

Cross-Party Group on Cancer

Monday 6th June 2022, 14:00-15:30, Virtual Meeting Via Zoom

Minute

Present

MSPs

Miles Briggs MSP (co-convener, chair)
Jackie Baillie MSP (co-convener)
Paul O’Kane MSP
Finlay Carson MSP

Invited guests

Deborah Roebuck, AbbVie
Daniel Cairns, Myeloma UK
John Greensmyth, CLL Support Association
Richard Lovell, Grayling
Mr Imran Liaquat, Scottish Adult Neuro-Oncology Network
Lindsay Campbell, West of Scotland Cancer Network
Jen Hardy, Cancer Card
Ian Pirrie, Cancer Card

Non-MSP Group Members

Gail Grant, AbbVie
Heather Baxter, Lilly UK
Ailsa Chandler, Atos UK
Neil MacDonald, Merck Sharp & Dohme (MSD)
Lesley Shannon, Individual member
Kirsty Craig, Atos UK
Ryan Devlin, Individual member
George Davidson, GlaxoSmithKline
Brian Forbes, AstraZeneca
David Weir, Gilead
Sandra Auld, Healthcare Public Affairs
John Macgill, Ettrickburn Ltd
Margaret Clark, Atos UK
Johnstone Shaw, Fight Bladder Cancer UK

Alice Clarkson, Pancreatic Cancer UK
Kirsty Lynn Smith, Macmillan Cancer Support
Karen McNee, Action Kidney Cancer
Christine Campbell, University of Edinburgh
Norman Pratt, NHS Tayside
Lorraine Dallas, Roy Castle Lung Cancer Foundation
Jo Broomfield, Novartis
Jennifer Cameron, Royal College of Occupational Therapists
Roseann Haig, Circle of Comfort
Emma Hall, Make 2nds Count
Stephanie Quigley, Cancer Support Scotland
Jennifer Forsyth, Obesity Action Scotland
Adam Gaines, Prostate Scotland
Joseph Woolcott, Prostate Cancer UK
Carolyn Sunners, Scottish Government
Fiona Fernie, Clan Cancer Support
Gillian Hailstones, Beatson Cancer Charity
Baron Armah-Kwantreng, The Brain Tumour Charity
Ben Lejac, Young Lives vs Cancer
Heather Rankine, Exact Sciences
Steve Brown, Roche
Christine Boylan, Aberdeen Myeloma Support Group
Michael Heggie, Cancer Research UK (Secretariat)
David Ferguson, Cancer Research UK (Secretariat)
Emily Hindmarch, Cancer Research UK (Secretariat)

Apologies

Foysol Choudhury MSP
Jo Williamson, Individual member
Rob Murray, Cancer Support Scotland
Helen Reilly, ABPI Scotland
Alison Tait, Individual member
Christine Mitchell, Individual member
Lynda Murray, Individual member
Greg Stevenson, Individual member
Fiona Brown, Pancreatic Cancer Action

1. Welcome & Minutes

Chair, Miles Briggs MSP (MB), opened the meeting and welcomed members. MB then briefly described the meeting agenda and etiquette.

Minutes for the meeting on 1st March 2022 were approved with no amendments.

2. AbbVie: Improving Blood Cancer Services in Scotland

MB welcomed Deborah Roebuck (DR), Daniel Cairns (DC), and John Greensmyth (JG). MB explained that they will be presenting the findings and recommendations from the report 'Improving Blood Cancer Services in Scotland'.

DR stated that the report was informed by desk-based analysis, complemented by the findings of a consultation with members of the blood cancer community, including policy makers, the haematology workforce, patient advocacy organisations and patients. The consultation aimed to identify perspectives on the provision of blood cancer care, treatment, and shared decision making specifically in Scotland.

DR of AbbVie, DC representing the Blood Cancer Alliance, and JG of CLL Support all gave a brief introduction to their respective organisations/groups.

DR noted that blood cancer is Scotland's fifth most common cancer and the third biggest cancer killer. Awareness of blood cancer, symptoms, care and treatment, remains limited relative to solid tumour cancers. The Scottish Government's (SG) NHS Recovery Plan didn't allow for a full public consultation, and as a result, there were limited opportunities to ensure the specific needs of people living with blood cancers were captured and fully represented in the plan. DR noted the opportunity for SG to include a defined approach for people living with blood cancer as it develops its long-term cancer strategy for Scotland. She added that while the report relates specifically to blood cancers the recommendations will have a beneficial impact across cancer care in Scotland.

DR, DC and JG then outlined and provided additional information on the report's key recommendations which are:

- 1) SG, in partnership with NHS Scotland, blood cancer patient organisations and industry, to commit to the collaborative development of a defined national strategy for blood cancer care.
- 2) SG and NHS Scotland to collaborate with patient organisations to develop a national public awareness campaign to encourage early diagnosis by improving knowledge, and awareness of blood cancer symptoms, and how to access care and treatment.
- 3) SG to ensure that all data relating to blood cancer patient care at a national and health board level is publicly available. Additionally, the Detect Cancer Early Programme to include blood cancers on the most common types of cancer listed on the getcheckedearly.org website and 'blood cancers' to be included as a grouping on Public Health Scotland (PHS) publications.
- 4) NHS Scotland to provide people living with blood cancer access to disease specific information immediately following diagnosis and appropriately signpost to blood cancer patient organisations for additional resources and support.
- 5) NHS Scotland to ensure all people living with blood cancer receive a personalised care and treatment plan following diagnosis.
- 6) The Scottish Medicines Consortium (SMC) and NHS Scotland to continue to review and reform their processes to allow early access to new medicines; working with the Medicines and Healthcare products Regulatory Agency (MHRA) to maximise the opportunities and timelines for approval and uptake of innovative medicines through early engagement with industry and patient organisations.

- 7) SG and NHS Scotland to ensure the sustainability of haematology services for the future, by developing a detailed multi-professional haematology workforce plan, aligned to broader oncology workforce plans.
- 8) SG and NHS Scotland to ensure all people living with blood cancer have access to a named and dedicated haematological Clinical Nurse Specialist (CNS) who can offer holistic support and guidance; implementing an 'opt out' model of patient care to deliver best in class blood cancer services.

DR stated that the reports three main asks are: 1) parity for blood cancers 2) patient access to innovative medicines as a key pillar within the next cancer strategy 3) embedding the principle of shared decision making. DR explained that AbbVie would like to see a collaborative approach in taking these recommendations forward into the new cancer strategy. They would also like SG to ensure that there is representation from the BCA and industry as part of the next steps for engagement.

MB thanked DR, DC and JG for their presentation and initiated the Q&A by asking whether their recommendations have been accepted in the Northern Ireland cancer strategy or if there has been any push back on some of the workforce challenges. DR noted that there was good collaboration in NI and that it was a very robust strategy. Blood cancer was called out specifically and there is a pillar for blood cancers in the strategy. DR added that there was also strong recognition that haematology and oncology services needed to be brought together. DC acknowledged that there are some really strong recommendations in the NI cancer strategy that it was an impressive piece of co-production. He also noted that NI is starting from a point further back from Scotland regarding its cancer services.

MB read out Jennifer Cameron's (JC) question from the Zoom chat bar regarding the work of the wider multidisciplinary team workforce alongside medics and clinical nurse specialists in providing support to people living with blood cancer. JG said that from a patient perspective it's critical to have access to a Clinical Nurse Specialist (CNS) but the availability of this type of service varies across Scotland.

Baron Armah-Kwantreng (BAK) asked JG about the blood test that diagnosed his cancer (JG mentioned this in his intro). BAK asked specifically whether the report has any recommendations 1) around cost benefit of the test 2) when and who should receive this blood test. JG said that the report didn't address this issue but added very specific tests like blood tests can be very effective in diagnosing blood cancers. BAK also welcomed JG's previous comments on the importance of CNSs.

MB then asked if the report looks at the statistics of which NHS Health Boards have CNSs available. DR clarified that the report didn't look at this but it's something they can go back to do in order to help with the workforce planning piece across the different Heath Boards. MB noted that this data would be helpful in influencing the new Scottish cancer strategy.

MB thanked DR, DC and JG for presenting and answering the groups questions.

3. Scottish Adult Neuro-Oncology Network (SANON): Update on Brain/Central Nervous System Cancer

MB introduced Mr Imran Liaquat (IL) who is a Consultant Neurosurgeon at the Royal Infirmary in Edinburgh and is part of the Scottish Adult Neuro-Oncology Network (SANON) Clinical Lead.

IL advised that there are roughly 400-450 adult tumour cases in Scotland a year, with around 40 paediatric cases. It's slightly more common in males than females (ratio 5 to 4). Around 75-80% are grade 4 tumours (poorest outcome). They have an average survival rate of 14-18 months after treatment, but many are not in a position to undergo treatment when they arrive as the tumour is already too advanced. It has a 1-year relative survival of 39.5% for females and 41.2% for males, with 5-year relative survival of 18.8% for females and 15.1% for males but usually this is in cases of low-grade tumours. SANON is one of the four National Managed Clinical Networks (NMCN) for cancer in Scotland. SANON is made up of clinicians, patient groups and charities, who work to improve equity of care and standardise the approach to the treatment of brain tumours. To achieve this, SANON have several objectives and projects in hand.

IL firstly spoke about Multi-Disciplinary Team (MDTs). There are four MDTs across Scotland (Glasgow, Edinburgh, Dundee, and Aberdeen) which are all seeing an increase in the volume and complexity of their workload. Inverness doesn't currently have an Oncologist or Clinical Nurse Specialist but Aberdeen is covering. IL then discussed the work of the Supportive and Psychological Care (SPC) subgroup which is led by Dr Ally Rooney. The subgroup hasn't met since the pandemic, but in 2017 they called for a new Quality Performances Indicator (QPIs) stating the need to have key workers assigned to each brain tumour patient. IL moved on to discuss education and explained that SANON meets annually where there is discussion and collaboration among clinicians, patient groups and charities. IL noted that one of the biggest roles of SANON is to drive improvement through the National Clinical Audit. In 2014 they set 11 QPIs which were then modified in 2017. The purpose of the QPIs was to break down the patient journey and identify key areas where a standard should be maintained. IL said that these QPIs have driven positive change and have helped maintain a high standard across the patient journey. However, they have struggled with some QPIs linked to molecular pathology, which can impact on patients getting a formal diagnosis. In 2020 they had the second formal review of QPIs where they retired 3, updated 7, and added 1 (SACT mortality).

IL explained that in recent years there has been a big drive in standardising clinical management pathways/guidelines. SANON is one of the pilot groups for this work and has developed Subgroups (neurology, radiology, pathology, surgery, oncology and SPC) to focus on different aspects of the management pathways. They've appointed a Chair to put these Subgroup guidelines together in one document. Next, IL discussed service mapping and noted workforce pressures are an NHS wide issue. IL explained that North of Scotland services are stable, there have been changes in services delivered in Edinburgh and Glasgow which have worked well, and in NHS Forth Valley GPs and Optometrists have formulated a pathway to refer patients with headaches and other brain tumour symptoms. IL noted that the views of patients and carers are focussed through the SPC subgroup. The subgroup also works with a number of charities, psychiatrists, and psychologists. The SPC subgroup is also continuing to collaborate through the Less Survivable Cancers

Taskforce. Regarding research and clinical trials, SANON introduced a QPI in 2017 to try and improve participation in research. This was below 5% but is now above 15%. There is currently brain tumour related research going on throughout four Scottish universities - Aberdeen, Dundee, Edinburgh, and Glasgow. University of Glasgow researchers are looking at a blood test that could identify brain tumours at an earlier stage. SANON has also developed a new website (www.sanon.scot.nhs.uk). Regarding service pressures, IL said that the main issues have been an increasing complexity of care, as well as challenges with cellular and molecular pathology with genomic medicine being the way ahead.

In summary, IL said that there has been good progress against all the objectives SANON set in 2014. The four centres have been supporting each other with good cross working, QPIs have been maturing and they've improved services. MB thanked IL and noted the development around blood tests and said that it would be helpful if SANON could keep the CPG updated on this work.

Norman Pratt (NP) praised how well organised SANON are and noted IL's earlier point on the challenges with molecular pathology/personalised medicine for all cancers. NP also noted the wider issue of biological understanding of disease and asked how we progress the issue of genomic medicine. IL said that SANON and others need to raise awareness with SG and keep it on their agenda. IL said that molecular stratification is getting more complex and stressed the need for the government to prioritise this issue. NP echoed the points made by IL.

BAK asked IL if he could elaborate on the NHS Forth Valley collaboration between GPs and Optometrists in identifying headache symptoms and the benefits of this work. IL explained the Forth Valley initiative was led by Dr Robin Grant, one of SANON's neurologists, who did a lot of work in symptoms research and fatigue. Through this research, Dr Grant identified that if a patient goes to the GP with a headache plus another symptom then the likelihood of the patient having an underlying mass lesion or tumour would be significantly higher. 1 in 500 patients who go to the GP with a headache will possibly have an underlying lesion of the brain. If a patient has a headache and some cognitive issues such as a change in memory, then there is a 65-70% chance the patient will have an underlying tumour or structural abnormality. IL explained if a patient has a combination of symptoms, they can be expedited to see a neurologist or a clinician who can access radiological imaging. IL said it's important to raise awareness of brain tumour 'headache plus' symptoms with GPs and replicate the success of the work in Forth Valley across Scotland.

MB asked about the current capacity for MRI scan referrals across Scotland. IL said that the demand for MRI scans is relentless which won't change, but the QPIs have allowed everyone to get an MRI scan before and after surgery. This is important in determining a patient's treatment after they have surgery to remove a tumour. IL said that access to MRI scans from primary care for patients with headaches and not specific symptoms is difficult, however CT scans can also pick up most structural abnormalities/brain tumours that need any surgery done. IL noted that quick access to CT scanning is a limiting factor. MB stated that the need to improve CT scanning capacity across the NHS is something we've heard in several CPG meetings.

MB concluded the discussion by thanking IL for his presentation and time.

4. Introducing Cancer Card

MB welcomed Jen Hardy (JH) and Ian Pirrie (IP) of Cancer Card. MB said that JH is the Chair of the Board of the charity and IP is the new CEO of Cancer Card.

JH explained that she has stage four secondary breast cancer, but her cancer is stable, and she is doing well thanks to the treatment and care she receives at the Edinburgh Western General Hospital. Following her diagnosis, JH decided she wanted to give back and use her background in IT and support to develop the Cancer Card concept. The charity's vision is to be a provider of community support and information sharing. They are currently developing their online support hub, which will be accessible to cancer patients, partners, families, friends, professionals, and employers. JH noted that cancer doesn't just affect patients but also their supporters who have different wants and needs. There are two sides to the online support hub with the first one being 'community'. They are asking people to submit content (written and video) as well as websites, podcasts, and forum recommendations which they can place on the hub. This is so users of the online hub can access content from someone who has experienced what they're going through. Currently, this information is not widely available in one central place. The other side of the online support hub will be directory listings of charities and services that provide cancer support. By using the hubs filter and search options Cancer Card will be able to provide users with the support they need quickly and easily.

IP stated that the ultimate vision for Cancer Card is to assist the NHS by supporting anyone who is affected by cancer, by enabling people to directly access relevant information, services, support, and products they will need. IP explained that they will also be producing a physical card that they can give to people with cancer as well as their support network. The card will have a QR code on one side that will take people to the new community hub. IP said that these cards are almost ready, and they also hope to have the online support hub go live at the end of June/beginning of July. The ultimate aim is for this work to be supported by the NHS. IP clarified that the website will be free to use with no financial implications for anyone joining. IP stated that Cancer Card is a service operation to provide users with the information they need. IP noted that they've had some early discussions with the NHS which have gone well.

JH then gave a demonstration of the new Cancer Card online hub. The homepage will ask users what they need and provide them with several search options. The hub homepage will establish whether the user is looking to access the service directory or community support, the user's cancer diagnosis, the user's relationship to cancer, direct people towards local services based on their location, ask what point the person is at in their cancer journey, and the stage of the person's cancer. The online hub will then direct people to relevant services or community support based on the search results. JH stated that the key aim of Cancer Card is to make things quick and easy for patients and their supporters using the website. IP noted that it's a busy time for Cancer Card with plans to onboard the details of 200+ Scottish and Northern Irish cancer charities onto the website over the next few months. They will be contacting organisations individually regarding this but they're also encouraging charities to get in touch. JH said the full website will go live in August. Development

ends in the next few weeks followed by data collection. The website launch will cover Scotland and Northern Ireland with plans to eventually go out to the rest of the UK.

MB noted all the positive comments in the Zoom chat bar regarding Cancer Card's new online support hub. MB began the Q&A by asking how the new website will capture all the local peer support groups and networks so some of the organisations doing work to bring this local information together can link into Cancer Card. JH spoke about CanDu, which is a local cancer network in Dundee, who provide a similar service to Cancer Card in their local area. JH said that they will contact CanDu and all organisations they list and replicate this on Cancer Card. They will do the same with other local networks and organisations across Scotland. JH said she thinks the list of organisations listed on the Cancer Card directory will continue to grow. She also said the website will provide valuable data which they can feed back to organisations.

MB noted that with the new Scottish cancer strategy being developed there is a space for more holistic support, which he suggested Cancer Card can investigate.

Lesley Shannon (LS) asked what kind of public relations and marketing Cancer Card is considering, as people knowing about the service will be crucial to its success. JH said that they are working with 8 Million Stories who are a digital marketing company based in Edinburgh. They have been very supportive and are helping them with Google Grants and search engine optimisation. 8 Million Stories are also helping Cancer Card with their social media strategy.

MB finished by thanking JH and IP for their positive presentation and said it would great to get them back in the future to update the CPG on how things progress.

5. AOB

There was no AOB at the meeting.

6. Close of Meeting

The next meeting will take place on Wednesday 14th September 2022, 18:00-19:30.

MB closed the meeting and thanked everyone for their attendance and participation.