



## Journey of developing Sarbojaya in KolGoTrg

---

Ovarian cancer- a disease that has the highest mortality among female population has seen gradual advancements in the treatment modalities over the last few years. Through advancements in treatment through research, the overall survival among the western population has been improving compared to the low-middle income countries such as India. One of the key reasons for this is the lack of a good number of research organisations/ research groups to provide the benefit of participation in a cancer clinical trial. There might be few small organisations working individually towards cancer research but incorporating into a tertiary cancercentre with equally trained manpower to initiate, regulate and maintain cancer research is very less. This led to the idea of developing a research organization that could cater the needs of the patients as well as provide them the scope to participate in clinical trials. Seven clinical and basic science institutes spread across Kolkata joined hands in developing a clinician- scientist platform to fight women’s cancer. This was how **KolGoTrg was formed** inside a tertiary cancer centre in 2017.

Though the idea was well accepted and appreciated, the initial problem was to identify capable manpower adept in regulating the research process and coordinating patient care simultaneously. There was a lack of knowledge regarding research among medical social workers and the concept of research nurse was non-existent.



The struggle was real when the nurses, who were initially working in the wards or clinics, were asked to perform duties outside of their usual clinical expertise. However, over time four nurses joined the group mentored by Dr Asima Mukhopadhyay and were thoroughly trained in fields such as colposcopy, quality of life, cervical cancer screening and genetic counselling and over the time they became proficient in their roles.

A medical social worker was identified with previous experience in an NGO and was trained to become expert in herfield. Gradually **the team grew** and there were data managers, scientists, trial coordinators and research fellows who gradually developed their knowledge and skill through practise and various forms of training andcourses.



The primary work of the research nurses and the medical social worker was to identify potential patients eligible for certain research and counsel them for the same. Almost all the ovarian cancer patients were followed up in their journey through quality of life questionnaire based assessment. If they developed any symptoms, they would be immediately referred to the clinics by the research nurses. Moreover they were also **referred to the Palliative team** for symptom assessment in the preliminary stage. The concept behind it is that the patients are usually referred the palliative team when the patient goes for end-of-life care. This can build up a sense of unwantedness among the patients as they may feel they are being sent to a new team at a last stage because there is nothing else to do. To reduce the dejection level and also to identify symptoms at an early stage, they are co-referred to the palliative team.

The **quality of life assessments** were long term follow-ups and the patients stayed in contact with their research nurses for over 2 years. This built up a strong interpersonal relationship between the patients and the research nurses. They would call up if they have symptoms, they would ask for any help that can be provided by the research nurses, and they even started giving gifts to the nurses, sent friend requests on social media and treated them like friends! During the demise of the patients, the patient relatives would ask for the presence of the research nurses and acknowledge their support and care in their funerals. There have been few instances where the patients/relatives had some conflicts with the healthcare or administrative personnel, but still during the funeral ceremony they had asked the presence of the team, and have acknowledged our support.



Gradually, these patients started assisting in the **snowballing technique** of cervical cancer screening, wherein they would help in organising screening camps in their localities. They would also act as local voice to provide cancer awareness in their communities.

An organisation worth mentioning, the “**Manisha Nandi Foundation**”, was formed by the husband and relatives of the Late Manisha Nandi, who succumbed to ovarian cancer at a very early age. Our team was with her during her journey and the husband and her relatives have been ever-grateful since then. They formed the organisation after her demise to provide funds to women with ovarian cancer. They have been a supporter of our organisation and have assisted in cancer awareness programmes.



With more interpersonal relationship between the patients and the nurses came the idea to start a **Survivorship programme**. The patient and their relatives were called up for participating in the programme, a venue was booked and the programme schedule was made. The programme comprised of cancer survivors (patients and/or relatives) who would express their journey and how they have been able to cope up with their cancers.

The survivorship programme was intended to be an academic involvement, hence was supported by staff members of SYMEC( systems medicine cluster), a grant from DBT India, the UKIERI grant and organizations such as STRAND Life Sciences and JIVDAYA Foundation. Eminent health care workers such as Sister Hanife joined our survivorship programmes to enlighten the team and the survivors about her experience in cancer care. There were various interactive sessions with the participants which provided a learning opportunity for both the team and the survivors and brought many facets of life.



The highlight of the programme was the performance of the cancer survivors alongside the health care providers which proved that they had not given up their dreams and hobbies and encouraged newly diagnosed cancer patients. The programme brought many survivors close to each other and provided a link among them.



Till date, we have had three survivorship programmes. The survivorship programme strengthened the bonds between the healthcare workers and the survivors as a result we got many job requests from the survivor family members. Many were eager to work voluntarily for our group as they became more aware about our activities.

A noteworthy mention is our **second Survivorship programme**. Professor Taniya Das, a renowned scientist of Bose Institute, Kolkata decided to involve all the attendees through music. As she sang, everyone present in the hall-the research team with their families, and the survivor families, sang in unison. It was a memorable moment for the entire team.





The team felt how music can bring everyone together. With this strong bond grew the idea of the Patient group- which was named **Sarbojaya by Prof Tanya Das**. Sarbojaya is the name of the most worshipped Hindu female deity in Bengal, Goddess Durga. Goddess Durga signifies power and strength and who fights the evil; Sarbojaya means the one who always wins. The name plays an important role in signifying their immense strength to overcome the disease and reminds them to never give up.

The logo (top page) shows goddess Durga (Sarbojaya) looking over the holy river Ganges and its residents in Kolkata offering her protection from the evil forces. The iconic Howrah bridge over the Ganges signifies the bridging bond between patients and their carer including health professionals and family members/friends and between clinician and scientists in KolGoTrg. The flowing river illuminated in the dark symbolizes the flow of life.

Initially, Sarbojaya was meant for the cultural programmes for the Survivorship programme. As more members participated in the group, there was exchange in knowledge regarding how cancers and research is perceived by them and how they can contribute to the research designs; thus, forming concept of a PPI group. Some of the examples of patient participation in research is depicted below.

There were strong opinions from patient advocates regarding various research questions such as **Willingness to pay for cancer for a research project named IPIROC (Intermittent PARP inhibitor for recurrent ovarian cancer) which is received a seed funding from CRUK-DBT India**. One patient claimed that the willingness to pay by the patient will be very different from the willingness to pay by the family members. The patient relatives would always agree to pay for any treatment, no matter how expensive it is, or how small the delay of recurrence is.

However, the patient would be reluctant to bear expensive treatment, if she feels that the cost of treatment outweighs the duration of lifespan she would benefit. She quoted, " I would rather die early than leave my family in debt". Such description coming from a patient of affluent background was a real changer of our perspective. With so much valuable knowledge coming from our survivor groups, we decided to set up the first Patient-public Involvement Group which will help strengthen



our research proposals. But it was a huge challenge for the team. There was no pre-formed PPI group in India to look forward to. Nor there were any Indian organisation with a PPI group who could provide a learning opportunity for setting up the system in KolGoTrg. **Cancer Research UK**, the leading organisation in Patient-Public Involvement, has a set of steps and proformas for starters planning for

PPI. We decided to incorporate their pattern of patient public involvement into our system. **Ovarian Cancer Coalition**, another reputed organisation dedicated to Cancer research and PPI, decided to help us in the process. Meetings were scheduled and the **first Patient-Public Involvement Group** was set up with 7 patients. Discussions on our upcoming trials were made with the group and more meetings are underway.

**Cancer Research UK (CRUK)** had immensely helped us set up our first organized PPI group through a seed funding awarded through CRUK-DBT (India) affordable cancer challenges call. They have offered to attend our upcoming meetings with the PPI team if feasible and will help us in determining the functionality of our PPI group while developing the research proposal. CRUK team also offered to give a shoutout about our group in their bi- weekly newsletters so that any survivor from the BAME background can join the KolGoTrg PPI group.

A recent milestone in the KolGoTrg history is participation in the **Gynae-Cancer Inter-Group (GCIG) Meeting in May 2020**. KolGoTrg is the first co-operative Cancer Research group to represent India on a global platform for cancer clinical trials in Women's cancer. Our upcoming studies on HIPEC and PARP inhibitors were presented and were greatly appreciated by all the members of the GCIG forum. KolGoTrg has offered to participate in various international research activities in the GCIG forum and initial proceedings are in process. This includes active participation in a survey on involvement of patient advocacy in participation in cancer clinical trials. Thanks to Sarbojaya- KolgoTrg could tick this box as well.

Till date, KolGoTrg has been able to accomplish many important milestones. Starting from a group of 5, it has come a long way to include a huge team of clinicians, research fellows, research nurses, data managers, medical social workers, trial co-ordinators, epidemiologists, statisticians, IT personnel, administrators, accountants, PhD students and many volunteers. To the patients, it is a help in need; to the staff members of KolGoTrg- it is an immense satisfaction and privilege to be able to help people in need. But there is still a long way to go. As Robert Frost said," But I have promises to keep, and miles to go before I sleep", KolGoTrg will grow bigger to better the cancer research scenario in India and integrated health care.



# KolGO Trg

Asima Mukhopadhyay  
Rahul Roy Chowdhury  
Biman Chakraborty  
Ranajit Mandal  
Santanu Tripathi  
Sanjoy Paul  
Rakesh Roy  
G S Bhattacharya  
Chanchal Goswami  
KK Mukherjee  
JaydipBhaumik  
Tamohan Chowdhury  
Chandan Mandal  
SusantaRoyChowdhury  
Jayasri Das Sarma  
IndraniRoyChowdhury  
Mitali Chatterjee  
Vilas Nasare  
Benubrata Das  
Chitra Mandal  
Sibsankar Roy  
Shilpak Chatterjee

Jayanta Chakrabarty  
Tapas Maji  
DipanwitaBannejee  
Manisha Vernekar  
Basumita Chakraborty  
SS Mondal  
Chinmoy Panda  
Sharmila Sengupta  
ShuvojitMoulik  
Siddikuzzaman  
Asama Mukherjee  
Ratnaprabha Maji  
Bijoy Kar  
Vaishali Mulchandani  
Supriya Mondal  
Barnali Ghosh  
Dona Chakrabarty  
Aparajita Bhattacharya  
Twinkle Sinha  
Mou Das  
Ajit Mukhopadhyay

Authors:

Dona Chakrabarty & AsimaMukhopadhyay

