

## **Scottish Parliament Cross Party Group on Cancer**

**23<sup>rd</sup> October 2018, 17.30-19.30**

### **1) Welcome**

Miles Briggs (The Chair) opened the meeting and welcomed the attendees and speakers to the meeting

### **2) Minutes of the Last Meeting**

The Minutes of the previous meeting of the Cross Party Group on Cancer on 19<sup>th</sup> September 2018 were approved by the group without amendments.

### **3) Ratification of the CPG Cancer's Annual General Meeting**

The elections of the Annual General Meeting, held on the 18<sup>th</sup> September, were ratified. Miles Briggs MSP and Anas Sarwar MSP were re-elected as co-conveners. Cancer Research UK was approved as the Secretariat.

### **4) Cancer Strategy Inquiry - discussion on inquiry documents**

The Secretariat discussed two documents outlining the process for the CPG cancer and the writing of the final report. These documents were circulated before the meeting and will be recirculated following the meeting for any comments.

### **5) The Chair then welcomed Shelagh McKinley (SM), Prof Aileen Keel (AK) and Liz Watt (LW) to discuss Improving Treatments as part of the Cross Party Group on Cancer's inquiry into the implementation of the Scottish Government's Cancer Strategy**

SM began by discussing the work of Myeloma UK and cancer medicines. Myeloma UK is the only organisation in the UK dealing exclusively with myeloma. SM noted that myeloma UK does a lot of policy and advocacy work around cancer medicines. Myeloma is a remitting and relapsing disease and becomes resistant to treatment so effective new treatments are crucial.

She then discussed the review of access to new medicines, noting its influence from the work of the Health and Sport Committee and that its recommendations were accepted by the Scottish Government. SM noted that access to end-of-life, orphan and ultra-orphan medicines were seen to have increased in the review and she welcomed the whole systems approach of the review as a touch stone for progress in medicines. The Scottish Government update to Health and Sport Committee on 17 May 2018 was also noted by SM.

SM then acknowledged the progress in the reviews actions. She noted that the SMC has committed to a more transparent way of working and introduced conditional advice. Changes to the systems for medicines not routinely accepted for use – with the introduction of the Peer Approved Clinical System (PACS) - was also noted. The introduction of the data scoping taskforce, a new definition and pathway for ultra orphan drugs and discussions on voluntary price alignment were also acknowledged.

The next steps for the access to new medicines was also discussed. SM highlighted the need for clear, timed communication and engagement for the Scottish Government on progress against the reviews actions and emphasised the importance of a 6 and 12 month review of the new PACS system. She also highlighted the importance of developments in the New Medicines Fund, improvements in engagement with industry, balancing access to treatments with the realistic

medicine agenda, Patient Reported Outcomes and the need for more horizon scanning and action around Advanced Therapy Medicinal Products.

LW then discussed the progress on the MSN on Children and Young People with Cancer's (MSN CYPC) plan for 2016-2019 following a £2.5 million investment in the Scottish Government's strategy to deliver the improvements set out in the MSN CYPC's plan. LW noted that there are around 200 cases of cancer in CYPC every year in Scotland. She noted that children's survival rates are often higher than in teenagers and young people, explaining this is partly due to differences in clinical trial access. Around 80% of children with leukaemia are currently entered into clinical trials, but only 15% of young adults are entered into trials.

Scotland is the only UK nation with a cancer plan for children and young people and LW noted that the plan was written for and by the teams who are delivering these services. She highlighted the actions to create a TYA (Teenagers and Young Adults) model of care and an age appropriate environment and support network with expertise of both cancer-site specific and Teenage and Young Adult teams. MSN CYPC also aimed to create a Hub and Spoke Model of cancer centres, with 5 cancer centres and 12 other treatment centres to support treatment, to allow equitable access to specialist TYA cancer services across Scotland.

LW then discussed the progress made by the MSN CYPC in completing some of the actions of the CYPC plan. She discussed advances: around: the workforce, the establishment of a national TYA MDT process to identify TYA cancer and allow TYA's to benefit from specialist care. She also discussed the establishment of seven outcome focused, evidenced based standards of care for TYAs for which an audit will be run and reported on in March 2019.

She concluded by highlighting the CYPC plan's actions around improving clinical trial entry for TYAs, gaining access to the EDGE system, the establishment of the MSN CYPC National Youth Advisory Forum (NYAF), the creation of age appropriate information and the increasing of peer to peer support.

AK then discussed the work of the Innovative Healthcare Delivery Programme (IHDP). She noted that the IHDP was set up 3 years ago with an aim to build a Scottish cancer intelligence framework and use data to improve patient care in NHS Scotland. Cancer survival in Scotland is lower than that of the rest of the UK or equivalent EU nations. AK emphasised that it is crucial for us to have the data to understand why this gap exists.

However, a number of barriers to having the full data landscape were highlighted by AK. These include the technical barriers of linking data, the heterogenous nature of health data in Scotland and the need for sensitivity around organisational barriers to a new data system in NHS Scotland. Collaborative working with clinicians is therefore important to create buy in.

AK then also highlighted the potential benefits of a linked up data infrastructure. These include better treatment data for clinicians, linked data for research, service managers and auditors, as well as the ability for patients to have access to their own data, allowing greater self-management of their treatment.

AK noted that the cancer strategy committed £2 million in spending to the IHDP to help them reach their aims. Amongst this work has been progress in breaking down barriers to data use across NHS Health Boards. AK noted that, in partnership with NHS National Services Scotland, the IHDP are developing data virtualisation technologies to allow data integration where silos of data are integrated without moving or duplicating the data.

It was emphasised that the aim of this joining up of the data is to allow for discussion and sharing, rather than to punish areas of poor performance. AK highlighted the need to move away from silos to a national system of care.

AK finally highlighted the impacts of the IHDPs work. She noted that IHDP has nurtured the 13 innovation projects in Scotland and brought teams across Scotland to work together on projects. She also noted the work to develop SCRIS (Scottish Cancer Registry and Intelligence Service cancer dashboard that will incorporate 10 datasets (4 of which are not currently available nationally).

Maggie Clark then spoke about Novartis' views of progress in the cancer strategy in this area. She noted that industry is involved in a great deal of partnerships with the NHS and Scottish Government around cancer medicines and treatments. She particularly highlighted work around diagnostics and the identification of molecular markers, ABPI's work with NHS Research Scotland on cancer trials and a range of work looking at new models of care.

The chair then asked about progress on MSN CYPCs online tools, such as my story. LW stated that this has been delayed due to issues around information governance.

Dr Alan Rodger discussed the work of the SMC's boards and the pressure that individual patient treatment decisions for not recommended drugs puts on clinicians, SM stated that it is important that SMC work to manage Scotland's finite pot of money around the increasing cost of medicines, but that the SMC is only one part of the process. She noted that scientific advances have not been met with similar changes in payment structures and that there is a need for more flexible ways of paying for drugs as well as better data for drug effectiveness.

Martin Coombes noted the challenges for SMC in judging medicines based on early trial data and highlighted a potential solution for pricing structures based on outcomes, highlighting the importance of better data.

Brain Tumour Action asked about the lack of paediatric neuro-oncology specialist nurses in Scotland. LW noted that there are currently plans to create two posts for paediatric neuro-oncology specialist nurses. Heather Goodare noted issues with the Scottish Cancer Referral Guidelines for breast cancer in young people. LW stated that the treatment pathway for young people with suspected breast cancer is often complex and difficult to pick up. The Chair suggested that a Parliamentary Question could be tabled on this.

Leigh Smith raised concerns about the SMC needing to control drugs spend and the need to begin bringing in PROMs data into price negotiations and decisions and for the need for clinicians to input to the approval process at all stages. Maggie Clarke noted that SG is aware of the issues around the sustainability of the drugs pricing and approvals process and are working on potential solutions for this.

**6) The Chair then welcomed Prof Aileen Keel (AK) and Prof Charlie Gourley (CG) to discuss research as part of the Cross Party Group on Cancer's inquiry into the implementation of the Scottish Government's Cancer Strategy**

AK began by discussing the Cancer Medicines Outcomes Programme (CMOP), a study that looks at the performance of cancer drugs in a real world setting. She noted that the programme was started in 2017 and is due to run for 3 years. The programme is based in the West of Scotland and is a collaboration between the University of Strathclyde and NHS Greater Glasgow & Clyde, with

aspirations to spread the programme across Scotland. The programme was set up to address the increasing cost of drugs, with the spend on drugs estimated to be increasing by 10% a year.

The study's early findings indicate that the results of clinical trials on cancer drugs are often not reflected in real world effectiveness. This could be due to the different demographics of those treated more widely than clinical trials. These patients are often older and have more co-morbidities, which negatively impacts the effectiveness of cancer drugs. CMOP has initially studied drugs used for melanoma and prostate cancer in Glasgow and there are plans to widen it to encompass more common cancers.

CG then discussed the other actions of the cancer strategy in relation to cancer research in Scotland. He noted the Scottish Government's ovarian and pancreatic exemplar studies. These studies are looking at the increasing individualisation of treatment and the targeting of drugs to patient groups. Pancreatic cancer has poor outcomes and the Precision Panc study is aiming to discover the molecular subgroups in pancreatic cancer that treatments can be targeted to these sub groups.

The ovarian exemplar is looking to identify similar molecular markers in ovarian cancer. The study has currently sequenced 700 cancer – 100 whole genome sequences and 600 panel sequences. This process has identified variations linked with outcomes in ovarian cancers, including the identification of a new patient group for one drug. He noted that the funding for the study is due to end next year, but that they hope to continue the project and it expand it to other cancers.

CG then discussed clinical trials regulation. He noted the long term aspiration to increase the number of clinical trials that are available in smaller hospitals in Scotland. However, CG noted that limited specialist skills and equipment these hospitals mean that these hospitals are often not able to perform the more complex trials that are becoming increasingly common.

CG finally discussed the ECMC network in Scotland. He stated that the ECMC network is crucial to Scotland as it maintains the nations competitiveness in clinical trials. The ECMC allows Scotland to take part in early phase clinical trials and also allows clinical research links to the rest of the UK. CG noted the continued investment from the Scottish Government to the ECMC centres in both Glasgow and Edinburgh, also noting its importance to the funding environment in Scotland.

Heather Goodare asked about the need for 2 or more patient representatives on clinical trials steering groups. CG, AK and other members all noted the importance of having multiple patient members on steering groups and there was a consensus that this was becoming common practice across all research in Scotland.

Leigh Smith asked about whether there is ongoing work into the genetic links between pancreatic cancer and melanoma, in order to discover new treatments for these cancers. CG stated that the links between these cancers are not as strong as others. CG noted that there is a need for better data that includes environmental data as well as genetic information to allow for the more accurate identification of links and to improve treatments in these cases. AK stated the IHDP is looking at the ability to link to data outside of cancer data to improve this.

Fiona Brown raised the issues around the staff levels of nurses who often work with patients around entering clinical trials, noting the funding of a nurse in Glasgow by Pancreatic Cancer Scotland. The chair then asked about the availability of EDGE, the clinical trials database. LW noted that EDGE is available in Scotland's cancer networks and that the MSN CYPC only has access to some through a clinician in the West of Scotland cancer network. She highlighted issues around young people only having access to trials that are open in their Health Board as the clinicians are unaware of the trial.

Dr Alan Rodger asked about the communication of CMOP to patients who are asking about medicines that they have found online, which have been shown to not be as effective in CMOP as the trial data suggests. AK noted that clinicians who have been involved in CMOP have said that it is helping to inform their conversations with patients where they discuss the treatment options, as it allows them to discuss outcomes from patients with a similar demographic. SM stated that it can be used as a shared decision -making tool between clinicians and patients, allowing communication about what matters to patients and improving the patient experience. AK noted the role of the third sector in promoting the patient experience amongst the clinical community.

## 7) A.O.B

- The Scottish Cancer Conference is taking place on 19th November 2018 at the Surgeon's Hall in Edinburgh. Visit <http://www.scottishcancerconference.org.uk> to see the programme and book a place.
- The Chair acknowledged that Brain Tumour Action awarded a Highly Commended by the BMA at their Awards Ceremony in London on the 25 September for their Epilepsy and Brain Tumour Booklet

**8) The Chair then closed the meeting.** Next meeting 17.30-19.30, Tue 23<sup>rd</sup> October 2018.

### Group Members

Member
Miles Briggs MSP
Brian Whittle MSP
MSN CYPC
Breast Cancer Now
Novartis
MASScot
Kidney Cancer Scotland
Cancer Research UK
BMS
Pfizer
Dr Alan Rodger
Pancreatic Cancer Scotland
Macmillan
University of Edinburgh
Innovative Healthcare Delivery Programme
Jeannie Erskine
Myeloma
Cochrane
Brain Tumour Action
ISD