The Strategic Intelligence Forum

Convened by Cancer Research UK

Summary

The Strategic Intelligence Forum was convened in January 2020 to discuss the availability of data and intelligence for local and regional planning, decision making and monitoring by and for Cancer Alliances (CAs). Presentations from CAs about initiatives happening locally and from national organisations supporting CAs were given, followed by discussions from which we have identified common themes emerging on the day. Based on these, we have developed a range of recommendations that will further support CAs to access and use data and intelligence going forward.

Concept of the event

Realising challenges faced by newly formed CAs, CRUK’s Cancer Intelligence team organised the first event for CAs in January 2018. We brought together representatives from CAs and national organisations responsible for providing intelligence on cancer care to discuss the challenges and opportunities of using data and intelligence to:

- inform plans
- drive improvements in cancer outcomes
- measure impact
- share lessons learned
- and how to manage or acquire analytic capacity.

This year the Strategic Intelligence Forum was based around four themes:

- workforce
- reducing variation
- early diagnosis
- treatment

To deliver on ambitions set out in the Long-Term Plan (including cancer waiting times, diagnostics access etc.) there is as great a need as ever to make informed, evidence-driven decisions. With this in mind, the Forum aimed to support local decision makers, whose responsibilities lie across the cancer pathway, to utilise existing intelligence more effectively and optimise patient outcomes. To support this, the event provided opportunities for locally run initiatives to be shared. Bringing together local and national organisations also provided the opportunity for local organisations to engage with and directly feed back to the national organisations.
overseeing the provision of such intelligence.

Presentations delivered on the day can be found here: https://www.cancerresearchuk.org/health-professional/learning-and-support/planners-and-commissioners/strategic-intelligence-forum-sif

Feedback

After the event we circulated a questionnaire seeking feedback on the usefulness of the event and if attendees are planning to act on any insights from the day. We have received 16 responses from attendees, nine of which were from CAs. All responders reported to have found the event useful, of which 14 said it was very useful. The same number (14) are planning to take an action as a direct result of the event. The actions reported range from recruiting a data analyst to committing to collaborate with new CA contacts made on the day. All responders would recommend the event and were motivated enough to add comments on how useful and informative they have found the event.

Recommendations

Following discussions on the day, we have put together a list of eight recommendations. When the time is right, we will be discussing with national organisations which of them will be an appropriate lead for each of recommendations and will be consulting with them on the best way forward. Being a lead does not imply sole responsibility for an area, and most recommendations require shared action across national and local organisations. However, it can be useful in ensuring progress is made if a single lead is responsible for driving and monitoring that progress.

1. Communicate data releases from national organisations in a more joined up way

At the moment there is a wide variety of data and analysis available publicly and through restricted NHS and PHE access. While a list of all resources is useful, it requires a degree of specialist knowledge to understand how they relate to each other and how they can be used.

2. Cancer Alliances would benefit from a national facilitator for their data access requests to guide them through the process.

While almost all CAs have access to secure dashboards now, an expanding range of responsibilities requires the use of increasingly granular data spanning different
service settings. Navigating data request systems of national data custodians involves a skillset of a data access specialist and in many cases involves a financial outlay. As such, standardised/centralised national guidance and facilitation for CAs in navigating such processes (e.g. NHS Digital DARS, PHE, ODR) was called for.

3. Additional support and further funding from national organisations to recruit cancer analysts to improve capacity and capability across all Cancer Alliances

In addition to CAs struggling to obtain local analytical resource, their deliverables require a much broader expertise not specific to a particular care setting in which analysts are usually based. National organisations admit that they are not able to customise their analyses to cater to quite specific local interventions. The organisations such as former Cancer Vanguards that were able to invest in data services have a better track record of embedding evidence in local decision making.

4. Improve access to linkable Primary Care datasets

Given that almost all general practices in England have had a patient management system in place, there is an untapped resource of clinical and operational data that can be used to improve patients’ outcomes.

5. Develop skills of senior decision makers to identify appropriate questions answerable with data

It was acknowledged that there is a virtuous cycle in producing good intelligence and making good decisions based on it. A deeper understanding of data by senior managers and leadership of how to develop questions and hypotheses through which the data can be used will also allow the embedding of a data driven culture in organisations across CAs.

6. Create a nationally organised professional network for Cancer Alliance analysts

The funding model of CAs means that it is difficult to fill short term contract vacancies. In addition to this an absence of professional networks prevents knowledge transfer and peer support in the cancer analysis sphere. While regional groups are beneficial for collaboration across regions, a nationally run network will also help to disseminate learnings across the country and provide analysts with a
comprehensive view of what is possible across different national organisations.

7. Provide enhanced support to Cancer Alliances to interpret data

With a shortage of cancer data expertise among analysts and managers locally, national organisations can improve the utilisation of new datasets and analyses by providing a greater amount of information on what the dataset contains, what it relates to, how best to use it and its limitations.

8. Data and analyses released nationally to incorporate more visually engaging elements

Suggested lead: CADEAS

To deliver on better cancer outcomes CAs need to engage multiple stakeholders across large areas. A visually engaging presentation of data and analyses allows them to concentrate on putting actions in place.

What makes good data?

The wider environment in which CAs need to make decisions was a recurring theme throughout the day.

The dismantling of cancer networks created a void in cancer data and analysis knowledge transfer locally. While CAs were established in part to address this gap, they have also been given responsibility for local workforce planning, waiting time and a range of other priorities. To deliver, CAs require access to rich data across a patient’s pathway, broad population characteristics, and intelligence that can offer an insight into both the current and future state of cancer services in their area. Whilst there is a vast amount of data available in England, strategic and operational decisions are made by organisations that are far removed from the source of data. The situation has been further complicated by the implementation of the Data Protection Act 2018 which has made it difficult for CAs to access contemporary data.

Throughout the event, CAs and national organisations were asked to consider what makes data the most useful for decision making. The following criteria were identified throughout the day. In some instances, data or datasets may adhere to most or some of these characteristics, in others less so. It would be useful for all stakeholders to consider these criteria to evaluate data provision to CAs going forward. Whilst these issues have been long standing and familiar challenges, they are still highly relevant for CAs.

Participants agreed that data for making decisions needs to be:

Contemporaneous and current
This is an ongoing concern for cancer services that is not specific to CAs. While CAs appreciate that high quality data requires a period of verification, they need up to date
data to make sure they are on track to achieve ambitious goals they are set

Accessible
While there has been improvement since the last event, there are still CAs that do not have access to the full set of dashboards provided by PHE and CADEAS. The most voiced concern though was about an absence of rich primary care data. This partially explains why CAs seem to be very secondary care focused where there is an abundance of data both clinical and processual.

Shared equally across all organisations
Information governance challenges and the impact they have on access to data have been an ongoing concern. With support in dealing with these challenges, CAs can then better fulfil their crucial work in establishing common understanding across their areas.

Standardised, i.e. allowing comparisons between areas, types of cancer etc.
There is an appetite for standardising metrics, where possible, as a result of common understanding of criteria for success across different organisations all the way up to the national level.

Broken down into elements relevant to different stakeholders
The data needs to be available at different levels reflecting stakeholders’ challenges such as a break down by services along the pathway for operational managers to identify blockages.

Engaging
Participants discussed different ways of making data engaging, such as creating stories or making the data visual. Both approaches are about distilling data into an unambiguous message and creating a narrative arc between the current situation and where cancer services should be aiming. Information should be as relatable as possible, which will vary depending on target audience.

Accompanied by interpretation or by a framework to help customise interpretation
This point has been mentioned as key in fostering shared understanding of the meaning and required actions that are revealed by data and analysis, and critical for subsequently engaging clinicians and healthcare professionals with data to improve patients’ outcomes.