

Cancer 52 Position Paper on Access to Medicines and Treatments

Introduction

In November 2015 Cancer52 held a meeting with its members to discuss an ever changing landscape in which the scope and impact of the Cancer Drug Fund (CDF), the Accelerated Access Review and NICE process are all under review. The points below summarise some key principles for Cancer52 on which we will base our responses to these consultations.

What we want for people with rare and less common cancers

1. More drugs/treatments for patients with rare & less common cancers being approved by NICE
2. A system rooted in the real world for real people
 - in our experience currently the patient voice is often shoehorned into processes in a tokenistic manner, too late and with little acknowledgement of what is actually happening in the real world
3. Early and genuine patient group involvement
 - that the patient voice be included at the beginning of any process, and that resource and funding be made available within any process to allow that to happen
4. Efficient appraisal process and decision
 - NICE Technology Appraisals (TA) take a long time. The CDF provided a speedier decision-making route and got drugs made available faster
5. Evidence flexibility
 - by definition rare and less common cancers affect smaller populations so there is greater need for flexibility about what patient evidence is accepted /acceptable
 - this must mean a broader definition of QALY (Quality Adjusted Life Year) than used at the present time, or reform of QALY system altogether

6. Drug price discussed early on

- some kind of 'in the region of' type marker needs to be introduced to negotiations early on in the process to ensure time is not wasted completing a Technology Appraisal when an ERG (Evidence Review Groups) QALY/ICER (Incremental Cost Effectiveness Ratio) score is clearly miles away from the usual cost thresholds and what the company claims it is

7. Use of real world data

- the data used on which to base decisions should be as current as possible and based on real world observation rather than just clinical trial data - however this is accommodated - through commissioning through evaluation; or SACT (Systemic Anti-Cancer Therapy Dataset)

8. Patient and clinician engagement system needs to change

- whilst currently patients or patient groups are invited to a NICE committee their input is limited – the TA Committees focus almost wholly on economic and clinical data
- a recent Cancer52 review suggest that the patient voice is better heard at the Scottish Medicine Consortium's PACE (Patient and Clinical Engagement) process and that this process should at least be reviewed by NICE as potential best practice, especially when assessing rare cancers or cancers of unmet need

9. Introduce two new separate entry points into NICE system

- again along lines of Scottish Medical Consortium (SMC) PACE process for End of Life and orphan drugs of which rare and less common cancers is one; and cancers of unmet need is the other

10. Proactive and responsive communications

- from all bodies involved - eg government, Arm's Length Bodies, NHS England - with the patient community