



RETHINKING CANCER: REALISING THE POTENTIAL FOR IMPROVED SURVIVAL

WEDNESDAY 9TH DECEMBER

With more and more people now living with, and beyond, cancer Bristol-Myers Squibb (BMS) brought together Parliamentarians, policy experts and patient groups for a roundtable discussion to consider the implications for patients, employers, the economy and society at large.

The event followed a recent report supported by BMS and prepared by the International Longevity Centre – UK (ILC-UK). In *Rethinking Cancer* the ILC-UK presented findings on how outcomes for cancer patients can be improved, exploring the challenges facing those living with and beyond cancer at home and in the workplace. The discussion was chaired by Jo Churchill MP, Vice-Chair of the All-Party Parliamentary Group (APPG) on Cancer. It also featured two specialist speakers: Brian Beach, Research Fellow at the ILC-UK; and Juliet Bouverie, Executive Director of Services and Influencing at Macmillan Cancer Support.

Jo Churchill MP opened the discussion by highlighting progress in the effectiveness of cancer treatment during the last decade in the UK. Despite the Government setting clearer strategies for improvement, policy makers, she said, need to prioritise improvements at ‘ground level’ – both at work and at home – where cancer can leave people unprepared for the challenges they will face after diagnosis. Cancer doesn’t always mean a ‘full stop’, she said, and she praised the ILC-UK report for providing a new perspective on this important issue.

Presenting the key findings of the ILC-UK’s report, **Brian Beach** explained that his team’s research focused on the economic and wider societal impact of cancer, two sensitive issues that have been overlooked too often but which are becoming more relevant as incidence and survival rates increase. The report’s findings reflect these themes, quantifying the contributions that cancer survivors make at work and in the domestic setting.

The report’s starting point was to estimate the financial impact of cancer. As the cause of death for 54,000 people in the UK aged under 70 each year, cancer has a profound impact on the economy; annually this amounts to a loss of £585 million in economic contributions. With around 500,000 working-aged people expected to die from cancer over the next ten years, the total cost to the UK economy could run to tens of billions of pounds.

A key recommendation from the report is that this economic cost could be reduced significantly by bringing the UK’s survival rates into line with those in Europe. Brian said that the gap in cancer survival rates between England and the European average has remained at around 10% for the last two decades. The additional survivors generated by just a single year of higher survival rates would contribute £1.2 billion to the UK economy across the rest of their lifetimes.

However, assessing cancer's economic impact alone is not sufficient. Equal consideration needs to be given to the contributions that survivors make at home through informal caring as well as domestic and voluntary work. To conclude, Brian said that it is important to remember that cancer's impact can be *underestimated* as it is impossible to fully quantify the emotional effect it has on their family, friends and local community.

Speaking on behalf of Macmillan **Juliet Bouverie** focused specifically on the issue of work and cancer, highlighting the main barriers that survivors face when returning to employment. Pointing to Macmillan research that shows work remains a priority for 80% of cancer survivors, she highlighted the following challenges:

1. *Public awareness is a barrier to returning to employment both for cancer survivors and the wider public.* This problem lies in the lack of understanding of cancer as a disability. Macmillan is working to rectify this through a public awareness campaign – “*Cancer isn't fair but your boss has to be*” – and by issuing a Working Through Cancer Toolkit.
2. *Lack of understanding and knowledge of employers.* Macmillan is working to educate trade bodies and human resources departments on what can work best for cancer survivors.
3. *The NHS needs a cultural change.* Health and social care professionals need to be trained to have a better understanding of employment issues. Alongside this, the health service should recognise ‘returning to work’ as a key outcome indicator.

Juliet also expressed concern at changes to the benefit system which could leave survivors £125 a month worse off, potentially forcing them back into employment before they are ready to return, something which could prove damaging to their health. Rounding off, she referenced Macmillan's endorsement of the Cancer Strategy for England, specifically its call for a greater allocation of funding to support cancer survivors.

After the opening speeches Jo Churchill invited comments from around the table.

Representing BMS, **Johanna Mercier** said that issues around survival are starting to be discussed more frequently, even in the most traditionally hard-to-treat cancers, thanks to advances in treatment. BMS, she said, has been a pioneer in the field of ‘Immuno-Oncology’ - a breakthrough treatment area which is having a positive impact on survival rates and may consequently have a profound effect on the way that we view and manage cancer at home and at work in the longer term. More emphasis must be placed on improving access to new medicines and technologies as part of the whole continuum of care if the UK is to close the survival gap with Europe, she said.

Barbara Wilson, Founder of Working with Cancer, an organisation that helps people back into work, said that recovering from cancer is not like overcoming flu; it takes time and individuals and employers underestimate this. Often it takes well over a year to get back to ‘normal’ and this takes survivors by surprise, mainly because nobody talks to them about it. Communication is often a major barrier for people returning to work and Barbara pointed out that it is part of the British psyche is to say “I'm fine” rather than seeking help that may be available. She added that employers also need to re-commit to employees that are in need of help and that it is slightly odd that there isn't currently a greater emphasis on this after companies have invested significantly in training and staff development.

Pauline Latham MP provided an example of a constituent's struggle with her employer which was attempting to make her redundant through constructive dismissal. They did not have any understanding, she said, of what it meant for their employee to have cancer. On this point, **Liz Egan**, representing Macmillan, explained that while small businesses do sometimes struggle to keep ill staff on board they more often resemble a family and will be more supportive of an employee due to their proximity. Liz also said that it is often those working for larger organisations that have greatest difficulty, due to corporate and public sector processes.

Jim Shannon MP made the observation that cancer treatments had progressed significantly in recent years and highlighted that survival rates were now close to 50%, and therefore cancer “doesn’t have to mean the end”. Jim said that his greatest concern was around Employment and Support Allowance payments to constituents and managing the transition from work, to having cancer and being on benefits, and then back to work again.

Emlyn Samuel, Senior Policy Manager at Cancer Research UK, said that the UK needs to look abroad, as well as internally, to improve. He said that the recommendations from the Cancer Strategy for England should be implemented as a priority. Emlyn argued that the issue of early diagnosis also has a massive impact on cancer outcomes, citing the South West of England as a particularly well-performing region. However, he said that this can only be effective if patients can access the best treatment; early diagnosis is no use without it. **Jane Lyons**, Chief Executive of Cancer 52, suggested that work can be done to break down the ILC-UK’s report by gender as domestic work was undertaken primarily by females. Jo Churchill agreed there could be scope to look at this across a range of diseases.

Wider practical challenges facing cancer survivors, such as commuting, were also considered during the course of the discussion.

Pauline Latham MP gave the particular example of a constituent who suffered from a brain tumour but was not legally able to drive and therefore get into work. **Liz Egan** explained that the Government’s ‘Access to Work’ scheme is designed to help those with a disability to travel to their place of employment.

However, **Sarah Lindsell**, Chief Executive of the Brain Tumour Trust, said that this scheme neglects those suffering with brain tumours which do not qualify as a disability. **Jo Churchill MP** connected these points with the arguments illustrated earlier about communication and public awareness and added that the lack of knowledge of ‘Access to Work’ demonstrated this.

Mark Durkan MP remarked on the importance of having this discussion about the wider impact of cancer and agreed with comments made by earlier contributors about the need to ensure that non-health related outcomes are used as key indicators within the NHS. He also welcomed the ILC-UK report’s findings because, in his opinion, the focus is all too often on the financial cost shouldered by the NHS when it treats patients, rather than looking at the value that survivors can contribute to society. Mark also expressed support for the recommendations of the Independent Cancer Taskforce and the emphasis put on effective cancer pathways. He also made reference to the parliamentary passage of the Welfare Reform Bill, where many of his colleagues in the House of Commons made the case for bespoke cancer welfare support. He suggested that there may be something more sophisticated and articulate in welfare support that could be developed, rather than a crude measure of working or not working.

Jo Churchill MP thanked attendees and brought the discussion to a close. Concluding, she said that the UK must catch-up with other European countries and increase survival rates. This, she said, can be achieved by increasing patient access to the most innovative treatment options and by fostering a better understanding of cancer as a long term condition. This means recognising the positive contributions of cancer sufferers at home and at work, as well as making the workplace more receptive to those returning to it after their illness.

Rethinking Cancer: Key findings from the ILC-UK's report

The Rethinking Cancer report considers the wider cost of cancer alongside the 160,000 deaths it causes each year.

- In a single year over 50,000 people of working age lose their lives to the disease and in 2014 these people could have contributed £585 million to the UK economy.
- The 1.8 million people living with and beyond cancer in the UK contribute approximately £6.9 billion to the UK economy each year through paid employment.
- The wider societal contributions of cancer survivors are significant and have been valued at £15.2 billion per year. This includes providing hours of informal care to others, along with voluntary and domestic work.
- 'Rethinking Cancer' outlines the changes required to increase survivorship and better support those living with and beyond cancer, their employers, families, friends and relatives.
- The report also demonstrates that, if employment rates for people with cancer were the same as for the rest of the population, survivors would contribute an additional £4 billion to the UK economy each year.

Macmillan Cancer Support's research on the challenge facing cancer sufferers reveals:

- 350,000 experience fatigue that can last for weeks, months, and even years.
- 300,000 experience issues relating to sexual performance.
- 200,000 experience continence problems.
- 83% of people face financial problems and insecurity.

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