

Decision aid for people with Hodgkin lymphoma

Case Study

Background

We were asked by a colleague, Dr Rebecca Shakir, for input into a forthcoming research project. Rebecca developed a decision aid for people with Hodgkin lymphoma (HL) who will be faced with a choice about whether 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 would 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.

What we did

Rebecca wanted to ensure that her research was informed by patient experience from the outset. The tool had 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, then, Oxford Blood Group (OBG) for input.

After an initial conversation with Rebecca, the OBG agreed that there were several stages of her research that would benefit from consultation with patients, and each of these stages would require a different approach: advisory group; wider qualitative consultation; promotion via national patient charities. As a first step, the OBG agreed an in-depth consultation was needed with a specially set up advisory group who could discuss their experience of making a similar decision about radiotherapy.

We recruited an advisory group of four patients from the OBG, all of whom had been treated for HL, and three of whom had also been treated with radiotherapy. The advisory group met twice. At the first meeting, Rebecca outlined the project, but most of the meeting was dedicated to hearing about individual experiences, 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 the process of decision making begins, and how people might be feeling at that point of their care pathway. The second meeting was dedicated to a discussion about Rebecca's wider patient consultation, which needed to include interviews with HL patients. The advisory group contributed to a discussion about how to recruit and what would be the best circumstances to conduct an interview.

What difference did it make?

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