)		
> 70 yrs	101 (33)	22 (30)	123 (32)			20 (27)	70 (27)	82 (22)	172 (25)			121 (32)	92 (28)	82 (22)	295 (27)		
Not available	< 5 (0)	< 5 (0)	< 5 (0)			< 5 (1)	< 5 (0)	< 5 (1)	< 5 (0)			< 5 (0)	< 5 (0)	< 5 (1)	< 5 (0)		
Ethnicity																	
Danish origin	173 (56)	57 (78)	230 (60)			49 (66)	216 (84)	126 (34)	391 (56)			222 (58)	273 (83)	126 (34)	621 (57)		
Immigrant, Western	41 (13)	6 (8)	47 (12)			5 (7)	16 (6)	66 (18)	87 (12)			46 (12)	22 (7)	66 (18)	134 (12)		
Immigrant, non-Western	90 (29)	7 (10)	97 (25)			16 (22)	20 (8)	162 (44)	198 (28)			106 (28)	27 (8)	162 (44)	295 (27)		
Descendant, Western	< 5 (0)	< 5 (3)	< 5 (1)			< 5 (3)	< 5 (0)	< 5 (1)	5 (1)			< 5 (1)	< 5 (1)	< 5 (1)	8 (1)		
Descendant, non-Western	< 5 (2)	< 5 (1)	6 (2)			< 5 (1)	< 5 (2)	9 (2)	14 (2)			6 (2)	5 (2)	9 (2)	20 (2)		
Not available	< 5 (0)	< 5 (0)	< 5 (0)			< 5 (1)	< 5 (0)	< 5 (1)	< 5 (1)			< 5 (0)	< 5 (0)	< 5 (1)	< 5 (0)		
Education																	
Primary school	189 (61)	43 (59)	232 (61)			46 (62)	158 (62)	189 (51)	393 (56)			235 (61)	201 (61)	189 (51)	625 (58)		
High school or vocational education	67 (22)	17 (23)	84 (23)			17 (27)	67 (26)	95 (26)	179 (26)			84 (22)	84 (25)	95 (26)	291 (24)		
Further education	34 (11)	13 (18)	47 (11)			8 (7)	29 (11)	59 (16)	96 (14)			42 (11)	42 (13)	59 (16)	115 (13)		
Not available	20 (7)	< 5 (0)	29 (5)			< 5 (4)	< 5 (1)	25 (7)	31 (4)			23 (6)	< 5 (1)	25 (7)	45 (4)		
Severe psychiatric comorbidity																	
Yes	36 (12)	1 (1)	37 (10)			6 (8)	16 (6)	40 (11)	62 (9)			42 (11)	17 (5)	40 (11)	99 (9)		
No	274 (88)	72 (99)	346 (90)			68 (92)	241 (94)	328 (89)	637 (91)			342 (89)	313 (95)	328 (89)	983 (91)		
Not available	< 5 (0)	< 5 (0)	< 5 (0)			< 5 (0)	< 5 (0)	< 5 (0)	< 5 (0)			< 5 (0)	< 5 (0)	< 5 (0)	< 5 (0)		
Civil status																	
Single	171 (55)	31 (42)	202 (53)			41 (56)	145 (56)	169 (46)	355 (51)			212 (55)	178 (53)	169 (46)	557 (51)		
Cohabitation/ registered partner	138 (45)	42 (58)	180 (47)			32 (43)	111 (43)	193 (52)	336 (48)			170 (44)	153 (46)	193 (52)	516 (48)		
Not available	< 5 (0)	< 5 (0)	< 5 (0)			< 5 (1)	< 5 (0)	6 (2)	8 (1)			< 5 (1)	< 5 (0)	6 (2)	9 (1)		
HbA _{1c}																	
Non-participants				66 (17)	309 (81)					55 (19)	52 (7)					361 (33)	
Participants				61 (15)	73 (19)					55 (16)	164 (23)					237 (22)	
Excluded										56 (16)	272 (39)					272 (25)	
Not available										211 (30)						212 (20)	

CfDH = Center for Diabetes and Heart diseases in the Municipality of Copenhagen, Denmark; ICAMB = Endocrinological Outpatient Clinic at Bispebjerg Hospital, Denmark.

Non-Western immigrants made up 11% of the included population at the CfDH compared with 25% at the ICAMB, whereas 44% of the excluded population at the CfDH were non-Western immigrants. Persons of Danish origin comprised 80% of the included population at the CfDH and 60% at the ICAMB. At both sites, the majority had primary school as their highest educational attainment. The prevalence of severe psychiatric comorbidity was 7% at the CfDH and 10% at the ICAMB. Overall, the mean HbA_{1c} was higher in the ICAMB population.

Regression analysis showed that non-Western immigration was a significant predictor for non-participation at both sites, with an OR of 0.18 (95% CI: 0.07; 0.41) at the ICAMB and an OR of 0.21 (95% CI: 0.09; 0.47) at the CfDH (Table 2 + Table 3). At the ICAMB, also Western immigration (OR = 0.26 (95% CI: 0.08; 0.67)), low educational level (OR = 4.06 (95% CI: 1.66; 10.09)) and severe psychiatric comorbidity (OR = 0.11 (95% CI: 0.01; 0.55)) were significant predictors of non-participation.

By applying the model estimated for the ICAMB to the excluded population at the CfDH, we estimated that the mean probability of participation would be 17% if they had not been excluded.

TABLE 2 Parameter estimates for the Endocrinological Outpatient Clinic at Bispebjerg Hospital, Denmark.

	OR estimate ^a (95% CI)	p value
Female	0.89 (0.24-1.43)	0.69
Age 50-69 yrs	1.24 (0.60-2.64)	0.56
Age \geq 70 yrs	0.58 (0.24-1.44)	0.24
Immigrant, Western	0.26 (0.08-0.67)	0.01
Immigrant, non-Western	0.18 (0.07-0.41)	< 0.01
Descendant, Western	5.03 (0.45-113.68)	0.20
Descendant, non-Western	0.63 (0.03-4.39)	0.68
High school or vocational education	1.76 (0.83-3.78)	0.14
Further education	4.06 (1.66-10.09)	< 0.01
Severe psychiatric comorbidity	0.11 (0.01-0.55)	0.03
Single	0.57 (0.33-1.0)	0.05

a) Reference: male, \leq 49 yrs, Danish origin, primary school, no severe psychiatric comorbidity and cohabitant or registered partner.

TABLE 3 Parameter estimates for the Center for Diabetes and Heart Diseases in the Municipality of Copenhagen, Denmark.

	OR estimate ^a (95% CI)	p value
Female	1.41 (0.81-2.47)	0.23
Age 50-69 yrs	0.79 (0.31-1.83)	0.60
Age \geq 70 yrs	0.57 (0.19-1.59)	0.29
Immigrant, Western	0.54 (0.19-1.78)	0.27
Immigrant, non-Western	0.21 (0.09-0.47)	< 0.01
Descendant, western	0.25 (0.01-6.69)	0.35
Descendant, non-Western	0.77 (0.09-16.26)	0.34
High school or vocational education	1.52 (0.73-3.31)	0.28
Further education	2.18 (0.82-6.29)	0.13
Severe psychiatric comorbidity	0.76 (0.26-2.57)	0.63
Single	1.12 (0.64-1.97)	0.69

a) Reference: male, \leq 49 yrs, Danish origin, primary school, no severe psychiatric comorbidity and cohabitant or registered partner.

Discussion

This study revealed considerable disparities in participation rates in the PRO diabetes questionnaire, especially among non-Western immigrants compared with Danish individuals. Language barriers, due to the questionnaire being available only in Danish, restricted access for non-Danish speaking PWD and their relatives. Additionally, participation among Western immigrants notably declined at the ICamb, suggesting that adapting to a new society as an immigrant affects healthcare engagement. This aligns with existing literature showing that immigrants face challenges in accessing healthcare services [4, 5].

At the ICamb, severe psychiatric comorbidity significantly hindered participation, possibly because mental health issues made it difficult for individuals to engage with the questionnaire. This is particularly important considering that people with conditions such as bipolar disorder or schizophrenia are at higher risk of mortality due to diabetes-related complications [7, 8]. Additionally, educational attainment played a role at the ICamb, with some participants struggling to download the MinSP app and locate the questionnaire within it [12].

Interestingly, participation rates were higher at the CfDH than at the ICamb. Apart from the proportions of non-Western immigrants and individuals of Danish origin, the two sites were relatively uniform with respect to patient characteristics. Distinct procedural differences existed between the sites; in particular, the option to complete the questionnaire at the CfDH reception, which likely contributed to higher participation rates.

Furthermore, PWD at the ICamb have a more complex type 2 DM, characterised by a higher burden of complications and comorbidities. This complexity, not accounted for in our analyses, may also have influenced participation rates. In contrast, patients at the CfDH actively engaged in rehabilitation alongside primary care, which may have increased their motivation to participate in initiatives such as the PRO diabetes questionnaire.

Beyond these factors, response rate differences reflect variations in organisational purposes and clinical approaches to PRO implementation. The CfDH operates within a holistic, patient-centred framework emphasising patient involvement and dialogue, whereas the ICamb functions primarily within a biomedical framework with greater time pressure and more complex patient profiles - factors that may contribute to reduced participation. Additionally, the results stem from a pilot study not designed to examine equitable access to the PRO diabetes questionnaire. The CfDH excluded patients based on ethnic background or severe psychiatric comorbidity, leading to a higher response rate than at the ICamb, which applied no such exclusions.

Implementing a patient-centred approach emphasising shared decision-making is key to improving diabetes outcomes [13]. Targeted interventions for PWD with low SES show promise in reducing health disparities [14, 15], which is important given research indicating an inverse correlation between SES and diabetes-related complications [1, 2, 4-6, 16, 17]. Immigrants, unemployed individuals and those with limited financial resources are especially vulnerable to adverse health outcomes [1, 4, 18]. Despite free and equal access in the Danish healthcare system, diabetes management favours well-resourced patients who can better navigate the system [19]. Feedback from the pilot study indicated that both patients and HCP valued the support achieved from using the questionnaire for tailored care, though concerns remained among HCP about reaching vulnerable groups [12].

While the CfDH appears more successful in promoting equity among its patients, the exclusion of certain subpopulations complicates this conclusion. Applying the ICamb parameter estimates to the excluded population yields an expected participation rate of 17%, indicating considerable potential participation and suggesting that the exclusion may compromise equity. Following pilot testing, the CfDH revised its procedures to include all PWD and implemented a more targeted approach to vulnerable patients, yielding a response rate of 85% in contrast to the low rate consistently recorded at the ICamb.

This study reveals disparities in access to PRO measures, reflecting previously documented ethnic and educational inequalities in PRO-based care [20]. Achieving needs-based care requires both implementing tools such as the PRO diabetes questionnaire and ensuring organisational flexibility to enable tailored consultations [19]. The successful integration of PRO measures further depends on HCP responsiveness, patient-provider trust, an understanding of PRO's purposes, alignment with existing care models and appropriate support for both HCPs and patients. Additionally, implementation must account for the specific needs of target populations, including ethnicity, language, education and health literacy [20].

Future research should develop sector-specific PRO implementation strategies, identify barriers among vulnerable groups to address and manage them, and promote inclusive approaches - particularly in hospital settings - to support equity in patient engagement.

Limitations of this study include its focus on a pilot test that aimed to assess acceptability for the majority rather than ensuring equal access, thereby potentially excluding vulnerable patients who may benefit most from patient-centred interventions. Additionally, PRO implementation was challenged by the COVID-19 pandemic, particularly in hospitals where HCP also had clinical duties that underwent considerable changes due to the pandemic.

Conclusions

This study highlights considerable disparities in participation in the PRO diabetes questionnaire, particularly among non-Western individuals. Western immigration, low educational attainment and severe psychiatric comorbidity were also significant predictors of non-participation. The primary aim was to assess acceptability for the majority rather than to ensure equitable access. Nonetheless, vulnerable groups who have the greatest need for patient-centred interventions risk unintentional exclusion unless the healthcare system actively invests in facilitating their participation and thereby reduces diabetes-related health inequalities.

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