Scottish Parliament Cross-Party Group on Cancer

Virtual Meeting (Zoom) Thursday 28th May 2020, 12:00 – 15:00

1.Welcome

Miles Briggs MSP opened the first virtual meeting of the Cross-Party Group on Cancer.

2.Update and Q&A with Jason Leitch (on behalf of Scottish Government)

Cancer care has not stopped, treatment is currently taking place across Scotland and the UK. This may have been moved or adapted, but much of this has continued. Some activity has been paused across cancer screening and the Detect Cancer Early Programme. Any changes to treatment should involve patients, they should always feel involved in their care decisions. The NHS is open.

Remobilisation: there has been a focus on moving into phase one of lockdown easing and reviewing the NHS Health Board remobilisation plans which includes cancer care. They were sent a framework and asked to set their plans within that framework for review. They are in partnership with staff, patients and social care colleagues. These will vary across health boards as appropriate.

Q&A

Claire Donaghy, Voluntary Chair of the Scottish Cancer Coalition

Covid-19 has had an impact on all aspects of cancer services in Scotland and this will be reflected in the results of the cancer strategy as it approaches its final stages. Prior to the outbreak of the pandemic, the Scottish Government had started the planning process for the new cancer strategy. As we move into the recovery phase, can you tell us what the amended timeframe and priorities might now be?

JL: There hasn't been an adjustment in the time frame yet, the teams have had to adjust their workplans. Covid has not changed the priority of cancer, it will require resourcing and stakeholder engagement. We don't anticipate that the cancer strategy will be deprioritised.

Gregor McNie: Update to the most recent cancer strategy. Some actions will be delayed.

A new strategy is due March 2021, it's still being considered whether this will be brought forward to consider Covid.

Marion O'Neill, CRUK

What national guidance and governance has been put in place for the recovery and restoration of cancer services – including national screening programmes, diagnostic services and treatments?

Cancer Treatment Response Group set up on 18th March. This was about putting our guidance and making risk-based judgements. There are three subgroups that broadly look into surgery, radiotherapy and chemotherapy. They will now start to think about the next phase, things will progress when safe to do so. The Golden Jubilee will remain a Covid-free zone where cancer treatment will continue.

There are virtual groups that have been set up that are planning the restarting of cancer screening, this also considers catching up on the screening missed. Screening will be restarted when safe to do so. These were paused due to the testing and staffing availability, this will have to be rethought before restarting. At this stage, they are looking to do this nationally not regionally.

Fiona Brown, Pancreatic Cancer Scotland

How are resources being managed in the medium to long term to ensure delivery of cancer diagnosis and treatment alongside Covid-19 demands and will the outcomes of patients whose pathways have been affected by Covid-19 be measured separately?

There are three principle levels of resource, local, regional and national which will continue. There have not been choices made due to lack of money, they have been due to workforce, lab space and safety. There will be continued discussion about how money will be spent in future.

Existing cancer data and the work of Aileen Keel will be vital to measure the cancer pathway. There will be global work looking into what has happened to cancer morbidity during Covid-19.

Alison Tait, Patient
We have shown great flexibility and agility with our resources to find a vaccine for Covid-19. Given that there's no guarantee a vaccine will be found or how quickly this will be available, what are we doing to apply this approach to other diseases and ramp up the speed at which these are being researched? Data has proved to be vital in managing the virus. Cancer patients/charities have been campaigning for data collection for over 10 years now, recently highlighted AGAIN to the Scottish government in December 2019 by Breast Cancer Now. A commitment was given to making this a priority. When will this happen and how can you reassure us that this won't once again drop off the cancer agenda?

This is a global problem and the research community has really stepped up to tackle this together, WHO have managed to help facilitate and support this. There are lessons to learn about this in relation to cancer research. Scotland will be at the forefront of this.

Erin McKee, The Glasgow Precision Oncology Laboratory University of Glasgow.

How can we best capitalise on Scotland's potential for cancer genomic testing and is there now (post-Covid-19) a new opportunity to use cancer genomic testing to improve cancer care pathways, and indeed, 'reverse' some of the disruption cause by the pandemic for cancer patients in Scotland?

Yes, this is something that we were on already. We may need help and would be happy to discuss what this may look like. SG will want to invest in genomics.

Melanie Sturtevant, Breast Cancer Now

Following on from the commitments made in the Cancer Strategy Update on secondary breast cancer, can the Cabinet Secretary confirm that the treatment and care needs (including access to clinical trials) of advanced cancer patients - including those with secondary breast cancer - will be recognised and addressed in recovery plans for cancer services?

Yes, remobilisation plans will be completed by local care teams. They have been done quickly so may not be perfect currently. Cancer teams and cancer departments will have to work on remobilisation plans for their board, patient and families and this will then be worked into a national plan. SG have provided framework to support this. The first priority is urgent cancer care. Elective surgery may come later, it's a risk-based approach.

Dawn Crosby, Pancreatic Cancer UK

What action are Scottish Government taking to support services to tackle the backlog in pancreatic cancer surgery cases, particularly in Glasgow and Aberdeen where pancreatic cancer surgery was paused for a total of 7 weeks and a long backlog accrued? Can you please clarify how long cancer patients who test positive for Covid-19 need to wait until reconsideration for surgery?

If there are specific people that they believe are waiting too long, please get in touch. Any urgent treatment urgent should be risk assessed with patients, families and care teams. Decisions should be made as part of a conversation.

People that have tested positive for Covid-19 will be considered for treatment following 14-days of isolation and a test, depending on their health. If it is possible, people will be asked to follow this plan. If you are sick, this may have to be shortened.

Peter Hastie, Macmillan Cancer Support

What can we do to ensure that people from lower socio-economic groups come forward more with suspicions of cancer and take-up cancer screening invites during and after the Covid-19 outbreak to ensure this period doesn't further increase inequalities in late diagnosis?

It's very difficult to close the gap. It needs to be third sector and community driven. We need to use our advertising and media skills to promote this, this should be done locally. Clinical leaders in the Scottish Government have the responsibility to get the message out to the public.

Both cancer and Covid-19, like most health problems, have worse outcomes among lower-socioeconomic groups. This is related to many risks including obesity, housing.

Question on research funding, backlog of complicated surgery, mental health and diagnostics (Note these questions now have fuller written answers)

Research funding is partly a UK Government problem. The public are still giving, people and organisations are still having to adapt with the current climate and be innovatively with their fundraising methods. There will be a gap, but funding will come back. They may have to look at pressure on broader economic support mechanisms both from the UK and Scottish Government.

Some complex cancer treatments? have stopped due to being high risk and involve multidisciplinary teams. This will be in the recovery plans.

Mental health services need more investment and more people, waiting times are currently down due to virtual consultations. This does not replace all 1:1 but does help. We will have to consider what we do with post-trauma services for ICU patients and cancer patients.

Diagnostics will be one of the key aspects of the remobilisation. Endoscopy and colonoscopy are high risk areas for Covid-19. Not as high risk for resumption of scans etc. We will have to think through what "cold" and "hot" sites mean for diagnostics too.

Brodie Pledge, Blood Cancer UK

Blood Cancer UK would be interested to know whether a decision was taken to not include people with chronic a. lymphocytic leukaemia (CLL) b. myeloproliferative neoplasms (MPN) in the shielding group and, if so, why?

There was no decision to have a blanket rule in or rule out for people with this condition. An example, MND has a long and varied course but when you first get it you do not need to be shielded and are not immunocompromised, and at the end of life stage people do not want to be shielded because this will not help. However, there is a middle stage where this is necessary. Shielding is not law, it's guidance. This should not be something people want as it's extremely hard, other than for the support that you may get alongside this. Shielding advice will be evaluated following its initial development by clinicians. It's not an exact science, but a judgement call with clinical teams in consultation with patients and families.

3.Diagnostics

Dr Lorna Porteous and Dr Hugh Brown, Co-Chairs of the Scottish Primary Care Cancer Group

LP: Dr Gregor Smith, CMO announced there had been a 72% drop in urgent suspected cancer referrals, that has improved slightly, possibly due to the NHS is Open campaign. There is still a 40% drop in referrals from what would normally be expected. This is likely due to a reluctance in people presenting to their GP, either because they're concerned about catching Covid-19 or burdening the NHS. If they do contact their GP, they are concerned about being referred on further. Again, this is partly due to fear of catch Covid-19 or long waits.

There has been a substantial increase in using telephone or video consultations. This can work well for many, but for some they may not have the tech or understanding to do this.

There's been a suspension of routine reviews of patients in primary and secondary care. These are helpful to notice symptoms.

With screening paused there will have to be many considerations put into place before they restart, but we hope that this is done soon. For cervical cancer screening, this has to be done in person and this will take a lot longer currently due to the additional safety measures. Some of these appointments may have to be at times or in places that they wouldn't typically be. This can increase anxiety and difficulty around this.

HB: Primary care has changed with social distancing and reduced face to face consulting. Telephone and video consulting are very different from telephone triage. Some patients are unsure of having limited access to new and appropriate technologies used for this way of consulting. They must ensure adequate safety netting, this was easier when you could meet someone, and it takes more thought virtually. It's also harder to help a patient plan or to reassure them with the changes.

In GP surgeries there are red and green zones, due to social distancing this means that there has been a significant reduction in capacity. Additionally, shielding and isolation are a strain on clinical teams.

The positives of this is that it re-emphasises the importance of taking a good history. The referral guidelines have not and should not change. It has also created a great training opportunity for some staff, as well as allowing for a redesign and at pace.

For secondary care there are several positives. The embracing of telephone and Near Me consultations should be embraced as it's possible to see more patients and can be less stressful. There is evidence of increased availability to speak to GP colleagues to give advice. Some patients are also easier to fast track.

The challenges come with referrals being handled differently either through process of changes to clinics, large number in pending pile waiting for investigation or treatments (e.g. endoscopy),

process lengthened for many and anxiety increased for both patients and staff; balance of risk benefit for some cancer patients, monitoring of patients on waiting list.

Discussion and Questions:
Gerard McMahon, Prostate Cancer UK
While it's welcome to see that the 72% drop in referrals is now at around 40%, the campaigns run by the Scottish Government have been useful, but what is problematic is that prostate cancer patients are often asymptomatic with signs identified during GP consultations. We could see a lot of people that miss out on early diagnosis which will have an impact on curative treatment. Prostate Cancer UK would like to see PSA testing made available to high risk groups with being balanced out with PPE and safety measures. Once moving to the secondary care setting, we hope that MP-MRI is ramped up to reduce biopsy.

Lorraine Dallas, Roy Castle Lung Foundation
We have some work to do in re-engaging communities. In lung cancer, coughing is a major symptom which if someone develops a new persistent cough they are currently being told to self-isolate, it will be difficult to move the concern from Covid-19 to cancer. We'll need to take a more proactive approach.

Marion O'Neill, Cancer Research UK

It's clear that it's not just a case of getting services back up and running, we also need to build public confidence in accessing primary and secondary care. In addition to the awareness campaign, is there any specific support we could/should be offering patients in advance of appointments for example about how we are trying to create safe spaces?

HB: We have to say that you can come, and it will be safe, but we do have to take a targeted approach.

Alison Johnstone MSP

Can I ask what help can be provided to patients who have had cancer ops cancelled and are very keen to proceed?

LP: I have been reassured by my secondary care colleagues that everything is being done on an individual basis after discussions with patients. From primary care, we would be happy to talk things through with patients and give further explanations. This is probably more suitable for answer by secondary care.

Peter Hastie, Macmillan Cancer Support
Where would you like to see potential innovation around health inequalities, how can we capture learning from this?

HB: Being able to take patient history and being able to conduct routine check ups in a different way. We will have to think innovatively.

Marion O'Neill, Cancer Research UK

Are there new tests/ways of working in primary care that can help manage the potential backlog of patients? For example use of FIT tests.

HB: We will be using FIT testing to deal with the backlog and new referral so that those with high scores can be prioritised for the return of colonoscopy.

LP: This is already happening, this is used differently across boards but will be used to help with backlogs.

Brian Whittle MSP
Can I ask where technology should be deployed in communication and collaboration between primary and secondary care - especially in recording and sharing patient history?

LP: There has been a lot more communication between primary and secondary care which has been helpful, we would like to continue this immediate contact. The recoding and sharing of patient history, the national digital platform will be helpful in future.

4.Cancer Support During Covid-19 and Beyond

Gordon McLean, Strategic Partnership Manager, Macmillan Cancer Support

There are approximately 21,000 people with cancer on the shielding list. A significant number are not shielding but are recognised as vulnerable and would benefit from the additional support provided to those shielding.

Delays in access to diagnostics and treatment will potentially have significant implications for the cancer population in the future and for service providers across acute and the community.

Macmillan carried out a review of 205 people affected by cancer across the UK on how they've been impacted by Covid-19. For cancer treatment the main topics that came through include:

- Experiences and fears about the impact of changes, delays and cancellations of tests and treatment
- Inadequate, inaccurate and inappropriate communication from HCPs e.g. around (Do Not Resuscitate) statements
- Uncertainty over when or whether to seek medical support or attend appointments, including fears over exposure to Covid-19 and lack of PPE
- Fears that cancer patients will not be given access to treatment, including ventilators, if diagnosed with Covid-19

For communications and guidance, the following was identified:

- Unclear or inconsistent public information on who is vulnerable, must shield, has priority access to food deliveries and use of DNR orders, and variations between nations
- Difficult to find or access Covid-19 and cancer-specific information, services and support.
- A need for more proactive outreach, especially to under-served communities, and more positive messaging
- Concerns over own and others' (including HCPs) ability and willingness to stay at home, physically distance and use PPE in line with guidance

Practical challenges

- Lack of information on or access to priority lists, delivery slots or community support; unable to order online or by telephone, or afford minimum required spend.
- Lack of access to transport, including to medical appointments, as demand for statutory and voluntary services increase while some services have ceased.
- Increase in need for financial information and advice in light of furlough, redundancy and increased food costs

- Other impacts on carers coping alone as regular support service are withdrawn e.g. challenging behaviour of those affected by brain tumours

Emotional and mental health impacts:

- Isolation from family and support networks, increased feelings of anxiety, loneliness, vulnerability
- Fears expressed by both people living with cancer and carers of exposure to Covid-19, risk of exposing others and whether people living with cancer would be treated if infected
- Fears around future/potential impact of delayed and cancelled cancer treatment on self, loved ones and peers
- Distress at inability to give or receive support at end of life and in bereavement
- Limited access to psychological support or counselling

For Macmillan, there have been several ways their services have been affects:

- Improving the Cancer Journey (ICJ) services in Glasgow City, Dundee City, Fife, West Dunbartonshire & Renfrewshire have transitioned from f2f to telephone virtual follow up.
- Most MoveMore services have been stopped with staff being furloughed. A couple have continued providing virtual input to the cancer population especially those more closely aligned with the NHS.
- All Welfare Benefits services continue to provide support via telephone.
- Most libraries have been closed but some services are providing a telephone buddying service. The latter is something that has been scaled up wider within Macmillan.
- Further ICJ developments in Angus, East Dunbartonshire & Perth & Kinross being progressed, and negotiations will be restarted with North & South Lanarkshire when the situation allows and initiated with Ayrshire & Arran and Dumfries & Galloway partners in 2020.
- All services that are still operating are being supported to move to using NHSNearMe/Attend Anywhere video consultations.
- Digital completion of Holistic Needs Assessments
- Finance remains the biggest area of need alongside an increase also in practical concerns highlighted via the Holistic Needs Assessment (HNA).

On looking ahead at the future of cancer support:

- A significantly different landscape available to support people affected by cancer.
- Financial constraints affecting all sectors but especially the 3rd sector
- Anticipated reduction in the available community assets to meet the identified needs.
- Important not to lose the digital advances that have been made and at the same time not to forget those individuals where this route of contact will not be suitable.
- Greater collaboration will be required across health, social care and the 3rd sector with increasing reference to prehabilitation, personal resilience & self-management support, peer support, local community supports and clarity of information & advice.

Discussion

Rob Murray, Cancer Support Scotland: It's been challenging for the organisation, all face to face operations have been paused. Digital counselling and self-help guides have been developed and are currently in place. For digital counselling, there has been an increase in demand which has been met due to the support of the SG Wellbeing Fund. There has been a fluctuation in calls about safeguarding concerns, with anxiety, depression and germaphobia increasing. There are ongoing

concerns about remaining accessible to people from lower socioeconomic backgrounds. When contacting people, they've found a range of issues including social isolation, financial, lack of food provisions and domestic violence have been raised.

MB (full name): The impact on funding, around 25% drop already – do you have any information to provide on that and what would be the impact?

GMc (we might want to be clear this was Gordon and not Gregor!): We're looking at 35%-40% reduction in funding.

RM: Similarly, looking at 35% - 40% drop in income.

Ian Walker, Director for Clinical, Population and Early Detection Research, CRUK: We're in a similar position, the sector is broadly looking at 25% - 40%. We're looking at a 3-year curve before funding returns to normal.

Julie Wardrop, CANDU: There are many supportive community-based initiatives working to connect and care for people living with cancer. In Dundee the CANDU network is working in a similar way to Cancer Support Scotland. Is there any way 3rd sector orgs can work to have a more coordinated effort?

RM: The Scottish Cancer Coalition is a good space for collaborative work, as is the CPG. The Coalition developed a signposting resource for people affected by cancer: https://vhscotland.org.uk/cancer-information-and-support-resources-during-covid-19/

MB: What levels of uptake have you seen on virtual support?

GMc: There has been a slight drop off, people have feared face-to-face contact. People from the most deprived areas are using the services available. With the move to online support numbers have remained high. On the previous point of collaboration, there is a role for the third sector to look at this, possibly looking further at long-term conditions and not solely on cancer.

MB: Do we have any understanding of how health boards have adapted differently?

GMc: Not much to comment on the island services. The benefits of having local support is crucial and will be something that needs to be looked at in future.

5.Treatments

Laura Kerby, Chief Executive, Myeloma UK

Myeloma patients are extremely clinically vulnerable and shielding. Currently, all treatment decisions are seen through the lens of Covid-19 risk. Shielding had also increased the need to take a holistic view to patient needs.

For Myeloma Treatment, the following have been impacted by Covid-19: HDT-SCT do we know the full name for this? suspended for all but the most clinically high-risk patients; alternative (oral) treatments, treatment breaks or treatment stopped; reduced number of patients in clinic due to social distancing; knock on effects of late presentation in diagnosis; recruitment to clinical trials suspended and the pause of the Scottish Medicines Consortium (SMC).

During Covid-19, the following actions have been taken to help myeloma treatment: Approval of alternative oral treatments through the National Cancer Medicines Advisory Group (NCMAG);

changes to treatment regimens and administration; reorganisation of services – 'clean' Covid-19 free sites, testing prior to treatment, telemedicine, increased social distancing and shielding.

Most patients have continued to receive treatment, but many patients will not be able to receive what would have been their clinicians' first treatment of choice, there are concerns about how this will impact outcomes over the longer term.

Priorities for recover include:

- Data on diagnosis rates and modelling on service impact
- Flexibility for as long as is needed and guarantee that patients can return to the point they left, where clinically appropriate
- New models of community treatment
- Restart clinical trials
- Restart Scottish Medicines Consortium
- Clean sites – not just for surgery, needed for chemotherapy also
- Test and Protect
- More transparent and inclusive process for developing shielding guidance
- More nuanced approach to risk – where evidence exists

Marion O'Neill, Head of External Affair (Devolved Nations), CRUK

We know cancer specialists are currently having to weigh up the risks associated with treatments that can weaken a patient's immune system and might make it harder for them to fight off coronavirus if they catch it. But a rapid response to this is required – the longer for example surgery rates stay low the more cancers will become inoperable

- All 4 nations' guidance on treatment acknowledges inevitable disruption, but nations have different approaches to approving interim SACT.

- Some patient groups e.g. blood cancers / sarcoma still reporting need for alternatives because of drop in surgery rates

- Exact proportion of surgeries cancelled varies nationally depending on how much capacity has been redeployed. Surgery for riskier procedures (lung, lower GI) and on sicker patients most affected. There has beena drop of around 30% chemotherapy treatments and around10% for radiotherapy activity. ·

Reduced patient experience of care and quality of life with charities reporting patient confusion about the impact of treatment delays on a) the progression of their cancer, b) when planned treatment can be delivered. The reality for many cancer patients is that delays to their treatment means many patients will face fewer treatment options and lower chances of survival. The longer for example surgery rates stay low the more cancers will become inoperable

A higher case load for the service to work through in relation to cancer treatment once it is possible to resume full services for cancer patients is expected. There are limited data/lack of concrete modelling figures to help understand how to get services back up and running and resolve backlog. Also, treatment appointments may take longer due to enhanced safety measures

For recovery, the national governments and health services should provide updated national guidance on the clinical management of cancer patients to Trusts and Health Boards. This should include:

- Clear expectations about how any alterations to patients' (pre-Covid) planned treatment should be decided and discussed with patients, including how disease progression over this period will be assessed and factored into decision-making.
- Highlight local examples of innovations in treatment delivery which may be suitable for adoption across a wider range of Trusts and Health Boards (e.g. increased administration of SACT outside of hospitals / wider use of evidence-based hypofractionated radiotherapy).
- Ensure treatment prioritisation categories outlined in national guidance are kept under review for their appropriateness. Efforts should continue to make interim treatment options available for patients in lower priority categories.

As a priority, the NHS at a national level should assess the surgical capacity now available in Covid-protected sites and identify any remaining gaps in provision (for instance, major surgeries requiring complex care and equipment).

Local decision-makers should put in place processes to coordinate treatment capacity on an appropriate geographical scale. This should be supported by appropriate local workforce and resource planning, based on the reality of a slower throughput environment.

Clear processes should be developed for local providers to systematically track and report to the NHS at a national level real-time data on treatment volume, across disease site and stage, to help benchmark and respond to stresses in the system.

Discussion

Rachel Downing, Target Ovarian Cancer: Around 50% of women have seen their treatment disrupted. Main treatments for this include surgery and chemotherapy, in particular, surgery can be extremely complex and often requires and ICU bed and involvement of other teams. We'd like to see surgery increase and back to normal, for this we will need green sites so this can go ahead safely. We'd also like to see the option for treatment across health boards.

Martin: Understandably members of SMC have re-focused on frontline services during the pandemic. However, cancer treatments are still being reviewed by NICE. Is there a case for Scotland to apply NICE guidance whilst SMC is suspended/catching up?

Anas Sarwar MSP: Have we looked at how we are reacting compared to the rest of the UK?

LK: We're looking to facilitate learning across the UK. For NICE, there has been a real acceleration and appetite for treatments. Anything that can be done to share information and resources is positive.

MO'N: International Cancer Benchmarking Partnership works across nations and we're going to a lot of effort to see what cancer services can and should look like after Covid-19. Treatments across the UK have been hit consistently at the magnitude that we have seen.

Melanie Sturtevant. Breast Caner Now: Do we have any sense of the extent to which patients are having to be prioritised for drug therapy as per the CTRG treatment guidelines?

MO'N: There will be a backlog and decisions will have to be made. Currently our sense is that decisions are not being made due to resources, instead this is due to patient risk.

LK: There has been a lot of work looking into the risk of treatment.

Lisa Cohen, CRUK: As discussed earlier, we know that delays and uncertainty are having major impact on patient's mental health. Do we have a clear timeline to implement the recovery plans for treatment and how will this be communicated to patients?

MO'N: Patients seem to understand the need to pause treatment, main concerns are around what this means for their disease progression.

AS: Looking at the route map published by the Scottish Government, do you think this is the right timeline?

LK: Any route map there needs to be a sense of fluidity, we welcome the welcoming of services opening again.

MO'N: It's about getting services fully operational and we need national guidance to support this.

Debbie Provan: If some surgeries are longer in duration, do we understand what the potential impact is upon outcomes and are we confident that we have minimised that risk as much as we possibly can through prehabilitation and enhanced recovery after surgery protocols? Similarly do delays present an opportunity for us to deliver prehabilitation and rehabilitation?

Dawn Crosby: I would reiterate Rachel's concerns around the quick and safe resumption of complex surgery with an ITU requirement. For pancreatic cancer patients, every day is vital and would urge that this need is prioritised in the next phase.

6.Research

Katie Robb, University of Glasgow University

There has been a pause on research and trials, there has been a similar drop across the UK and abroad. By April 2020, there were 95% fewer patients entering clinical trails compared to April 2019.

The Association of Medical Research Charities estimated £253m shortfall in charity research medial sector. For CRUK, it's estimated there will be a 25% drop in income leading to cuts of £44m in research. Medical research charities spend 87% on their funding in universities and the higher education sector has forecast a 90% reduction of economic output this quarter.

The same disciplines for cancer research are used in Covid-19 research, this means that there have been many researchers redeployed to the later.

Priorities for the recovery phase include:

- Government maintain their strong commitment to supporting science, research and innovation
- Cancer must be a priority on the public and research agenda
- Protect the researcher pipeline – early career researchers, carers, redeployed.
- Restarting research when safe and commensurate with capacity.

AS: A few people have noted their concerns about the redeployment and shift towards Covid-19 research from cancer research. Passing onto Ian Walker, of CRUK to discuss.

IW: CRUK fund around 50% of cancer research in the UK. Universities are closed across the UK, meaning that cancer research has stopped. Several CRUK scientists have been using their expertise to aid the Covid-19 efforts.

It's very clear there has been a significant impact on clinical trials for cancer research. Clinical trials for cancer patients may be the only therapeutic option for patients, therefore it is a critical element that has been stopped and this must be looked at.

There is a major challenge with patients' safety, including PPE and safe environments and capacity with researchers being redeployed. There is an appetite to restart this quickly, but it's likely to be closer to 6-12 months until this return to normal.

David Cameron, Clinical Director of the CR UK Edinburgh Centre: Comment about clinical research - the UK has stopped cancer clinical trials more than some other European countries. Even some New York hospitals, hit harder than Scotland, have continued to do clinical trials. However, the good news is that they are now starting to re-open in the UK with a priority being given to Covid-19 research.

Debs Roebuck: I wanted to ask what consideration has been given to including cancer patients in Covid-19 vaccine trials? To ensure cancer patients don't miss out/are not delayed in receiving access to potential Covid-19 vaccines & therapies.

Steven: The company (private pharma) I work for has run 50+ clinical trials at 17 hospitals across Scotland in each of the last 4 years. All that stopped with Covid-19 emergence and all our (and others) efforts went into researching treatments for Covid-19 and its complications. Covid-19 trials were set up in 2 weeks compared to over a year normally. Cancer studies were put "on hold" but have not disappeared. We are hopeful that the learnings from rapid initiation of quality studies in Covid-19 translates into the rapid restart of clinical trials in cancer in Scotland (and across the world).

Lesley Stephen, patient: I'm a patient living with metastatic breast cancer, 4.5 of those years on a phase 1 clinical trial at the Beatson. I've heard that phase 1 trials may be the last to open - is that correct? I assume because of funding issues, but it's very worrying for those of us patients who depend on trials to extend our lives.

Alison Tait, patient: Also, a metastatic breast cancer patient and a question from very much a layman's perspective, if researchers can work in the current environment on Covid-19 what is different to them working in that environment on cancer?

Becky Rice: Do we need to see this time as an opportunity to better integrate clinical trials into the healthcare system? So that their restoration, particularly for patients relying on clinical trials for their only treatment option is prioritised like other treatments?

IW: What we don't know and won't know for some time is whether we have been overly cautious. At CRUK, we have been proactive in reviewing this. We are pushing the system to learn from what we, and others, have done during this time. We must capture learnings from Covid-19 research, some of these Covid-19 trials have been set up rapidly but we've not had time to evaluate these yet.

The slower start to cancer Phase 1 trials will be monitored. We would agree that these trials are critical and often a final option.

Recruiting cancer patients on to Covid-19 vaccine trials may not be the best for patients.

LS: Are funds raised by the public for cancer research now being used for COVID research within, for example, CRUK? Or is the money supporting the CRUK Covid-19 research coming from a separate fund?

Jen Hardy, patient: Was the cancellation of cancer research a directive from the Scottish Government? Is it the Scottish Government that can give the go ahead to restart trials?

Julie Wardrop: Cancer survivor and previous cancer research scientist - also interested in how charity raised funds are being used re: covid v cancer.

IW: For funding, trying to understand the impact of Covid-19 on cancer patients will be for the benefit of cancer patients. Specifically, we have spent less that 1% of funding on Covid-19 research and we will discuss with Governments to recuperate this money.

Following Government guidelines, Covid-19 researchers are key workers while cancer researchers are not on this list. For these researchers to be active, they have focused their efforts on Covid-19 as they are unable to conduct cancer research.

GMc: How are we assessing risk both from the patient's perspective and from the service providers perspective regarding the decisions about whether the trials should be restarted or not?

IW: There are multiple tiers to risk assessment. There must be some sort of prioritisation for clinical trials.

AS: Question on key worker status on cancer research, with the easing of lockdown and people returning to work will this include cancer research?

IW: Over the course of the next 4-5 weeks we should be seeing lab-based research up and running. We also have to consider if there is a second peak that we do not stop research again.

7.CPG Business

AS: Prior to this meeting, we launched an insight survey to help inform today's discussion and provide evidence for a paper following this meeting. I would like to thank those that have been able to complete this, we've had around 20 responses so far, we ask that if anyone would like to participate the response date has been extended until COP Thursday 4th June.

A position paper will be drafted shortly after the meeting. We will circulate for comment before finalising. We will then invite the Cabinet Secretary to the CPG to discuss what we have heard during this meeting.

Minutes from the previous meeting were approved.

Due to Covid-19 and developing new ways of working, we were unable to hold our meeting scheduled for 17/03. Members were thanked for their understanding and we will update them with a virtual meeting agenda for our next meeting that is scheduled for June in due course.

The Cabinet Secretary was due to update on the cancer strategy and participate in a Q&A at our previous meeting in March. Unfortunately, the response to these questions have been delayed due to COVID prioritisation. Once these have been approved, we will ensure they are shared among members.

Close

Attendee List

Note: This is a list of individuals that accepted the invitation. We do not have organisations listed.

Seona Carnegie	Anna Morris
Marion O'Neill	Preston, Elizabeth
David Weir	Bruce, Lorna
Daniel Cairns	BROWN, Hugh (DALMELLINGTON MEDICAL
Erin McKee	PRACTICE (80202))
Charlotte Wickens	Lisa Cohen
Peter Hastie	Melanie Sturtevant
Roebuck, Deborah	Sandra Bagnall
Joe Woollcott	Lorna Porteous
Annie Anderson	Robert Music
Lesley Shannon	Debbi Jennings
Fiona Brown	Lauren MacRae
Shona Cardle	Christine Campbell
Leigh Smith	R Coron, Blood Cancer UK
Provan, Debbie	Ben Chiu
Kate Sanger	Macdonald, Neil Roderick
Bradley Price	Corbett, Vicky
Rob Murray	Samborek, Claire
Alice Russell	Elizabeth Hurst-High
Grieve, Kathleen	Lorna Patrick, BMS
Coombes, Martin	Graeme Rose
Carson F (Finlay), MSP	MACDONALD, Murdina (NHS FIFE)
Lorraine Dallas	Rosa MacPherson
Gillian Phillips	Alison Tait
Hamill, Fiona [JACGB]	Alikhani, Bobby
OROURKE, Donna (NHS HEALTHCARE	FAWCETT Tonks
IMPROVEMENT SCOTLAND)	Dawn Crosby
Lesley Stephen	Rachel Downing
CAMPBELL Christine	Tom Martin, CRUK Ambassador
George Davidson	Briggs M (Miles), MSP
Claire Headspeath	Michael Cousins
Thomson, Evelyn	Rebecca Devine
Mathers, Marie	Brodie Pledge
CAMPBELL, Lindsay (NHS GREATER GLASGOW &	Rebecca Rice
CLYDE)	Elaine Douglas
Duncan Sim	Lesley McGregor
Corrie Drumm	Jen Hardy
Susie Cooke	