

User Engagement Group

Breast Cancer Clients 27th October 2023

The aim of this user engagement group was to gather qualitative data from clients diagnosed with Breast cancer in the last 18 months. During the session, the clients discussed their experience, thoughts, and ideas on how the Mulberry Centre meets their needs and what other opportunities they would like to see at the centre about The Mulberry Centre services.

The session was to coincide with October Breast cancer Awareness month and took place in The Mulberry Room at the Centre on Friday 27th October from 12.30-2pm

Marketing and promoting this engagement group began in advance through posters throughout The Centre, at The West Middlesex University Hospital outreach table and also in the breast clinic. Leaflets were displayed in The Centre and the information was advertised on our website, through the monthly activity's newsletter and social media. Following the format of previous user engagement groups, this was pitched as a social event. As it was lunch time sandwiches drinks and biscuits were supplied. Ten days before, an email invitation was sent to all registered breast cancer clients and due to lack of bookings this was repeated again two days before the event.

Ninety minutes were allocated for the user engagement group session and in the absence of the Community Engagement Lead was moderated by The Complementary Therapy Lead, Amanda as part of her role is to plan new classes and activities at The Centre.

A total of five clients participated in the session all female. One client dropped in so was not part of the group discussion however gave useful feedback.

The group demographics were as follows:

Age	Number of Participants	Ethnicity	Number of Participants
40	1	White uk	2
50-55	1	Chinese	1
60-66	3	Asian other	1
		White other	1

At the start of the session the clients were informed of the aims and purpose of the session, namely:

- To focus on developing the support we offer to our clients with breast cancer, with our clients being part of defining what this will look like.
- To get an idea of what currently works for the clients, what changes need to be made, and what new services they would like to see and think would benefit the community.

These themes were addressed through discussion around the following questions:

1. Which services do you currently use?
2. How do you use the Centre? What do you get most out of when visiting the Centre?
3. What do you get most out of when visiting the Centre?
4. How could the Centre improve to support more people with breast cancer in the community?

6. What would make you use the Centre more?

7. Communication: How do you think we could reach more people affected by breast cancer, both those already registered and new clients?

8. What is stopping you from accessing services?

10. What else you would like to add or share?

To help the participants gel together, the intention was to have an ice breaker quiz in pairs about our services followed by answering the questions placed around the room, by commenting using post-it notes. However, the clients relaxed and began chatting amongst themselves early in the session.

Amanda introduced herself and explained her role at The Mulberry Centre establishing ground rules of respect and privacy.

The clients quickly began talking about their hospital experiences, comparing it to the support that The Mulberry Centre offered meaning Amanda had to bring the Conversation back in line, reiterating the history and context of The Mulberry Centre being an independent charity and not part of the hospital or NHS. Most clients were not aware The Mulberry Centre was an independent charity.

Dialogue revealed that not all the clients had accessed our support services such **as counselling, complementary therapies, or wellbeing classes.**

- One client said that she avoided emotional support after her diagnosis as felt that it would break her resolve as at the time, she was overwhelmed by other situations on top of the cancer diagnosis.
- A second client said she was too overwhelmed with her diagnosis that she didn't read the vast collection of leaflets provided.
- Another client was told by her nurse there was no support for her. She found a leaflet at the Outreach table at The Hospital on a subsequent visit.
- One client had to go back to work promptly.
- One client had not accessed any of our services other than the welcome assessment, however booked a few after the user engagement session.
- All agreed that The Mulberry Centre leaflet given by the breast team was one of many that the clients put aside due to overwhelm.

With regards to Wellbeing and Social activities:

- One client attended Table Tennis and Health walks, however it was during her Chemotherapy treatment, so her energy levels were low, and her concerns were around slowing others down. She now attends regular Pilates classes.
- One client mentioned feeling averse to being in a mixed cancer type group for fear of hearing of other symptoms that may make her concerned that her cancer had returned / metastasised. The same client accessed workshops such as Nutrition, Look Good Feel Better.
- Two had attended Relaxation and Breathwork.
- Another client is considering booking onto sessions

Complementary therapies

- 3 Clients had engaged in Complementary Therapy: Shiatsu, Acupuncture and Aromatherapy.
- 1 Client went on to add her name to the waiting list after the session.

- 1 client works 9-5 and wasn't aware we were open until 8 on a Wednesday so will look out for any opportunities going forward.
- 1 client had complementary therapies during her chemo sessions and was very enthusiastic about how it benefited her at the time.
- 1 client had wished this had been available to her at such a stressful time.
- One client felt that at the end of their 4 sessions, clients should be given the option to give a donation for ongoing treatments at The Centre. Amanda explained the set up with the service being offered by volunteers in addition to pressure on our complementary therapy services in general in addition to our onward referral system.

Counselling

- One client's husband had taken up this opportunity.
- One client wished she had done this earlier and arranged to go on the waiting list after the session.
- One client was currently mid-way through her 6 sessions and reports finding it very beneficial.
- One client prefers unstructured chatting in a social setting.

Wellbeing

- One client found sessions were more aimed at older age. She was very fit pre diagnosis and would like to see more wellbeing classes aimed for younger more able.
- One client thought our seated yoga was for wheelchair users.
- Another client assumed by the names of the classes they were aimed at older clients.
- One client works full time and hadn't realised that we are open late on a Wednesday evening.
- One client doesn't exercise and never has.

Communications

All clients thought our communication was spot on and they always read the information sent.

Ideas for future classes and workshops and services

- One client would like to see a legal workshop, specifically on employees' rights. Clients cannot always rely on the good will of employee, and everyone should be educated on legislation disability rights and understand laws around 'reasonable adjustment'.
- One client would like to help us set up a buddy system to pair up two clients with the same diagnosis, one further down the line so that they could hear real life accounts of post-surgery complications, side effects etc.
- From this there was discussion around the possibility of cancer specific support groups such as breast cancer with visits from surgeons, breast care nurses. It was agreed that these could lead to the clients having an informal group both at The Centre and away from The Centre to encourage community.
- Also age specific groups
- A workshop that highlights practical tips hints and techniques for subjects such as Cancer and travelling or other issues surrounding living with cancer. Some clients were unaware they were entitled to free prescriptions.

- All clients would be interested in the previous Workshop that we *offered Dealing with emotions once cancer treatment ends.*
- Self-massage for scars and cording/axillary web syndrome and lymphatics post 6 week check up
- A lymphedema specialist
- Dance classes
- Information on clinical terms/ understanding why blood count matters etc.

The clients were asked: *How do you think we could reach more people affected by breast cancer, both those already registered and new clients?*

- All clients agreed that the leaflet they were given at diagnosis wasn't enough to raise awareness of The Centre as it wasn't the right time to get the information. They wondered why our services were not linked to the hospital in any way.
- One client suggested a Mulberry Centre volunteer could be in the clinic on breast clinic days.
- One client is keen to do more fundraising at work, to set up a committee, a team of other clients with breast cancer' a community within a community' to do fundraising such as bric a brac tables in school fairs.

Clients were asked *How do you use the Centre? / What do you get most out of when visiting the Centre?*

- One client drops in for a chat after her hospital appointments to chat to whoever is attending at that time. She describes The Centre as a Home from Home and always feels welcomed by the staff and volunteers. She lives alone so comes for company.
- Others mainly only attend The Centre around the time of their appointments.
- There was praise of the garden and it was mooted as an incentive to stay at the centre a little longer in summer.
- None of the clients knew that that could borrow books from the library.
- All felt it would be good to see some fiction as the library space was somewhat depressing as the books were all about cancer. They would prefer escapism and diversion.

Amanda wrapped up the session asking ***one word to describe what they got out of the centre.***

- Companionship
- Feeling heard
- Calm
- Welcomed
- Feeling seen

Conclusion

In summary, the key insights from this user engagement session are:

- In general, The Mulberry Centre is meeting their needs and communication is very good.

- Opportunities for younger age clients would attract more engagement to The Centre
- Advertising appeared to be geared up to older and infirm clients.
- Breast cancer specific groups would be well received.
- Communication between the Hospital and The Mulberry Centre would reach more clients.
- Mulberry Centre leaflets at the beginning of their journey/ early diagnosis is not necessarily the most useful time.