

It's time to rethink how we do cancer research

December 5 2017, by Eileen Parkes



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"[A devastating failure of medical research.](#)" This was the response of one cancer survivor on hearing the news that [over half](#) of European Medical Agency-approved cancer treatments between 2009 and 2013

had no evidence of impact on quality of life or overall survival. As a cancer researcher, my goal above all is to improve patients' lives – the fact we are failing at that struck me deeply.

Understandably, some people living with cancer are angry, feel betrayed, and are questioning why we do the research we do. Have cancer researchers lost sight of what is important in patient care?

Most anti-cancer treatments are first trialled in patients where cancer has already spread beyond a curable reach (the metastatic stage). This is because we feel we can't offer an unproven [treatment](#) when others are available. Drug [trials](#) then tend to move to an earlier stage – take the example of [Herceptin](#), which was developed to combat metastatic disease, but had such a huge impact it quickly moved to the curative early treatment stage.

This approach may seem to make sense, but right now, there is a bottleneck of treatments that have only limited benefit in delaying further spread of cancer in the metastatic stage. For many of these treatments, it is unlikely they will move to the curative stage as the benefits just don't seem good enough.

Given all this, I think we need drastically to rethink our approach.

Patients first

We need to listen to what matters to patients. It is [often argued](#) that research needs space for blue sky thinking, the freedom to explore pathways and structures. But is there still room for that when we are confronted with the realities of increasing cancer rates, poor quality of life, with a 40-year-old with metastatic pancreatic cancer, for whom survival rates have [not improved](#) in the past four decades?

It is over ten years since the landmark [MacMillan Listening Study](#) published its findings from in-depth consultations with groups of cancer patients and carers about their experiences. At that time, as now, the highest priority for patients was learning to live well with cancer. New treatments lagged significantly behind, coming in at number seven in patient's priorities for cancer research. Yet fundraising campaigns still often focus on "finding a cure". The emotional grab of a potential new anti-cancer treatment is seized on by reporters whereas the subtler improvements in quality of life are not. This means that funding for cancer research is skewed towards finding new treatments.

We know early detection of cancer is key to improving survival — research in this area is not easy and doesn't move quickly. Only this year has exclusive funding from Cancer Research UK [been set aside](#) for early detection. But we need to encourage more research in this area.

Another area of chronic underfunding is [biomarker research](#) – many currently available treatments don't benefit everyone, but we don't know how to select which individuals they do benefit. Making our existing treatments better rather than continuing to chase new treatments is often neglected.

We have seen some improvements in this area in recent years, particularly in the inclusion of patients and carers in developing [cancer research](#). In my experience, these are motivated, caring individuals who are, more often than not, supportive of the research we do. But researchers need to be wary that we do not simply invite those whose voices we wish to hear – we must also include those who dissent with our views and challenge our research.

Clinical trials

Clinical trials tend to be designed around what we as researchers want to

know, not always what patients need. I remember an impassioned plea for improved innovative trials from a woman who had lost her husband to melanoma. Even though they didn't end up receiving the standard chemotherapy treatment (the control arm), her fear of her husband being selected for standard chemotherapy was so overwhelming it was now all she could remember. Can we focus our energy on making our trials better, switch up the design?

And of course, the trials are often funded by pharmaceutical companies, who want to show their drug in the best light. Today, many of our patients are too old for clinical trials, with the result that trials don't necessarily reflect the real world of clinical treatment. In addition, several pharmaceutical companies can chase the same target, each hoping theirs is "the best". This can saturate the market with "me too" drugs and stifle real innovation. The pharmaceutical industry has an important role to play, and they often play it well, of driving new treatments forward. But their need to keep an eye on the bottom line can be a distraction from the patient-centred research we need.

So what are some ways forward? We need a shift in research, away from a drug-focused approach to a more patient-focused approach, enshrining quality of life as a key outcome in [clinical trials](#), ensuring we don't accept inferior measurements of clinical benefit to approve a treatment. Most importantly, we need to value [patients](#) and carers as key partners in the progression of research.

By turning to those experiencing [cancer](#) treatment for the next big research questions and listening carefully to their answers, we can ensure those funding and performing [research](#) don't get lost in a science maze, but have a clear view of the patient with every experiment.

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