cancer • campaigning • group

Position statement – Value-based pricing
Updated June 2013

Background

The Cancer Campaigning Group (CCG) is a coalition of over 50 cancer charities. One of the six key areas the group campaigns on is access to treatment and services. The CCG therefore feels that it is important to set out the group's position in relation to the introduction of value-based pricing (VBP). This position has been developed by the membership, but does not reflect the views of any one individual charity.

The CCG believes that all cancer patients should have access to the clinically effective medicines their clinicians recommend for them, from the point of diagnosis through to the end of life. We want to see a system of drug pricing and assessment that makes this possible. In order to build a system which works for patients it is essential that patients and patient groups are able to contribute to this development process as well as being part of the implementation of the policy. Unfortunately, we do not feel that the Government has done enough to meaningfully involve us or consult effectively with patients and the public over these changes. Despite being set for introduction in January 2014, few details are available about how VBP will work in practice. This has prevented us from engaging substantively in the debate. It remains unclear what the DH is aiming to achieve from the introduction of a new pricing system and how value will be defined and assessed.

This document sets out the CCG position on a number of key areas and asks specific questions which the Department of Health needs to answer to ensure that any policy change does not restrict access for cancer patients to the treatments their clinicians wish to prescribe.

- **Improving access to medicines –** The CCG believes that if the introduction of value-based pricing does not give cancer patients the same level or improved access to cancer treatments then we may not be able to support its implementation. Although the Pharmaceutical Price Regulation Scheme (PPRS) and National Institute for Health and Clinical Excellence (NICE) technology appraisal systems are not perfect, any new system must be shown to improve access to clinically effective treatments.

- **The pace of change** – As VBP is due to be introduced in less than 8 months, the CCG urges the DH to consider introducing it incrementally to allow for an evidence based assessment of the impact of the changes to take place.

- **The role of NICE & Health technology assessment (HTA) –** The CCG welcomes the Government's confirmation that NICE will be responsible for the full value assessment of medicines under the new system and that VBP will build on NICE's current HTA process. We recognise that any health economic assessment is an art rather than an exact science and therefore developing the methodology for any HTA process is likely to be iterative and develop over time. We call on NICE to consult publically on the changes it will need to make to its current HTA process to implement VBP, paying particular attention to the role of patient groups in the appraisal process, as well as any on-going assessment of medicines in clinical practice. More clarity around the types of information that will be accepted from patient groups in the appraisal process would help ensure patient views are meaningfully engaged. We also urge NICE to ensure that the additional assessments under VBP do not delay new medicines being made available on the NHS.

The CCG would like to see a more sophisticated system in valuing quality of life issues, beyond clinical efficacy/benefit, which more systematically takes into account issues that are currently outside the perspective of NICE. Issues we would like to see included are:

- Side effects of drugs and their impact on quality of life
- Fatigue
- Emotional wellbeing over and above anxiety and depression which are currently included, but are too narrow a definition to encompass a person's full circumstances
- Mode of administration and patient's preferences (i.e. being able to take a new treatment orally rather than intravenously)

- **End of life criteria –** We support the inclusion for weighting drugs that give people nearing the end of their lives precious extra time. The end of life criteria currently utilised was brought into the system in 2008 due to a demonstrable need and has led to the approval of some treatments which would have otherwise not been made available. Losing these criteria would mean drugs we know people value will not be made available.

  We understand that two pieces of recent research looking at public perceptions on spending on end of life drugs have shown contradictory results in terms of whether or not the public support such funding.

  We are also concerned about the proposal to only prioritise 'end of life' drugs that treat people who are not already near average life expectancy. This would disadvantage older people and does not allow the flexibility to account for people who would, if treated, live well beyond an average life expectancy.

- **Wider societal benefits -** We have serious concerns about the equality issues of the proposals to weight drugs for their impact on wider societal benefits. The DH's assessments show that weighting drugs in this way will mean that older people (mainly those between the ages of 70 and 79), children and men will be disproportionally disadvantaged in terms of health spend.

  The focus on getting people back to work does not account for the past contributions of older people, who would have 'paid into the system' for their working lives, or the future contributions of young people. Additionally, disinvesting in health care for older people could have serious consequences on the social care system, especially considering the ageing population. We have recently seen a welcome focus on ensuring that clinical trials in the UK include older people. Restricting the availability of treatments for older people would not only undermine this work, but could, in the longer term deter pharmaceutical companies in the UK away from investing in developing treatments which affect people in later life.

  We are also concerned that the DH's approach would inappropriately disadvantage men, according to calculations presented at the DH's equalities workshop in February. Women already live longer than men and men are more likely to die from cancer[1], so it would seem doubly unfair to introduce a system which actively disinvests in their treatment and care.

[1] http://publications.cancerresearchuk.org/cancertype/mens/inequalities-in-men.html

- **Therapeutic innovation -** The DH stated in their 2010 consultation that VBP will also prioritise drugs which represent greater scientific breakthroughs in order to incentivise pharmaceutical companies. It would be helpful to understand how the DH will measure and reward innovation, whilst also valuing quality of life and other improvements arising from incremental innovations.

- **Uptake of new medicines –** The CCG welcomes the Government's assurance that NHS organisations will continue to be legally required to fund treatments recommended by NICE in its technology appraisal guidance. However, we already know that despite having this funding signal in place there is variation in the uptake of new medicines across the country. We would urge the Government to consider what else can be done to ensure cancer treatments are made available equitably across the country.

- **Impact on rarer cancers –** Consideration will need to be given to how the system will apply to treatments for rarer cancers, where small patient population sizes can mean that robust evidence is less readily available. Making sure that patients with rarer cancers are not put at a disadvantage through a value-based pricing system is critical to CCG members.

Questions to the Department of Health

The CCG urges the Department of Health to answers the following key questions about value-based pricing to give patient groups the information they need to fully engage in this debate.

- How will value-based pricing improve access to treatments for cancer patients?
- How is the DH planning to measure the value of new medicines and what assessment have they made of the impact will this have on access, in comparison to the existing system?
- What assessment has the DH made of how a move to VBP will affect the time it takes to make recommendations on use of treatments in the NHS?
- How will the proposed weightings for wider societal benefits, therapeutic innovation and burden of illness be determined and incorporated into VBP assessments?
- What will happen to treatments currently funded through the Cancer Drugs Fund when it ends in March 2014? We know that individual patients will be able to continue to access treatments through the fund as long as they are clinically effective, but we have not yet heard what will happen to those treatments already on the market but not approved by NICE.
- How will patients and patient groups be formally involved in the implementation of VBP?
- Will there be an opportunity for patient input in the on-going (re)assessment of the value of, and consequently levels of access to, medicines in clinical practice?
- How will the impact of VBP be measured as it is unlikely to have a material effect for a considerable time after it is implemented?
- Will the Department of Health commit to engaging with the CCG and other patient groups through the development of the remainder of VBP policy?

Contact details

For further information please contact the Cancer Campaigning Group secretariat on ccg@mhpc.com.