

Annual Progress Assessment on Achieving World-Class Cancer Outcomes – October 2017

Prepared by the independent National Cancer Advisory Group for the Secretary of State for Health and the CEOs of: NHS England, Public Health England, Health Education England, Care Quality Commission, NHS Improvement, National Institute for Health and Care Excellence

A. Summary

This is NCAG's assessment of progress on delivery of the Cancer Strategy over the last 12 months, with some suggestions for national decision makers on priorities for the coming year. In summary, we welcome the continued focus, and priority, being given to cancer by the NHS and Government at a national level. The recent publication of 'Next steps on the NHS Five Year Forward View' reiterates this commitment, as does the engagement from the National Cancer Director across all of the strategic priorities the Strategy set out.

At its core, the Strategy is an agenda for transformation. To deliver this agenda successfully, in an NHS facing a multitude of challenges, including significant workforce shortages, requires a sustained programme of activity. There are a number of areas of progress we want to celebrate, building on our comments from last year's commentary:

- **Transformation Funding (TF):** we strongly welcome the £200m investment into cancer transformation that is now being deployed via the Cancer Alliances. Targeted funding, focusing on changes that will deliver the greatest patient benefit, is essential if we are to meet the ambitions of the Five Year Forward View and Strategy by 2021;
- **Patient experience:** there has been good stakeholder engagement in this area, in particular in developing mechanisms to measure experience in Children, Teens and Young Adults. Work to address issues around access and equality, on the back of insight from successive Cancer Patient Experience Surveys, is also welcome;
- **Quality of Life metric:** progress in this area has been consistent, with research and stakeholder involvement embedded in the development of a national pilot that commenced in April of this year;
- **Radiotherapy:** there has been a concerted effort to redesign the radiotherapy service through networks, coupled with welcome investment in the replacement and upgrading of linacs. This is an area that had been overlooked for a number of years, and therefore we applaud the engagement with the community and the investment in this area.

The most recent data available demonstrates that we have seen an overall improvement in key outcome metrics, which is remarkable given current pressures. However, improvement has not been seen in all areas, and there remains a step change required in the years ahead if we are to meet the trajectory set out in the Strategy.

The unanimous view of NCAG is that severe workforce deficits, across key stages of the cancer pathway, represent the single biggest barrier to delivering world class cancer care for patients. It is impossible to overstate how much more impact could be made in transforming outcomes if we had a properly resourced workforce, in terms of both capacity and skills. We are therefore extremely disappointed that, despite highlighting this issue in the Strategy and in the two years since, there has been little tangible progress. Our understanding is that a plan is now in development, due for publication later this year. We urge you to ensure that this plan is thorough and fully funded, setting out actions that will be taken by the end of the financial year to immediately address shortages, in addition to longer term planning to bolster the workforce and ensure it is fit for the future.

B. Progress Against Strategic Priorities

Spearhead a radical upgrade in prevention and public health

We welcome the publication of the Tobacco Control Plan, and the broad ambition to become smokefree, and share the concern regarding the health inequalities associated with smoking. However, to deliver the plan and realise its ambitious five year targets, there needs to be adequate funding. A sustainable solution for funding vital local public health services is desperately needed, notably smoking cessation services, which are highly cost-effective.

While a childhood obesity plan has been published, there has been little action to tackle obesity in the adult population. A year on, we believe the Government should bring together key partners to consider where further action is necessary and possible. Specifically the Plan did not make provisions for marketing restrictions and we believe consideration of these should be the next step.

Drive a national ambition to achieve earlier diagnosis

We recognise that the NHS is under significant pressure. A number of performance targets are being missed and as the population continues to grow and age, pressures will only increase. Cancer services are not immune to this, as we have seen in the routine failure to meet one of the cancer targets (62-day wait), although we know this is now being addressed with urgency.

Early diagnosis is clearly a priority for the national programme, and we welcome progress on establishing the 28-day standard and the new pathways for earlier diagnosis being tested through Transformation Funding. However, progress in this area is of real concern as workforce shortages are likely to undermine efforts and limit the success of interventions. Several new initiatives and funding commitments have been announced, which we welcome. Work should be focused on evidence-based action which shifts the stage of diagnosis (as well as speeding it up).

The continuation of the Be Clear on Cancer Campaign is welcome, especially as this demonstrates the value of continuing to invest in proven initiatives over a prolonged period of time. However, we are uncertain as to the approach the initiative will take over coming years, including how it can be better aligned with the service to mitigate against capacity pressures, and would welcome clarity.

We welcome the commitment to introduce new pathology tests to improve bowel screening and cervical screening. These tests are being rolled out over the next couple of years. However, their impact could be undermined because of workforce deficits:

- Staff shortages are currently having a detrimental effect on cervical screening, where the cytologist workforce is severely depleted in anticipation of the change to HPV as the primary test;
- The Faecal Immunochemical Test (FIT) is expected to be introduced into the bowel cancer screening programme at a relatively low sensitivity because of limited endoscopy capacity. We urge NHS England and Public Health England to plan to increase the sensitivity annually to achieve the optimal level by 2021 as additional endoscopy capacity is made available.

Establish patient experience as being on a par with clinical effectiveness and safety

Putting patient experience on a par with clinical outcomes is a pivotal ambition of the Strategy. As noted above, stakeholder engagement in this area has been strong and there has been progress on aspects of access and equality. Nonetheless, patient experience has started from a lower base than

other areas and, two years in, we fear this still remains a “nice to do”, as opposed to being engrained in the mindset, governance structures and clinical practice of Alliances.

We welcome the creation of the patient experience metric, and its inclusion in the cancer dashboard and the CCG IAF. The CPES continues to be a valuable source of insight into the experiences of people affected by cancer in England. It is essential that assurance is given by Government that this vital survey will be continued, given uncertainty following the National Data Guardian Review. Furthermore, linkage with other datasets, such as the Cancer Outcomes and Services Dataset (COSD) and the Systemic Anti-Cancer Therapy Dataset (SACT), would enable richer insights into patients’ experiences of treatment and care. It is currently unclear what progress has been made in this area, and when/if this information will be available for use.

One of the main themes to come from patients when consulting on the development of the Strategy was the need to improve communication from the NHS with them, particularly as they navigate across different providers. The Strategy recommends that: ‘from confirmation of a diagnosis, all consenting patients should have the ability to access all test results and other communications involving secondary/tertiary care providers online’. We think this could be transformative, not only in speeding up diagnostic pathways and improving how the service communicates with patients, but also in driving efficiencies by reducing the number of repeated appointments due to lack of access to scans or pathology reports. We would like to see tangible progress on this in the next twelve months.

Transform our approach to support people living with and beyond cancer

Whilst we have seen considerable progress on developing a new measure of Quality of Life, progress on other key areas of this strategic priority has been slower.

National rollout of the Recovery Package and Stratified Follow-up Pathways has been slower than anticipated. While good efforts are being made towards delivery in some local areas, crucial TF to support implementation has been delayed. Whilst we understand, and welcome, the focus on resolving breaches of the 62-day target, this should not be at the expense of initiatives that are integral to improving patient outcomes. We have been reassured that an assessment will be made of the impact of delays to release of TF, and would urge that plans for the coming year seek to ensure that we remain on track to provide access to a Recovery Package for everyone with cancer by 2020.

Although the Strategy recommended rollout of stratified pathways for breast cancer, with pilots to be carried out for colorectal and prostate cancers, we agree with NHSE’s approach to gather evidence to support rollout of colorectal and prostate stratified pathways without further pilots if possible. However, this research has been delayed and is only now starting. We hope that this work will progress with pace.

We would encourage better data collection on the roll-out of the Recovery Package, and perhaps its inclusion on the Cancer Dashboard, as this would facilitate its monitoring and evaluation by Cancer Alliances. For example, we know from the Cancer Patient Experience Survey that the number of breast cancer patients who receive a care plan is low and there is no insight into the number of patients attending Health and Wellbeing events, which could make a big difference in preventing recurrence and secondary breast cancer. We would encourage better means to monitor and evaluate the impact of the different elements of the Recovery Package for those who receive it as well as those who receive a care plan. In addition, the Recovery Package should be adapted to meet the needs of people with secondary cancers.

Overhaul processes for commissioning, accountability and provision

The foundations for embedding transformation across the country are now in place in the form of a national cancer team and regional Cancer Alliances. It is positive that their establishment has been a priority, and we are encouraged by the increasing amount of joint working from the Arms Length Bodies to ensure that Alliances are appropriately directed and supported, for example through the work of PHE to develop analytical support. It will be important to ensure that all Alliances continue to be strongly supported by national and regional teams to deliver change and provide uniformly high standards of care across the country. Alliance delivery plans currently highlight considerable variance, from their strategic approach through to the level of patient and third sector involvement. This risks exacerbating geographical variations that already exist. There needs to be adequate support in place from the national bodies to drive transformation and improvement, with a shift in emphasis to sharing best practice across the country and bolstering wider engagement from across the cancer community.

The announcement of substantial Transformation Funding (TF) in December 2016 was very welcome. Providing additional resource to drive targeted action in selected strategic priorities is a clear signal about the scale of change that is expected to be delivered by Alliances. Release of some of this funding was delayed due to continued breaches of the 62-day wait metric across the country. We urge no further delay in release of this funding to drive the much needed improvements. It is important that the impact of this funding is properly evaluated.

The Arms Length Bodies should work together, through the National Cancer Director, to tailor and focus support, and provide a clear steer on priorities, to drive improvement across the country – building on the positive work underway to set up a community of best practice. This should include the dissemination of relevant guidance, whether from NICE or the clinical groups convened by NHS England.

Our experience is that the Clinical Reference Groups of direct relevance to cancer are working well and therefore should be more integrated into the work of the programme. We are pleased that the Clinical Advice for the Provision of Breast and Lung Cancer Services was disseminated via Cancer Alliances in August (with the Advice for Bowel Cancer Services expected in November), following the work of the relevant Clinical Expert Groups. We would encourage a commitment to using this Clinical Advice, with appropriate support and resource for the Clinical Expert Groups. The implementation of best practice pathways will advance breast, bowel and lung cancer outcomes towards those envisaged in the Strategy.

It is essential that the Cancer Alliances work with STPs to ensure an integrated approach to cancer services. We also strongly encourage NHS England and the Alliances to proactively involve patients in development and implementation of the support needed to transform performance.

Early progress was made in the development of the cancer dashboard, which has proven to be an effective tool. We should now look to enhance this offer and ensure there is a focus across the NHS in capturing the data needed to drive further change. For example, data collection on recurrent and secondary breast cancer by all NHS Trusts in England was mandated in 2013, with a view to this being rolled out for all secondary cancers. However, there are still no data available on the number of people diagnosed with secondary breast cancer in England each year. In addition, the dashboard currently only allows for measurement and comparisons for the four most common cancers. This excludes just under half of all cancers diagnosed in the UK and more than half of all cancer deaths in the UK. We suggest prioritising access to data (which already exists) for rare and less common

cancers to ensure that these cancers are represented. At the very least, there should be an option to select data that excludes the four tumour groups already represented to provide a top-level indicator of the level of care being delivered to those with rare and less common cancers.

Make the necessary investments to deliver a modern-high quality service

The lack of a clear plan to address current and future issues within the cancer and diagnostic workforce is the most significant barrier to the successful implementation of the Strategy and remains our largest area of concern. Adequate staffing levels and the right mix of skills is essential to be able to implement many of the more ambitious recommendations. The significance of this across the pathway cannot be underestimated. This needs to be addressed with urgency.

The Implementation Plan (May 2016) announced that Health Education England would develop an action plan to address current capacity issues in cancer services by September 2016 and lead on developing a vision for future services by March 2017. We now understand that this plan will be in place by the end of 2017. We strongly urge that it is fully funded, has Government commitment, and that action is taken by the end of the financial year to start implementing it.

Whilst we appreciate that access to new cancer medicines was not one of the main recommendations of the Strategy, and is therefore not a priority for the TB, we would nevertheless welcome an update on how the changes to the CDF, together with the introduction of the Budget Impact Test, are impacting. In addition, given the recent publication of the Life Sciences Industrial Strategy, we feel there is an opportunity for a national conversation on the future of access to cancer medicines – and the role that approaches such as outcome-based pricing may play.

Finally, two years into the programme of transformation, and with the recent publication of the Life Sciences Industrial Strategy, it is timely to reflect on the need to ensure that the NHS continues to support world-class cancer research. There are many cancer questions to which we do not yet know the answers, and outcomes will only continue to improve if we are in a strong position to evaluate new interventions. Crucially, this includes giving every cancer patient the opportunity to find out about relevant research studies.

C. Effectiveness of the programme

The significant amount of resource, across the Arms Length Bodies, into the cancer programme of transformation is welcome. However, it could be further enhanced to give greater support to the National Cancer Director.

First, we want to emphasise the importance of having the right resource and approach within NHS England, Public Health England and Health Education England to deliver the Strategy, in terms of capacity and leadership, and openness to collaboration. The National Cancer Director has been instrumental in the delivery of the programme, but must continue to be supported with senior leadership from across the ALBs. There is a significant wealth of expertise across the cancer sector, which was instrumental in developing the Strategy; this could be better leveraged as it is being implemented. We remain concerned that patients' voice and experience is not being built on. For example, Cancer Alliances should be actively encouraging the development and integration of patient leadership in the change process to truly embed transformation in the service.

Secondly, it is apparent that there is a considerable amount of work underway that many key stakeholders are not aware of. A coordinated and sustained approach to stakeholder engagement and communications would enhance this, and enable a more productive dialogue with the service, third sector, professional bodies and patients. We would like to see publication of Alliance plans and clearer communication of the timescales for implementation of all the recommendations in the Strategy, not just those for which implementation is under way. There is little visibility on those recommendations which would particularly impact on the outcomes of people with rare and less common cancers and those that are hard to reach or seldom heard.

D. Background – the National Cancer Advisory Group

The independent National Cancer Advisory Group is comprised of representatives from professional bodies, the third sector, and patients. Through the organisations and extensive networks represented it is able to access expertise and insight into how the Cancer Strategy is being implemented. This informs our advice to the national Cancer Transformation Board (TB),

Harpal Kumar - Independent Chair
Charlotte Beardmore - Society and College of Radiographers
Nicola Beech - Royal College of Nursing
Emma Greenwood - Cancer Research UK
Johnathan Joffe - Royal College of Physicians
Mark Kroese - Faculty of Public Health
Kate Lee - CLIC Sargent
Suzy Lishman - Royal College of Pathologists
Jane Lyons - Cancer52
Delyth Morgan - Common Cancers Coalition
Paul O'Flynn - Royal College of Surgeons
Linda Pepper - patient representative
John Reeve - patient representative
Richard Roope - Royal College of General Practitioners
Nicola Strickland - Royal College of Radiologists
Fran Woodard - Macmillan Cancer Support

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