

## Fifth User Group Meeting

The Fifth User Group meeting was held via Zoom on 24<sup>th</sup> November 2021. There were six attendees, which was a slight increase on previous meetings, however there is certainly room for more people to join future meetings.

All but two of the attendees had completed the Questionnaire prior to joining the meeting and, of those two, one had looked at it beforehand but not completed it as she did not live in a "borough" as per question 2 and so thought that she was not eligible to fill in the Questionnaire. The wording of this question should be changed in future to make it clear that anyone can complete the Questionnaire, regardless of where they live.

There were two basic questions for consideration and discussion at the meeting: what workshops should the Mulberry Centre put on over the next year or so, whether repeated ones or suggestions for new areas that could be covered in our ongoing program of workshops, and what colour should we paint the Mulberry Room.

Before the group discussed these questions, they did want to discuss two issues that were important to several members of the group. All of the participants in the meeting were current service users, but only by being members of regular groups offered by the Mulberry Centre, and one was a current volunteer.

The first issue raised was in relation to the Mulberry Centre's plans for continuing with allowing remote access to their services. Whilst there was acknowledgement that it may be helpful for some people to start coming back into the centre, a number of the group felt that, at the very least, we should continue offering zoom access to events in addition to face to face- i.e. a blended approach.

People raised concerns about getting on the bus to come to the centre or where people, often with very good reason, simply could not come into the centre.

One member of the group was disappointed that she had previously indicated a wish to volunteer with the Mulberry Centre but has been told that, as she continues to be a user of the services, she cannot volunteer with the Centre until two years after she has stopped using these services. As she was an active member of one of the clubs, she was not going to stop being "a user" any time soon but felt that she wanted to volunteer and had a skill that she could impart to others but was being prevented by a rule that felt somewhat arbitrary.

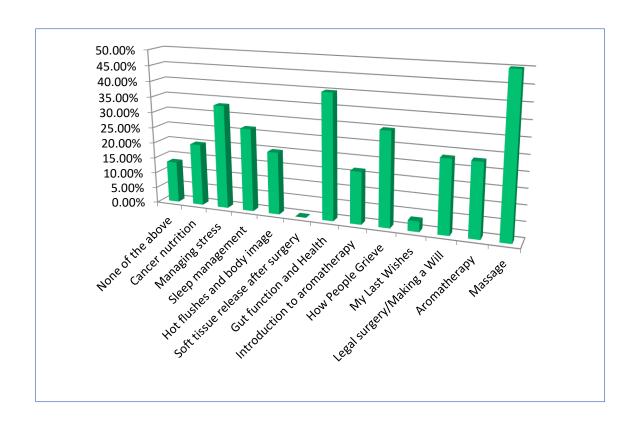
There were 30 replies to the Questionnaire, 22 by women and 8 by men. With this level of responses, it is difficult to draw any firm conclusions.

As in previous exercises there was a good geographical spread, with Hounslow, Richmond and Ealing being the most common boroughs mentioned and Southwark, Surrey and Hillingdon all mentioned at least once.

The age range was similar to previously, with one Respondent in the range 0 to 18 years old, one aged 19-44, 13 aged 45-64, 10 aged 65-74 and 5 aged 75 or over.

Would you be interested in attending a workshop on the following, repeated subjects (tick all that apply):

	Responses	
None of the above	13.33%	4
Cancer nutrition	20.00%	6
Managing stress	33.33%	10
Sleep management	26.67%	8
Hot flushes and body image	20.00%	6
Soft tissue release after surgery	0.00%	0
Gut function and Health	40.00%	12
Introduction to aromatherapy	16.67%	5
How People Grieve	30.00%	9
My Last Wishes	3.33%	1
Legal surgery/Making a Will	23.33%	7
Aromatherapy	23.33%	7
Massage	50.00%	15



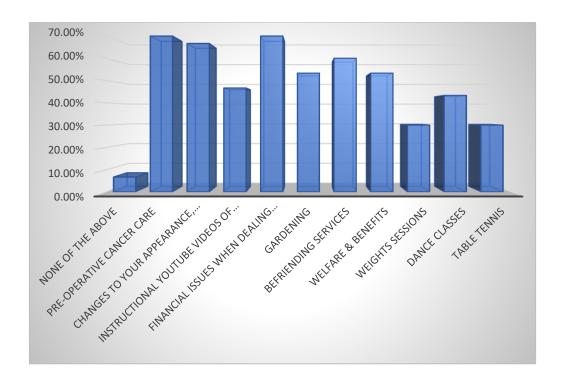
Once again there were a range of ethnicities with most referring to themselves as White British (18 respondents), two people who described themselves as Asian Indian or White/Irish and one each of Asian Pakistani, White/Other, Black African, Black/Other. Three people describe themselves as coming from another ethnic group and one preferred not to say.

Question 5 asked whether Respondents would be interested in attending (or attending again) workshops that had been run previously and the graphic below shows the range of responses, with all except Soft Tissue Release after Surgery and My Last Wishes proving popular. All 30 Respondents answered this question, with four feeling that none of the subjects should be repeated. Multiple selections were allowed

Question 6 asked for views on the type of topics that were appropriate for coverage in a workshop and allowed for multiple selections. Again all 30 respondents answered this question, with two saying that none of the subjects listed were appropriate. The range of answers, and the numbers picking each one as being appropriate, are shown overleaf.

Do you think the following are appropriate services for us to provide (tick all that apply)?

	Responses	
None of the above	6.67%	2
Pre-operative cancer care	70.00%	21
Changes to your appearance, including hair loss, after cancer treatment (for		
men and women)	66.67%	20
Instructional YouTube videos of some of our more unusual classes	46.67%	14
Financial issues when dealing with cancer- getting insurance, paying for		
prescriptions etc.	70.00%	21
Gardening	53.33%	16
Befriending services	60.00%	18
Welfare & Benefits	53.33%	16
Weights sessions	30.00%	9
Dance classes	43.33%	13
Table tennis	30.00%	9



Question 7 provided for open responses about suggestions for any other services we could provide. Eight people answered and there were several suggestions, as given below:

"I would love to see art classes back on your list."

"Acupuncture"

"Stretch class (without too much up and down off the floor which I/some others find difficult. The only reason that I haven't ticked more in question 5 is because either they are not relevant to me (for example Hot Flushes) or I have done the session already. They are all worthwhile and so could be attended more than once. I have ticked all in 6, as while some may not appeal to me, I can see their value for others (for example Gardening)."

"Mr Winkler gives a talk on prostate cancer in November, do any other cancer consultants give talks?"

"I think it would be useful for you to conduct regular surveys where users of the specific services can provide feedback on the individual and companies that are providing that service to your client in an anonymous way."

"Crafting workshop."

"Reiki."

"It would be wonderful if you could bring back the art/painting classes."

Anecdotally, several people have asked whether Mr Winkler will be giving his usual talk, which is now set for 8<sup>th</sup> December, and a couple of men have asked whether we are putting anything

for men's health month, which was November. Due to the men's support group being on hiatus we were not able to offer anything specifically for men in November.

Other suggestions given at the User Group meeting were talks/workshops on healthy eating, sleep and dealing with fatigue, cancer nutrition (all already suggested) and possibly reinstating the coffee mornings. One new suggestion was that we offer a workshop or series of workshops on employment issues for people looking to return to work after a long period out of the job market, for example whilst they have been received cancer treatment. It does seem that this is something that no other local cancer centre offers.

The final question, which everyone answered, asked what colour we should paint the Mulberry Room and gave four options. Nine people picked mulberry or green, eight picked a neutral colour (the examples given were cream, white etc.) and three said "none of the above."

Within the user group several suggestions were given, including the three options above. Then the discussion widened, and it was generally felt that having a feature wall, where three walls are painted a neutral colour (white, cream etc.) and the fourth a strong colour, would look nice, with mulberry or green being preferred. One participant felt that it would look good with stripes and a couple felt that there should be frosted transfers or stencils of plants or butterflies or mulberry trees and place them on the windows facing the alley.

## You said, we did

Since this report was completed, sent to the Trustees and published on the website, we have undertaken a review of the workshops we are offering and will look to incorporate some or all of the suggestions, depending on being able to find volunteers to run the classes.

We also took on board the comments regarding painting the Mulberry Room and will shortly be starting work on repainting the room. As suggested, most of the room will be a neutral colour with one wall, almost certainly the one leading into the garden, painted green, so that it accentuates the view from the room out into the garden.

There will likely be a clash with the orange blinds currently there so these are likely to be replaced in time.

We are also looking at putting frosted transfers or stencils on the windows facing the alley.

Thank you for all the suggestions received. We hope that you will be happy with the changes we put in place.