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**This is the author's manuscript**

*Original Citation:*

*Availability:*

This version is available <http://hdl.handle.net/2318/1694951> since 2019-08-29T15:18:02Z

*Published version:*

DOI:10.1080/09638237.2019.1581341

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# Questionnaire on Attitude towards Research and Care (QuARC): a survey of patients with psychosis

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## Introduction

Evidence-based information derived from research about health care orients clinical practice. The persons affected by the illness are the essential source of this information. Subjective patient perspectives, clinical variables and outcomes are therefore fundamental in the psychiatric clinical research effort (Roe, Mashiach-Eizenberg, & Lysaker, 2011; Rossi et al., 2018).

The acceptance and adherence to a research protocol is influenced by the information, beliefs and experience of the affected persons and is shaped by their attitude to research in general and towards a specific protocol, especially in the case of clinical trials. More information and involvement in clinical trials may improve the general attitude toward the research protocol (Cameron, Pond, Xu, Ellis, & Goffin, 2013; Ohmann & Deimling, 2004; Sood et al., 2009).

Patients, their family, friends and caregivers are essential sources of information. Many instruments have been created to detect the patient's perspective with the aim to obtain patient-reported outcomes; generally, these are self-administered questionnaires including a series of questions regarding both general as well as specific aspects arising from a particular disorder and/or treatment. The use of these instruments is often considered a possible source of bias and limitation reflecting a doctor-oriented perspective.

Yet over the past decades, the "patient-centeredness" has become an internationally recognized approach to evaluate and improve the quality of health care and outcome research (Luxford, Piper, Dunbar, & Poole, 2010; Scholl, Zill, Harter, & Dirmaier, 2014).

As reported in The Tallinn Charter (2008), The World Health Organization defined a high quality health care system as "responsive to people's needs and preferences, treating them with dignity and respect when they come in contact with the system"; in other words "... Neither is the king and neither is the sun..." " (Bardes, 2012).

Moreover, studies with subjects with severe mental illness demonstrated, although with a substantial heterogeneity, decision-making capacity related to research participation or clinical treatment (Jeste, Depp, & Palmer, 2006).

Nonetheless, only few persons are approached for consent to participate, tending researchers to involve less severely ill and with better outcomes patients with possible recruitment bias (Patel et al., 2017).

If so, in a patient-centred perspective, the feedback from patient about care and protocol research is essential to share decisions and optimize health services and enrolment in research projects.

If we acknowledge the possibility of introducing a bias using self-reported outcomes, but at the same time these are essential elements of a research clinical protocol, there is an indisputable need to control the bias in order to exit from this impasse condition. One solution could be to control/covary for satisfaction and attitude toward research in general as well as the specific protocol. Such an evaluation necessarily bases its

roots primarily in patient satisfaction with the healthcare services and secondarily in research. Unsatisfied patients can hardly have a good attitude and offer unbiased information.

In a systematic review of validation studies of patients' satisfaction measurement instruments applied in healthcare services, the authors found that there were many different instruments being used, but there was no gold standard or a standardized instrument for satisfaction measurements in health services (Almeida, Bourliataux-Lajoie, & Martins, 2015).

In psychiatric services and outpatient clinics, the issue of satisfaction is more complex and fragile than in general hospitals. Many variables contribute to this complexity: patients may be hospitalized against their will, and high levels of aggression, paranoid ideation, and lack of insight may be present (Yanos, Vayshenker, Pleskach, & Mueser, 2016).

Several studies showed that patients' views towards receiving care and their satisfaction can be quantified (Barak et al., 2001). In recent years, however, even if several studies measured patient satisfaction in a variety of mental health care settings, the psychometric properties of the questionnaires used have not been adequately evaluated, with acceptability, validity and reliability rarely reported (Gigantesco, Morosini, & Bazzoni, 2003; Haynes, Richard, & Kubany 1995).

As to the enrolment in research projects, there has been an effort to gain insight into the difficulties encountered when conducting research in psychiatry and particularly in patients suffering from psychosis (Candilis, Geppert, Fletcher, Lidz, & Appelbaum, 2006). In a study of satisfaction in a sample of persons with mental illness admitted to an inpatient research unit, research participants who completed the protocol were significantly more satisfied with their clinical care than those who did not complete the protocol (Rosen et al., 2007).

A lack of understanding, attunement and alignment to the participant perspectives and a failure to consider motivation and the experiences of patients enrolled have been found among clinical researchers (Roberts & Kim, 2014; Warner, Roberts, & Nguyen, 2003). These issues are relevant also because of an ethical nature, such as the so-called "therapeutic misconception". This means that psychiatric patients taking part in a protocol, do not fully realize that a clinical researcher is not exclusively dedicated to the patient's best interests, misunderstanding the motives, goals and responsibilities of the clinical-investigators. This issue is crucial in the case of patients enrolled in clinical trials (Misra, Socherman, Hauser, & Ganzini, 2008; Thong et al., 2016), but it is difficult to appreciate and address.

Desire to help others, curiosity, positive experiences with clinicians have been found to influence the decisions to participate in a research protocol (Schafer et al., 2011; Warner et al., 2003). On the other hand, practical issues, such as the timing to spend, researchers' communication skills and concerns about potentially harmful to the health can represent barriers to participation. The knowledge of the attitude toward the protocol, including these issues, can maximize recruitment rates and minimize the risk of selection biases (Woodall, Howard, & Morgan, 2011).

In a study of the attitudes of patients with schizophrenia and depression to psychiatric research in seven European countries, a self-report questionnaire was used to evaluate the factors that influence patients' readiness to participate. Differences between patients and researchers priorities were observed, indicating the opportunity of involving patients and their relatives in the design of research protocols and increase their role in the whole research process (Schafer et al., 2011).

The aim of this study was to develop a standardized measure of attitude towards research involvement and to test its construct validity and reliability, in terms of internal consistency, in persons suffering from psychotic disorders.

## **Methods**

## Participants

The sample consists of 116 patients (68 men; mean age 39.44, SD 12.35; educational level, as number of completed years of education 10.77, SD 3.18 years), consecutively admitted to inpatient ( $n = 56$ , 48.3%) or outpatient psychiatric facilities of the University of L'Aquila, Naples and Turin between December 2015 and May 2016. All the recruited subjects fulfilled the questionnaire without missing data.

Enrolled patients were affected by Schizophrenia ( $n = 60$ ), Schizophrenia spectrum disorders ( $n = 20$ ), Mood disorders with psychotic symptoms ( $n = 17$ ), Schizotypal Personality Disorders ( $n = 4$ ) and other psychotic disorders ( $n = 11$ ).

The inclusion criteria were diagnosis of a mental disorder with psychotic features and recruitment in one of the research protocols approved by the ethical committee. The patients were enrolled only in observational studies for whom signed informed consent was obtained. The informed consent was also obtained from all participants for the fulfillment of the attitude towards research involvement questionnaire. The research procedure was reviewed and approved by the ethical committee of each University involved expanding the previous research protocols (L'Aquila 29/CE/15/3.12.2015; Naples: 1604/16.11.2015; Turin: 769/13.1.2016).

A clinical form was filled in with demographic and clinical data (i.e. age of onset of the first psychotic episode, the course of the disease and treatments), using all available sources of information (patient, family, medical records and mental health workers).

Each enrolled patient was asked to fill in a questionnaire on attitude towards research involvement and received treatment. The patient was given no time limit to complete; explanations and support in completing the questionnaire were provided if needed. The inpatients filled in the questionnaire few days before the discharge.

### Questionnaire on Attitude towards Research and health Care (QuARC)

The questionnaire has been developed for the present study aims and its content validity evaluated as suggested by Haynes et al. (1995). The choice of fields to be investigated was based on a review of the literature available in MEDLINE in the last 15 years. The search terms included patient-centred care, patient-reported outcome measures, patient satisfaction and attitude towards research, in mental health care services.

The patient's attitude toward research and satisfaction with health were identified as domains to be investigated. The research team (A.R., P.S., S.G.) developed a pool of 15 related items to be included in the questionnaire. The three psychiatrists had at least 30 years of extensive clinical and research practice in mental health services and psychometrics.

After extensive discussion, all the research team members agreed on 10 items that eventually formed the self-report questionnaire of the patient's attitude and satisfaction toward research. Five items were relevant to the quality of information needed to evaluate the research in which the person is involved, perception of wasting time in participating, privacy protection, personal contribution to scientific knowledge, encouraging others to take part in research. Five items are relevant to satisfaction with health care, with the treatment, with the relationship with the Mental Health Services and with their own mental, physical and economic well-being ([Appendix](#)). Items related to recruitment of ethnic minorities, as well as items related to physician, personal and monetary payment were excluded. Also items related to role of nurses and use of technology to recruit and enrol patients in clinical trials were excluded.

Item endorsement was scored on a Likert scale from 1 to 5 in response to the (Krosnick & Fabrigar, 1997): 1="Not at all", 2="Slightly", 3="Moderately", 4="Very" and 5="Extremely". Higher scores correspond to a

better opinion except for the second item, represented by “wasting time in participating in research”, which has a reversed score.

## Statistical analyses

Independent-samples *t*-test was used for comparisons. Exploratory factor analysis (EFA) based on a principal component with oblimin rotation using Kaiser's criterion for factor retention (i.e. eigenvalue = 1) (Kaiser, 1960) was conducted using IBM-Statistical Package for the Social Sciences (SPSS) 20.0 program (IBM SPSS Statistics, Armonk, NY). Internal consistency was evaluated by computing Cronbach's alpha (Henson, 2001).

## Results

### QuARC scores

Means and SD of the items and QuARC total score are reported in Table 1.

TABLE 1. MEANS AND SD OF THE QUARC ITEMS AND TOTAL SCORE.

QuARC	Total sample (n. 116)		Gender				t test p<	Education <sup>a</sup>				t test p<
			Male (n. 68)		Female (n. 48)			Compulsory school (n. 53)		Non-compulsory School (n. 63)		
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
1. Sat with INFORMATIONS (INFO)	3.47	0.99	3.60	0.93	3.27	1.06	3.62	0.99	3.33	0.99	NS	
2. WASTING TIME (WST)	4.03	1.13	4.00	1.17	4.08	1.09	4.02	1.14	4.05	1.13	NS	
3. Sat with MENTAL HEALTH DEPARTMENT (MHD)	3.48	1.13	3.53	1.08	3.42	1.20	3.76	1.01	3.23	1.17	.01	
4. Sat with ECONOMIC CONDITION (EON)	2.51	1.05	2.63	1.02	2.33	1.08	2.47	1.06	2.54	1.04	NS	
5. PRIVACY (PRV)	3.43	1.09	3.38	1.10	3.50	1.09	NS	3.40	1.11	3.46	1.08	NS
6. Sat with MENTAL HEALTH (MHS)	3.28	1.14	3.51	1.15	2.96	1.07	0.01	3.49	1.20	3.10	1.07	0.10
7. PARTICIPATION (PART)	3.47	1.13	3.56	1.14	3.33	1.11	NS	3.82	1.07	3.15	1.09	0.001
8. Sat with TREATMENT (TRT)	3.39	1.13	3.37	1.18	3.42	1.07	NS	3.71	1.10	3.10	1.10	0.005
9. CONTRIBUTION to RESEARCH (CNT)	3.41	1.11	3.51	1.11	3.25	1.12	NS	3.65	1.04	3.18	1.14	0.05
10. Sat with PHYSICAL HEALTH (PHS)	3.19	1.08	3.43	1.12	2.85	0.945	0.005	3.47	1.13	2.93	0.98	0.01
Total score (TOT)	33.58	6.31	34.49	6.18	32.29	6.32	0.10	35.42	7.00	31.92	5.12	0.005

Sat: satisfaction.

Comparisons by gender and education (n. 116).

<sup>a</sup>In the Italian scholar system 8 years of education refers to primary school (5 years) and lower secondary school (3 years). These 8 years of education are compulsory. Non-compulsory education consists of upper secondary school that lasts 3 years.

The values for asymmetry and kurtosis are between +1.2 and -1, considered acceptable in order to prove normal univariate distribution.

Comparisons by gender showed a significantly higher score for males in satisfaction with mental and physical health. Comparisons were also made by educational level, splitting the sample in persons who completed compulsory education only vs. those with a higher education level. These latter ones showed a lower degree of satisfaction towards the relationship with the mental health department, treatment and physical health and had a less positive attitude towards research (Table 1).

### Validity results

Cronbach's alpha on the 10 items was 0.77. Two items whose exclusion increased the overall reliability value were identified: one item was relevant to the attitude towards research (i.e. privacy protection) and the other one to the satisfaction with health care (i.e. satisfaction with the economic aspects). The two items were excluded from calculations and new Cronbach's alpha on the eight remaining items was 0.80.

Exploratory factor analysis performed on QuARC eight items showed a Kaiser–Meyer–Olkin value of 0.767 and a Bartlett's test of Sphericity of 279.793,  $p < .0005$ .

Two factors had eigenvalues greater than 1 and explained 58.30% of the total variance (42.16 and 16.22, respectively). The rotated component matrix is reported in Table 2.

Table 2. Factor analysis: rotated factors (oblimin with Kaiser normalization).

	Factor I	Factor II
1. Sat with INFORMATIONS (INFO)	0.658	
2. WASTING TIME Reverse (WST)	0.658	
3. Sat with MENTAL HEALTH DEPARTMENT (MHD)	0.733	
6. Sat with MENTAL HEALTH (MHS)		0.866
7. PARTICIPATION (PART)	0.758	
8. Sat with TREATMENT (TRT)	0.773	
9. CONTRIBUTION to RESEARCH (CNT)		0.674
10. Sat with PHYSICAL HEALTH (PHS)		0.755

Sat: satisfaction.

Five items loaded on the first factor: three items on the second one.

Three items concerning attitude (1, quality of information about the purpose of the research; 2, perception of wasting time in participating in protocol; 3, enthusiasm in encouraging others to take part in research) loaded on the first factor, together with two satisfaction items (i.e. satisfaction with Mental Health Department and with treatment). Two items on satisfaction (i.e. 1, satisfaction with health care; 2, satisfaction with physical well-being) and one concerning attitude (i.e. personal contribution to scientific knowledge) loaded on the second factor. According to the content analysis, the two factors were named External Factor (EF) and Internal Factor (IF), respectively.

Cronbach's alpha determined for the two factors from the principal component analysis were 0.77 for EF and 0.68 for IF.

## Discussion

We developed and validated a brief questionnaire for the assessment of both attitude and satisfaction with research protocol and care in subjects with psychoses, either in outpatient or inpatient treatment.

We observed a good internal consistency for both the entire questionnaire and its different constructs. According to the item content of the two factors, we labelled them as EF and IFs, respectively. The constructs from the EFA are quite different from the original issues addressed by the authors on the basis of the literature and their experience (*i.e. attitude and satisfaction*).

Although these issues are covered in the questionnaire, the factor structure seems to favour a quite different perspective, prevailing different conceptual constructs closer to the patient opinion on the research and personal condition. These constructs identify dimensions useful to delineate and understand the patient's experience of participating in a scientific project as well as their satisfaction with the care offered.

EF includes items primarily relevant to the relationship with third parties, such as doctors, or information and treatment received. IF instead involves the relationship with the disease itself, evaluation of subjective well-being and contribution to scientific knowledge.

Interestingly, the contents of these factors are in line with other studies.

In a review about the impact of patient-reported outcome measures on routine practice, the explored contents have been divided into three categories: patient satisfaction (patient-reported satisfaction with the consultation, treatment or care overall), health status (patients' health and well-being as indicated by clinical measures or patient reports) and resource use (patients' subsequent use of health and other services) (Marshall, Haywood, & Fitzpatrick, 2006).

The factorial structure of a subjective quality of life and treatment satisfaction scale showed that satisfaction with the physical health, mental health and personal safety, loaded on one factor, whilst satisfaction with the job situation, friendships, leisure activities, accommodation, and partner/family loaded on another factor (Priebe, Golden, McCabe, & Reininghaus, 2012). Our IF can be considered coherent with that former factor.

Several authors categorized factors predictive of satisfaction in *endogenous* (i.e. patients' characteristics) or *exogenous* (i.e. structure, process, and outcome of care) (Xiao & Barber, 2008; Zendjidjian et al., 2014), similar to the factors that we obtained.

Our results are only partially in agreement with those reported by Schäfer et al. (2011). They found that relevant reasons to participate in a research protocol were of an altruistic kind (i.e. "to help other patients", "to improve my chances of recovery", "to help the medical profession") compatible with our IF.

They further report that economic satisfaction and privacy are relevant to participate while this is not the case of our results for the items which do not enter our factor structure (i.e. satisfaction with the economic condition, item 4, and concern with privacy protection, item 5). A possible explanation can be due to the inclusion of persons with psychosis only, which can be less concerned with these issues than persons with non-psychotic affective disorders. Although these two items are excluded from our factor structure, their use in studies of non-psychotic patients could be advisable.

Some limitations have to be considered. Even though we could have elaborated a similar questionnaire starting from a systematic review, we based our item selection on the experiential approach from explicit perspectives on focused topics.

Our investigation is focused on the elaboration of a new instrument with a relatively small sample, sufficient however to evaluate its construct validity and internal consistency. Concurrent validity was not assessed and it is part of the ongoing research. The study must therefore to be replicated using a larger sample involving subjects with different diagnoses (e.g. mood and anxiety disorders), making it possible not only to increase the statistical power, but also allowing for subgrouping.

According to our data, patients have a positive attitude towards the research protocol and experience a good level of satisfaction with care. This positive attitude to the research protocol for which they were recruited may be partially mediated by the sample selection. The patients accepted to be enrolled and therefore had already expressed a positive reaction to the inclusion in a research protocol. We lack evaluation of satisfaction in patients who have never participated in a research protocol. Our participants however were research protocol "naive", having never previously participated in other investigations.

These patients were enrolled in protocols not involving change or discontinuation of a drug therapy. The possibility that these conditions could have favoured a more positive attitude cannot be excluded. In this regard, some authors found that, despite the fact that only 16% of a sample of patients with schizophrenia reported to be against clinical trials in principle, more than 55% would not be willing to participate in a placebo-controlled clinical trial, most often because of fear that not receiving medication might worsen their condition or slow their symptom improvement (Hummer et al.). Results in line with our findings have been reported in previous researches. Positive attitudes to psychiatric research in different psychiatric care settings, especially towards protocols without "invasive" methods like medication trials, have been found by many authors (Edlinger et al., 2010; Misra et al., 2008; Ruggeri et al., 2007; Schäfer et al., 2011; Summers, M., & Happell, B. 2003).

We developed here an easy to use instrument, with a good level of acceptance and psychometric properties in people with mental disorders with psychotic features. Even though there is no agreement on whether "generic" or "specific" instruments for different health care settings and diagnoses should be used (Boyer et al.; Peytremann-Bridevaux et al.), QuARC can be used also in non-psychotic samples with the advantage of detecting dimensions such as the patient's experience in participating in a scientific project and their satisfaction with care.

With this approach, the analysis of research attitude and reliability in people with severe mental disorders could be enhanced.

## Disclosure statement

None of the authors have any conflict of interest to disclose.

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