The APPG for Radiotherapy

Evidence submitted by APPG-RT to Health and Social Care Committee for 1st May 2020

Radiotherapy – The treatment option to avoid unnecessary collateral cancer deaths during Covid-19

The APPG for Radiotherapy undertook a rapid mini-Inquiry into Radiotherapy and Covid-19 emergency

Executive Summary

It is now widely accepted that the UK will mourn the loss of more lives from cancer, as a result of the understandable focus on Covid-19, than we are able to save from the virus, unless urgent and co-ordinated action is taken by the Government and the reality of the situation fully understood.

This tragic possibility has been increasingly featured in the media and has been raised with increasingly frequency and urgency by various politicians. However, what has not yet featured is that it simply doesn't have to be this way. The double tragedy of losing as many (or more) of our citizens to cancer than we save from the virus is not an inevitability. There are ways to avoid this without detracting from the overall Covid-19 response. Principal among amongst these is to boost radiotherapy services, rather than deplete or constrain them, as is currently the case. Surgical options for cancer treatment are reduced as these require an Intensive Care capacity which is now redeployed to the Covid-19 response. Chemotherapy and immunotherapy options are reduced as they tend to disrupt the immune system. Radiotherapy is the treatment that can, and should, be more widely deployed during the pandemic. Many people are surprised to learn that 1 in 4 of the population will need radiotherapy at some point in their lives and that it is already necessary in 4 out of every 10 cancer cures. It is already used in 50% of cancer patients and during the Covid pandemic it is now becoming a "go to" treatment for an increased range of tumours.

The Government and senior NHS managers have a unique opportunity to prevent a very significant amount of so called 'collateral' cancer deaths. To do this, they need to recognise the unique characteristics of radiotherapy, that make it still viable during the pandemic and create a National Task Force encompassing the whole of the NHS radiotherapy sector, industry, and the private sector. Most importantly of all, they need to put as much political and managerial energy and focus

into this as they into the overall Covid response. This should include ministerial responsibility and oversight, developing a national strategy with an effective operational delivery team. Radiotherapy should be prioritising as a critical service, bureaucracy sweeping away to allow rapid introduction of advanced techniques, and the availbale IT and technical solutions funded and rapidly introduced. This can be done and should be done.

The NICE NG162 28th March guidelines have completely disrupted the radiotherapy service by recommending avoiding and delaying radiotherapy treatment. A flash survey in the last 4 days by the charity Action Radiotherapy of over 300 radiotherapy professionals found the following:

- Only **32%** of front-line staff felt they had access to full and appropriate levels of PPE
- 50% reported between **30-60%** of patients had their radiotherapy treatment disrupted
- **35%** were not able to introduce advanced radiotherapy with SABR to shorten treatment and **24%** reported poor or very poor IT.
- Unused machine capacity has increased **5- fold**, with some centres reporting 6 hours per day spare machine
- The percentage of prostate cancer patients (the lowest priority in the guidelines) who were already in the system who had their treatment actively delayed ranged from **30-100%** with the time delay being planned for **2-6 months**
- **24%** felt radiotherapy services were severely undervalued and **40.2%** undervalued by senior policy makers in Government and the NHS
- **69%** felt that NHS managers do not understand the impact of the current situation on the radiotherapy workforce

Far from being a service that is being prioritised and boosted to play a critical role in averting the double tragedy of large numbers of avoidable 'collateral' cancer deaths, the current UK radiotherapy service is being stripped of some vital resources, machines are lying underused, staff are struggling with a severe lack of PPE and the professionals who are working heroically are reporting low morale as they feel undervalued and that their ability to avoid these unnecessary deaths is not being harnessed. This is evidenced by the following quotes given as free text in response to our survey. As follows:

1. 'The radiotherapy service (and wider cancer service) has been completely overlooked in the current crisis, and lives will be lost in the longer term as part of this'
2. …'the street cleaners in China, who are spraying the streets with disinfectant have better PPE than I do. The government is expecting us to risk our lives and the lives of our families to do our jobs…'
3. ……'it is becoming apparent that labelling NHS workers as "heroes" appears to be a strategic way of priming the public to accept the healthcare worker risks, infections and deaths as a necessary and heroic wartime type sacrifice instead of the reality that no worker needed to be at risk if maximum level PPE was provided to ALL NHS workers'….

4. …..' Asking our doctors to drop days doing their planning work to work on the covid wards results in further delays for their cancer patients…'

5. ….' Radiotherapy is a critical component of curative cancer treatment for many patients and one of the safer treatments to deliver at the current time. It is vital that resources are directed to ensure that treatment can continue as minimally disrupted as possible'….

6. ….'Act now before it's too late'……'Do not side-line us'……'Please pay attention!'... 'Do not delay it, the backlash will be worse than that from the Covid19 Virus'

Evidence from other countries confirms that boosting and protecting radiotherapy services is indeed a very successful way to avoid delaying large numbers of cancer treatments. Recent data from China suggest, cancer patients receiving radiotherapy are at no greater risk of dying from Covid than people that do not have cancer.

The need for action to harness the potential of radiotherapy to avoid very large numbers of avoidable cancer deaths is urgent. It is frustrating that the findings of the APPG-RT inquiry of 2019 were not addressed, the recommendations in the APPG-RT manifesto of 2018 not acted upon. We were concerned that delays in not modernising radiotherapy for the past seven years was likely to cost cancer patients lives, but this is now almost certainly the case.

Patients are already suffering from both the medical and emotional consequences of treatment disruption or cancellation. The APPG and its secretariat (Action Radiotherapy – the leading charity in this area, with a strong reputation for leadership on the role of radiotherapy in cancer treatments both during this unprecedented time and during more normal times), stand ready to work with the Government, NHS management and other stakeholders.

Background

The APPG for Radiotherapy were contacted by, and have been working with, the radiotherapy community since the start of the Covid-19 emergency. There are concerns from patients, medical professionals, industry, MPs and confirmation internationally that delays and disruptions to treatment will result in patients unnecessarily dying from cancer. Frustratingly, there is insufficient awareness at senior NHS and political levels that these deaths are avoidable without detriment to the overall Covid-19 response and that the most effective way of achieving this is by prioritising and boosting radiotherapy services. Indeed, it is evident that radiotherapy is not being prioritised as a critical service during this time. Evidence has been gathered from a number of sources for this rapid mini review and can be found at https://www.appgrt.co.uk/publications

Background to Radiotherapy

RT is treatment needed in around 50% of patients with cancer and is needed in 40% of cancer patients who are cured, being second only to surgery in its curative impact. However,

it has to date been seen by many as a 'Cinderella' medical speciality to date, chronically underfunded and undervalued. NHSE has failed in its 2014 plans to modernise the service so it can benefit from all the IT and technology that is now available for this high tech, multidisciplinary speciality. There is no commercial lobby and the speciality has no overall effective unifying leadership. In response to this dire position an APPG for Radiotherapy was formed in 2018 and their manifesto has attracted supported from across all parts of the community. However, those who hold the funding and control the commissioning appear to have turned their back on the necessary required advances that could, and should, have been made. They appear to have been in denial about the severity of the problem and have failed to undertake the simple and doable steps needed. Instead, many sections of the service believe they have prioritised bureaucracy, process and delay over science, economics and patients' lives. This has led to a service unready to respond as it should to the Covid-19 crisis and unnecessary cancer deaths. This is not acceptable, and the Government must take immediate action to reverse this and get on with saving lives - not losing them.

1. Patient concerns

Concerns from patients have been expressed via a number of channels;

- **(i)** Directly to MPs.
- **(ii)** Via the charity Action Radiotherapy
- **(iii)** Via other charity hot lines, twitter and main-stream media stories and news bulletins.

Patients are concerned and incredibly anxious about delays and disruptions to their treatment. Some patients feel that the changes, due to Covid-19, are leaving their treatment plans unnecessarily compromised, with one patient describing themselves as feeling "hopeless and low". One patient phoned into a department with suicidal feelings.

The patients that are being treated have voiced concerns around the lack of PPE for staff. They are nervous that they are at risk of contracting the disease, which would mean that their treatment would then be delayed posing a risk to their recovery or long-term survival. Some patients are also finding it difficult to attend their appointments due to the difficulties in transport. Anecdotally, a few cancer patients have received mixed messages around whether they should attend for their treatment due to self-isolation rules.

2. Professional's concerns

Evidence has been received from:

1. Individual professionals from all the disciplines involved in delivering the RT service
2. Edinburgh group assessing international emerging literature on cancer and Covid-19

3. Modelling group from King's College London, Institute of Cancer Policy and The London School of Hygiene and Tropical Medicine are leading with the UICC on the effect of the response to the pandemic and cancer and in particular radiotherapy
4. A survey of professionals carried out by the charity Action Radiotherapy

A clear picture is emerging of a service given inconsistent and patchy guidance with senior NHS managers having insufficient knowledge of the service to assist appropriately. Concerns expressed included:

1. Inadequate provision of PPE.
2. Inadequate IT resources.
3. NICE guidance that needs urgent updating if we are to avoid a catastrophic backlog of patients.
4. A failure by policymakers and senior management to understand the damage done to the sector, and its ability to cope with the consequences of the current pandemic by the years of postponement of modernisation and investment.
5. A perceived lack of willingness to invest in the service, sweep aside constraints such as the restrictions on centres that are able to use advanced radiotherapy even though they have the machines capable of delivering it and replace internal tariffs that incentivise centres to treat 'less effectively, more often' rather than 'more effectively, less often'.

3. Industry Concerns

Industry has expressed a range of concerns about the delays in introducing modern technology and IT. Industry have expressed concerns that their discussions with NHSE about modernising radiotherapy with IT have been actively postponed. Industry groups are frustrated that NHSE cannot see that improved IT is a solution to many of their Covid-radiotherapy challenges, and instead are using the crisis as an excuse to abandon talks.

The radiotherapy Industry submitted a join letter willing and keen to work with the UK government on IT and technology solutions. They summarised a number of areas where they have products, many already approved by the NHS, ready to go to transform the safe and complex working needed for radiotherapy.

4. Evidence from MPs

MPs have been involved in a number of ways, including as follows:

1. MPs, as individuals and on behalf of their constituents, have expressed concern about the delays and disruption to cancer services and the poor communications.
2. A letter has been forwarded from Diana Johnson MP, confirming rather than accelerating commissioning of SBRT, NHSE are using the Covid-19 crisis as a way of delaying it, despite SBRT being recommended within NICE guidelines.

Increasing local access to SABR remains an important objective and it is planned to continue to expand the number of NHS radiotherapy providers offering it from 26 to all 51 over the course of 2020-22, subject to Trusts wishing to offer it.

At this stage it is not possible to be definitive about the impact of Covid-19 on the expansion programme. However, at the very least, it is likely that less progress will be made during 2020 than originally planned. Where this is the case, every effort will be made to support Trusts to make up any lost ground in 2021.

The APPG for RT has not had a response from the Secretary of State regarding their letter of concern sent on 4th April 2020.

5. International experience

The APPG-RT note the recently formed Global coalition for Radiotherapy which was formed to link professionals, societies, agencies and industry to provide rapid communication of the experience of radiotherapy delivery during the pandemic including data, solutions and research https://www.actionradiotherapy.org/global-coalition. The group's first meeting included 41 of the major radiotherapy professional groups and societies from around the world and it has already received first-hand experience of how the radiotherapy service in Wuhan, China reacted effectively to the crisis. Radiation related research is being developed and industry stimulated to focus and share their IT and technology solutions.

Recommendations

It is a matter of some regret that NHSE seemed unable to respond to the APPG for Radiotherapy manifesto or Inquiry of last summer. If some of the problems highlighted at that time had been addressed, we would be in a position to save more lives now. The evidence gained suggests that NHSE control of commissioning radiotherapy is going in the opposite direction from what is needed. Radiotherapy is the major front- line curative treatment in this crisis and needs to be boosted rapidly, not provided with more delaying bureaucracy. Not to so is totally unacceptable and will cost many cancer patients' lives unnecessarily. Our recommendations include:

1. Awareness and acceptance of current situation

The Government must be aware that RT is needed in 50% of patients with cancer and this need is now rising with the pandemic as some treatments have to move away from surgery, immunotherapy and some chemotherapy. It is needed in 40% of cures, and this need is now increasing. The Government must be aware that the UK RT service was in a perilous state before this pandemic due to a failure to modernise it (see APPG-RT inquiry). All the recommendations in the APPG-RT manifesto had they been introduced would have addressed many of the current problems and would be saving lives now. When presented to ministers these proposals were judged as making economic sense

and were supported. The Government must act now and transform the service and not delay any further; this can be done- it simply needs a will to do this and to remove the multiple artificial blocks the NHS has put in the way and that had been delaying this transformation, a modest cost effective investment and an organisational structure fit for purpose. What has not been done in last 7 years needs doing in next few months.

2. The need to RT to be designated a critical service

The AR survey provided live data and so reflects the service delivery for patients already in the system i.e. before the drop- in cancer referrals. Therefore, all the current disruption is due to changes which resulted from the recommended by NHS (with only anecdotal evidence of patients preferring not to attend). This situation is currently unsustainable, and a backlog developed in a service which usually runs at capacity. Therefore, guidelines have to be rapidly reviewed this week. Data from China and USA and emerging data from UK suggests cancer patients are not necessarily at increased risk of dying of cancer and the Chinese data suggests curable cancers (stage 1-3) are no more at risk of dying form Covid-19 than general population and radiotherapy treatment is not associated with an increased risk of dying of Covid-19. This would entirely fit with our understanding of the pathology of Covid-19 and the effect of radiotherapy. Therefore, there appears no reason currently for curable cancer patients to be not receiving their radiotherapy. The policy of avoid and defer in the NG 162 28 Match guidelines for radiotherapy must therefore be urgently revisited and radiotherapy classified as a critical service that needs additional support to delivery treatment during the pandemic.

3. National action plan

A national coordination of RT service (62 centres) is requested urgently needed as current devolving down to individual Trust is not working (lack of understanding by senior management) and networks (ODNs) are not yet functioning and the complexities of maintaining access to RT significant and there is a postcode lottery now with some centres. RT service is delivered by multiple high- tech professionals with complex technical work- flows on large fixed machines with patients having to travel in daily for multiple treatments over several week. The current NHS structures are inadequate to deliver what is now currently needed in this process. The advantage however is that there are only 62 RT centres in the UK and around 5000 highly trained and committed professionals and the solutions are mainly logistical and IT based so completely doable if they are effectively coordination. If the Nightingale centres can be organised in 2 weeks so can this, but it will need the right people put in charge with the right remit with a modest amount of upfront funding. Not to do this will result in a catastrophe in a few month's time when RT services are overwhelmed, and cancer patients start to die unnecessarily. Radiotherapy services will need to look very different until the pandemic and its after- effects is completely over next 2-5 years.

The current radiotherapy principles advised in the pandemic is RADS: remote, avoid, defer and shorten. This should be refined and there should be as in all top- class organisations: clear effective leadership with accountability, focus on delivery (patient safe treatment and increasing cure rates), investment in IT and modern equipment, and safe and supportive clearly communicated working practices (for staff and patients)

To make these changes we immediately need:

(i) A minister with responsibility and accountability for RT working with a group of experts with an effective leader for organisation/delivery

(ii) Bureaucracy and artificial funding constraints to be swept away to allow fast action and direct accountability.

(iii) A national standard of practical working in line with international advice to be introduced and enforced for all RT departments addressing their complex needs around adequate PPE, testing of staff and patients attending daily, decontamination of equipment, safe working distancing, segregation. This will protect staff and patients and allow a full service to resume.

(iv) National logistics around daily patient transport need addressing where needed as local volunteers can no longer provide this safely

(v) The advanced RT techniques and IT networking currently available which have been actively delayed for so many years need introducing nationally immediately. The machine manufacturers have written a joint letter agreeing to work with the government and NHS to assist in the rapid introduction of the IT and systems which are available for both training and delivery. This will be the single best thing to allow safe remote working for staff, reduced visits for patients, improvements in survival and go somewhere to address the imminent capacity issues in terms of staff and machines. It is now totally unacceptable for the NHS to delay such modernisation any further.

(vi) Rapid and effective feedback systems to see what is working and what is not

(vii) Sort term planning: Collaboration with the private sector for future capacity and travel issues for common cancers but also for advanced techniques such as protons and some image guided techniques.

(viii) Medium term planning: Technology and machines need keeping up to date even more so. £140M was needed as of last December just to catch up with old out of date machines in England ; a central coordinated machine replacements programme is long overdue which can support the staff and patients and this should include funding the approx. ten asked for satellite/networked new centres that have been requested over the last ten years and well as bringing forward new technology e.g. consider a network of new image guided technology which allow non- invasive most precise treatment which will significantly reduce side effects and reduce subsequent need for NHS care. Workforce issues need solving.