

Decision aid for people with Hodgkin Lymphoma

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What was the study about?

We were asked by a colleague, Dr Rebecca Shakir, for input into a forthcoming research project. Rebecca is developing a decision aid for people with Hodgkin lymphoma (HL) who will be faced with a choice about whether or not to have mediastinal radiotherapy after a course of chemotherapy. Radiotherapy can reduce the risk of relapse of HL, but it is also associated with significant risks to long-term health, including heart disease and breast cancer. The decision aid will collate information about risk factors associated with late effects, to provide more individualised information about these and support better informed and personalised decision making for patients and their clinicians.

How were patients and/or the public involved?

Rebecca wanted to ensure that her research was informed by patient experience from the outset. The tool will be something that has to be integrated into a care pathway, providing adequate and appropriate information to support informed decision making. For the tool to work, Rebecca needed to gain an understanding of what it is like to have to make that decision, and what sorts of issues are pertinent to patients. She sought the opinion of people who had faced a similar decision in the past, and asked the Oxford Blood Group for input.

After an initial conversation with Rebecca, we agreed that there would be several stages of her research that would benefit from consultation with patients, and that each of these stages would require a different approach: advisory group; wider qualitative consultation; promotion via national patient charities.

As a first step, we agreed that what was needed was an in-depth consultation with an advisory group who could discuss their experience of making a similar decision about radiotherapy. We recruited a group of four patients from the membership of the Oxford Blood Group, all of whom had been treated for HL, and three of whom had also been treated with radiotherapy.

The Advisory Group has met twice to date. At the first meeting, Rebecca outlined the project, but most of the meeting was dedicated to hearing about individual experiences, and sharing thoughts about what information is useful, how it should be presented, how it should be accessed, and ensuring that the information can be tailored to differing information needs. This meeting also resulted in lots of discussion about when that process of decision making begins, and how people might be feeling at that point of their care pathway.

The second meeting was dedicated to discussion about Rebecca's wider patient consultation, which will include interviews with HL patients. The group contributed to discussion about how to recruit and what would be appropriate circumstances to conduct an interview.

What was the impact of involving patients and/or the public?

The input of the group fundamentally changed Rebecca's thoughts about her project. Talking to the group about decision making, it became apparent that this begins much earlier

on than Rebecca anticipated, and that for the project to be a success it would require wider consultation with colleagues in haematology:

“I think the main things I would like to get across is how incredibly helpful having Alison, Adam, Craig and Isabelle on board has been. Their lived experience and insight has offered a perspective that I wouldn’t have been able to get from anywhere else. They’ve added validity to the study, and personal reassurance to me that the work is worthwhile. Their input has been particularly beneficial in ensuring that we engage haematologists early in this research, and in the design of the qualitative study. For the latter, their involvement will ensure that the study is sensitively designed, and asks the pertinent questions to ensure as full an understanding as possible of the factors involved in the decision making process.”

What advice do you have for other researchers considering patient and public involvement activities?

The project has been a great success to date, because it illustrates that thinking about your research from the perspective of patient experience will challenge your thinking in productive ways.

My advice for other researchers would be to not be afraid of talking to patients. For all the talk about methodologies and evidence and guidelines, involvement doesn’t have to be rocket science. Listening to people’s experiences, and thinking about how that might influence your research, is not difficult and can be very enjoyable. I think that researchers are often fearful of PPI: how to do it; what will happen as a result; whether or not patients are going to be “unreasonable” or “unrepresentative.” But PPI at its essence is about consulting people whose perspective might be valuable and challenging – in the same way that you would consult your colleagues. You need people to participate to allow your research to come to fruition: it simply doesn’t make sense to design that research without some idea of your participants’ perspective.

However, it does take time. Please don’t use involvement as a rubber stamp two weeks before a submission deadline. Think strategically about how to involve people, prepare for that process to change and improve your research, and get people involved as *early* as possible.