

All Party Parliamentary Group on Cancer, Britain Against Cancer, Westminster, 8 December 2015

This was hosted by the All Parliamentary Group on Cancer. Attendance was good and delegates included Clinicians, Health and Social Care Workers, Commissioners, Policy makers and Patients.

MORNING SESSION

Opening speech provided an update on the activities of the group in the past year and the cancer strategy. It also highlighted that the survival figures in the UK are 13% lower than the best in Europe. Early diagnosis is still extremely important and is key for successful treatment especially in rarer cancers. Local levels CCG's need to promote and plan for earlier diagnosis. It was also highlighted that there are 1 in 4 people living with cancer that have on going disabilities following cancer treatment and these people need better support to live well with cancer and help to overcome disabilities. Statistics have shown that patients diagnosed via Accident and Emergency twice as likely to die from cancer than patients diagnosed by other routes. This is probably due to later presentation, resulting in the need to attend Accident and Emergency.

Sean Duffy and Sir Harpal Kumar gave a 'conversation style' presentation and invited input from the audience. Both presenters gave an overview on their areas and challenges faced going forward. The presentation covered the increase to 27 million people in England that will get cancer. Significant improvements have been made with survival doubling in the 10 years since first strategy was published. Despite these improvements, England still lacks behind other countries. This highlights the need for cancer strategy to provide framework for focusing on the right areas for improvement. The strategy has consulted with a wide range of stakeholders, with over half of the input being from patients. The input resulted in 96 recommendations grouped as 6 priorities:

- More investment is required in diagnostics. Radiotherapy equipment currently has no committed funding. Designated funding could save 30,000 lives a year by 2020.
- A collaborative approach that includes NHS England and PHE Health Education. Monitor and NHS E policy impact on incentives are required to deliver outcomes as well as a change in mindset for delivery.
- Single source of intelligence to drive services – developing dashboard and utilised at every level, including data within it. Dashboard information is currently important but data contained within it is insufficient.
- Diagnostic capacity needs heavy investment in order to deliver early diagnosis.

- 28 day metrics to remove existing gaps and a move away from referral waiting times. This could knit primary and secondary care together, instead of the hand over process that currently exists.
- Long term effects of cancer and recovery package. Issues exist across whole care pathway to address short term and long term deficiencies. Short term deficiencies need to be addressed now to meet 5 year challenge.

Cancer alliances are the cornerstone of enabling the strategy delivery. Accountabilities for the cancer strategy will act as drivers, including addressing rare cancers. The role of PHE is about preventing illness, whereas NHS England is concerned with taking care of individuals when they become ill. There is a degree of disconnect between local and national initiatives.

Patients are at the centre of pathway in all parts of the strategy. However the benefits of the strategy does need to be measured, published and paid for. Cancer patients have a role – cancer alliances bring together local level all inclusive groups/alliances which should not be set up without patients. Metrics for patient experience are vital, such as longer term outcomes and quality of life etc. Patients must also play a role in Arms Lengths Bodies. Multidisciplinary diagnostic models can provide new pathways.

Expert Panel Discussion, followed the presentation. Surprisingly, primary care representation was not included. This was resolved by the co-opting of the GP that highlighted the deficiency to the panel. Questions from the floor covered;

- Priorities for 2016
- Responsibilities on patients
- GPs for diagnosis
- Data-sharing
- Issue of investment and flexible ways for budgeting are needed to help make savings

A lot of data exists, from treatment of cancer patients, all of which flow to cancer registration system. Part of the cancer strategy is to bridge gap between intelligence and outcomes. Access to data needs to be addressed. Data linkage to the research community is needed to gain insight. This also means involving patients to ensure understanding of the data required needs to be collected and shared without exploitation. Concerns were noted that restrictions on use of data may be so restrictive that delivery of benefits are not fully realised. It is more difficult to obtain good quality data on rarer cancers.

Improvements in transition of care needs to be seamless between all care providers and organisations:

Campaigns: The cancer strategy highlights the importance of early diagnosis and outcomes, and what needs to be done for education. Campaign methods need to be considered, which involves getting into schools to talk about cancer and help improve information and awareness of cancer.

This will help empower individuals to be in control of their own care and health. Data can be picked up within weeks of a campaign starting.

Doctors Training: It is also acknowledged that Doctors train in diagnostics rather than prevention. Improving doctor's educations could help provide opportunities to enquire with patients about improvements in lifestyles. They also need to get better at understanding patient concerns, to access information on new treatments, and the role of the cancer drug fund.

Education and Cancer pathway: Patient voice needs to be incorporated at regulatory and local level. Patients often present with synchronous disease. Systems may require redesign to incorporate the way studies are designed and knowledge sharing. Small centres should be able to link with big centres to improve access to treatments. Data could be available to help identify the cancer incidence per practice, which could then help promote a learning environment for the patient. Significant event analysis taken in Wales could help identify data requirements that would help deconstruct the data, and to identify where responsibilities lie for late diagnosis. This will in turn help focus educational needs.

Cancer Outcomes and Equality: A collaborative approach is needed with patients as the patient voice, including children and young persons, needs to be central to pathway early on for innovation. The cancer journey from the patient perspective needs to be understood from the pre diagnostic phase through diagnosis and treatment in order to incorporate outcomes that matter to patients.

A question from the floor by Dr Adrienne Morgan, Chairman ICPV: Dr Morgan highlighted concerns that existed following the care.data issues which resulted in lots of patients opting out of data sharing. 900,000 patients opted out of data being moved elsewhere in the system. This could significantly impact decision making abilities. *"Lack of data use can cause patient deaths but over-use of data will not"*.

National Cancer Director, Cally Palmer Leading Implementation for Cancer Strategy

Noted that deaths from cancer are decreasing but this is not occurring quick enough. The task ahead is about connecting up pathways, supporting patients through the cancer journey and early diagnosis. It is considered mission critical that fewer people get cancer, have better outcomes and better experience. Collaborative working across boundaries for the benefit of patients with better use of resources and funding focused where it can have best effect. One aim is to have quicker implementation for research bench to bedside. NHS E announced in September a new cancer vanguard looking at whole pathway to see if accountable clinical networks for cancer can be set up and effective. Having data that is integrated will enable a whole pathway approach to service provision and incorporates patients living with and beyond cancer. Understanding what diagnostic test are involved is required to help model the pathway and achieve the Strategies 4-week target for getting a definitive diagnosis. National Cancer Transformation Board is to be put in place to oversee the transition and implementation of strategy.

Comments from the floor highlighted the importance of knowing what the good examples of work is and where it is located so that it can be built on.

AFTERNOON SESSION Chaired by Baroness Morgan of Drefilin

Ms Alexander, Shadow Health Secretary Ms Alexander's presentation, from my perspective, felt like a party political speech, rather than a joint party approach. She did, however, highlight that efficiency savings will be ongoing and there will be less spending per head of population. New regulations from the EU will mean that the time taken for research trial to be set up will need to be reduced. The scope of the third sector participating in the delivery of cancer services will need to increase as the NHS will be unable to provide services, eg support in the home, information portals, *"holding politicians to account."*

Workshop session on Generating Data for Use in Research

I felt honoured to be asked to facilitate a discussion table in the workshop session on Generating Data for Use in Research. Three short presentations were given:

1) NCIN Issues Accessing Data to Support Research, by Adrienne Morgan (ICPV)

Access to data for patients and researchers is a big problem that has resulted from poor communication about the care.data programme and the fears that data may be used by private companies to make money. There is a Use My Data initiative to increase the involvement of cancer patients on how data is used and communicate the importance of this work.

2) Data Dissemination, by Martin Severs (HSCIC)

Highlighting that HSCIC is looking to implement processes that will improve transparency and validation by introduction of an online tool (DARS online) that will help improve the research application process. Two groups within HSCIC are involved in the process to ensure a sensible balance:

- Data Access and Advisory Group (DAAG)
- Independent Group Advising on Release of Data (IGARD)

Audits of data involve:

- Patients assisting HSCIC
- Consent for research and identifying where data is going, which is required to provide a legal basis.
- Highlight what activities are being undertaken.

3) Consent, by Michael Chapman (CRUK)

Patients, Researchers and policy makers need access to data to help deliver better care. Consent is a complex area. Delays to obtaining data has financial implications for research costs. It is not

possible to use data without the appropriate consent. However it is not possible to gain specific consent as is currently required for everything, as it is impossible to identify what could be required in the future.

The three presentations were then discussed by the various tables and results consolidated for feedback.

Jeremy Hunt gave the penultimate speech of the day, acknowledging the work and progress made so far, as well as noting his understanding that there was still much left to do. In the league tables for West Europe the UK is still amongst the worst for cancer outcomes. There is the need to look at what can be done differently. Mr Hunt gave an overview of the key activities: The Independent Cancer Task force report in July

- Funding settlement of 3.8 billion pounds real time funding settlement for the NHS in November.
- Spending review plans of the 209 CCG's to be finalised in spring of 2016
- UK Government is also committed to the 28 day timescale for confirmation/diagnosis
- Commitment for 300 million pounds for diagnostics
- Planned that by 2018 200 Endoscopists will be in post
- 280,000 cancer patients will have a full recovery programme identified, including post diagnostic support
- New quality measures will include;
 - the number of cancers at stage 1 and 2
 - The number of cancers diagnosed in emergency care
- Indicators will also incorporate the holistic cancer care offered by CCGs from pre-diagnosis through to end of life care
- Rating will be assured by an independent committee chaired by Sir Harpal Kumar
- A culture of mutually supportive learning throughout the NHS will be encouraged

Mr Hunt stated his aspiration as ***“I want the NHS to offer the safest, highest quality care in the world”***. It was also highlighted that 2016 will provide patients access to their GP records.

In response to a question from the floor asking *“What action is being taken to demonstrate data is being unblocked to enable sharing”*, Mr Hunt responded that ***“data will need to be protected and looked after”***. Dame Caldicott and CQC are looking at security and human factors involved in providing confidence on the security of data. Mr Hunt also noted that: ***“patients should be able to change consent at any time”***.

Closing Remarks by John Baron John Baron thanked all presenters and delegates and delivered the notification of the ‘Best Stand’ award which went to the Cancer detection dogs.