

## Background

Public Health England (PHE) issued a notice recently saying:

“Further to the cancellation of the Cancer Data Conference this year, we are beginning to explore how we might run other events that we have planned for later this year such as our one-day genomics and molecular data event in the autumn.”

We were asked by PHE if our membership would like to suggest topics for their future events.

We asked the use MY data Advisory Group for their thoughts, which we have collated into the following list of suggestions. The numbering is not meant to imply any ranking or importance - it is purely for ease of reference.

## Our suggested topics

### 1. The changing data landscape

- What has changed in the patient data landscape as a result of COVID 19 and what are PHE planning to retain and build on for the future?
- How much of the PHE/NCRAS vision<sup>1</sup> will be delivered before the end of 2021?

### 2. Data collection and linkages

- What are the plans for linked GP and secondary data to support whole pathway research?
- What new data sources have NCRAS planned to collect, and how/when will they be made available for research?

### 3. Data management and governance

- We now have a new Executive Director of Master registries and data spanning NHS Digital and PHE. What are the plans for integration of the PHE & NHS Digital Services with pre-linked data and a single data access process?
- What plans do you have to publish more routine, aggregated, operational data which can be shared with the public (CancerStats vs. CancerData)
- In which areas are the rest of the UK ahead of England, and what plans are in place to learn from them?

### 4. Use of data

- How has the Simulacrum been a success and is it a model which should be adopted more widely?

- In August 2016 it was stated<sup>2</sup> that “the [SACT] resource we have will allow us to monitor the quality of chemotherapy treatment given to all patients across the NHS in near real-time.” How has this been done and what are the future plans?
- What new analyses are planned by PHE and particular what are the plans for the extension of Routes to Diagnosis into primary care data?
- What plans are in place to publish statistics on metastatic breast cancer?

## 5. Data release for research

- Researchers find it hard to get access to linked screening and cancer registry data particularly in relation to bowel cancer. Why is this, given PHE controls both databases?
- How has access to data (for research and other uses) improved and what further plans are in place?

## 6. Equality and Inequality

- What plans does PHE have to understand and utilise the data that they hold about patients from BAME backgrounds
- Who decides on the priorities of analysis for data to highlight inequalities

## 7. Communications, Engagement and Involvement

- What has been done to improve public/patient awareness of the cancer registry? What does the evidence show about whether this has worked?
- In the (continued?) absence of the annual conference, what plans does PHE have to (help) showcase and disseminate cancer data research that would otherwise have been submitted as abstracts, posters and presentations?
- What plans do you have to involve patients in your work?

## 8. Policy questions – perhaps suited for a strong and robust panel debate?

- The UK has a lot of great data<sup>3</sup> and a lot of great scientists, yet breast cancer survival is amongst worst in Europe - and Covid19 similarly. If public health is truly data driven, what is going wrong?

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<sup>1</sup> PHE Cancer Board Plan, 2017 – 2021;

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/672086/PHE\\_Cancer\\_Board\\_Plan\\_2017\\_2021.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/672086/PHE_Cancer_Board_Plan_2017_2021.pdf)

<sup>2</sup> Public health matters; Chemotherapy is powerful stuff but data is too;

<https://publichealthmatters.blog.gov.uk/2016/08/31/chemotherapy-is-powerful-stuff-but-data-is-too/>

<sup>3</sup> “The National Cancer Registration and Analysis Service collects richer, more-timely data on greater number of patients than any other country; data quality for key data items such as cancer stage.”

(PHE Cancer Board Plan, 2017 - 2021, Section 2, page 19 para 1)

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/672086/PHE\\_Cancer\\_Board\\_Plan\\_2017\\_2021.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/672086/PHE_Cancer_Board_Plan_2017_2021.pdf)