Appendix 1

TOOL 1- PROFILE OF THE WOMEN WITH BREAST CANCER

1. Socio-demographic background
   1.1. Respondent number :
   1.2. Name (optional) :
   1.3. Age :
   1.4. Mother tongue :
   1.5. Religion :
   1.6. Caste :
   1.7. Education :
   1.8. Occupation :
   1.9. Marital status :
   1.10. Child status :
   1.11. Income category :
   1.12. Occupation :
   1.13. Current occupational status :

2. Case profile
   2.1. Do you have a family history of cancer?
      a) Yes       b) No
   2.1. A. If yes, who had cancer in your family and what cancer was that?

   2.2. History of the illness
      a) When did you observe the first symptom and what was that?

      b) After seeing the initial symptom were you able to identify that it is of breast cancer?
         a. Yes       b. No

      c) Where/whom did you consult after observing first symptom and what made you take this decision?
d) When did you consult an oncologist or a speciality hospital?

2.3. Did you have any hesitation to consult a doctor initially? specify the reason
   a) Yes
   b) No

2.4. Treatment undergone
   a) Surgery (specify)
   b) Radiotherapy
   c) Chemotherapy
   d) Combination of treatments (specify)
   e) Nuclear medicine
   f) Not Applicable
   g) Others (specify)

2.5. Are you using any external prosthesis- (breast form and or hair loss accessories)?
   a) Yes b) No

2.6.1 If Yes, Why?

2.6.2. If No, Why?

2.7. What do you think about the usage of external prosthesis and hair loss accessories can make positive influence on your body image and self esteem?

3. Observations
Appendix 2

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies.

### PHYSICAL WELL-BEING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lack of energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of my physical condition, I have trouble meeting the needs of my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am bothered by side effects of treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel ill</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am forced to spend time in bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### SOCIAL/FAMILY WELL-BEING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel close to my friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get emotional support from my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get support from my friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family has accepted my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with family communication about my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel close to my partner (or the person who is my main support)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the next section.

I am satisfied with my sex life .......................................................... 0 1 2 3 4
FACT-B (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

### EMOTIONAL WELL-BEING

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Some bit</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>GE1</td>
<td>I feel sad ........................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GE2</td>
<td>I am satisfied with how I am coping with my illness ........................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GE3</td>
<td>I am losing hope in the fight against my illness ........................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GE4</td>
<td>I feel nervous ........................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GE5</td>
<td>I worry about dying ........................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GE6</td>
<td>I worry that my condition will get worse ..........</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### FUNCTIONAL WELL-BEING

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Some bit</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>GF1</td>
<td>I am able to work (include work at home) ......</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GF2</td>
<td>My work (include work at home) is fulfilling ..</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GF3</td>
<td>I am able to enjoy life ................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GF4</td>
<td>I have accepted my illness ........................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GF5</td>
<td>I am sleeping well ...............................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GF6</td>
<td>I am enjoying the things I usually do for fun ...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GF7</td>
<td>I am content with the quality of my life right</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
FACT-B (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<table>
<thead>
<tr>
<th>ADDITIONAL CONCERNS</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have been short of breath</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am self-conscious about the way I dress</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>One or both of my arms are swollen or tender</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel sexually attractive</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am bothered by hair loss</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry that other members of my family might someday get the same illness I have</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry about the effect of stress on my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am bothered by a change in weight</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to feel like a woman</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have certain parts of my body where I experience pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
## FACT-B Scoring Guidelines (Version 4)

**Instructions:**
1. Record answers in “item response” column. If missing, mark with an X.
2. Perform reversals as indicated, and sum individual items to obtain a score.
3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.
4. Add subscale scores to derive total scores (TOI, FACT-G & FACT-B).
5. The higher the score, the better the QOL.

### Subscale Item Code Reverse item? Item response Item Score

#### PHYSICAL
<table>
<thead>
<tr>
<th>Item Code</th>
<th>Reverse item?</th>
<th>Item response</th>
<th>Item Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP1</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>GP2</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>GP3</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>GP4</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>GP5</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>Score range: 0-28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP6</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>GP7</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
</tbody>
</table>

#### WELL-BEING (PWB)

#### SOCIAL/FAMILY

#### EMOTIONAL

#### FUNCTIONAL

### Score range:

**FACT-B Scoring Guidelines (Version 4) – Page 2**

### Subscale Item Code Reverse item? Item response Item Score

#### BREAST
<table>
<thead>
<tr>
<th>Item Code</th>
<th>Reverse item?</th>
<th>Item response</th>
<th>Item Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>CANCER</td>
<td>B2</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>SUBSCALE</td>
<td>B3</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>BCS</td>
<td>B4</td>
<td>0</td>
<td>+</td>
</tr>
<tr>
<td>B5</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
<tr>
<td>Score range: 0-36</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B6</td>
<td>4</td>
<td>-</td>
<td>=</td>
</tr>
</tbody>
</table>
To derive a FACT-B Trial Outcome Index (TOI):

\[
\text{Score range: } 0-92 \\
\frac{\text{PWB score}}{\text{FWB score}} + \frac{\text{BCS score}}{} = \text{FACT-B TOI}
\]

To Derive a FACT-G total score:

\[
\text{Score range: } 0-108 \\
\frac{\text{PWB score}}{\text{SWB score}} + \frac{\text{E WB score}}{\text{FWB score}} + \frac{}{} = \text{FACT-G Total score}
\]

To Derive a FACT-B total score:

\[
\text{Score range: } 0-144 \\
\frac{\text{PWB score}}{\text{SWB score}} + \frac{\text{E WB score}}{\text{FWB score}} + \frac{\text{BCS score}}{} = \text{FACT-B Total score}
\]

*For guidelines on handling missing data and scoring options, please refer to the Administration and Scoring Guidelines in the manual or on-line at www.facit.org.
Appendix 4

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies.

### ADDITIONAL CONCERNS

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some</th>
<th>Quite a</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel peaceful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have a reason for living</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My life has been productive</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble feeling peace of mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel a sense of purpose in my life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to reach down deep into myself for comfort</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel a sense of harmony within myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My life lacks meaning and purpose</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I find comfort in my faith or spiritual beliefs</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I find strength in my faith or spiritual beliefs</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My illness has strengthened my faith or spiritual beliefs</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I know that whatever happens with my illness, things will be okay</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix 5

SUPPORTIVE CARE NEEDS OF WOMEN WITH BREAST CANCER

(Interview schedule)

1. Can you specify your needs for physical assistance according to the following categories?

<table>
<thead>
<tr>
<th>Category of physical need</th>
<th>Management of side effects</th>
<th>Management of Symptoms</th>
<th>At home</th>
<th>At hospital</th>
<th>At work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete physical assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial physical assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. What are the major physical issues related to illness and treatment side effects? How do you manage it?
2. What do you think about your physical support needs related to the disease symptoms and treatment side effects?
3. What do you think about your psychological well-being and expected support from hospital, society and Government?
4. Who all are supporting you from your family and the society? What do you expect from them for your well-being?
5. What do you think about your illness in spiritual terms- fate/ Karma/ Will of God?
6. What do you think about the spiritual support for better adjustment to the disease?

7. Can you specify your physical needs associated with -
   
   a. Diagnosis, tests and examinations
   
   b. Treatment
   
   c. Follow up
   
   d. Services
   
   e. Other (specify)

9. What do you think about information you have about the illness and treatment is enough to avoid usual confusions during the course of treatment?

10. Have you ever felt need for more explanations and involvement in treatment decisions and procedure?

11. Do you think the information system of the hospital is adequate to meet the informational needs of the patients? Specify the reason also-

12. What do you think about help of a professional in discussing your needs with hospital authority?

13. Do you think patients need more information about services and programmes of Government and other organisations in this field?

14. Do you have any suggestions to improve the welfare of the patients and information system of the hospital?
Additional questions

1. What kind of difference do you feel in your relationship with friends and family as well as function your roles? (If applicable)
2. How is the response of your family members towards your illness?
3. Who all are there to support you (physically, financially and emotionally) when you are in need?
4. Who communicates the details of your illness and treatment to you and doctor?
5. Are you satisfied with the information and the communication patterns about your illness with you? What more do you expect? (If applicable)
6. Do you feel any difference in your sex life after the diagnosis of cancer? If yes, could you specify how your illness affected it?
7. Do you experience any problems in your marital relationship because of your body image after diagnosis? If yes please specify how is that?
8. How do you cope with the issues or changes in your sexual relationship with spouse?
9. Is your illness impacting the finance of your family in a serious way? Please specify how it affects-
10. Did you approach any services provided by Government or other organisations for help? Please specify the responses-
11. Are you aware about or connected to palliative care clinics? How do you feel the link with that?
12. What all factors make you worried after the diagnosis of your illness?
13. Do you feel that sharing your anxieties, stress and emotions can help your emotional well being?
14. If yes, what all factors make you adjust with your illness?

15. Have you ever thought of seeking help of a counsellor a medical social worker?
   Please specify the reason-

16. Do you find consolation or comfort when you think about role of fate or will of God recount your illness?

17. Do you think your faith and spiritual beliefs help you to cope with the illness?
   Please specify how?
Appendix 6

Interview guide for Treatment Professionals

Name:

Designation:

Hospital/Institute:

Number of years of working at the oncology department:

Dear Sir/Madam,

My name is Milincy Mathews T and I am pursuing Ph.D from The Department of Social Work, Jamia Millia Islamia, Delhi. The topic of my research is ‘Health related Quality of Life and Supportive Care Needs of Women with Breast Cancer’. A section of my research work involves understanding the view point of the treatment professionals (support system) about the supportive care needs of the women with breast cancer. The semi structured interview schedule is designed to understand the same. The questions aim to understand your thoughts and it does not aim to assess or evaluate your point of view about your own Institution or about support needs of patients in your own institution. All the same your identity will be kept confidential.

This will take around 25 to 30 minutes of your valuable time. Thank you for taking out your time and your inputs.

Warm Regards,

Milincy Mathews T
1. Gaps in the available supportive care services and possible supportive care services - Physical concerns of the women with breast cancer

2. Gaps in the available supportive care services and possible supportive care services - Psychological concerns of the women with breast cancer

3. Gaps in the available supportive care services and possible supportive care services - Social concerns of the women with breast cancer

4. Gaps in the available supportive care services and possible supportive care services - Spiritual concerns of the women with breast cancer

5. Gaps in the available supportive care services and possible supportive care services - Sexual concerns of the women with breast cancer

6. Gaps in the available supportive care services and possible supportive care services - Informational needs of the women with breast cancer

7. Gaps in the available supportive care services and possible supportive care services - Concerned with health care service delivery in relation to breast cancer
TITLE
Health related Quality of life and Supportive Care Needs of Women with Breast Cancer

Introduction
We request you to take part in a research study of Regional Cancer Centre, Thiruvananthapuram; about Health related Quality of life and Supportive Care Needs of Women with Breast Cancer. We would like to learn the physical, psychological, social and spiritual well being of women with breast cancer and through which develop and propose a better supportive care model for the patients. We ask you to take part in this study because your experience and suggestions can contribute in developing supportive care models as well as to provide better services.

Procedure
If you decide to take part, we would be interviewing women with breast cancer. In this we would ask the experiences you have gone through and still in; so that we can measure your quality of life and find out the supportive care needs. We expect which will arrive at better service and care as well. The interview would take only one session of up to 45 minutes of your valuable time.

Risks involved in participation
There would not be any physical procedures or discomforts other than which is part of the disease and treatment. When we ask your experiences there may be psychological disturbances. Researchers would not compel you to say anything which is against your willingness. She or he would be asking questions with the consideration of your physical and mental state as well as other factors.

Benefits
We would like to stay that you will not be benefited directly from taking part in this study. We are responsible to inform the results of this study if it is needed.

Confidentiality
Everything we learn about you in the study will be confidential. If we publish the results of the study in a scientific journal or book, we will not identify you in anyway. The results of the study will be submitted to Department of Social Work, Jamia Millia Islamia, New Delhi for Ph D Degree of Ms. Milincy Mathews T. Ethics committee may also want to see your records which identity you as a subject in this study.

Your participation is voluntary
Your decision to take part in the study is voluntary. You are free to choose not to take part in the study or to stop taking part at anytime. If you choose not to take part or to stop at any time, it will not affect your future medical care at the Regional Cancer Centre, Thiruvananthapuram. We will tell you about any significant new findings which develop during the course of this research which may relate to your willingness to continue taking part.
Clarifications
If you have questions any regarding this, feel free to ask us, if you have additional questions later or you wish to report a medical problem which may be related to this study, Dr. Chandramohan can be reached at (work - 0471 2522413, home phone/after-hours -0471 2552110. If he is not available, Ms. Milincy Mathews T may be reached at 9746326104. The Regional Cancer Centre committee that reviews research on human subjects (Institutional Review Board) will answer any questions about your rights as a research subject.

We will give you a signed copy of this form to keep. Your signature indicates that you have decided to take part in this research study and that you have read and have understood the information given above and explained to you.

Informed consent

Patient Name ………………………………..

CRNO:…………………………

My doctor has explained the details of the above study. I understand the purpose, the potential benefits and risks of taking part in the study. I understand that I can withdraw from the study any time without affecting my future treatment at RCC. By signing this form I give my free and informed consent to participate in this study.

……………………….
Signature of the patient

……………………………..
Name

…………………..
Date

……………………….
Signature of witness

……………………………..
Address of witness

……………………………..
Name

…………………..
Date

……………………….
Signature of investigator

……………………………..
Name

…………………..
Date
Appendix 8
MEMORANDUM OF UNDERSTANDING

Between
Regional Cancer Centre,
Trivandrum, with its headquarters at Thiruvananthapuram, Kerala
and
Department of Social Work
Jamia Millia Islamia, New Delhi. 110025

This Research Collaboration and License Agreement is entered into on 01/01/2013 (the “Effective Date”), by and between Regional Cancer Centre (herein after referred to as “RCC”), an autonomous National Institute sponsored jointly by, Government of India and Government of Kerala and Department of Social Work, Jamia Millia Islamia (a Central University), New Delhi (here after referred to as “JMI”). RCC and JMI may be referred to herein as a “Party” or, collectively, as “Parties.”

1 PURPOSE: The purpose of this Memorandum of Understanding (MoU) is to establish a mutual framework governing the respective organizational relationships, responsibilities, and activities between the Parties. This agreement is primarily for utilization of expertise of RCC and JMI for research leading to development of programmes. The areas of responsibility and relationships presented herein provide the concept under which the program will be executed.

BACKGROUND: RCC is a flagship research institution in India having excellent facilities and expertise for cancer research. Social Research in diverse areas has always been a major activity of the department of Social Work, Jamia Millia Islamia. A number of research and action projects are ongoing in the department and it has the expertise in developing programmes for the betterment of the research problem.

2 RESEARCH COLLABORATION:

3.1 Scope of Research Collaboration. The Research Collaboration will focus on the feasibility of conducting this study- health related quality of life and supportive care needs of women with breast cancer. RCC and JMI shall conduct the Research Collaboration on a collaborative basis is intended to propose a contextualized supportive care model by understanding the problem in a clinical set up. The research work will be executed in RCC and JMI and the facilities would be shared by both Parties.

3.2 Research Plan: The research shall be conducted in accordance with the initial research plan agreed upon and exchanged by the Parties concurrent with
the execution of this Agreement. The Research Plan defines the key decision points, timing to key decision points, resource and funding allocation and other details.

3 Responsibilities.

I. RCC Responsibilities: RCC will provide the following services and or goods.

a Support for the research data collection.
b Supervision and cooperation to conduct the research in the institution.

II. JMI’s Responsibilities.

a Preparation of the tool of data collection.
b Analysis and report preparation

3 MANPOWER AND RESOURCES: No additional manpower is anticipated to be required from either Party. Each Party will execute its responsibilities from the resources available with each institute. Manpower and resources through external funding is allowed and encouraged, and in these cases funding guidelines will be followed.

4 FUNDING:

a Apart from own funds, wherever possible funds can be generated through co-submission of research proposals to external funding agencies like DST, DBT, ICMR, KSCSTE and other suitable agencies.

5 UTILIZATION AND DISTRIBUTION OF FUNDS

a Funding guidelines will be followed for utilization.
b Separate auditable accounts will be kept by both agencies and made available for audit to authorities.
c Utilization of funds will depend on the project and will be determined separately for each project.
6  **APPLICABLE LAWS:** The applicable statutes, regulations, directives, and procedures of the Govt. of India, shall govern this MoU and all documents and actions pursuant to it. Unless otherwise required by law, all work undertaken by RCC and JMI shall be governed by the policies and procedures by the respective institutions.

7  **DISPUTE RESOLUTION AND ARBITRATION**

Should there be any difference of opinion between the Parties or if any dispute arises as to any of the matters provided for in this Agreement, the Parties shall endeavor to settle such differences and/or disputes in an amicable manner through mutual consultation.

In case such differences or disputes cannot be mutually settled, the matter shall be decided by Arbitration held at Thiruvananthapuram in accordance with the provisions of the Indian Arbitration and Conciliation Act, 1996 or the corresponding legislation in force for the time being and the Award made by the competent authority, shall be final and binding on the Parties.

8  **WARRANTIES**

Both parties in no way guarantee Research Services performed pursuant to this Agreement and make no warranties express or implied, regarding the quality of product produced under this Agreement.

9  **INTELLECTUAL PROPERTY:** If and only if any “invention” arises from the performance of this agreement this clause shall apply. ‘Invention’ shall mean any discovery, concept or idea whether or not patentable, resulting from the project.

- Patent rights to an invention made solely by Scholar of the Department of Social Work, JMI shall belong to JMI.
- Patent rights to an invention made solely by employees of RCC shall belong to RCC
- Patents rights to an invention made jointly by JMI and RCC shall be held jointly by JMI and RCC

10  **Records:** During the term of this Agreement and for a period of licensing thereafter, the Developing Party shall keep complete and accurate records pertaining to the results and other details.
**11.2 Audit:** During the term of this Agreement and for a period of two years thereafter, both parties shall keep complete and accurate records of the projects.

**11 CONFIDENTIALITY:** A Party in receipt of Confidential Information from other Party must not use or disclose the other Party’s confidential Information without that other Party’s prior written consent other than (i) for the purpose of carrying out this MoU, provided any disclosure is only to such of the receiving Party’s personnel or to its related company and its personnel who need to know and who are made subject to the confidentiality requirements of this MoU or (ii) as required by law.

Neither Party may make any public announcement in relation to this MoU without first obtaining the approval of the Other Party.

Confidential information means (i) the subject and terms of this MoU and (ii) all information (in whatever form) disclosed by one party to the other, whether before or after the date of this MoU but excludes information which (iii) is or becomes public knowledge other than through a breach of this MoU (iv) the recipient can show to the discloser’s reasonable satisfaction to have been in the recipient’s lawful possession prior to disclosure or (v) the recipient can show to the discloser’s reasonable satisfaction to have been lawfully received from a third party not obliged to keep that information confidential.

Regional Cancer Centre Page 4 of 8 Department of Social Work, JMI

Each Party shall not use any name, logo, trade name, trademark, service mark or symbol associated with the other Party without the prior written consent of the other party.

**12 REPORTS AND PUBLICATIONS:** Each Party to this Agreement recognizes that the publication of papers regarding results of the Research Collaboration, including oral presentations and abstracts, may be beneficial to both Parties provided such publications are subject to reasonable controls to protect Confidential Information.

Accordingly, each Party shall have the right to review and approve any paper proposed for publication by the other Party regarding results of the Research Collaboration hereunder, including oral presentations and abstracts, which utilizes data generated from the Research Collaboration and/or includes confidential Information of the other Party. Before any such paper is submitted for publication, the
Party proposing publication shall deliver a complete copy to the other Party at least 30 days prior to submitting to a publisher. The receiving Party shall review any such paper and give its comments to the publishing Party within 14 days of the delivery of such paper to the receiving Party. With respect oral presentation materials, the Parties shall make reasonable efforts to expedite review of such material, and shall return such items as soon as practicable to the disclosing Party with appropriate comments, if any, but in no event later than 7 days from the date of delivery to the receiving Party. The disclosing Party shall comply with the other Party’s request to delete references to such other Party’s Confidential Information in any such paper and agrees withhold publication in order to permit the Parties to obtain patent protection, if either of the Parties deem it necessary, in accordance with the terms of the this Agreement.

13 NOTICES: Any notices or communications provided for in this Agreement to be made by either of the Parties to the other shall be in writing, in English, and shall be made by prepaid mail with return receipt addressed to the other at this address set forth below. Any such notice or communication may also be given by hand, or facsimile to the appropriate designation. Either Party may by like notice specify an address to which notices or communications shall thereafter be sent.

Notices sent by mail, facsimile or cable shall be effective upon receipt and notices given by hand shall be effective when delivered.

Regional Cancer Centre                  Page 5 of 8                  Department of Social
Work, JMI

If to RCC

    Prof. Paul Sebastian
    Director
    Regional Cancer Centre
    Thiruvananthapuram – 695 011
    Kerala

If to JMI

    Prof. Zubair Meenai
    Head, Department of Social Work,
    Jamia Millia Islamia,
    New Delhi. 110025
14 MISCELLANEOUS:
   a Other Relationships or Obligations. This MoU shall not affect any pre-existing or independent relationships or obligations between the Parties.
   b Survival. The provisions of this MoU that require performance after the expiration or termination of this MoU shall remain in force notwithstanding the expiration or termination of the MoU.
   c Severability. If any provision of this MoU is determined to be invalid or unenforceable, the remaining provision shall remain in force as unaffected to the fullest extent permitted by law and regulation.
   d This Agreement shall be binding upon and inure to the benefit of the successors and permitted assigns of the Parties; provided, however, that any such permitted assignment or delegation shall not relieve the assigning Party of its responsibilities for performance of its obligations under this Agreement. Any assignment not in accordance with this Agreement shall be void.

15 REVIEW: This agreement will be reviewed annually to ensure adequate identification of support requirements. Additional reviews may take place when changing conditions or circumstances require substantial changes or development of a new agreement. Minor changes may be made at any time by correcting the existing document or attaching a memorandum to a basic document. Changes must be coordinated and initialed by a representative of both parties.

16 AMENDMENT AND MODIFICATION: This MoU may be amended or modified only by written, mutual agreement of the Parties.

17 TERMINATION OF THE AGREEMENT

Failure by either party to comply with any of the obligations herein contained shall entitle the other Party to give the Party in default written notice requiring curing such default. If such default is not cured within 60 days after receipt of such written notice, the notifying party shall be entitled without prejudice to any of their other rights conferred on them by the Agreement or by law, to terminate this Agreement by giving written notice to take effect immediately. The right to either party to terminate this Agreement shall not be affected in anyway by any waiver or failure to take actions with respect to any previous default.
Upon terminations of this Agreement, RCC and CESS shall cease to have any right to use and practice of the Know-How and the Process gained from the other and shall return all documents and information received from the OTHER related to the said Know-How within such times as may be specified by RCC and JMI.

18 **FORCE MAJEURE**

Except as hereinafter provided, no Party hereto shall be liable for failure to perform as required by any provision of this Agreement where such failure results from a cause beyond control of the parties such as acts of God, Government regulations, other acts of civil or military authorities, fire, flood, epidemic, quarantine, restrictions or/riots, delay in transporting and inability due to causes beyond control of such Parties to obtain necessary labor, material or manufacturing facilities or strikes, lock-outs, or other concerted actions of workmen or any circumstances of whatsoever nature beyond the control of either Party; provided that the Party claiming that the force majeure has affected its performance shall give notice to the other Party immediately, but not later than 15 days after becoming aware of the first occurrence of force-majeure, giving full particulars of the case or event and the date of first occurrence thereof. Notwithstanding the foregoing however if performance required by this Agreement be delayed or prevented for more than three continuous months, either party may terminate this Agreement by giving notice (either before or after expiration of such six months period) of its intent to terminate this Agreement to the other party.

19 **EFFECTIVE DATE:** This agreement becomes effective upon the date of last approving signature and will remain in effect indefinitely until superseded, rescinded or modified by written, mutual agreement of both parties.
ACCEPTANCE OF AGREEMENT:

Prof. Zubair Meenai
Head, Department of Social Work,
Jamia Millia Islamia,
New Delhi. 110025

Dr. Paul Sebastian
Director
Social Work,
Regional Cancer Centre
Medical College Campus,
Thiruvananthapuram-695011
Kerala

Prof. Zubair Meenai
Head, Department of
Jamia Millia Islamia,
New Delhi. 110025

Date: 01/01/2013

Witness

Dr. K. Chandramohan
Addl Professor
Surgical Oncology
Regional Cancer Centre
Thiruvananthapuram-695011
Kerala

Department of Social Work,
Jamia Millia Islamia
New Delhi 110025

Date: 01/01/2013
Signed this on ………………………...in the City of New Delhi and on …………………...in Thiruvananthapuram, Kerala.

END OF DOCUMENT
Signed in Duplicate