



MEMBERS UPDATE - DATA SPECIAL

15th February 2019

Dear All,

Get Data Out - What's next from NCRAS?

Hope you are well.

I am writing to ask for your help as we have had a request from PHE/NCRAS to help prioritise the next cancers to be included in their Get Data Out programme.

It involves completing a [spreadsheet](#) and returning it to us by Wednesday 27th February 2019.

The request from PHE is below, and the spreadsheet that you will need to complete and return is linked. I think the copy explains the request well, any queries [please let me know](#).

We are delighted that PHE is progressing so well in the Get Data Out programme - which is literally getting data out on rare and less common cancers - as we have been [advocating for better access to data](#) for this group of cancers for many years.

We are also delighted that PHE is seeking members' views on priorities for the next cancers to be looked at, and hope that members will take up the opportunity to let their views be known.

As brain, ovarian, pancreatic and testicular tumours are already underway or complete - with data about sarcoma tumours already scheduled - I would suggest we don't need feedback from charities working in those sectors, and instead from those that could be covered in the future.

Best wishes,

Jane Lyons
CEO
Cancer52

Get Data Out - What's next from NCRAS?

The [Get Data Out programme](#), from the National Cancer Registration and Analysis Service (NCRAS) at Public Health England, publishes in-depth, anonymous data about small groups of cancer patients to support research. So far the programme has published data about brain, ovarian, pancreatic and testicular tumours, with data about sarcoma and prostate tumours due soon. **For 2019, the Get Data Out team would like to work in collaboration with Cancer52 to select which tumour groups to publish data on next.**

In [this spreadsheet](#), we have listed the groups of tumours which we have not yet published data on. Each tumour group has been assigned a rating depending on how challenging it is. Over the next year, we estimate we can complete 20 points worth of work, divided into two rounds of 10 points. We would like Cancer52 to help us decide which tumour groups we should focus on next.

If you would like to 'get data out' about as many tumour groups as possible, we recommend you choose groups with low rankings. But, if you want us to focus on

a group with a high ranking, we might only be able to publish data about two groups over the next year.

Once you have chosen your 20 points of work, we would also like to know what your next preferences might be for the remaining tumour groups. We want to know this in case we get data out faster than we expect, so we can start working on your next preference.

Please return your completed spreadsheet to info@cancer52.org.uk by Wednesday, 27th February as Jane has been asked to feedback Cancer52's member views to inform final choice to the Get Data Out team on March 4th.

For any questions about the programme, please get in touch with Sophie Morris - Sophie.morris@phe.gov.uk.

What's involved in producing data for the Get Data Out Programme?

The Get Data Out team works closely with charity partners to produce data about each tumour site. The Get Data Out programme is unique amongst NCRAS publications because it produces data about much smaller groups of patients, where each group contains 100 patients which have the same characteristics. We work closely with our charity partners to decide how we should group patients into these smaller groups.

One of our previous collaborators, Rebecca Rennison from Target Ovarian Cancer, has this to say about the Get Data Out programme:

"We all want to see more data on rare and less common cancers made available. Working with the Get Data Out Team was a great opportunity to understand more about the data on ovarian cancer that is out there and how it can be used. It also gave us the opportunity to talk through the different options with both data analysts and clinicians to work out what would prove most useful in ovarian cancer. The data subsequently released has given a real boost to our campaigning work – we produced a [data briefing](#) based on the information that came from Get Data Out which received coverage in The Times, Metro, the Independent, Mail, Sky News and over 150 local/regional news outlets and which we shared with MPs as part of our parliamentary work. The Get Data Out team were fantastic to work with and really helpful in explaining how everything works, I'd strongly recommend other charities taking up the opportunity to get involved and shape the data that is out there on different cancers."

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