Value-Based Pricing:
Getting it right for people with cancer

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The facilitators

Carole Jones
Head of Pharmaceutical Advisory at Matrix

Evelina Bertranou
Principal Economist at Matrix

Alexis Wieroniey
Campaigns Manager at PCUK
Agenda

- Facts about cancer in the UK
- The “new” National Health Service
- Introduction to Value-based Pricing (VBP)
- Context of the change
- Research approach and findings
- Key policy recommendations
- What the research has achieved
- Group exercise

Facts about cancer in the UK

- More than 1 in 3 people in the UK will develop some form of cancer during their lifetime
- Around 324,579 people were diagnosed with cancer in 2010 in the UK
- There were 157,275 cancer related deaths
- 51.2% survive five or more years
- Breast, lung, bowel and prostate cancers together account for over half of all new cancers each year
- More than three out of five cancers are diagnosed in people aged 65 and over

Source: Cancer Research UK
Facts about cancer in the UK

• In 2008/09 NHS expenditure on cancer services was approximately £6.3 billion
• However survival rates from cancer in the UK are significantly lower than the rest of Europe
• A report in 2009 showed that an estimated 10,000 deaths a year could be prevented if England’s one-year survival rates were as good as the best in Europe
• There remain wide, unexplained variations in the performance of cancer services, patient experience and in the types of treatment available across the country

Source: Cancer Research UK and EUROCARE-4 study
The “new” National Health Service

New funding arrangements

The “new” National Health Service

Regulating and monitoring the quality of services
Introduction to VBP

• From January 2014, it is proposed that all new branded drugs will be subject to a revised process of drug pricing known as Value-based Pricing (VBP)
• VBP is intended to ensure prices reflect the value a drug provides to patients and the NHS. This new process also aims to incentivise drug companies to invest in innovative products that address unmet medical needs
• These changes represent a significant opportunity to improve problems with the current system:
  • the NHS adopts new cancer drugs relatively slowly compared to other countries;
  • there are variations in access to medicines across the UK

However, given the potential magnitude of the impact that VBP will have, many are concerned that the Department of Health has not done enough to:
• engage with patients and the public about the changes
• provide additional details defining each element of VBP and how individual drugs will be assessed and the mechanism for implementing VBP
Context of the change

- VBP is intended to replace the Pharmaceutical Price Regulation Scheme (PPRS) for new medicines

- The PPRS is a voluntary scheme operated between the Government (represented by the Department of Health [DH]) and the pharmaceutical industry (represented by the Association of the British Pharmaceutical Industry [ABPI]) which is formally renegotiated on a regular basis

- The PPRS is currently used to set drug prices by allowing companies to earn profits from branded drugs within a maximum limit

VBP framework (as of June 2012)
Context of the change

- Under VBP the price a drug company can charge will instead be determined by:
  - the ‘burden of disease’: the extent to which the drug treats diseases which have the greatest physical and emotional impact on patients;
  - the degree of innovation provided in terms of therapeutic benefits (over and above current treatment options) to patients; and
  - the contribution to wider societal benefits – such as the benefits to carers

- This would go much further than the current methods of measuring benefits. NICE and the SMC currently only consider the effect of the drug on the patient in terms of additional years of life and/or improvement in the quality of life.

Context of the change

- Until now, there has been no formal relationship between the PPRS and appraisal bodies such as the National Institute for Health & Care Excellence, the Scottish Medicines Consortium or the All Wales Medicines Strategy Group.

- A pharmaceutical company can set a competitive price for a new drug within the rules of PPRS whilst at the same time the appraisal bodies can deem the drug to be too expensive to receive NHS funding.

- Negotiations between the DoH and ABPI on the framework for VBP for new drugs started in October 2012. The PPRS will continue to cover medicines that are already on the market.
About the research

- Prostate Cancer UK, working in partnership with 22 other leading UK cancer charities commissioned research to ensure the views of people affected by cancer are put at the heart of the Government’s new VBP policy.

- Matrix lead the UK-wide research for this project over a period of 6 weeks from mid-August 2012 to the end of September 2012.

Research approach

- Evidence Review
- Deliberative event (N= 22 cancer charities)
- Qualitative enquiries with people affected by cancer (N = 31)
- Survey of people affected by cancer (N = 412)

Key Messages regarding VBP from the perspective of people affected by cancer.
Recruitment of patients

- Prostate Cancer UK recruited participants for the survey and the qualitative enquiries using the following methods:
  - asked members of the Cancer Campaigning Group and Cancer 52 to publicise the research across their networks;
  - sent the details of the research activities to PCUK’s volunteer network (approximately 1,200 people) and campaign supporters (approximately 800 people);
  - advertised the research activities on the home page of PCUK’s website and created a dedicated web page on the project to provide further information;
  - tweeted information - with over 100 re-tweets from other charities, organisations, and politicians;
  - posted information on Facebook about the research (reaching over 6000 people, with almost 300 engaged users); and
  - sent ‘Letters to the Editor’ about the survey to regional titles across the UK.

“The shift to value-based pricing of new drugs is an opportunity to move away from a slow and unwieldy system that focuses too much on price to one that better reflects the value medicines bring to patients, promotes innovation and gives people timely access to vital medicines based on their individual need”

Owen Sharp
Chief Executive
Prostate Cancer UK
Key Policy Recommendations

- Reform of the current system must lead to significant improvements in access to effective drugs
- People affected by cancer must have an equal role in the design of the VBP system
- A new method for involving people affected by cancer in the process of appraising individual drugs should be introduced
- Drugs that improve people's quality of life should be given the greatest value
- The wider societal benefits of drugs should be carefully considered

Key themes

The research findings have been organised according to three thematic areas:

- Patient Voice
- Value
- Access
Patient Voice

‘Don’t ask for us [people affected by cancer] to be involved and then fail to listen to what we have to say.’

- The Government has not done enough to engage people affected by cancer and other patient groups in the development of value-based pricing
- People of all ages affected by cancer want equal status to the pharmaceutical industry and the Government in the design of the VBP system
- Charities representing people affected by cancer should have a key role in ensuring their voices are heard at each stage of the development of VBP

Patient Voice

‘I expressed my opinion and felt I was there so they [NICE] could say [I’ve] been on the panel and then that voice is completely ignored.’

- General consensus that the current processes for assessing the value of individual drugs do not enable the views of patients to be heard sufficiently
- A new process is needed to ensure that the views of people affected by cancer can be considered in a meaningful way alongside evidence on the clinical and cost effectiveness of drugs
- People affected by cancer who contributed to our research felt that this could best be done through a new formal ‘collective’ body or group comprised of patient representatives who are provided with appropriate information and training to participate in appraisals of individual drugs
Value

‘Every life is exceptional.... every life is a life that is valuable.’

• ‘Value’ is a complex issue for people affected by cancer and it was felt that it would be evaluated differently based on a range of circumstances
• People affected by cancer support a broadening of the definition of ‘value’ when it comes to assessing medicines
• Three dimensions of value were considered in the research:
  • The value of improvements to the quality of life of an individual affected by cancer;
  • The value of innovation;
  • Value to the wider society

Quality of life

‘Your well-being, how happy you are...it’s just as important as the physical ones.’

• Currently there are five elements of ‘quality of life improvements’ a drug is assessed against to determine its value in relation to an individual’s relative state of health:
  • Level of mobility;
  • Ability to independently self-care;
  • Ability to engage effectively in usual activities;
  • Level of pain/discomfort; and
  • Level of anxiety/depression
• Those people affected by cancer found it difficult to place elements in a hierarchy, however pain was given the highest priority
Quality of life

- All participants felt that there are additional factors which should be included in the assessment of the impact of a drug on quality of life:
  - Side Effects
  - Fatigue
  - Emotional well-being

The Value of Innovation

- Innovation is a complex concept for people affected by cancer to define for the purposes of VBP. In addition to valuing drugs that are better than existing treatments, a value should be given to:
  - innovative drugs which would provide treatment for a disease where no current treatment exists;
  - improvements in modes of administration and treatment convenience;
  - drugs which make a small but valuable difference to the quality of people’s lives and
  - drugs which can help make people well enough to expand their treatment options in the future
Wider societal benefits

‘We don’t value older people in society and anything that weights employment above other things would be discriminatory.’

• Most important measure of ‘social value’ was the benefit a drug can have to carers and family members of the person who has cancer
• Then the ability of a person with cancer to work, pay their taxes and financially look after their dependents
• However, concerns were raised about the possible consequences of including returning people to employment as a primary societal benefit as it could potentially disadvantage many people affected by cancer

Access

Equitable access to approved drugs

‘I spent days and days filling in forms...patients should not have to fight bureaucracy as well as the cancer.’

Equitable access to clinical drug trials

‘When I was ill I was always interested in [clinical drug trials] but no-one seemed to know anything about them and there was no information to hand.’

Timely process for the approval of drugs

‘You’re waiting for longer term evidence; in the meantime, people are dying.’
Access

‘I spent days and days filling in forms…patients should not have to fight bureaucracy as well as the cancer.’

Equitable access to approved drugs

• At present there is considerable variation within Scotland and across England in terms of which approved drugs are being funded by NHS commissioners and this has contributed to a post code lottery
• The process required to challenge funding decisions was reported as ‘difficult’ and ‘stressful’
• In some cases, where treatment had been refused by the NHS, patients had to turn to their private insurers and the Cancer Drug Fund to seek access to drugs which provided them with quality and extension of life beyond their original prognosis

Access

‘When I was ill I was always interested in [clinical drug trials] but no-one seemed to know anything about them and there was no information to hand.’

Equitable access to clinical drug trials

• Those affected by cancer would value the opportunity to be involved in clinical drug trials so they can contribute to the evidence base and have the opportunity to try a new drug which might provide effective treatment
• Although information on how to get involved in clinical trials is available, it is not getting through to people affected by cancer in a consistent manner
Access

‘You’re waiting for longer term evidence; in the meantime, people are dying.’

Timely process for the approval of drugs

• Where UK data is limited international data should be used to inform decisions regarding the approval of drugs;
• A streamlined system needs to be in place to ‘fast track’ the assessment of particular drugs;
• Less rigorous long term impact assessments must be introduced for end of life drugs;
• Access to cancer drugs should be fast-tracked once cost-effectiveness has been proven

What has the Prostate Cancer UK research achieved?

• The report received wide-spread media coverage
• The charities who supported the report have agreed to join a working group to explore how we can strengthen the patient voice in the drug appraisal process
• We presented the report to the Association of the British Pharmaceutical Industry (ABPI)
• We have been invited to workshops which discuss aspects of VBP such as “equality issues”
What has the Prostate Cancer UK research achieved?

• We secured one meeting with DoH officials in April
• The research report has been quoted in follow on publications which have progressed many of the themes, e.g. “Value-based pricing: the wrong medicine for the nation?” by Barbara Arzymanow, Julia Manning, May 2013

Group Discussion

• What are the key barriers to involving patients in the drug appraisal process? What steps can be taken to overcome these barriers?
• What information should drug appraisal bodies seek from patient representatives? How robust should their contributions be? Is anecdotal evidence enough to help the decision making process?
• Should the patient voice have the same weight as evidence about a drug’s clinical and cost effectiveness? If so, how can the patient voice be strengthened to make this a reality? If not, what is the best way to involve patients?
• How can we ensure the patient voice is representative of the views of other patients? Could a ‘collective body’ of patients, which supports individual patients to become involved in appraisals help achieve this?
• How do you engage with the relevant authorities to ensure that the views of patients are at the heart of drug treatment debates and innovations?
Thank you for your participation

Please contact carole.jones@matrixknowledge.com for a copy of the PCUK report or for further information about the services which Matrix offers.