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 for input.

After an initial conversation with Rebecca, the Group 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, the Group agreed an in-depth consultation was needed 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 met twice. 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 needed to 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 difference did it make?

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 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.”