

Transcript from the roundtable session with clinicians and practitioners, feedback session (ECS0048)

Transcript of feedback session for the roundtable event held with the Health and Social Care Committee Cancer Services Expert Panel and cancer service users, Thursday 27th January 2022.

Jane Dacre: In order to wrap up, and to see what each of the groups were talking about, I want to ask our panel members who were facilitating the groups to just give us a couple of points of feedback on how things went for you. Shall we start with Jeanette?

Jeanette Dickson: I'd like to echo what Jane said about the fact that everybody was very open and very honest and very truthful about all aspects of their care, and I'm very grateful to hear that and for you to take the time to tell us that. There was a great mixture of care; everybody had some aspect of their care that was really great, everybody had a bit that was really bad, and people were very good about telling us what that was. Some of it was about diagnosis, some of it was about treatment and some of it was about support. Some of what we heard was about disjointed care and communication between teams and between hospitals. Some of it was about the need for more information and support, and the need to be signposted towards good and valuable resources- Doctor Google is wonderful, but only when you know it's good and when it's not good. I do like the fact that radiotherapy was very shiny, sorry Jane but I had to say that, I have to say that radiotherapy was very shiny. There was a bit about delay. There was some talk about the language used by medical teams and nursing teams to patients, and when a treatment changes or an option changes having that proper discussion with the patient and making people understand why things have changed. And on that information point, don't mention something causally or in passing that you haven't mentioned before. I think that was a reasonably summary and I hope that the group don't feel that I have misrepresented anything. Thank you.

Jane Dacre: OK, thank you. Nikki, is there anything from your group to add to our conversation.

Nikki Morris: We covered much of the same. I would say that it was absolutely emphasised- quite rightly- that these issues are so important. People are fighting for their lives and it's really important that we get these right. There was a thing around the fact that we've got a group of very articulate, informed people who have all had to advocate for themselves, to a larger and lesser extent, and therefore we need to think about people who can't do that who are coming through the system. There was a bit about COVID and how that's changed things. There was a thing around discrimination and that came up in many of the sections, including access to clinical trials, and that there were presumptions made beforehand. Care plans were a very mixed picture. The need to be holistic and they need to be useful to the patient, so having information that's useful to the patient when the patient's at home was felt to be really important. Innovation was seen as important, but there was also a feeling that getting care right is as important as innovation. There were many examples of where people were benefitting from innovation, but they wanted reassurance that the medication would continue for them from a financial point of view, other people having access to them no matter where they were geographically, and also getting care right throughout the pathway.

Jane Dacre: Thank you, that's really helpful. Next up is Minesh.

Minesh Patel: A lot of similar points were discussed in our group, but there are two additional things that I would pull out. So again there was a big emphasis on quality of care, that tailored care, from

healthcare professionals and also thinking about people's mental health needs, their psychosocial needs, as well as their physical needs. And recognising that that doesn't stop after somebody has reached a point of recovery, so thinking about what comes after that is pretty important. And the second points we discussed, or had thoughts on, was around the charities and that network of support and making sure that that doesn't come at the expense of quality, tailored care from healthcare professionals. But similar points otherwise to what Jeanette and Nikki have both said.

Jane Dacre: Thank you and last, but not least, I'm going to ask Janet to share the key points from her group.

Janet Brown: We also had a lot of the same points, and I would like to thank you all for your honesty within my group. We expressed good things about the care received, and some not so good points. We also similarly said that you needed to be on top of everything and that there was a pressure to be your own advocate. Having read up on things and researched, was felt to have made a definite difference as to what treatment you got which was a pressure. Some of the people in the group said that they got an inconsistency in the care, and not seeing the same person each time, often seeing locums when there were staff shortages, and lots of different nurses, which wasn't helpful. Whereas other people with other cancers maybe didn't experience that. On care plans, we discussed the need to have revised care plans in patients who have long cancers journeys. The main gap was, again, around mental health and psychological support and knowing about things like benefits and funds to travel. There was a lot of mention of delayed diagnosis, particularly in younger patients with cancer, and that needs to be vastly improved. We also looked at the post code lottery of things like trials and how trials have been affected by the pandemic, with people in different parts of the country having to travel beyond what they would do to go in a trial, or to have certain advanced technologies- although some people in the groups had benefitted from these increased things. There was also an expressions that we've done COVID vaccines in two years, and can we now do the same with cancer treatments to move it forward with the same rate of gusto, and to somehow streamline those things going forward.

Jane Dacre: Thank you very much everybody, from all the team here. Now onto the next steps. This meeting has been recorded, and the transcript will come back to you to make sure that you feel comfortable with everything that has been included. The information that you told us today will feed into our evaluation. Once it's written our evaluation report will be given to the select committee, and they will include it in their report, which is sent to the Government. It just remains for me to say thank you to everybody for giving us your time and it's been lovely to meet you all.

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