

## Scottish Parliament Cross Party Group on Cancer

Wednesday 11<sup>th</sup> December, 17:30-19:00

### Minutes of AGM and Ordinary Meeting

Attendees and apologies noted in appendices

#### 1) Welcome

Malcolm Chisholm (“the Chair”) opened the meeting, welcoming all attendees and speakers.

#### 2) Minutes of Last Meeting

A hard copy of the minutes was distributed to attendees to be approved at the end of the meeting.

#### 3) Annual General Meeting

##### a) Approval of Annual Return

The Draft Annual Return, distributed in advance of the meeting, was approved for submission.

##### b) Election of Office Bearers

Malcolm Chisholm MSP and Nanette Milne MSP were reappointed as co-convenors. It was agreed that Cancer Research UK continue to act as secretariat of the group. The AGM was thereby closed, with the Chair introducing the first speaker to the group.

#### 4) Speakers and Discussion

##### a) Kathryn Fergusson (KF), Head of Medicines Branch, Scottish Government

KF advised the group that the Cabinet Secretary for Health and Wellbeing would attend the next group to discuss the outcomes of the Scottish Medicines Consortium’s (SMC) review and wider aspects of cancer policy. KF reminded the group of the process to date and how the inquiry of the health committee, and wider parliamentary interest and support, has ensured the outcomes of the review are consensual. The SMC review is working to a tight timeline (reporting to Scottish Government by Christmas), with a focus on very rare diseases and end of life treatments. There are a lot of positive changes that will be seen in the coming months around transparency and patient/public engagement but the absolute priority is that the review will have an impact on decisions. As the Health and Sport Committee identified if we are going to see a shift around access to medicines then this is what will achieve that. KF described the SMC as moving from a NHS advising body to a more public facing one, with the appropriate resource to support that from Scottish Government. The Individual Patient Treatment Request (IPTTR) process will be replaced, following the implementation of the change in approach at a national level within SMC.

Responding to a wide range of questions KF said that:

- The SMC review is on course to meet its deadlines and on the basis that the report matches expectations of Ministers and Parliament this this will be public in January.
- Health boards were implementing the current IPTR process with the addition of flexibility but if there are any concerns about this Scottish Government happy to hear them,
- Increased access was a key message being conveyed to the SMC in its terms of review and was clear message from this Parliament.
- Experiences in other nations were being examined
- Scottish Government would consider the financial implications from the SMC review
- Recognition was being given to access to drugs for rare diseases
- The onus to present new drugs for consideration was on manufacturers but part of the review was to give due recognition to cases where significant patient and clinical demand should influence decisions
- The post-review decision-making process may not be any quicker but should ensure more first-time acceptances and less requirements to resubmit
- The SMC consideration process was quick by international comparison
- There would be greater scope for patient involvement in the process with specific resource in place to support this

b) Les Horne (LH), Edinburgh and Lothian Prostate Cancer Support Patient Engagement

LH described his experience of his patient support group making a submission to SMC. He praised the SMC for its support of their efforts and the seminars they ran to support submissions.

He identified scope for the SMC to better communicate with patient support groups and that he had held positive conversation in this regard with an SMC official. He would continue to pursue this area of improvement and after provided the following contact details to be included in the minute:

Katy Penman Patient Focus Public Involvement Advisor  
Healthcare Improvement Scotland  
Delta House | 50 West Nile Street | Glasgow | G1 2NP  
t: 0141 225 6892 ext. 8634  
e: [katy.penman@nhs.net](mailto:katy.penman@nhs.net)  
e: [contactpublicinvolvement.his@nhs.net](mailto:contactpublicinvolvement.his@nhs.net)

LH then spoke about the Scottish Conference of Cancer Support Groups, highlighting the networking benefits of the event and the quality of workshops on offer many of which included very practical areas of advice. He shared the following contact details for the event to be included in the minute:

Clare Davidson (Conference Organiser)  
PO Box 10513,  
Aberdeen.  
AB12 9DF  
Tel: 01224 781583  
Email: [claredavidson@btinternet.com](mailto:claredavidson@btinternet.com)

[www.SCCSG.org](http://www.SCCSG.org)

KF followed on from LH's talk, highlighting the doubling of the SMC budget and specific resource to engage with patient groups. Following a discussion around the mechanics of keeping patient group informed of SMC work and decisions, KF agreed to examine introducing some functionality on the SMC website for patient groups to sign up to hear key information.

In wider discussion KF also said that the pharmaceutical industry would be able to engage with the SMC at earlier stages of development and the Association of the British Pharmaceutical Industry have a place at the SMC, thereby giving a strong foundation for future engagement.

- c) Emma Greenwood (EG), Head of Policy Development, Cancer Research UK  
Latest cancer policy developments and challenges

EG introduce Cancer Research UK and its policy work to the group. She said that a lot of work in response to the radical health reforms in England had helped develop wider policy positions that could apply across all the UK nations.

Cancer Research UK is the world's largest cancer research charity, receiving no statutory funding and funding over £350 million in UK research last year. The organisation funds researchers, centres of excellence and early trials. In Scotland £34 million was invested in research last year, some 13% of the total UK spend.

At a European level, more work was needed to encourage pan-European trials with the UK often too small a trial sample size. There was also ongoing work around faster licensing of medicines.

Particular work was being undertaken around stratified medicine with a project underway to look at possibilities of stratified treatments for lung cancer. EG pointed to radiotherapy as still the most effective treatment outside surgery and work with NHS England on a 5-10 year view on what a successful radiotherapy service should look like. Gaps in public and patient awareness in this area were also being studied.

EG also pointed to the *Better Cancer Care* plan as one that was very important and successful since its inception and Cancer Research UK, and others, were encouraging a new cancer plan for Scotland.

There was a general discussion with the following points noted:

- That if Scotland or the UK were to leave the EU, participation in international trials would still be very possible but perhaps a little more difficult to administer. Trails beyond the EU are already operating successfully.
- Early diagnosis is a significant part of Cancer Research UK's work, including advising and supporting various government's early diagnosis schemes, and providing toolkits and materials for GPs.
- A report on cancer surgery across the UK will be published in the New Year.
- A review of the Cancer Research UK's 5-year funding strategy is underway and this will involve more preventive and early diagnosis work. Behavioural intervention research would also increase.
- Various tumour groups identified as "cancers of unmet need" will receive greater focus and funding, including brain cancers.

#### 5) Minutes of Last Meeting

These were approved

#### 6) AOB

Gregor McNie (GMC) advised that planning for the Scotland Against Cancer conference was underway although the originally set timelines had been revised to ensure a strong programme and accommodate full consultation on this. The dates of 26<sup>th</sup> of May or 2<sup>nd</sup> June were looking the most likely to hold the event and the group would be informed in due course. GMC encouraged proposals for the programme and would contact the group about this.

Annie Anderson reminded the group of the Scotland Cancer Prevention Network's annual conference on 4<sup>th</sup> February in Edinburgh and encouraged timely booking to secure places.

#### 7) Date and topic for next meeting

The next meeting would be held on 4<sup>th</sup> February 2014, 17:30-19:00 with the Cabinet Secretary for Health and Wellbeing speaking on the SMC review and taking general questions.

Subsequent meeting dates are 20th May; 23rd September; and 16th December, all 17:30-19:00 in Committee Room 4.

## Appendix 1: Attendees

Malcolm	Chisholm	MSP (Co-convenor, Chair)
Nanette	Milne	MSP (Co-convenor)
Jackson	Carlaw	MSP
Aileen	McLeod	MSP
Gregor	McNie	Cancer Research UK (Secretariat)
Emma	Greenwood	Cancer Research UK
Alan	Summer	Boehringer Ingelheim
Alex	Holme	SCAN / NHS Lothian dermatology
Alistair	Haw	Prostate Cancer UK
Ali	Walker	South East Scotland Cancer Network (SCAN)
Chloe	Cowan	Cancer Research UK Senior Nurse
Jeannie	Erskine	Cancer Patient
John	MacGill	GSK/ Scottish Cancer Industry Group
Kate	MacDonald	SCAN (Network Manager)
Ben	McKendrick	Myeloma UK
Kate	Morgan	Myeloma UK
Kirsty	Henderson	Breakthrough Breast Cancer
Karen	McNee	James Whale Fund
Leslie	Horne	Edinburgh and Lothians Prostate Cancer Support Group
Lorraine	Dallas	Roy Castle Foundation
Kathryn	Fergusson	Scottish Government
Davie	Hutchison	Scottish Government
Neil	Pryde	Fife NHS (Lead Cancer GP)
Peter	Hastie	Macmillan
Adam	Gaines	Prostate Scotland
Robert	Steele	Scottish Cancer Foundation
Robin	Lester	Edinburgh and Lothians Prostate Cancer Support Group (Chair)
Roseann	Haig	Circle of Comfort (Chair)
Sandra	Bagnall	SCAN (Patient Involvement Manager)
Susanne	Cameron- Nielsen	Royal Pharmaceutical Society
Suzanne	Spencer	Cancer Research UK Ambassador
Ruth	Bittern	Student

## Appendix 2: Apologies

Alan	Rodger	
Alison	McInnes	MSP
Colin	Selby	NHS Fife, SCAN
Dawn	Crosby	Teenage Cancer Trust
Elspeth	Atkinson	Macmillan
Fiona	Hamill	
Gregor	Stevenson	Roche
Frank	Buckley	Pancreatic Cancer Scotland
Jackie	Baillie	MSP
Janice	Malone	Macmillan Programme Manager
Julie	Uttridge	Clinical Trials Service Manager
Karen	Bell	Former acting CRUK senior research nurse for Chloe Cowan
Mhairi	Simpson	Nurse Consultant Cancer Care, NHS Lanarkshire
Mia	Rosenblatt	Breast Cancer Campaign
Rebecca	Patterson	Palliative Care Scotland
Sheena	Dryden	Clinical Nurse Specialist, NHS Lothian
Shirley	Fife	NHS Lothian
John	Sleith	Royal Environmental Health Institute of Scotland
Philip	Atkinson	
Sara	Taylor	Almirall
Ellen	Finlayson	Clic Sargent
Frances	Reid	Target Ovarian Cancer
Stella	MacPherson	
Bill	Paton	NAPP
Alison	Harrow	Cancer Research UK Senior Research Nurse
Helen	Reilly	BMA Scotland
Paul	Baughan	Forth Valley Lead GP, Cancer and Palliative Care
Shelagh	Bonner-Shand	Interim NOSCAN Manager