Recent news

Your DNA Your Say survey

What if our DNA and medical information were part of our online footprint?

Interested in ethical issues surrounding big-data sharing of patient genomic information? Then take the Wellcome Trust survey (https://surveys.genomethics.org/) on behalf of the Global Alliance for Genomics and Health (GA4GH).

The survey looks to get the public's opinion on whether or not medical data, and DNA information in particular, should be stored and made accessible online and if so, how protected should it be? Who should be able to access and use it?

The survey has several sections:

- What characterizes your online footprint?
- How do you feel about others being able to access your online data, especially medical data?
- Should doctors, non-profit researchers, for-profit researchers be able to access and use health data?
- In what way could this data storage be harmful?
- What expectations do you have in sharing their personal DNA information?
- How much trust do you have that information will be secure?

This survey is anonymous, takes 20 minutes and is open to everyone – knowing which issues people have with having their personal medical data being stored online and their perceptions, fears and expectations of a data sharing program will be valuable information for future developments in the field.

The online survey can be found here: https://surveys.genomethics.org (https://surveys.genomethics.org)

To find out more about who's running the survey, check out The Global Alliance for Genomics and Health (https://genomicsandhealth.org/), The Wellcome Trust (http://www.wellcome.ac.uk/) and its Genome Campus (http://www.sanger.ac.uk/about/campus)

About Cancer Core Europe

Six leading cancer centers have joined forces to form Cancer Core Europe - a European cancer association carrying out innovative research propelling cancer medicine into a new era. Cancer Core Europe's efforts will pave the way for a multi-site cancer institute, which will drive the development of new treatments and earlier diagnoses for patients and more effective cancer prevention for Europe's citizens.

Main pages

- Who we are (who-we-are/)
- Press releases (press-releases/)
- Task Forces (task-forces/)
- Get involved (get-involved.html)

Members

- Cambridge Cancer Centre (members/cambridge-cancer-centre.html)
- German Cancer Research Center & National Center for Tumor Diseases (members/dkfz-nct.html)
- Gustave Roussy (members/gustave-roussy.html)
- Karolinska Institutet (members/karolinska-institutet.html)
- Netherlands Cancer Institute (members/netherlands-cancer-institute.html)
- Vall d’Hebron Institute of Oncology (members/vall-d-hebron-institute-of-oncology.html)

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