Preliminary Report on the Validation of a Questionnaire Measuring Patient Satisfaction with Services at the Sickle Cell Unit in Jamaica

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ABSTRACT

Objective: *Patient satisfaction has become an increasingly important component of quality assessment. This cross-sectional study was conducted to assess the psychometric properties of a Patient Satisfaction Questionnaire modified for use in the Sickle Cell Unit, Jamaica.*
Methods: *A total of 85 persons were interviewed. Construct validity, including exploratory factor analysis and internal reliability were assessed. Data were analysed using SPSS (version 11.5 for Windows) and Intercooled STATA (version 8.2).*
Results: *The Patient Satisfaction Questionnaire modified for use in the Sickle Cell Unit demonstrated good internal reliability for the 'doctors', 'nurses', 'social worker' and 'facilities' subscales (Cronbach's $\alpha \geq 0.70$). Exploratory factor analysis revealed only four of the seven 'specific' subscales retaining a single factor , namely the 'nurses', 'facilities', 'appointments' and 'social worker' subscales. Those who attended more frequently gave a statistically significant higher score for 'facilities' and lower score for 'nurses'. However there was no statistically significant difference in the mean scores by age, gender and genotype. The 'general satisfaction' subscale scores showed a significant positive correlation with scores for 'doctors', 'nurses', 'laboratory' and 'facilities' and 'appointments'.*
Conclusion: *This preliminary report on the validation of the Patient Satisfaction Questionnaire modified for use in the Sickle Cell Unit reveals it has the potential for serving as a useful tool in the assessment of patient satisfaction among sickle cell patients. However, further work is necessary on the instrument.*

Reporte Preliminar sobre la Validación de un Cuestionario para Medir la Satisfacción de los Pacientes con Respecto a los Servicios de la Unidad de Anemia Falciforme en Jamaica

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RESUMEN

Objetivo: *La satisfacción del paciente se ha convertido en un componente cada vez más importante de la evaluación de la calidad. Este estudio transversal se llevó a cabo a fin de evaluar las propiedades psicométricas de una Cuestionario de Satisfacción del Cliente, modificado para su uso en la Unidad de Anemia Falciforme, Jamaica.*
Métodos: *Se entrevistó un total de 85 personas. Se evaluó la validez del constructo, incluyendo el análisis exploratorio de factores y la confiabilidad interna. Los datos fueron analizados utilizando el SPSS (versión 11.5 para Windows) e Intercooled STATA (versión 8.2).*
Resultados: *El Cuestionario de Satisfacción del Cliente para uso en la Unidad de Anemia Falciforme demostró buena confiabilidad interna para las subescalas de 'doctores', 'enfermeras', 'trabajadores sociales' e 'instalaciones' (Cronbach: $\alpha \geq 0.70$). El análisis exploratorio de factores reveló solamente cuatro de las siete subescalas "específicas" que retienen un solo factor, a saber, "enfermeras", "instalaciones", "citas" y "trabajadores sociales". Aquellos que asistían con mayor frecuencia,*

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arrojaron – desde el punto de vista de las estadísticas – una puntuación significativamente más alta para las "instalaciones", y una puntuación más bajas para las "enfermeras". Sin embargo, no hubo diferencias estadísticas significativas en las puntuaciones promedio por edad, género o genotipo. Las puntuaciones de subescala de la "satisfacción general" mostraron una correlación significativamente positiva con respecto a las puntuaciones para "doctores", "enfermeras", "laboratorio" e "instalaciones, y "citas".

Conclusión: *Este reporte preliminar sobre la validación del Cuestionario de Satisfacción del Paciente, modificado para su uso en la Unidad de Anemia Falciforme, revela que esta Unidad tiene el potencial necesario para servir como instrumento útil a fin de evaluar el grado de satisfacción del servicio entre los pacientes de anemia falciforme. No obstante, el instrumento requiere ulterior elaboración.*

INTRODUCTION

Patient satisfaction has become an increasingly important component of quality assessment. Fitzpatrick (1) opines that there are five broad areas of the healthcare experience which have a major impact on the amount of satisfaction experienced by patients. These five areas are: interpersonal skills of health professionals, information-giving from health professional, technical competence, organization of healthcare and time. Pascoe (2) defines patient satisfaction as a healthcare recipient's reaction to salient aspects of the context, process and result of their service experience. There are three reasons why health professionals should take measurement of patient satisfaction seriously (1). Firstly, there is convincing evidence that this is an important outcome measure as it may be a predictor of (a) compliance with recommended treatments; (b) whether patients return for follow-up treatment and (c) whether they change healthcare providers. Secondly, it is useful for assessing consultations and patterns of communication. Thirdly, the feedback can be used systematically to choose between alternatives in organizing or providing healthcare. Both quantitative methods, such as surveys and qualitative methods are used to measure patient satisfaction (3).

The Sickle Cell Unit (SCU) of the University of the West Indies is the only comprehensive sickle cell centre in Jamaica and has been operational since 1973. Many of the services offered are similar to those seen in the general practice setting. Grogan *et al* (4) developed a questionnaire designed specifically for use in the British general practice context. It was later assessed as a valid and reliable tool for use in general practice (5). It was hypothesized that a modified version of this instrument would serve as a useful tool for assessment of patient satisfaction at the Sickle Cell Unit. However, an important prerequisite is that the reliability and validity of this modified instrument be tested. For the purpose of this study, the consistency among items or internal reliability and construct validity which assesses the correspondence between scores on the instrument and scores on similar or different constructs were estimated. Results from factor analysis were also used to assess construct validity.

SUBJECTS AND METHODS

Sample

A cross-sectional survey was conducted between December 2005 and February 2006 among 85 adult patients (18 years and older) out of a total of 722 patients eligible for participation. A convenience sampling technique was employed. (There are no formal statistical calculations to determine sample size when the outcome is to determine construct validity and internal reliability). This technique was chosen for a combination of reasons: a) the survey instrument was lengthy; (b) the clinic is one of high throughput, a single interviewer was to be used in a limited sampling time period of approximately 40 days. Patients were deemed eligible for the study if (a) they had attended the clinic at least twice in the past 12 months (b) had already been seen by a clinician on the day of the interview and (c) had a sickle haemoglobinopathy or was an AA genotype who has been a member of one of the cohorts under study at the Sickle Cell Unit. Patients were excluded if (a) deemed mentally unfit (b) unwilling to participate or (c) involved in the annual cohort review (*ie* came on a visit for the annual cohort review-additional services are rendered to these patients at that visit).

In all, 55 patients were female (64.7%) and 30 were male (35.3%) [Table 1]. The mean age was 33.2 years with a standard deviation (SD) of 11.3 years. Persons had to have attended the Sickle Cell Unit at least twice in the last twelve

Table 1:   Distribution of participants by gender, mean age and genotype.

Characteristic	Count (per cent)
Male	30 (35.3)
Female	55 (64.7)
Age	
< 30	37 (43)
30-39	28 (33)
40-49	12 (14)
50-59	5 (6)
≥ 60	3 (4)
Genotype	
SS	67 (78.8)
SC	9 (10.6)
Others	9 (10.6)

months and been seen by a physician. Some 49.4% had achieved at least a secondary/high school education with 58.8% currently employed. Just over sixty per cent (63.5%) visited the clinic 1–3 times per year and 21.2% stated that they visited once per month on average. The majority of participants (78.8%) had homozygous sickle cell disease (SS) genotype.

Interviews were conducted by a researcher who was not employed to the Sickle Cell Unit. Ethical approval to conduct the study was granted by the Ethics Committee of Faculty of Medical Sciences/The University Hospital of the West Indies. Recruitment of patients was attempted after seeing a physician and receiving any other service offered. Those who agreed to participate in the study were then taken to a private area in the clinic. Written informed consent was obtained prior to completion of the interviewer administered questionnaire. This consent included an assurance of confidentiality of all subjects within legal limits.

The Patient Satisfaction Questionnaire
The reference Patient Satisfaction Questionnaire (PSQ) is a 46-item scale developed specifically for use in the British general practice context. It has five 'specific' subscales to measure satisfaction which include doctors (20 items), nurses (4 items), access (8 items), appointments (4 items) and facilities (4 items) plus a separate six-item subscale to measure general satisfaction with the service provided by the practice.

This instrument was modified by researchers at the Sickle Cell Unit (hereafter referred to as PSQ-SCU) to reflect the differences in services provided at the Unit and care between the UK and Jamaica [Appendix]. This PSQ-SCU instrument instead has a 50-item scale with seven 'specific' subscales to measure satisfaction with 'doctors' (20 items), 'nurses' (6 items), social worker (2 items), access (6 items), appointments (3 items), 'facilities' (5 items) and 'laboratory' (3 items). There is also a separate five-item subscale to measure 'general satisfaction'.

The response choices maintained the traditional Likert-type approach with five choices ranging from *strongly agree* to *strongly disagree* reflecting the assumption that satisfaction itself is a continuum. The answers 'strongly disagree' to 'strongly agree' were scored from one to five with the direction of the scale being dependent on whether the question was a positive or negative statement. A low score indicated dissatisfaction and a high score, satisfaction. A balance of positively and negatively worded items were included to control for bias due to acquiescent response set (ARS), a tendency to agree with statements of opinion regardless of content. This ARS was found to be a noteworthy problem in the development of other patient satisfaction questionnaires (6).

Statistical Analysis
Internal reliability was calculated using Cronbach's α statistic and subscales were considered internally reliable if they had a Cronbach α of 0.7 or more. Construct validity was tested utilizing exploratory factor analysis (7). Factor analysis is a technique designed to reduce a set of observed variable or items to a smaller set of variables that reflects the inter-relationships among these items (8). All items were placed in the factor model to determine the number of factors retained. Factors were retained if they had an eigenvalue (9) greater than or/equal to one [Kaiser's Rule of thumb] (10). A Scree Plot was also used to assist in the retention of factors (9). Factor loadings which were greater than or equal to 0.5 were considered relevant to interpretation of the factor (5). Additionally, factor loadings were rotated using 'varimax' rotation to increase interpretability of the findings. Also, to facilitate comparison of the reference and modified questionnaires, exploratory factor analysis was used to test if the underlying factor structure of the five specific subscales in the *reference PSQ* and the two new subscales of 'social worker' and 'laboratory' remained uni-dimensional in the PSQ-SCU.

RESULTS
Patient satisfaction
The mean scores and standard deviation on each subscale are shown in Table 2. In general, there was greater variation in satisfaction with the social worker than any of the other aspects of service.

Table 2:   Descriptive statistics of score* distributions for each subscale *(no. of responses, minimum score, maximum score, median score, mean score, SD).*

Subscale	n	Minimum	Maximum	Median	Mean score (SD)
Doctors	85	2.15	5.00	3.90	3.93 (0.55)
Nurses	85	1.17	5.00	3.83	3.66 (0.76)
Lab	84	2.33	5.00	4.00	3.81 (0.59)
Social worker	21	1.00	5.00	4.00	3.74 (1.06)
Facilities	81	1.40	5.00	3.40	3.34 (0.72)
Appointments	84	2.33	5.00	3.67	3.70 (0.51)
Access	12	2.00	4.17	3.25	3.26 (0.56)
General satisfaction	81	1.60	4.80	4.00	3.77 (0.62)

* Subscale score = $\dfrac{\Sigma \text{ Individual scores within subscale}}{\Sigma \text{ number of responses x number of items}}$

Internal reliability

The subscales related to doctors, nurses, social worker, facilities and general satisfaction had good internal reliability (Table 3).

Factor analysis

Exploratory factor analysis on all the items revealed an instrument that was 10-dimensional. The scale had no clear-cut dimensions (doctors, nurses, facilities, access, appointments) as in the reference PSQ used in the British context.

Exploratory factor analysis was also carried out on the seven specific subscales hypothesized for the modified instrument, to test if each retained one factor *ie* remained unidimensional or whether any subscale had 2 or more factors. Tables 4–6 show the items in the subscales, together with the

Table 3:   Reliability coefficients.

Subscale	No. of items	Cronbach's α coefficient (no. of responses)
Doctors	20	0.90 (85)
Nurses	6	0.83 (85)
Lab	3	0.40 (84)
Social worker	2	0.83 (21)
Facilities	5	0.66 (81)
Appointments	3	0.15 (84)
Access	6	0.24 (12)
General satisfaction	5	0.68 (81)

Cronbach's α coefficient internally reliable ≥ 0.7

Table 4:   The 20 'doctors' items on the Sickle Cell Unit patient satisfaction questionnaire showing mean scores, standard deviations (SD) and rotated factor loading values.

Item	Mean score (SD)	Factor 1 loading value	Factor 2 loading value	Factor 3 loading value	Factor 4 loading value
10. The doctor clearly explains what is wrong before giving any treatment	4.14 (0.74)	0.27	0.17	**0.69**	-0.27
13. The doctor does not tell me enough about the treatment[a]	3.65 (1.07)	0.05	-0.39	**0.78**	0.04
15. The doctor fully explains how the illness will affect my future health	3.72 (1.05)	0.30	-0.07	**0.57**	-0.26
16. The doctors are careful to check everything when examining me	4.01 (0.93)	**0.81**	-0.05	0.22	-0.14
22. Sometimes the doctors make me feel I am wasting his/her time[a]	3.99 (1.21)	0.42	-0.54	-0.05	0.19
24. The doctor is always interested	4.24 (0.75)	0.42	-0.10	0.25	-0.45
25. The doctor always asks how my illness affects daily life	3.72 (1.18)	0.11	-0.07	0.44	-0.64
27. I don't feel confident discussing my problems with the doctors[a]	4.07 (0.91)	0.11	-0.81	0.18	-0.09
29. The doctor seems to want to get rid of me as soon as possible[a]	4.20 (0.87)	**0.62**	-0.53	0.05	0.04
30. The doctor gives me every chance to talk about all my problems	4.07 (0.97)	**0.67**	-0.22	0.20	-0.19
32. The doctor sometimes fails to appreciate how ill I am[a]	3.59 (1.14)	0.07	-0.78	0.06	-0.22
37. Even when the doctors are busy I am examined properly	4.07 (0.91)	**0.65**	-0.13	0.02	-0.16
39. I sometimes feel I have not been given enough information by the doctors[a]	3.28 (1.18)	0.26	-0.46	0.43	-0.10
41. I do not feel rushed when I am with the doctor	4.09 (0.77)	0.30	-0.51	0.17	-0.35
43. The doctors know when tests are necessary	4.05 (0.65)	0.16	0.05	0.04	-0.69
44. The doctors are very understanding	4.21 (0.79)	**0.59**	-0.39	-0.003	-0.46
46.The doctors do everything needed to arrive at a diagnosis	3.96 (0.75)	**0.75**	0.0008	0.17	-0.15
47. The doctor always puts me at ease	4.05 (0.69)	0.43	-0.23	0.14	-0.59
54. The quality of care given by each doctor is about the same	3.38 (1.18)	0.15	-0.29	0.03	-0.66
55. I have absolute faith and confidence in the doctors	4.02 (0.90)	**0.63**	-0.36	0.12	-0.35

[a] Score reversed
Boldface items ≥ 0.5 were those that loaded significantly for a particular factor

Table 5:   The 6 'access' items and the 3 'laboratory' items on the Sickle Cell Unit patient satisfaction questionnaire showing mean scores, standard deviations (SD) and factor loading values.

Item	Mean score (SD)	Factor 1 loading value	Factor 2 loading value
Access			
9. I feel it is easy to speak to a doctor by telephone	2.71 (1.22)	-0.16	**0.66**
17. It is easy to get advice over the phone	3.13 (1.20)	0.08	**0.81**
21. The receptionists / cashiers explain things clearly to me	3.54 (0.97)	**0.91**	0.18
23. I am satisfied with the hours the clinic is open	3.55 (1.14)	**0.84**	0.06
38. It is often difficult to get to see the social worker[a]	3.29 (1.19)	**0.89**	-0.20
48. The location of the clinic is convenient	3.51 (1.15)	-0.008	-0.86
Laboratory			
50. It usually takes me a long time to get tests done at the laboratory[a]	3.88 (0.83)	**0.84**	0.03
51. The laboratory staff are usually courteous	4.14 (0.73)	0.27	**0.94**
53. The laboratory staff do not spend any time to explain the procedure to be done[a]	3.42 (1.06)	**0.79**	-0.36

[a] Score reversed
Boldface items ≥ 0.5 were those that loaded significantly for a particular factor

Table 6:   The items on the 'nurses', 'facilities', 'appointments' and 'social worker' subscales of the Sickle Cell Unit patient satisfaction questionnaire showing mean scores, standard deviations (SD) and factor loading values.

Item	Mean score (SD)	Factor 1 loading value
Nurses		
12. The nurses do not take care to explain things[a]	3.79 (0.99)	**0.63**
20. The nurses sometimes fail to understand how ill I'm feeling[a]	3.16 (1.16)	**0.67**
33. The nurses do not always listen carefully when I talk about my problems[a]	3.64 (1.00)	**0.77**
36. The nurses are always caring	4.12 (0.91)	**0.79**
42. The nurse shows a genuine interest in my problems	3.91 (0.93)	**0.87**
49. I don't feel confident discussing my problem with the nurses[a]	3.38 (1.15)	**0.74**
Facilities		
14. The building could do with some improvements[a]	2.68 (1.23)	**0.59**
18. The waiting room is uncomfortable[a]	3.35 (1.09)	**0.87**
19. The daycare/treatment room is comfortable	3.73 (0.98)	0.34
34. There are not enough seats in the waiting room[a]	3.62 (1.08)	**0.80**
40. The waiting room seats are uncomfortable[a]	3.44 (1.09)	**0.61**
Appointments		
11. Getting an appointment for a convenient time is easy	4.04 (0.75)	**0.72**
28. Appointments are easy to make whenever I need them	4.00 (0.60)	**0.76**
52. It is easy to see the doctor of my choice	3.06 (1.07)	0.29
Social worker		
6. The social workers do their best to assist me	4.05 (1.16)	**0.93**
7. I don't feel confident discussing my problems with the social worker[a]	3.43 (1.12)	**0.93**

[a] Score reversed
Boldface items ≥ 0.5 were those that loaded significantly for a particular factor

mean score (SD) and factor loading value for each item. Only four of the seven 'specific' subscales retained a single factor, namely the 'nurses', 'facilities', 'appointments' and 'social worker' subscales. The variation in these satisfaction scores were as follows: nurses, 55.9%; appointments, 39.12%; facilities, 44.38% and social worker, 85.67%.

Comparison of User Groups

In order to determine whether the modified questionnaire differentiated between user groups, comparisons were made between mean scores on the questionnaire. Statistical analysis using t tests was conducted on the dichotomous groupings of gender, genotype and frequency of attendance. Amongst the five subscales with good internal reliability, namely general satisfaction, doctors, nurses, social worker and facilities, there was no statistical difference in the mean scores by gender and genotype. However, those who attended the clinic more frequently gave a statistically significant lower score to nurses (p-value = 0.01) and higher score for facilities (p-value = 0.03).

Mean scores by age group using ANOVA were also compared. However, the 'social worker' scores were excluded because of the very low response rate and the fact that when these scores were further classified into 5 age groups any difference that emerged would be unstable. A comparison of the other scores revealed no statistically significant difference in the mean scores by age group.

Correlation of subscale scores with general satisfaction scores

Construct validity was further tested by calculating Spearman correlation coefficients between total scores on each subscale and general satisfaction scores (Table 7).

Table 7: Correlation between subscales and general satisfaction scores (r) and ß weights from multiple regression analysis.

Subscale	r	ß
Doctors	0.58**	0.26
Nurses	0.68**	0.63
Laboratory	0.38*	-0.26
Social worker	0.35	-0.27
Facilities	0.45**	0.19
Appointments	0.35*	0.23
Access	0.45	-0.52

*$p < 0.01$; **$p < 0.001$

General satisfaction subscale scores showed a significant positive correlation with scores for doctors, nurses, laboratory, facilities and appointments. In order to assess the independent contribution of these to general satisfaction, a multiple regression analysis was performed with the factors of interest *ie* doctors, nurses, laboratory, facilities and appointments being the predictors. The strongest predictor of general satisfaction was satisfaction with nurses.

DISCUSSION

The PSQ-SCU demonstrated good internal reliability for four of the seven specific subscales as well as the general satisfaction subscale. The 'nurses', 'social worker' and 'facilities' subscales demonstrated good internal consistency and construct validity with each subscale remaining unidimensional.

All items on the 'nurses' subscale loaded highly in factor analysis. It appears to measure the same construct when applied in the Jamaican and British settings *ie* it shows transferability. Baker (11) reports that transferability is the extent to which the instrument continues to measure the same thing when applied to groups of patients of different age, social class or geographical region.

The 'doctors' subscale emerged as a four-dimensional construct which suggests that the patients at the SCU differentiate between different aspects of the consultation. The 'social worker' subscale was a newly created construct but had two main limitations: (i) there were only two items in the subscale – as a rule of thumb it is ideal to have 3 or more items in each construct for factor analysis (12) and (ii) the response rate to all the items in this subscale was only 25%. The low response rate may be explained by the fact that interaction with the social worker is optional and perhaps reflects the proportion of patients that utilize this service.

The specific subscales not satisfying the minimum criteria of 0.70 for internal reliability were the 'laboratory', 'appointments' and 'access' subscales. Reasons postulated are as follows: a) the 'laboratory' subscale was another newly created subscale; b) the 'appointments' subscale had one item *'it is easy to see the doctor of my choice'* which had a very low factor loading value – this seemed to suggest that this item may have measured the same construct 'appointments' as the two remaining items; c) the 'access' subscale had a low response rate of 14% (12/85) which may reflect that although telephone access is possible, most of the interaction between staff and clientele has been face-to-face.

An overall Cronbach's alpha was not calculated on the instrument as has been done in other studies (13). We concur with the opinion of Sitzia *et al* (14) that in multidimensional instruments such as this modified PSQ, high inter-subscale correlations would be redundant as the dimensions of satisfaction are assumed to be fairly independent.

There was a highly statistically significant relationship between scores on five of the seven 'specific' subscales and the general satisfaction subscale. This suggests that each of these 'specific' subscales measure some aspect of patient satisfaction.

Construct validity was also tested by investigating whether the sociodemographic characteristics of age, gender, genotype and frequency of attendance significantly affected patient satisfaction. The findings did not support the trends reported in the literature that women and older persons report greater satisfaction (2, 5, 15). Additionally, there was no

statistically significant difference in the mean scores when the genotype was dichotomized into SS (the most common type) and the other haemoglobinopathies. This clearly demonstrates that these characteristics have no significant influence on satisfaction in the provision of services at the SCU.

This study had some limitations. Firstly, the sample size of 85 participants may be considered too small for robust factor analysis. There is no universally accepted methodology for determining the number of cases needed for factor analysis. A number of arbitrary "rules of thumb" have been posited (12). For example, the "Rule of 100" suggests that the minimal number of subjects in the sample should be five times the number of variables being analysed. In this study fifty items were being analysed and hence the sample size should ideally have been greater than or equal to 250 persons. Secondly, one construct, namely 'social worker', had less than three items. For exploratory factor analysis to be robust, Thurstone recommends each construct should have a minimum of three items (12). Thirdly, the PSQ-SCU has no other PSQ developed for use in patients with sickle cell disease as a reference for comparison. As such, the development of this instrument may have introduced biases. Validation is recognized as a continuous process and additional studies will need to be conducted to improve the instrument. Fourthly, selection bias may have been introduced for a number of reasons, namely: a) the sample selected may not be representative of the clinic population as there was greater gender bias towards females when compared with the male to female ratio of the adult clinic population b) there exists no other alternative centre providing comprehensive care for patients with sickle cell disease in Jamaica and where many services are also highly subsidized; (c) the interviewer did not make any explicit statement to the fact that she was independent of the organization. Persons not satisfied may have refused to participate for this reason. This is possible given that only 12% of the subjects who met the eligibility criteria were subsequently enrolled in the study.

The evaluation of the psychometric properties of the PSQ-SCU demonstrates that with further refinement it has the potential for serving as a useful tool in the assessment of patient satisfaction among sickle cell patients in settings similar to the SCU in Jamaica. Further work is planned on the instrument. A more rigorous process of content validation is to be undertaken to improve the response rate on all items. A re-evaluation of the psychometric properties of the revised instrument will be done with an increased sample size in order to decrease sampling variability in factor analysis. If the revised instrument is proven to be reliable and construct valid, further evaluations of its transferability will be tested in general practice settings among patients with other chronic disorders. In the long term, the SCU proposes to use this instrument to study the link of patient satisfaction with measures of health outcomes such as morbidity and mortality.

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Appendix: Patient Satisfaction with the Sickle Cell Unit Questionnaire

This study seeks to assess patient satisfaction with the services offered at the Sickle Cell Unit. Information collected will be used maintaining strict confidentiality at all times.Please circle the correct response or fill in the blanks where required.

<u>**Personal information**</u>

Sex: Male / Female

D.O.B.: ___ / __ / _____   Age: _____
           dd   mm   yyyy

Genotype: SS / SC / SB0Thal / SB+Thal/ Other / Don't know

Marital Status: Single / Married / Not married but cohabiting/Separated / Widowed / Divorced

Clinic: Cohort / Main

Parish of permanent residence: _____

1. What is your highest completed education level?
   a) No school
   b) Primary
   c) Secondary / High
   d) Vocational / Skills training
   e) Tertiary / University

2. Are you currently employed?
   a) Yes
   b) No

3. If yes to #2, what type of job do you have?
   a) Wages
   b) Self-employed

4. On average, how often do you visit the Sickle Cell Unit?
   a) 1-3 times a year
   b) Once a month
   c) Once a week
   d) 2-3 times a week
   e) Other _____ (specify)

5. Have you ever consulted with the social worker at the Sickle Cell Unit?
   a) Yes
   b) No

If no to # 5 skip questions 6 and 7 and go directly to question 8

Patient satisfaction

Please indicate your level of agreement with the following statements by placing a tick in the appropriate box. There are no right or wrong answers – we are simply interested in your views. ALL answers will be kept confidential.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
6. The social workers do their best to assist me [social worker]	□	□	□	□	□
7. I don't feel confident discussing my problems with the social worker [social worker]	□	□	□	□	□
8. Patients receive the best care from the staff working at the SCU [general satisfaction]	□	□	□	□	□
9. I feel it is easy to speak to a doctor by telephone [access]	□	□	□	□	□
10. The doctor clearly explains what is wrong before giving any treatment [doctors]	□	□	□	□	□
11. Getting an appointment for a convenient time is easy [appointments]	□	□	□	□	□
12. The nurses do not take care to explain things [nurses]	□	□	□	□	□
13. The doctor does not tell me enough about the treatment [doctors]	□	□	□	□	□
14. The building could do with some improvements [facilities]	□	□	□	□	□
15. The doctor fully explains how the illness will affect my future health [doctors]	□	□	□	□	□
16. The doctors are careful to check everything when examining me [doctors]	□	□	□	□	□
17. It is easy to get advice over the phone [access]	□	□	□	□	□
18. The waiting room is uncomfortable [facilities]	□	□	□	□	□
19. The daycare/treatment room is comfortable [facilities]	□	□	□	□	□
20. The nurses sometimes fail to understand how ill I'm feeling [nurses]	□	□	□	□	□
21. The receptionists/cashiers explain things clearly to me [access]	□ □	□ □	□ □	□ □	□ □
22. Sometimes the doctors make me feel I am wasting his/her time [doctors]	□	□	□	□	□
23. I am satisfied with the hours the clinic is open [access]	□	□	□	□	□
24. The doctor is always interested [doctors]	□	□	□	□	□
25. The doctor always asks how my illness affects daily life [doctor]	□	□	□	□	□
26. I am not satisfied with treatment received in the day care/treatment room [general satisfaction]	□	□	□	□	□
27. I don't feel confident discussing my problems with the doctors [doctors]	□	□	□	□	□
28. Appointments are easy to make whenever I need them [appointments]	□	□	□	□	□
29. The doctor seems to want to get rid of me as soon as possible [doctors]	□	□	□	□	□
30. The doctor gives me every chance to talk about all my problems [doctors]	□	□	□	□	□
31. I feel perfectly satisfied with the way I am treated at the SCU [general satisfaction]	□	□	□	□	□
32. The doctor sometimes fails to appreciate how ill I am [doctors]	□	□	□	□	□
33. The nurses do not always listen carefully when I talk about my problems [nurses]	□	□	□	□	□
34. There are not enough seats in the waiting room [facilities]	□	□	□	□	□

35. I am not satisfied with the doctors [general satisfaction] □ □ □ □ □
36. The nurses are always caring [nurses] □ □ □ □ □
37. Even when the doctors are busy I am examined properly [doctors] □ □ □ □ □
38. It is often difficult to get to see the social worker [access] □ □ □ □ □
39. I sometimes feel I have not been given enough information by the doctors [doctors] □ □ □ □ □
40. The waiting room seats are uncomfortable [facilities] □ □ □ □ □
41. I do not feel rushed when I am with the doctor [doctors] □ □ □ □ □
42. The nurse shows a genuine interest in my problems [nurses] □ □ □ □ □
43. The doctors know when tests are necessary [doctors] □ □ □ □ □
44. The doctors are very understanding [doctors] □ □ □ □ □
45. There are one or two things about the SCU I am not happy about [general satisfaction] □ □ □ □ □
46. The doctors do everything needed to arrive at a diagnosis [doctors] □ □ □ □ □
47. The doctor always puts me at ease [doctors] □ □ □ □ □
48. The location of the clinic is convenient [access] □ □ □ □ □
49. I don't feel confident discussing my problem with the nurses [nurses] □ □ □ □ □
50. It usually takes me a long time to get tests done at the laboratory [lab] □ □ □ □ □
51. The laboratory staff are usually courteous [lab] □ □ □ □ □
52. It is easy to see the doctor of my choice [appointments] □ □ □ □ □
53. The laboratory staff do not spend any time to explain the procedure to be done [lab] □ □ □ □ □
54. The quality of care given by each doctor is about the same [doctors] □ □ □ □ □
55. I have absolute faith and confidence in the doctors [doctors] □ □ □ □ □