

# Foreword

**Cancer52 exists to provide a voice for those organisations that represent people with rare and less common cancers. As such, we have a duty to speak up when we see clear evidence of the inequalities in treatment and care that exist in the field of cancer - inequalities that have a significant impact on both the quality of life and the prognosis of people with rare and less common cancer.**

That is why we commissioned an analysis of the results from the national cancer patient experience survey, focused solely on the experiences of people with rare and less common cancer. We wanted to understand more about where care and cancer services differ between those with the big four cancers and everyone else, as well as understanding more about the impact that has on people with cancer and their families and friends.

We knew that there were likely to be disparities between the experiences of people with different types of cancer. But what surprised and shocked us was just how widespread and how big those differences are.

People with a rare or less common cancer have a poorer experience in almost every aspect of their treatment and care. Some of the differences between tumour groups are large - as much as 30-40% in some areas, with those who have one of the big four cancers having a significantly better experience. Some of the differences in care are also hard to explain - why should you be more than twice as likely to receive information if you have one type of cancer compared to another? Why is it that people with a rare or less common cancer are less likely to see a clinical nurse specialist or be given a choice of treatment? These are big questions to which we need some urgent answers.

People with a rare or less common cancer are disadvantaged at every step of their journey with cancer. From the speed of diagnosis through to treatment and research, people with rare and less common cancers often get a second class service and a poor deal. It is time to level the playing field - by ensuring that people are treated equally, that they get the specialist treatment they need and that they are properly supported to live their lives as fully as possible. It is time for policy makers, health professionals and commissioners to acknowledge the differences in patient experience and to take positive and meaningful steps to address them.

**Jonathan Pearce**  
Chair of Cancer52

