Scottish Parliament Cross Party Group on Cancer

23rd October 2018, 17.30-19.30

1) Welcome

Miles Briggs (MB) opened the meeting and welcomed the attendees and speakers. Main purpose is to launch Cancer Strategy Inquiry report and consider next steps for CPG.

2) Minutes of the Last Meeting

The Minutes of the previous meeting of the Cross Party Group on Cancer on 23rd October 2018 were approved by the group without amendments.

3) Cancer Strategy Inquiry Report Discussion

MB started the discussion by thanking all for their contribution to the inquiry and stating that he considers it to be a model approach for a CPG. The report welcomes the progress with the Strategy to date but highlights that significant action that is required if targets are to be met by March 2021

He noted that the Scottish Government has been warned for years about concerns around workforce planning across Scotland. One case-in-point is the shortfall in the radiology workforce in NHS Highland. There is a pressing need to address issues around training and retention and MB highlighted the red action around nurse endoscopists training.

MB also highlighted the work that was needed to be done around GP referrals, as well as the need for increased focus on the less survivable cancers. He also highlighted the importance of information campaigns, noting that the work of the DCE programme is welcome but emphasised the need to take the work forward, noting the Teenage Cancer Trust schools programme.

Peter Hastie (PH), Policy and Public Affairs Manager Scotland at Macmillan Cancer Support then spoke about the background to the cancer strategy. He noted that the original plan was to merely refresh the previous Scottish cancer strategy, but that, after the publication of the more ambitious 2015 cancer strategy in England, it was decided that a more substantial revision was needed, and the Scottish strategy was published in 2016.

Peter echoed Miles Briggs' comment that he was not aware of any other CPG which had undertaken a significant inquiry of this nature. Now that it has been completed, the report will need to be updated e.g. moving ambers to red or green.

In Living with and Beyond Cancer, he noted that the 2nd Cancer Patient Experience Survey is ongoing but there is a need for another survey within this Parliament, spaced-out to allow Health Boards to take on the results. England has had 6 CPES to date. He noted the support for Transforming Care After Treatment in the Parliament.

PH concluded that, in the NHS, there is a need for greater sharing of best practice and upscaling projects. This is a key concern.

Claire Donaghy (CD), Head of Scotland at Bowel Cancer UK then discussed the implementation of the actions around early diagnosis. CD noted that early diagnosis is crucial for improving cancer survival and that nearly everyone survives bowel cancer when diagnosed at an early stage. She noted the progress that has been made, with Scotland being the first UK nation to introduce the FIT bowel screening test. CD noted that reports indicate a circa 10% increase in uptake. In some areas, this has led to a 100% increase in screening referrals to endoscopy in one month. She noted that the funding

in the Strategy has so far failed to achieve swift endoscopy access and that, according to the latest figures, more than 5,000 people waited more than 6 weeks for endoscopy.

The action to increase nurse-endoscopists training has yet to be met and CD highlighted the need for the Scottish Government to invest in workforce planning in order to address the backlog and provide sustainable staff levels in the future. Moreover, the quality assurance for endoscopy services is not as developed in Scotland as in other parts of the UK. There are no JAG accredited services in Scotland.

CD noted that an endoscopy plan was announced in June but it has not yet been published and that it needs to address workforce and training issues. CD concluded by stating the need for a gold standard endoscopy service for every bowel cancer patient.

Finally, Anas Sarwar (AS) began by thanking everyone who contributed to the report. He highlighted that it is not a political report, but rather its content was driven by expert CPG members. Anas noted that in the Cancer Patient Experience Survey, the respondents largely feel that the quality of service is good in hospitals but that the main weaknesses are in diagnosis and care after hospital. Indeed, many patients report that they 'fall off a cliff' when they return to the community.

AS noted the massive challenges that exist within the diagnostic workforce, but stated that it isn't a question of ambition, but a people problem and he noted the vacancies that exist in radiology and endoscopy services. AS stated that this is the biggest challenge to delivering the strategy by 2021 and that, while there are no easy fixes, there is a clear need for a workforce plan to meet the ambition.

There were several positives in the report, such as the action around prevention and improving survival. However, AS noted the concerns about treatment delays. In Living with and Beyond Cancer, he noted the need to bring together support services and highlighted the crucial role of the 3rd sector. AS concluded that there is also a need for research into less high-profile cancers.

The group agreed to invite the Cabinet Secretary to the CPG to respond to the report.

Ashleigh Simpson from Breast Cancer Now highlighted the need, following Perjeta being approved for use, for closer scrutiny of the Montgomery Review to see where action can be taken to speed up the availability of drugs for patients in Scotland.

Prof Steele then discussed the issues around bowel screening, drawing on his experience as a member of the UK National Screening Committee (NSC). He noted that the FIT test introduced to Scotland is more sensitive than the proposed test sensitivity in England. However, he noted that the UK NSC has recommended making the FIT test more sensitive than it currently is in Scotland. That, in turn would put greater pressure on Scotland's diagnostic services at a time when there are also concerns about the quality of colonoscopies. He noted the importance of training other health professionals, not just doctors, and noted that research is underway into alternative testing that would reduce the burden on endoscopy. He also discussed the future of lung cancer screening, noting that lung CT screening trials showed a 30% reduction in cancer deaths and that there might be value in a screening programme for high risk individuals, a programme that England has announced.

AS then also highlighted the potential use of digital tools to ease burden on diagnostic services. Fiona Easton from Cancer Research UK raised the issue of patient transport to hospital. Irene Hopkins from Brain Tumour Action noted that in East Lothian, many patients can't drive to appointments and have issues getting to hospital. Tom Martin, a Cancer Research UK ambassador,

noted that other countries' systems allow for patients to receive multiple tests in one day, cuttingdown on frequent travel to hospital. PH noted that this is an issue that is often raised in CPES and that it is an issue that we can raise with the Cabinet Secretary.

Christine Campbell from the University of Edinburgh asked to what extent Scotland dovetailed with rUK in screening and the England review of its screening programmes. Prof Steele noted that there is an unpublished review for the Scottish screening service.

Ewan Shannon raised the importance of early diagnosis, in light of his late-daughter's experience. He stressed the need for action on GP education and referrals to achieve greater recognition of the increasing rates of cancer among young people.

Niamh Cashell from MASScot highlighted that most of the money for melanoma was not spent on campaigns and raised issues about the number of skin cancer consultants.

Dr Alan Rodger said that the inquiry report was honest and very commendable. He noted that there has been heavy investment into world leading radiotherapy equipment but there isn't the staffing capacity to use the equipment with all appropriate patients. The best IMRT treatments require greater staff time and this might be impacting its use.

Lesley Shannon lost her daughter to late-diagnosed bowel cancer. Mrs Shannon is a strong supporter of the work of Bowel Cancer UK. She noted that one hospital's endoscopy service is being assessed for accreditation and that we need to ask the Scottish Government to improve endoscopy services.

4) A.O.B

- Irene Hopkins from Brain Tumour Action mentioned a series of videos, paid for by the Leighanne Easton fund, which are currently being produced to raise awareness of the symptoms of brain cancer. The videos will be released in June and will feature patients. The series of videos are in production, but Brain Tumour Action need to appoint a new film company to complete the series. Any suggestions as to which companies might be able to help can be sent to the secretariat to pass on. Miles Briggs offered to help promote the video series.
- Stella MacPherson a SCAN patient rep drew attention to the newly produced 'Getting a Head Start' leaflet and business cards which were developed as a legacy of the Macmillan-funded Transforming Care after Treatment programme (TCAT). As part of the programme, a national cancer experience panel (CEP) was set up to support user involvement. The 'Getting a head Start' leaflet summarises the key learning points from the CEP experience over the life of the programme and will be of use to patients or carers wishing to set up their own groups and for professionals working within the field. If you would like to receive a copy of the booklet, please contact the secretariat.
- Ben Sundell mentioned that a Teenage Cancer Trust report will be released tomorrow, entitled: "13-24 year olds with cancer in England: Incidence, mortality and survival". It can be viewed here.
- **5) AS closed the meeting with thanks to all involved.** Next meeting 17.30-19.00, Tue 19th March 2019.

Group Members

Member
Miles Briggs MSP
Anas Sarwar MSP
WoSCAN
Cancer Research UK
Scottish Cancer Foundation
Pancreatic Cancer Scotland
Pancreatic Cancer UK
Breast Cancer Now
Breast Cancer Care
Brain Tumour Action
Dr Alan Rodger
Bowel Cancer UK
Macmillan Cancer Support
University of Edinburgh
Teenage Cancer Trust
Scottish Clinical Trials Research Unit
Myeloma UK
Ewan and Lesley Shannon
Jeannie Erskine
Cancer Support Scotland
Prostate Scotland
ABPI