INFORMED CONSENT FORM

Researcher is grateful to you for participating in the study ‘PARTICIPATION IN THE COMMUNITY AND QUALITY OF LIFE OF PEOPLE LIVING WITH SCHIZOPHRENIA’. This informed consent form gives a brief description about the study, participation required from people living with schizophrenia and other stakeholders. It also explains the rights of the participants’ and stakeholders’ while participating in this study.

This aim of the study is to understand the perception of PEOPLE LIVING WITH SCHIZOPHRENIA on their participation in the community and quality of life; to locate the areas, meaning, and outcome of their participation in the community; and its implication on their quality of life. This study will provide an understanding on the perception of people living with schizophrenia on their life which is less known and the involvement of NGO, family, and other significant persons in the process of rehabilitation. There are no known risks for participating in this study.

Data collection is proposed to carryout using the methods of observation, in-depth interview, and secondary sources available at the NGO. The main participants of this study are people living with schizophrenia. Data will also be collected from other stakeholders such as family members, significant others, professionals and para professionals at the NGO. Tools of data collection consist of interview guide, observation guide, and background information sheet.

The anonymity of the participants and stakeholders will be maintained. Name of the organisation, people living with schizophrenia, their family, significant others, professionals and other staffs will not be revealed. Confidentiality of the information shared will be maintained. The researcher will not undertake any kind of intervention either with the participants or with their family members. The researcher will stop the process of the interview if it disturbs the person living with schizophrenia and refer
him/her to the professionals at the organization for help. Thesis may include the quotes of participants without sharing the key identifying information. The study is completely meant for academic purpose, and will be published as a PhD thesis at TISS library. Contents or parts of this study will be published in academic journals.

The interviews will be recorded by using a voice recorder which will enable researcher to capture the experience of participants and stakeholders in their own words. This recorded information will be heard and used only by the researcher. In case if the participant is not comfortable with recording, she/he has the right to ask not to record or switch off the recorder. The participant can ask for a review of the transcripts if she/he feels to verify it or clarify her/his doubts regarding it. Participants has the right to withdraw from the study any time she/he feels till 29th February 2011, in that case all the information provided by the participant consisting of recorded data and its transcription will be destroyed.

Researcher will be glad to provide individual consent forms in case participants and stakeholders wish to keep it for further reference.

Researcher: Participant/stake holder:

In case of any clarifications please feel free to contact,

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APPENDIX-2

Participants and stakeholders perspective on LS, PIC, and QOL

<table>
<thead>
<tr>
<th>Participants</th>
<th>Living with schizophrenia</th>
<th>Participation in the community</th>
<th>Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Affected various areas of functioning</td>
<td>-Self care and grooming, -Maintaining personal space, -Interaction with fellow members, -Communicating with others -Outings with family members, helping at home, attending social functions, -Following rehabilitation centre activities -Education and work</td>
<td>-Sense of Insecurity, No home to stay, Could not achieve a job, conflict between parents, schizophrenia sexual exploitation, Incomplete education, no career, lost parents, lost interest in everything, poor self care, schizophrenia, fought with family -Improvement over the period in various areas -Hope for a better future</td>
</tr>
<tr>
<td>Family</td>
<td>-affected various areas of functioning -better behavior if on regular medication</td>
<td>Behavior towards family Initiating household works Performance of activities at rehabilitation center medication</td>
<td>QOL is bad QOL deteriorated after illness Changes over the period of time - Illness - Self - Social</td>
</tr>
</tbody>
</table>
| Professionals | - affected various areas of functioning  
| - limited involvement in treatment decisions  
| - PLS with positive symptoms face cognitive difficulties  
| - PLS with negative symptoms have issues in interaction and communication  
| - irregular medication and relapses | Day to day activities  
| Decision making  
| Interaction and communication  
| Medication  
| Family  
| Education  
| Work | Personal life  
| - Self care - grooming, cleaning, neatness  
| - Happy in life  
| - Satisfied in self,  
| - Able to cope with deficits  
| - independent/ self dependent  
| - Occupied in something, distract negative thoughts  
| - professional life  
| - Occupation/work, pursue some interest and talents, good job, vocational training  
| - Social life  
| - Staying or at least spending time with family (LSH)  
| - good family support |
APPENDIX 3

INTERVIEW GUIDES

PEOPLE LIVING WITH SCHIZOPHRENIA (PLS)

1. Introduce self (Details about themselves)
2. Day to day activities they engage in (at NGO and when they are at home)
3. Differences of routines followed at NGO and home
4. Their view on the importance and effectiveness of these activities on their life and reasons for it
5. Perception on participation in the community
6. People they interact in their daily life and perception on this interaction level
7. People who support them (economically and emotionally)
8. PLS perception on these supports
9. Their perception regarding own life
10. Their understanding regarding ‘Quality of life’
11. Perception on the relationship between ‘participation in the community and quality of life’

KEY INFORMANT INTERVIEW GUIDE

PROFESSIONALS (MENTAL HEALTH PROFESSIONALS AND OTHER STAFFS)

1. Designing the activities for PLS at NGO
   a. Type of activities
   b. Daily routine of PLS in different centres of NGO (RFS has three centres)
   c. Involvement of PLS in the designing and implementing these activities
   d. Changes these activities brought in PLS and in their different areas of life
   e. Influence of these activities and programmes in the day to day functioning of PLS
2. Participation in the community and quality of life
   a. Definition of the term ‘participation’ in the context of rehabilitation of PLS provided by the NGO
   b. Definition of ‘community’ in context of rehabilitation of PLS
   c. View on ‘participation in the community’ in context of rehabilitation of PLS
   d. Enhancement of ‘participation in the community’ through the process of rehabilitation of PLS
   e. Effect of ‘Participation in the community’ in different areas of life functioning of PLS
   f. View on quality of life of PLS and reasons
   g. Perception on implications of ‘Participation in the community’ on ‘quality of life’ of PLS

FAMILY AND SIGNIFICANT OTHERS

1. Schizophrenia and rehabilitation
   a. Understanding on Schizophrenia and its consequences
   b. Understanding on rehabilitation for PLS and its outcome
   c. Understanding on role of family in rehabilitation of PLS in from own experience
   d. Sources of support (both monetary and kind) available
   e. Implications of these support on rehabilitation of PLS

2. Participation and community
   a. Perception regarding ‘participation’ of PLS in different areas of life
   b. Perception on what constitute of ‘community’ in context of PLS
   c. Perception on PLS participation in the community

3. Quality of life
   a. Perception on ‘quality of life’ of PLS
   b. Factors contributing to ‘quality of life’
   c. Implications of ‘participation in the community’ on ‘quality of life’ of PLS
APPENDIX 4

OBSERVATION GUIDE

Areas of observation

1. Personal
   a. Self care
   b. Daily routines
   c. Cognitive and emotional functioning
   d. Behaviour changes
   e. Medication
   f. Side effect of drugs

2. Interpersonal/group
   a. Group activities and participation
   b. Communication
   c. Type and level of participation
   d. Initiatives and planning of activities
   e. Task assignment and completion

3. Social functioning
   a. Communication with family
   b. Communication with staff
   c. Vocational activities
   d. Financial accountability
APPENDIX 5

DESCRIPTION OF “IDEAS”

General guidelines:

- IDEAS is suited best for the purpose of measuring and certifying Disability.
- It is therefore a brief and simple instrument, which can be used, even in busy clinical settings.
- Some training is required in the use of IDEAS.
- This is to be used only on out-patients and those living in the community. Not appropriate for in-patients.
- Rating should be done only based on interviews of the Primary Care Givers. Case records and patient interviews can be used to supplement information.
- Only in rare instances when no primary care giver is available should the rating be based only on patient interview. This should then be documented.
- The gender specification “he” has been used for convenience and refers to both genders.
- Probe questions help to guide one through the interview and to help identify dysfunction in one or more activities.

Diagnostic Categories:

Patients with only the following diagnoses as per ICD of DSM criteria are eligible for disability benefits:

- Schizophrenia
- Bipolar Disorder
- Dementia
- Obsessive Compulsive Disorder

Duration of Illness:

The total duration of illness should be at least two years. For the purpose of scoring, the number of months the patient was symptomatic in the last two years (MI 2Y-months of illness in the last two years) should be determined.

Who does the assessment?
Diagnosis and certification can be done only by the Psychiatrist. Administration of IDEAS can be done by trained social workers, psychologists, or occupational therapists.

Frequency of Re-certification

Psychiatric Disability will be reassessed every two years and re-certified. The feasibility of doing this in the rural areas will however have to be examined.
Items:
I. Self Care: Includes taking care of body hygiene, grooming, health including bathing, toileting, dressing, eating and taking care of one’s health.
II. Interpersonal Activities (Social Relationships): Includes initiating and maintaining interactions with others in a contextual and socially appropriate manner.
III. Communication and Understanding: Includes communication and conversation with others by producing and comprehending spoken / written / nonverbal messages.
IV. Work: Three areas are Employment / Housework / Education Measures and one aspect.
   1. Performing in Work / Job: Performing in work / employment (paid) employment / self employment / family concern or otherwise. Measure ability to perform tasks at employment completely and efficiently and in proper time. Includes seeking employment.
   2. Performing in Housework: Maintaining household including cooking, caring for other people at home, taking care of belongings etc. Measures ability to take responsibility for and perform household tasks completely and efficiently and in proper time.

Scores of each item:
0 - NO disability (none, absent, negligible)
1 - MILD disability (slight, low)
2 - MODERATE disability (medium, fair)
3 - SEVERE disability (high, extreme)
4 - PROFOUND disability (total, cannot do)

TOTAL SCORE (range: 0-20)
Add scores of the 4 items and obtain a total score
MI 2Y: Months of illness in the last two years. Interview with informant and case notes if available should be used to determine for how many months in the last two years the patient exhibited symptoms. (range: 1-4)

MI 2Y: < 6 months: score to be added is 1
7-12 months: add 2
13-18 months: add 3
> 18 months: add 4

GLOBAL DISABILITY:
Total Disability score +MI2Y score = Global Disability score (range: 1-20)
Percentage:
For the purpose of welfare benefits, 40% will be the cut-off point. The scores above 40% have been categorized as Moderate, Severe and Profound based on the Global disability score. This grading will be used to measure change over time.
Score of 0 - No Disability = 0%
1 - 7 Mild Disability = < 40%
8 and above = >40%
(8-13 Moderate Disability; 14-19 = Severe Disability; 20 = Profound Disability)

MANUAL FOR “IDEAS”
In order to score this instrument, information from all possible sources should be obtained. This will include interview of patient, the care giver and case notes when available.

1. SELF CARE
This should be regarded as activity guided by social norms and conventions.
The broad areas covered are
a) Maintenance of personal hygiene and physical health.
b) Eating habits.
c) Maintenance of personal belongings and living space.

Guiding Questions
a) Does he look after himself, wash his clothes regularly, take a bath and brush his teeth?
b) Does he have regular meals?
c) Does he take food of right quality and quantity?
d) Does he dress appropriately (weather conditions, over dressing)?
e) Does he take care of his personal belongings with reasonable standard of cleanliness and orderliness?
f) Does he seek treatment for health conditions and comply with advice?

Scoring of Disability

0 = No disability
Patient’s level and pattern of self-care are normal, within the socio-cultural and economic context.

1 = Mild
Mild deterioration in self-care and appearance (not bathing, shaving, changing, clothes for the occasion as expected). Does not have adverse consequences such as hazards to his health. No embarrassment to family.

2 = Moderate
Lack of concern for self-care should be clearly established such as deterioration of physical health, obesity, tooth decay & body odours

3 = Severe
Decline in self-care should be marked in all areas. Patient wearing torn clothes, would only wash if made to and would only eat if told. Evidence of serious hazards to physical health. (Malnutrition, infection, patient unacceptable in public).
4 = Profound
Total or near total lack of self-care (Example: risk to physical survival, needs feeding, washing, putting on clothes etc., Constant supervision necessary)

II INTER PERSONAL ACTIVITIES
Includes patient’s ability to form and maintain social relationships. This would be applicable to family, friends, colleagues and society at large. Ability for emotional response such as showing tolerance, responding to criticism or praise, and love and affection. Activities of engaging in physical intimacy. Ability to interact in a socially appropriate manner (reduction or excess).

Guiding Questions
a) What is his behaviour with others?
b) Do you think his behaviour in social situations (at work, social gatherings) is appropriate?
c) What is the nature of his relationship with other family members?
d) Is he able to regulate verbal and physical aggression?
e) Is he able to initiate social interactions on his own?
f) How does he behave with strangers?
g) Is he able to maintain friendship?
h) Does he show physical expression of affection and desire?

Scoring
0 = No
Patient gets along reasonably well with people. No friction in inter – personal relationships
1 = Mild
Some difficulty in initiating and maintaining social interaction. Friction on isolated occasions. However, his social behaviour is generally acceptable to others.
2 = Moderate
Definite difficulty in social interaction and interaction considered unhealthy / inappropriate. May be seen on more than few occasions. Could isolate himself from others and avoid company.
3 = Severe
Serious difficulty in initiating and maintaining social interaction. Behaviour in social situations is undesirable and generalised. Causes serious problems in daily living / or work. Patient is socially isolated.
4 = Profound
No attempts at engaging in any kind of social interaction. Family afraid of potential consequences.

III COMMUNICATION AND UNDERSTANDING
Understanding spoken messages as well as written and non-verbal messages. Ability to produce meaningful messages in order to communicate with others. Ability to converse in groups (such as chatting and discussing) Use of communication devices such as
telephone, email, internet etc. Any reduction / excess of these behaviours should be considered. All modes of communication should be considered.

1. Questions
a) Does he avoid talking to people / talk excessively at times?
b) Is he able to start, maintain and end a conversation?
c) Does he indulge in reading, writing and other communication devices such as telephone, e-mail etc?
d) Is he able to comprehend verbal / non-verbal communication?
e) Are others able to comprehend his communication?
f) Do you need to encourage him to be more communicative?

Scoring:
0 = No disability
Patient communicates with people as much as can be expected in his socio-cultural context. No difficulty in comprehension.

1 = Mild
Patient described as uncommunicative. Communication inappropriate (as in excitement). No active avoidance, but speaks only when spoken to. Could have some difficulty in comprehension.

2 = Moderate
A narrow range of communication. Communication can be too brief / in excess, incomplete or incomprehensible.

3 = Severe
Evidence of more generalised, active avoidance of any kind of communication. Serious difficulty in comprehension.

4 = Profound
All communication is nil or a bare minimum. Communication totally incomprehensible.

IV. WORK
This includes employment, housework and educational performance.
Score only one category in case of an overlap.
Guiding Questions
a) Is he / she employed / unemployed / housewife / student?
b) If employed, does he go to work regularly?
c) Does he like his job and is he coping well with it?
d) How is his competence at work?

Scoring:
0 = No disability
Patient goes to work regularly and his output and quality of work performance are within acceptable levels for the job.

1 = Mild
Noticeable decline in patient’s ability to work, to cope with it and meet the demands of work, may threaten to quit.

2 = Moderate
Declining work performance, frequent absences, lack of concern about all this. Financial difficulties foreseen.

2 = Severe
Marked decline in work performance, disruptive at work, unwilling to adhere to disciplines of work. Threat of losing his job.

4 = Profound
Has been largely absent from work < termination imminent. Unemployed, and making no efforts to find jobs.

House-wives
In similar ways, housewives should be rated on the amount, regularity and efficiency in which tasks in the following areas are completed. Consider the amount of help required completing these. Acquiring daily necessities, making storing and serving of food, cleaning the house, working with those helping with domestic duties such as maids, cooks etc., looking after possessions and valuable in the house.

Students:
Assess the score on performance in school / college, regularity, discipline, interest in future studies, behaviour at the educational institution. Those who had to discontinue education on account of mental disability and unable to continue further should be given a score of 4.

IDES
(Indian Disability Evaluation and Assessment Scale)

SCORING SHEET

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<thead>
<tr>
<th>ITEMS</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>4</th>
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<tbody>
<tr>
<td>I. Self Care</td>
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<td>II. Interpersonal Activities</td>
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<td>III. Communication &amp; Understanding</td>
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<td>IV. Work</td>
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</table>

A. TOTAL SCORE (I+II+III+IV) (Range 0-16)

B. MI 2Y SCORE (Range 1-4)

GLOBAL SCORE (A + B) (Range 1-20)

Percentage of disability (< 40% / > 40%)