"People with rare cancers get a raw deal in research and care"

Today, around 850 people in the UK will be diagnosed with cancer. Over half of them will have a cancer of the breast, bowel, prostate or lung. The government says it is committed to all cancer patients having access to the best possible treatment, care and support – but do people with rarer cancers get a raw deal compared with those who have the “big four”?

There have been dramatic improvements in survival times in breast and colon cancer in recent years. Prostate cancer survival has improved, too. However, lung cancer survival has barely improved in the past few decades. So big numbers don’t guarantee a better outcome.

Do certain cancers rule the research roost? Research into breast cancer accounted for 20% of site-specific research funding in 2010, more than the combined expenditure on stomach, oesophagus, pancreas, brain and lung cancer research (National Cancer Research Institute, 2010).

The Cancer Drug Fund gives access to treatments that were unavailable on the NHS and has been hailed as a success for people with rarer cancers. It was set up partly in response to criticisms of the National Institute for Health and Clinical Excellence’s cancer drug appraisal process.

But, if there is a dearth of research into rarer cancers, is it a surprise that NICE has a problem sanctioning new drugs for them?

As for public awareness, certain cancers take centre stage. What cancer do you associate with pink? If you said breast, that is due to the work of charities in raising awareness and supporting those affected by breast cancer. That the biggest site-specific charities are associated with some of the better-outlook cancers shows their invaluable support for cancer survivors.

Better outcomes in rarer cancers need the resources to replicate breast cancer’s model of rapid referral and diagnosis, multidisciplinary care, access to information and support, access to clinical trials and partnership with the voluntary sector.

Good cancer care isn’t just about treatments and outcomes – it’s about people. Everyone living with and beyond cancer should be empowered to manage their condition according to their needs and preferences, regardless of cancer type. Everyone approaching the end of their life should have the support they need to die well.

Directing patients to expert sources of information and support such as the Macmillan Support Line can help to achieve these aims. Web forums such as Macmillan’s online community and the Rarer Cancers Foundation let people share experiences across health authorities and continents.

While a cancer may be rare, the practical, emotional and financial issues are often all too common. Knowing where patients can find professional and peer support can be a first step in ensuring they have the information and care they need.

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Reference

**HIGHLIGHTS**

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**SPOTLIGHT**

When planning IT, consider the human issues

Is it just me or does it seem at least a century since the NHS IT strategy was launched? Since then, all we seem to hear about it involves delays and budget over-runs. But the NHS must bring its IT infrastructure up to date.

In many ways, it matters little to individual health professionals whether that modernisation is part of a huge national initiative or a small local project – its biggest impact on them is that they have to learn new ways of working. So, the success of IT initiatives of any size depends on how skilfully it is introduced.

Our discussion on page 26 looks at the main factors to consider when planning and implementing an IT upgrade. Based on the experience of introducing a relatively small development, its lessons on staff engagement and professional values apply regardless of the scope or type of project.

**When planning IT, consider the human issues**