

Scottish Parliament Cross Party Group on Cancer

Wednesday 7th December 2016, 17.30-19.00

1) Welcome

Jenny Marra (JM) opened the meeting by paying tribute to Alex Johnstone MSP who passed away on 7th December. JM then welcomed all attendees and speakers to the meeting.

2) Minutes of Last Meeting

The minutes from the previous Cross Party Group on Cancer meeting on 28th September were approved by the group without amendments.

3) The Chair welcomed Dr Brian Montgomery (BM), Chair of the Independent Review of Access to New Medicines to speak about the review.

BM began by establishing the report of the review is yet to be published. BM then discussed the background of the review, stating that it was a review of the changes that were made to the Scottish Medicines Consortium (SMC) decisions process in 2014 that aimed to improve access to orphan, ultra-orphan and end-of-life drugs. He emphasised that this review was not solely on a cancer agenda and the review looked at the approvals of drugs for a wide range of areas.

BM stated that the review was largely based on an engagement process, rather than purely on the numbers of approvals before and after the changes. He discussed the audiences that were engaged including patients, clinicians, boards, and the pharmaceutical industry.

In terms of themes, the review aimed to look at whether access to new medicines is: equitable, safe, clinically effective, cost effective, affordable and transparent. He highlighted the specific pressures on affordability as NHS budgets are a finite resource and the pressures on that resource are only increasing.

BM noted that the timing of the review's commissioning coincided with the publishing of the Chief Medical Officer's Realistic Medicine report. He stated that the realistic medicine report was written as a challenge to the medical profession around its engagement with patients to create a more collaborative dynamic between doctors and patients. He also stated that the report highlighted the issue of the overdiagnosis and overtreatment of patients.

BM then outlined some of the figures around access to medicines before and after the changes in the SMC process. He noted that access to orphan and end-of-life cancer drugs had risen significantly since the changes. The only area where the approval rate by the SMC has fallen is in what are called true ultra-orphan drugs, which are high cost drugs which are used for very rare conditions. BM also stated that the numbers of drugs that have been assessed each year by the SMC has risen significantly since the changes to the approval process.

The new system of Individual Patient Treatment Requests (IPTR) was then discussed. BM stated that they were designed to give patients access to treatments where special circumstances exist. BM stated that it was thought that the increase in SMC approved drugs would cause the number of IPTRs to fall. This has not been the case, he pointed out, noting that this could be due to an increase in the drugs that are available. He also noted that in 2012/13, before the changes in the SMC process, around 50 IPTRs were not approved and 50 were approved. In 2014/15, 50 were not approved but 550 were approved.

BM then spoke about the challenges that the drug approval process is facing. The first of these was the definitions of orphan, ultra-orphan and end-of-life drugs, as drugs become increasingly specific due to the influence of genomics. He stated that data is an issue as much of the data that exists measures the systems (the administration of drugs) rather than the medicines (the outcomes from the use of those drugs). He also noted the need to weigh up the access to drugs with the benefit they provide – and for effectiveness measures to include input from patients and families about the impact of drugs on quality of life. The PACE system was also discussed by BM who stated that, while it is working, more needs to be done to clarify to patients how their input impacted decisions.

BM then discussed the need for a new relationship between the SMC and the pharmaceutical industry. He stated there was the need to move away from the adversarial nature of the current relationship to a more collaborative one where the SMC are involved earlier in the drug development process. The New Medicines Fund was also addressed, BM noted that the Fund started as a temporary funding stream to allow HBs not to refuse drugs on the basis of affordability. He stated that it has proved to be very useful but warned that the money is time limited and that the system will see a rise in demands, as has been seen in the English Cancer Drugs Fund. BM also stated that there is the need to look at the possibility for looking at the possibility of a Scottish Model of Value for the worth of drugs but stated that the review could not be used as the populations it looked at were not typical enough of the wider Scottish population. Finally he pointed to the need for the system to be sustainably and to the difficult choices that are ahead. BM said that no one group can make these choices and that discussions between patients doctors, health boards and politicians are needed to collaboratively make these choices.

BM concluded his talk by highlighting the model he used while to effectively run the NHS Fife Health Board. He discussed the need to balance quality of care with value and sustainability and funding preventative measures which improve the health the population. He stated that this was pertinent to the NHS currently and noted that the routes to gain further funding for cancer treatments are to: divert money from within the NHS, to divert money from other areas of the public sector, or to use the Government's new powers over tax.

4) Questions to BM

JM thanked BM for his presentation before questions were taken from the group. On the subject of cancer drugs not benefitting from the IPTR system when compared to other drug types, BM stated that the gap is closing but that the increasing cost of some drugs is making approvals difficult in some cases. On the subject of a letter from the Chief Medical and Pharmaceutical Officers stating that all requests for drugs should be approved if clinically useful during the SMC change process, BM stated that the letter has changed expectations of doctors away from the IPTR process being for exceptional circumstances to an expectation that all applications be approved. When asked who makes the decisions in the drug approvals process, BM stated that the first decision is always made by the SMC, an independent organisation, and that IPTR requests are deliberated by Health Boards. BM also agreed with a question that said that increasing workforce costs should also be considered on top of the increasing costs of drugs. On a question on the fact whether prevention takes away from the quality of care or reduces stress on the care givers, BM stated that prevention would save money but it is often moved off the agenda by more immediately pressing matters.

5) JM then welcomed Kelly Shiell-Davis (KS-D), Senior Evidence Officer, Macmillan Cancer Support and Mary Wells (MW), Professor of Cancer Nursing Research and Practice, University of Stirling to discuss the results of the Cancer Patient Experience Survey.

KS-D talked first, discussing the figures produced by the survey. She began by introducing the Scottish Government and Macmillan funded survey that looked at the individual experience of the care and treatment a person has received, starting with their positive or negative experiences of being diagnosed, through their experience of the entire cancer pathway. She stated that the survey is a tool which can provide health and social care professionals, policymakers, people affected by cancer, NHS staff, charities and academic researchers alike a rich insight into what patients think about their experiences of care.

The survey was sent to almost 8000 patients who had received a cancer diagnosis between July 2013 and March 2014 and had a hospital day or inpatient stay between January and September 2014. The survey had a response rate of 61%.

KS-D noted that 11 tumour types represented, as well as those classified as 'other' or 'unknown.' The most common were breast, colorectal, prostate, haematological and gynaecological cancers.

The positive findings were then noted with 94% of respondents highly positive of their care, 84% given the name of a clinical nurse specialist (CNS) and 87% saying that doctors and nurses always treated them with respect and dignity. She then discussed some of the areas with mixed response such as: diagnosis, where 86% of patients were told that they had cancer sensitively, however 28% were not allowed to have someone present, 25% did not fully understand the explanation given and 1 in 3 were not given written information about their cancer; Information, where positive comments about the information received fell following operations, chemotherapy and radiotherapy.

KS-D concluded by discussing where improvements were needed. Firstly, the need for more patients to receive a care plan which are shown to lead to more positive experience of the overall care, more care and support from health and social care services and better information about financial benefits help. The importance of CNS specialist was also noted with an improved experience of information around: support or self-help groups, the day to day impacts of cancer and financial issues when a CNS was available.

MW then discussed the qualitative results of the survey. She began by noting the importance of the patient experience, pointing to research which shows links between a better patient experience and improved outcomes from treatment. She then stated that the Scottish Cancer Patient Experience Survey was designed to have more qualitative feedback than in the surveys undertaken in other nations, with 7 detailed questions asked, one for each section of the survey.

The responses were coded into different key themes and the most common themes amongst the positive responses were around support, information, clinical care, efficiency and trust. MW then noted that the negative comments fell into two wider categories: confidence (that contained problems with care, difficulty getting into the system and inconsistent information) and not feeling that needs were met (with included poor communication, a lack of involvement & choice and a lack of emotional support & responsiveness).

The demographics of the positive and negative responses were then discussed. The most positive were men, those who are retired and those with lung cancer. Younger patients, full-time workers, those who are unemployed and those with less common cancer types were found to have given the most negative responses.

MW then discussed the key messages from the survey. These messages included: that confidence in the system can be shaken at any stage of care; the lead up to diagnosis and the period following treatment were most in need of work; there is a need for a more patient orientated view, that

relationships are crucial to patient happiness; that patients when staff are informed and work together effectively; and that timely assessment is needed throughout care. She then concluded by discussing the need for a multi-agency system with greater connectedness between different areas of the NHS, noting that patients are not aware of the divisions between these areas, and by discussing research into how person-centred care can be promoted.

6) Questions to KS-D, MW and Dr Maggie Cunningham (MC), Senior Research Fellow, University of Stirling.

JM thanked KS-D and MW for their presentations before questions were taken from the group. On the issue of the lack of time given to patients to digest a cancer diagnosis, MW noted that when patients feel lost, it leads to a loss of confidence in the system. When asked about why specialists do not direct patients to support service, MC answered that this could be due to fragmented care and MW restated the need for areas of the NHS to work together more effectively. On whether face-to-face interviews were needed to get better feedback from patients, MW pointed to the issue of resource but that hospitals are now using focus groups to guide services. When asked about the issue of staff shortages in certain areas affecting care, KS-D responded that workforce is increasingly becoming an issue and that there are questions about priorities in the NHS.

On the need for greater training for GPs to improve levels of early diagnosis, MW stated that it is often difficult for GPs who may only see a case of some rare cancers once in their career. When asked about the importance of people understanding the information they are given, both KS-D and MW agreed that this was an important issue and MW pointed out that this was the most negative area of the responses that focussed on communication. Finally, on the subject of the survey not representing those with the worst survival times, KS-D stated that this is being looked at for future surveys or that it may be addressed in future research and MW pointed to the work being done by charities on specific experiences.

8) A.O.B

JM gave an update on the actions from the previous meetings. She stated that letters have been sent to the Cabinet Secretary for Health and Sport and Minister Public Health on the topics of Radiotherapy, Screening and measures to tackle obesity. She noted that there has not been a response yet, but that the Cabinet Secretary will be speaking at the next meeting of the CPG. JM also stated that a number of issues that did not relate to the presentations of the meeting on the 28th September have been put as Written Parliamentary Questions and the responses will be shared after the meeting

7) Close of Meeting

JM then closed the meeting. Next meeting: 17:30-19:00, Wed 1st March, 2017

Attendees

Group Members

Name	Organisation
Marie Newcombe	Beatson Cancer Charity
Debbi Jennings	Beatson Cancer Charity
Ewan Shannon	Beatson Cancer Charity Working Group
Lesley Shannon	Beatson Cancer Charity Working Group

Lynne Barty	Brain Tumour Action
Janice McClure	Brain Tumour Action
Irene Hopkins	Brain Tumour Action
Alice McGregor	Brain Tumour Action Support Group
Nicolas White	Breast Cancer Care
Mary Dunlop	Cancer Research UK
Mona Vaghefian	Cancer Research UK
Gregor McNie	Cancer Research UK
Jonathan Roden	Cancer Research UK
Moira Adams	Challenge Breast Cancer Scotland
Ryan Devlin	CRUK Ambassador
Rosa MacPherson	CRUK Ambassador
Jo Williamson	CRUK Ambassador
Florencia Pistritto	CRUK Ambassador
Rob Lester	Edinburgh and Lothians Prostate Cancer Support Group
Heather Goodare	Edinburgh Health Forum
F Norton	Heads Up Support Group
Alex McCaffery	Heads Up Support Group
Philip Atkinson	Health Policy Scotland
Peter Hastie	Macmillan Cancer Support
Kelly Shiell-Davis	Macmillan Cancer Support
Gillian Hailstones	Maggies
Neil Pryde	NHS Fife
Murdina MacDonald	NHS Fife
Colin Selby	NHS Fife/SCAN
Sally Clive	NHS Lothian
Robin Grant	NHS Lothian
Lorna Bruce	NHS Lothian/SCAN
Mark Parsons	NHS Tayside
Douglas Pattullo	Office of Miles Briggs MSP
Suzy Mercer	Pancreatic Cancer UK
Gregor Stevenson	Roche
Tonks Fawcett	University of Edinburgh
Lindsay Campbell	WoSCAN
Jenny Marra MSP	
Finlay Carson MSP	

Invited Attendees

Name	Organisation
Brian Montgomery	Access to Medicines Review

Jeannie Erskine	Cancer Patient
Zoe Miller	Cohesion Medical
John MacGill	Ettrickburn/Scottish Parliament Magazine
Leigh Smith	MASScot
Professor Mary Wells	University of Stirling
Maggie Cunningham	University of Stirling
Brian Whittle MSP	
Julie Roberts	