INSTITUT
JULES BORDET
INSTITUUT

Advancing precision medicine : the role of data sharing

Philippe Aftimos, MD
Clinical Trials Development Leader
Clinical Trials Conduct Unit (CTCU)
Institut Jules Bordet

12th Belgian BSMO/Bordet Symposium
23-24 November 2018

ULB iris

Key questions

1. How does data sharing contribute to science and scientific advances?

2. What impact for data sharing on treatment of patients and on clinical research?

3. Opinions and patient contributions?

What is data sharing?

Data sharing is the use of research data by individuals other than those who generated the data.

INSTITUT
JULES BORDET
INSTITUUT

ULB iris

Data sharing of research results: advantages

- Allow an independent replication
- Avoid duplication of efforts
- Generate or test new hypotheses
- Contribute to the progress in clinical and biological understanding of pathological processes

The 21st Century Cures Act

National Institutes of Health

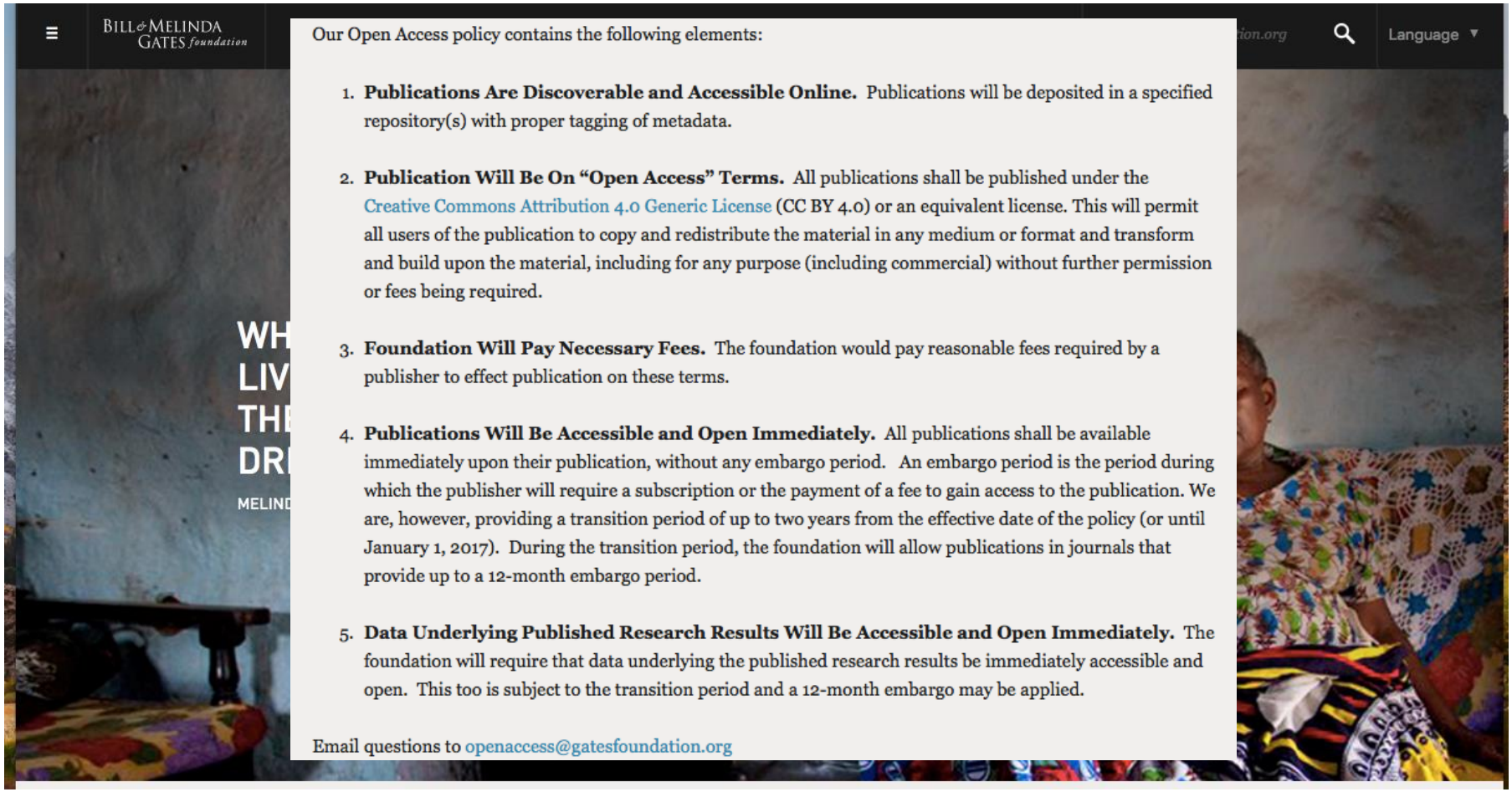
- Signed by President Barack Obama on 13 December 2016
- Allows the Director of the National Institute of Health to require data sharing of NIH studies with other researchers
- Introduces a measure of data privacy protection using confidentiality certificates for potentially “identifiable” data
- Allows the NIH to conserve and preserve biomedical data that could lead to the identification of an individual

INSTITUT JULES BORDET INSTITUUT

21st Century Cures Act, H.R. 34, 114th Cong. (2015)

ULB iris

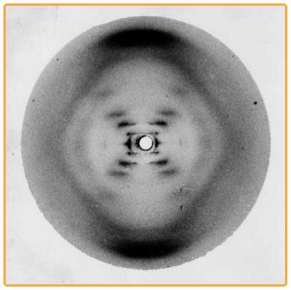
A large number of organizations require data sharing of projects that they financed



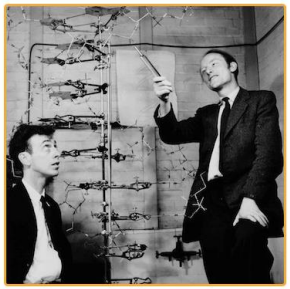
INSTITUT JULES BORDET INSTITUUT

ULB iris

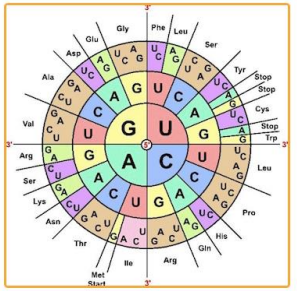
“Rapid” advances in the field of genomics



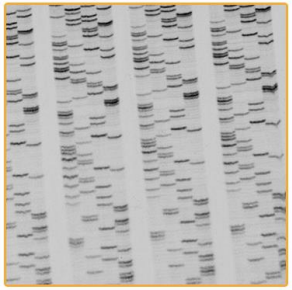
1951: Rosalind Franklin’s photograph showing the helical shape of DNA



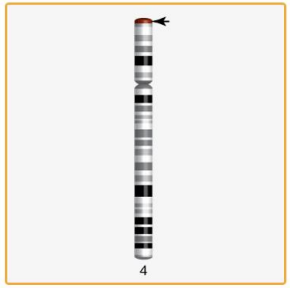
1953: Watson and Crick discover the double helix structure of DNA



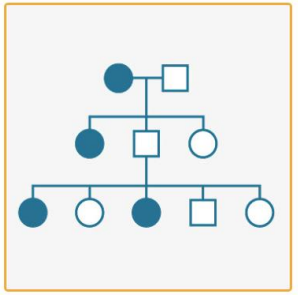
1961: Marshall Nirenberg cracks the genetic code for protein synthesis



1977: Frederick Sanger develops rapidDNA sequencing technique



1983: First genetic disease mapped, Huntington’s disease



1990: First evidence provided of The existence of the BRCA1 gene

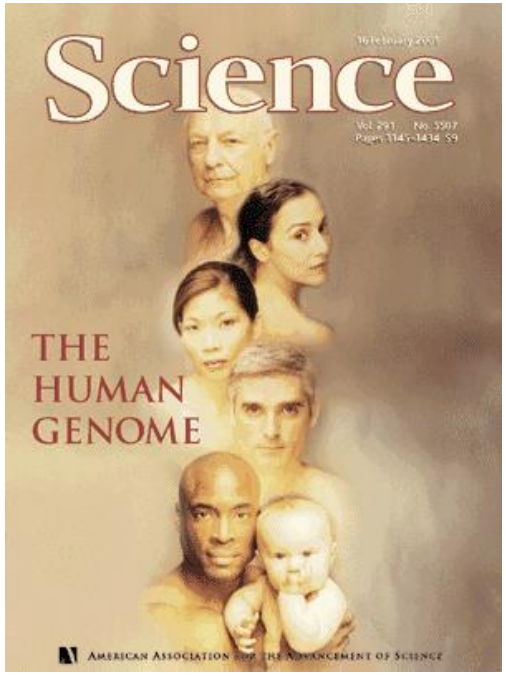
INSTITUT
JULES BORDET
INSTITUUT

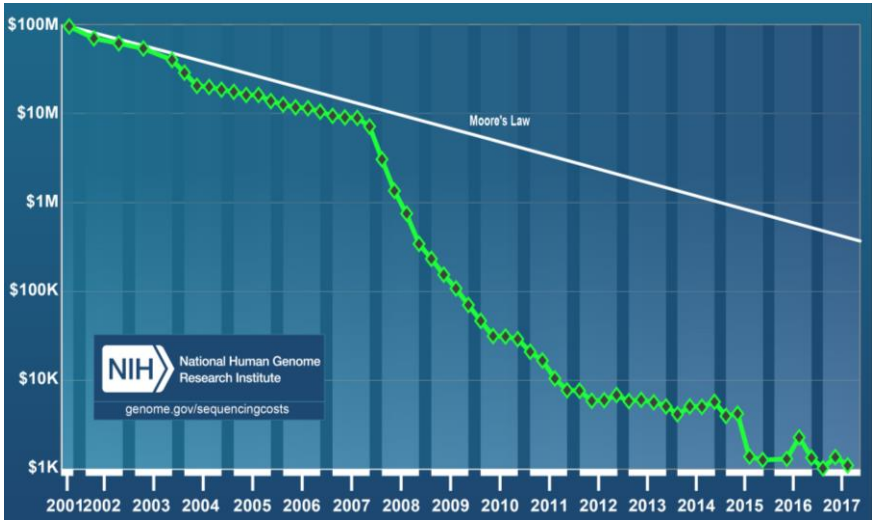
ULB
iris

Bermuda principles

- The Human Genome Project leaders met in 1996 in Bermuda
- Consensus:
  - All human genomic sequences generated by a center receiving financing for genomics research should be made available for free in the public domain within 24 hours of data generation.

The genome was decoded and technological advances accelerated…

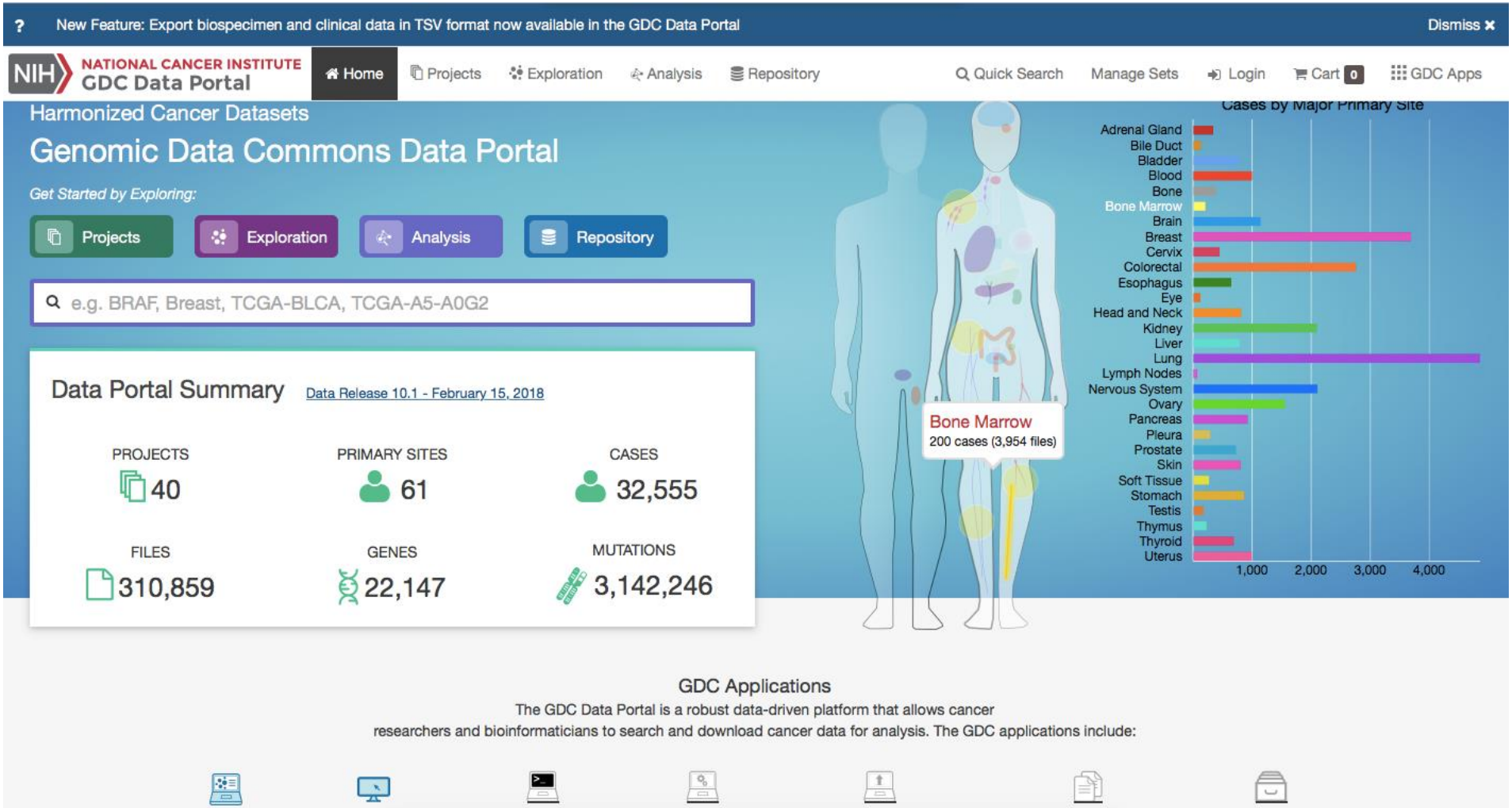




INSTITUT JULES BORDET INSTITUUT

ULB iris

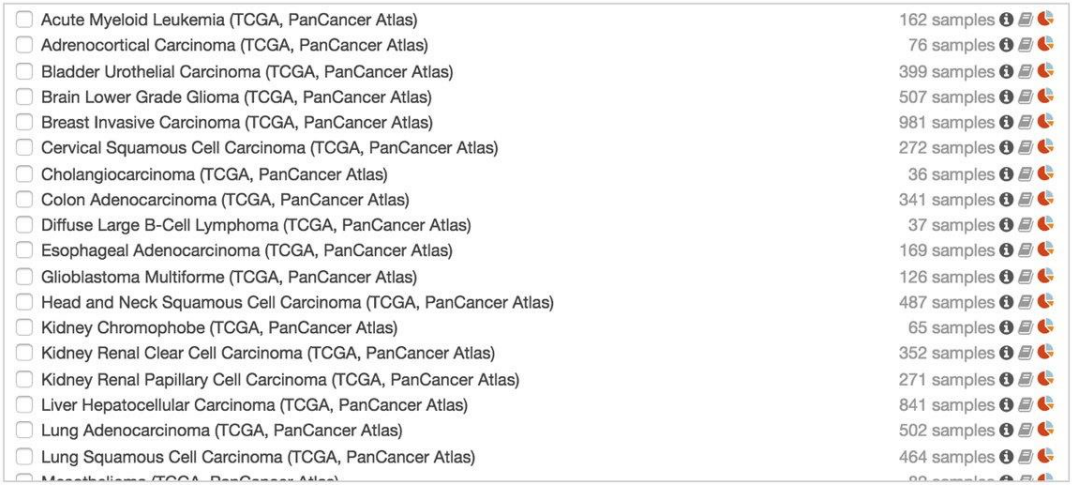
The Cancer Genome Atlas (TCGA): tool continuously enriched for researchers looking for data…

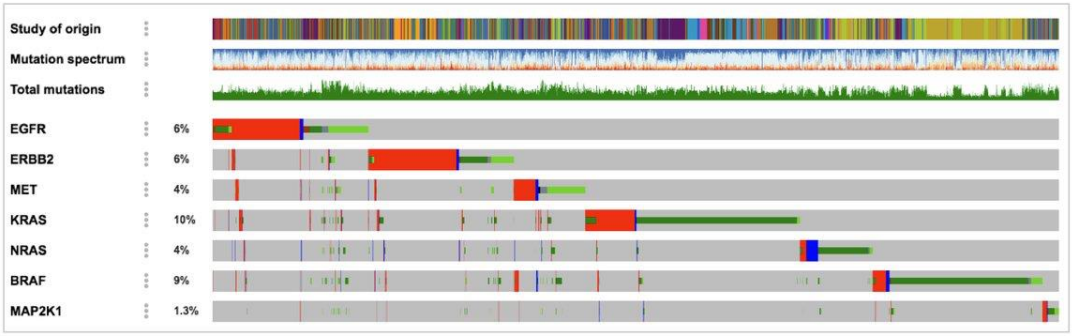


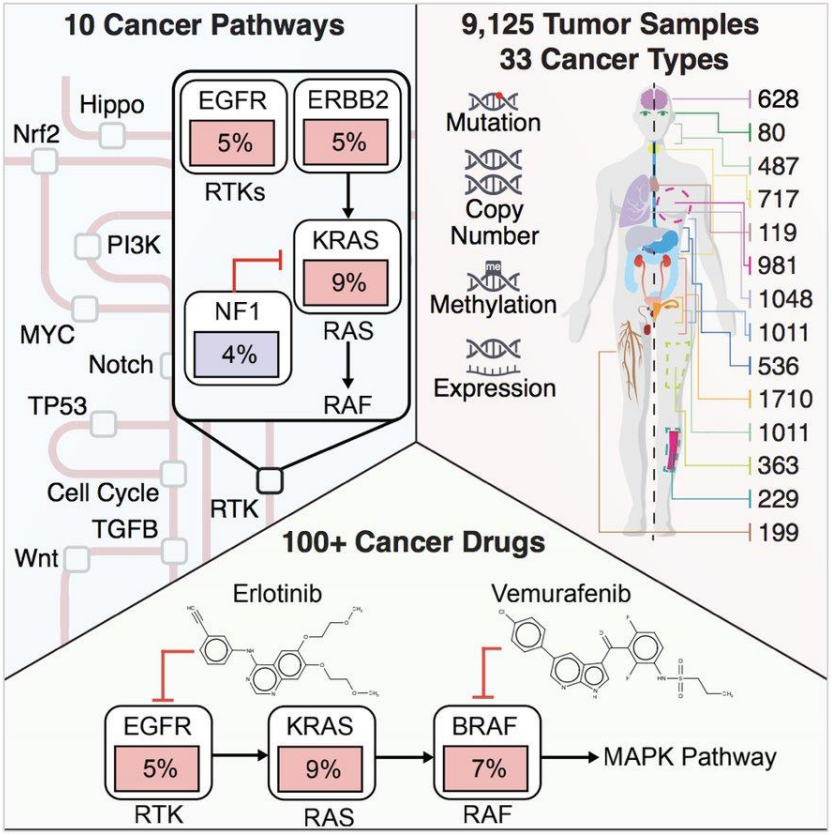
INSTITUT JULES BORDET INSTITUUT

ULB iris

Genomics data available on cBioPortal







INSTITUT
JULES BORDET
INSTITUUT

ULB
iris

cBioPortal: portal for the visualization, analysis, and downloading of large genomic datasets

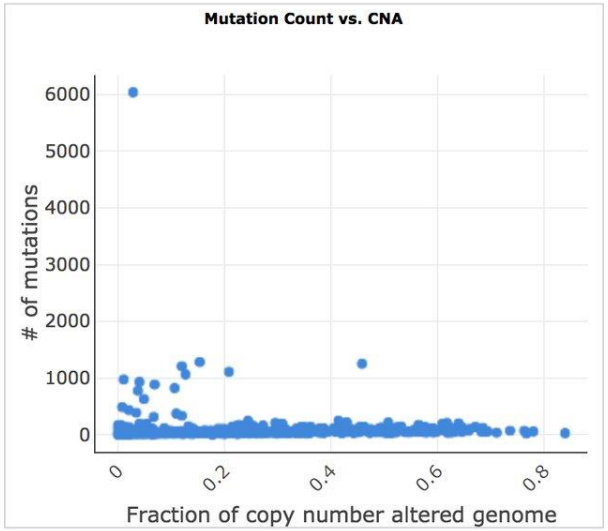
Prostate Adenocarcinoma (MSKCC/DFCI, Nature Genetics 2018)

Whole Exome Sequencing of 1013 prostate cancer samples

Study Summary | Clinical Data | Mutated Genes

Selected: 1013 samples / 1013 patients

query genes - click to expand | Query | Select cases by IDs | Add Chart



Mutated Genes (1013 profiled samples)

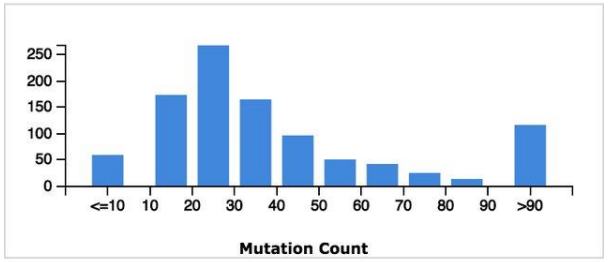
Gene	# Mut	#	Freq
ERG	310	308	30.40%
TP53	195	189	18.66%
TTN	208	151	14.91%
MUC16	134	113	11.15%
SPOP	93	92	9.08%
SYNE1	90	73	7.21%
FOXA1	71	69	6.81%
KMT2C	79	66	6.52%
KMT2D	77	65	6.42%
CSMD3	64	61	6.02%
HMCN1	64	55	5.43%

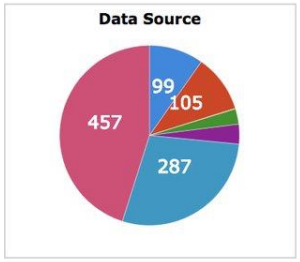
Search...

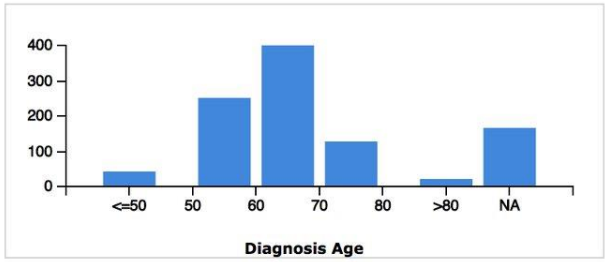
CNA Genes (1013 profiled samples)

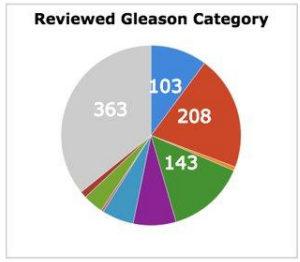
Gene	Cytoband	CNA	#	Freq
AR	Xq12	AMP	127	12.54%
PTEN	10q23.31	DEL	124	12.24%
NDRG1	8q24.22	AMP	101	9.97%
MAP3K7	6q15	DEL	95	9.38%
OBSCN	1q42.13	DEL	93	9.18%
PNRC1	6q15	DEL	90	8.88%
EPHA7	6q16.1	DEL	89	8.79%
AGO2	8q24.3	AMP	88	8.69%
PTK2	8q24.3	AMP	87	8.59%
NUTM2A	10q23.2	DEL	86	8.49%
CHD1	5q15-q21.1	DEL	83	8.19%

Search...





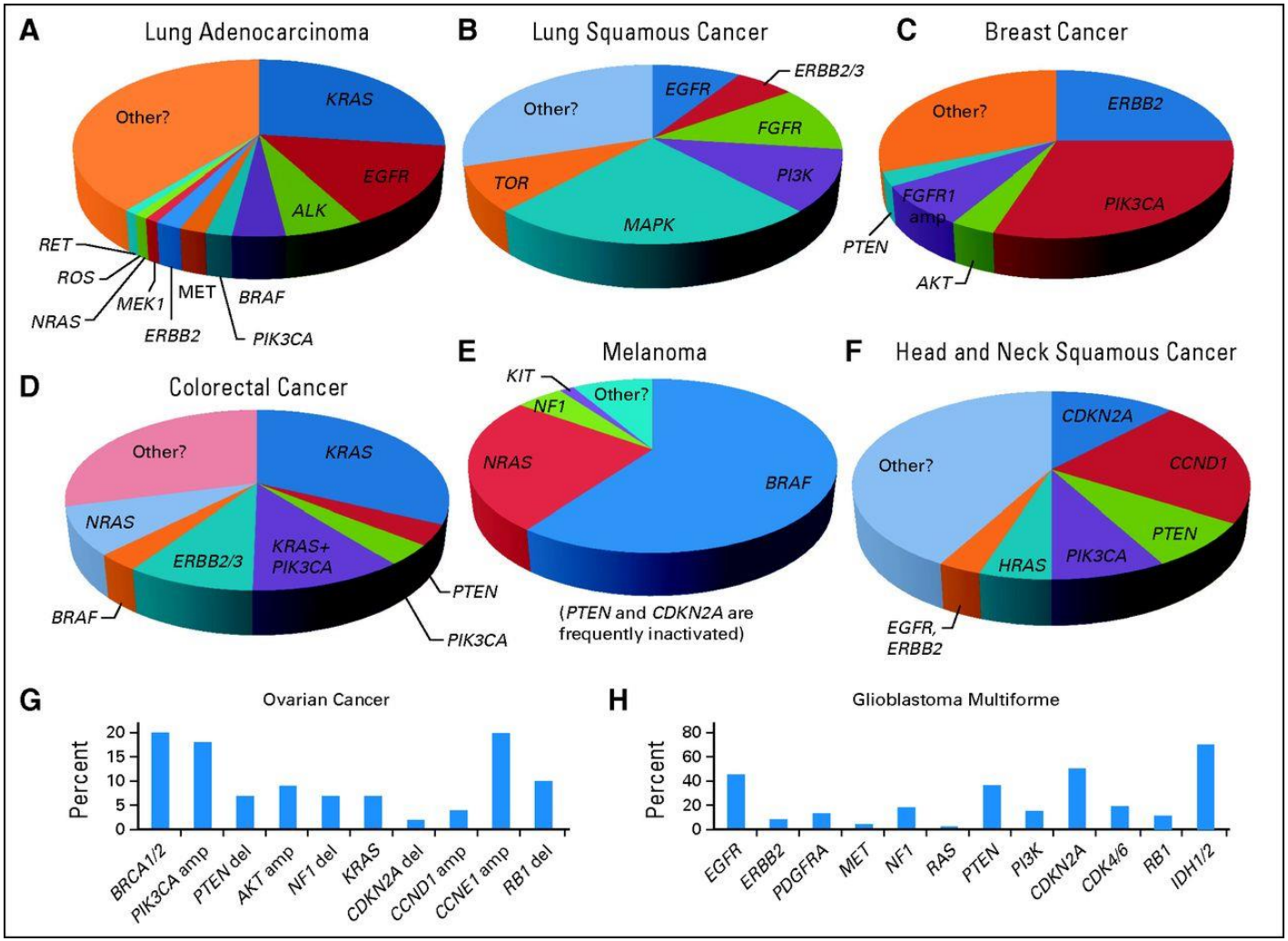




INSTITUT JULES BORDET INSTITUUT

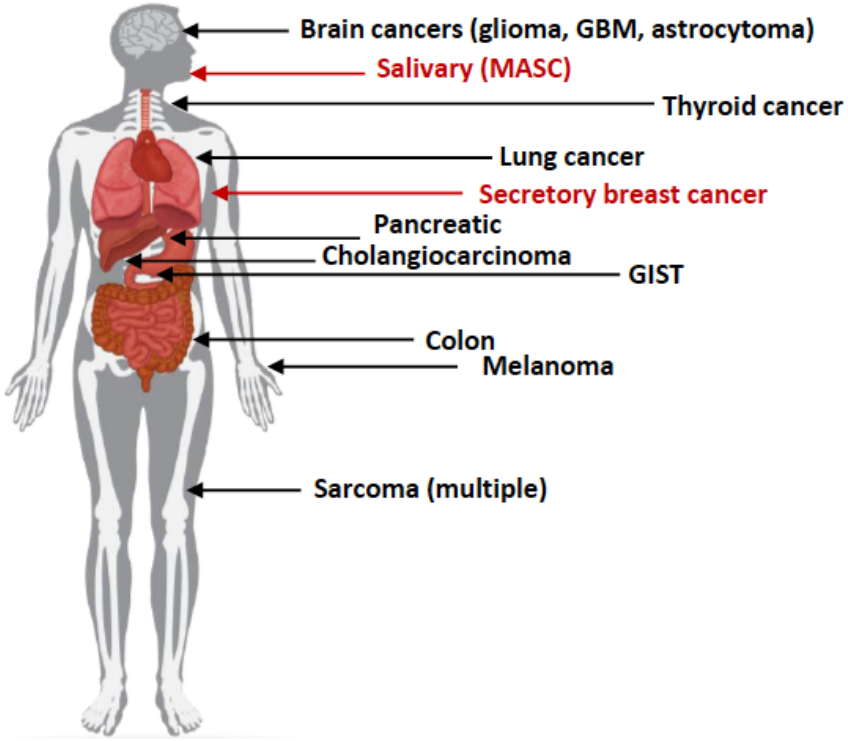
ULB iris

Common cancers are now rare



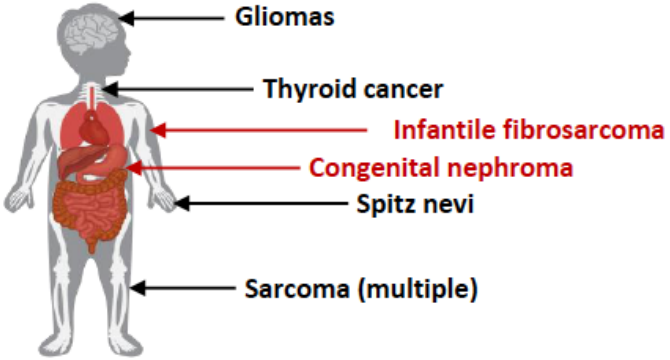
Garraway LA, J Clin Oncol 2013;31:1806-1814

TRK fusions found in diverse cancer histologies



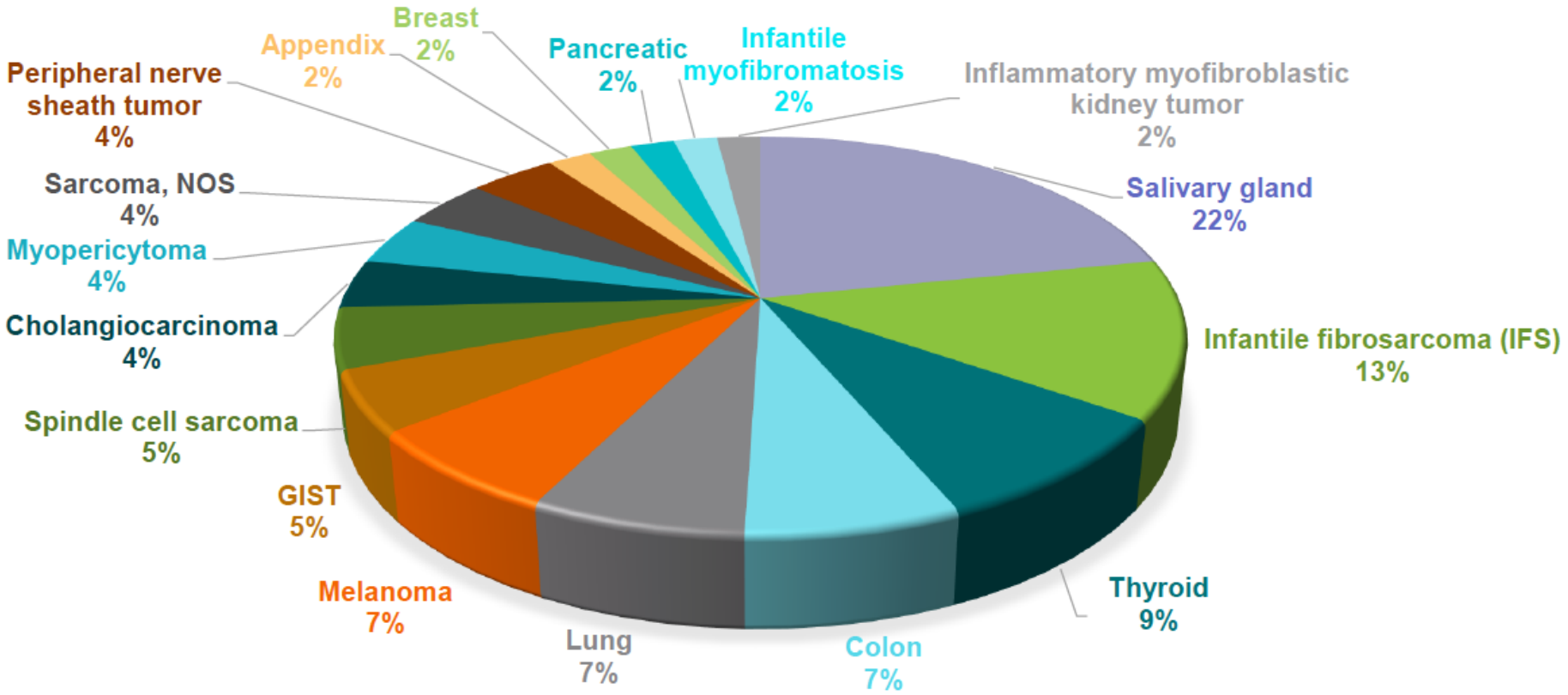
■ Common cancer with low TRK fusion frequency

■ Rare cancer with high TRK fusion frequency



Estimated 1,500–5,000 patients harbor TRK fusion-positive cancers in the United States annually

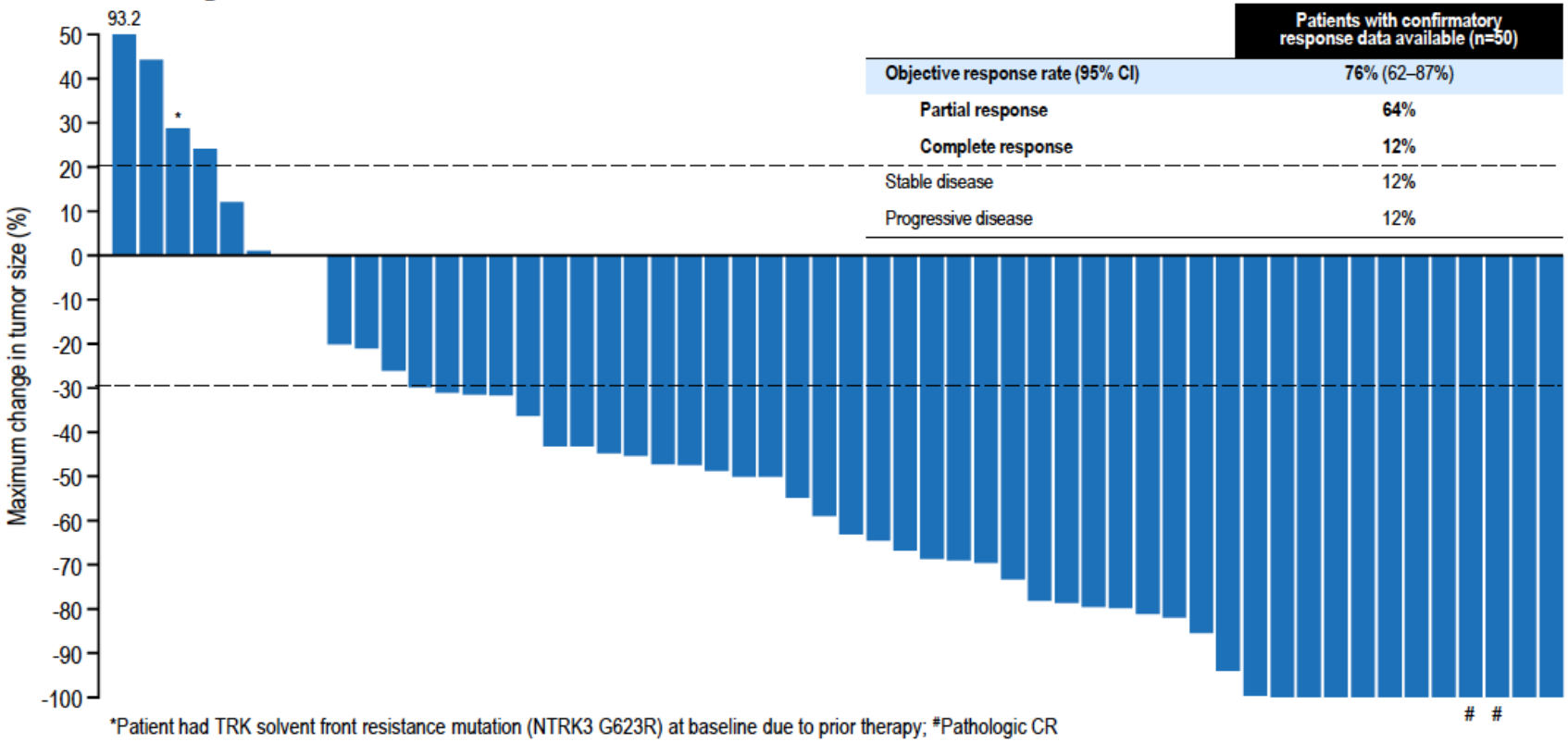
Diversity of cancers treated - 17 unique types



INSTITUT JULES BORDET INSTITUUT

ULB iris

Efficacy of larotrectinib in TRK fusion cancers



	Patients with confirmatory response data available (n=50)
Objective response rate (95% CI)	76% (62–87%)
Partial response	64%
Complete response	12%
Stable disease	12%
Progressive disease	12%

*Patient had TRK solvent front resistance mutation (NTRK3 G623R) at baseline due to prior therapy; #Pathologic CR

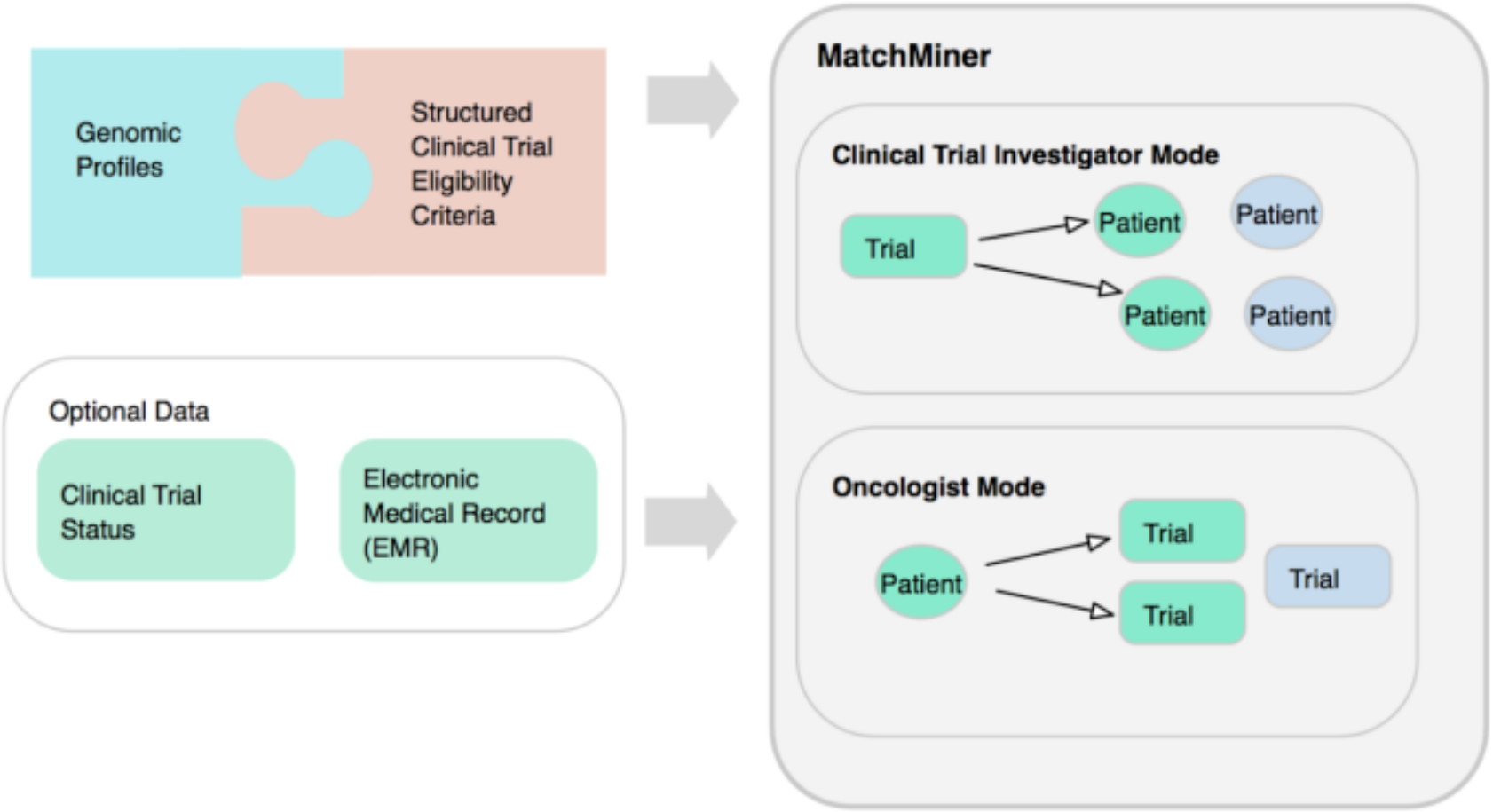
Note: One patient not shown here. Patient experienced clinical progression and no post-baseline tumor measurements were recorded.

TRK fusions

- Can be harbored by **1%** of all cancers
- Targeted treatments are very potent
- How can patients be screened without universal molecular screening?
- **Is recruitment possible in clinical trials without clinical and genomic data sharing?**

MatchMiner

Developed at Dana Farber Cancer Institute but soon Open Source



INSTITUUT

iris

Data sharing of EMRs within networks

ORIEN ONCOLOGY RESEARCH INFORMATION EXCHANGE NETWORK

> 50 000 patients par an aux US

MOFFITT CANCER CENTER

The James
The Ohio State University Comprehensive Cancer Center

Stephenson Cancer Center
The University of Oklahoma

City of Hope

University of Virginia Health System
UVA Cancer C

Dartmouth-Hitchcock Norris Cotton Cancer Center

University of Iowa Holden Comprehensive Cancer Center
University of Iowa Health Care

University of Colorado Cancer Center

UNM Comprehensive Cancer Center

Emory Winship Cancer Institute

Morehouse School of Medicine

Rutgers Cancer Institute of New Jersey

John P. Murtha Cancer Center

USC Norris Comprehensive Cancer Center
Keck Medicine of USC

Huntsman Cancer Institute University of Utah

INSTITUT JULES BORDET INSTITUUT

ULB iris

INSTITUT
JULES BORDET
INSTITUUT

Patients are contributing

ULB iris

patientslikeme®

Sign in | Join now!

PATIENTS CONDITIONS TREATMENTS SYMPTOMS RESEARCH

A chance to change the future of personalized health.

Living with ALS or lupus? Find out how you can join DigitalMe™

Learn more

CHRISTINE // LIVING WITH LUPUS

Our digital health learning system uses the most advanced technologies to help you better understand wellness, aging, and disease. As new understanding emerges, you will gain access to tools, information and connections–to people like you–to find a clearer path forward to your own future health.

INSTITUT JULES BORDET INSTITUUT

ULB iris

ROS1 alterations are diagnosed in 0.6 à 2% of NSCLC…

INSTITUT
JULES BORDET
INSTITUUT

ULB
iris

Phyllis
@Groz_P Follows you

DCIS 1995 ➡️ metastatic breast cancer 2008. Did 2 clinical trials (LEE011,SRN927). On doxil now, then hope to do more trials.
youtu.be/8szg7xreVd0

boston area
METUP.ORG
Joined July 2012

Robin Holmes
@Majormac1 Follows you

Breast cancer advocate in honor of my warrior husband living with breast cancer. Time to change the status quo in breast cancer advocacy. Tweets are my own.

Tennessee, USA
metup.org
Joined August 2009

Jo Taylor
@abcdiagnosis Follows you

Founder of After Breast Cancer Diagnosis - breast reconstruction, signposting, support, patient advocate, blogger, campaigner, activist, living with secondaryBC

Saddleworth
abcdiagnosis.co.uk
Joined October 2012

April Hines
@owlchick_april Follows you

delusionally optimistic. snarkastic. thirty-something wife. metastatic breast cancer. advocate. 2016 Hear My Voice ambassador. #metup

Soddy-Daisy, TN
Joined February 2015

april knowles
@akknowles1 Follows you

trying to find a balance between LIVING and living with metastatic breast cancer @metuporg

Florida, USA
Joined May 2009

Beth Fairchild
@bethfairchildnc

Wife. Mother. Artist. Yogi. Advocate. Lover of all that lives. Terminal Optimist. Living with Stage IV Breast Cancer.

New Bern, NC
bethfairchild.org
Joined August 2009

Beth Caldwell
@CultPerfectMoms Follows you

Living with metastatic breast cancer since 2014; Deprogramming Women Since 2013; 2016 Democratic presidential elector; Co-founder, METUP.org

Seattle, WA
cultofperfectmotherhood.com
Joined January 2014

Dr. Kelly Shanahan
@stage4kelly Follows you

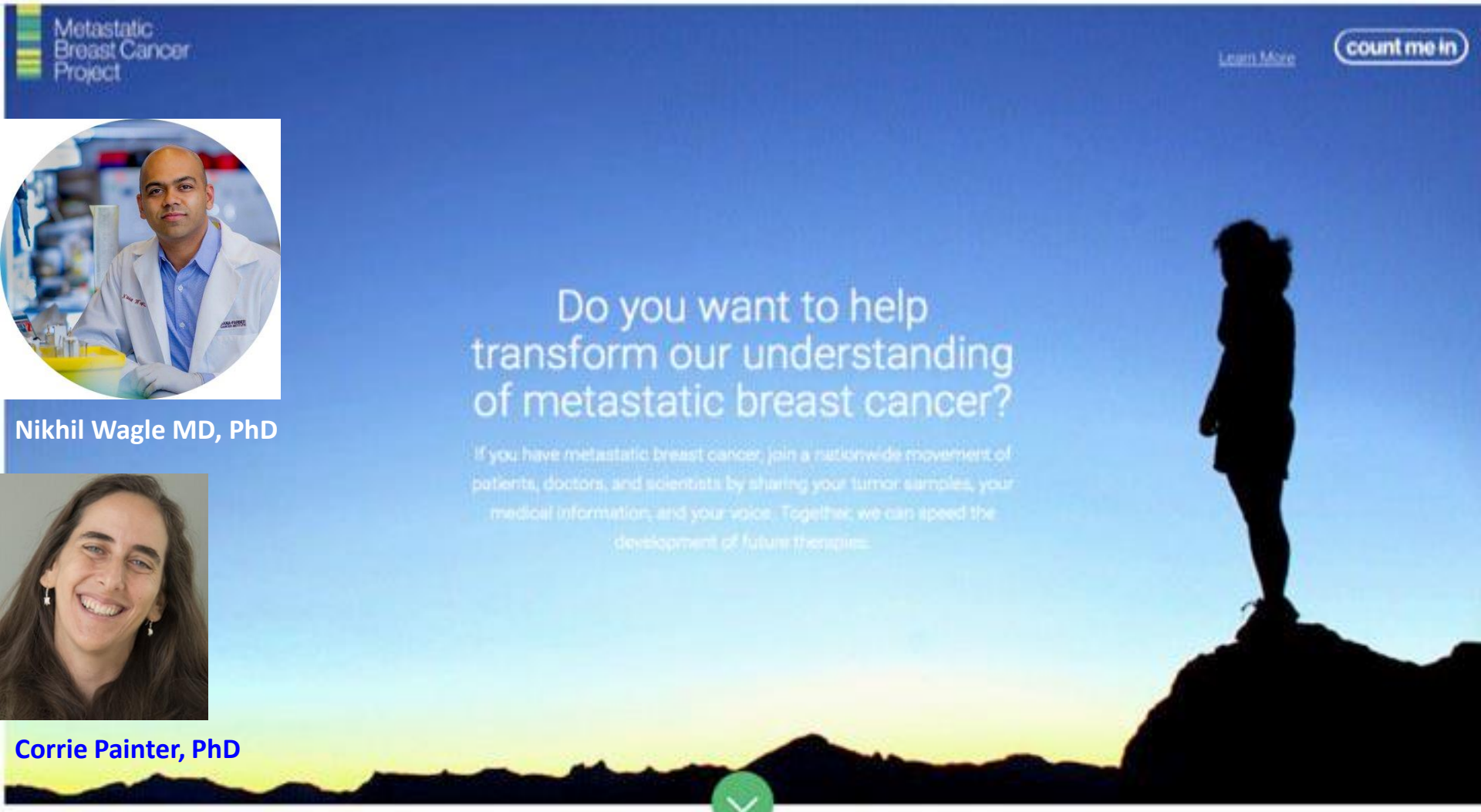
Doctor, mother, wife, woman LIVING with metastatic breast cancer. Medical director of @METUPorg. How am I? Not dead yet!!

California, USA
Joined October 2015

INSTITUT
JULES BORDET
INSTITUUT

ULB
iris

The Metastatic Breast Cancer Project
MBCproject.org



Nikhil Wagle MD, PhD

Corrie Painter, PhD

Source: www.mbcproject.org

Metastatic Breast Cancer Project

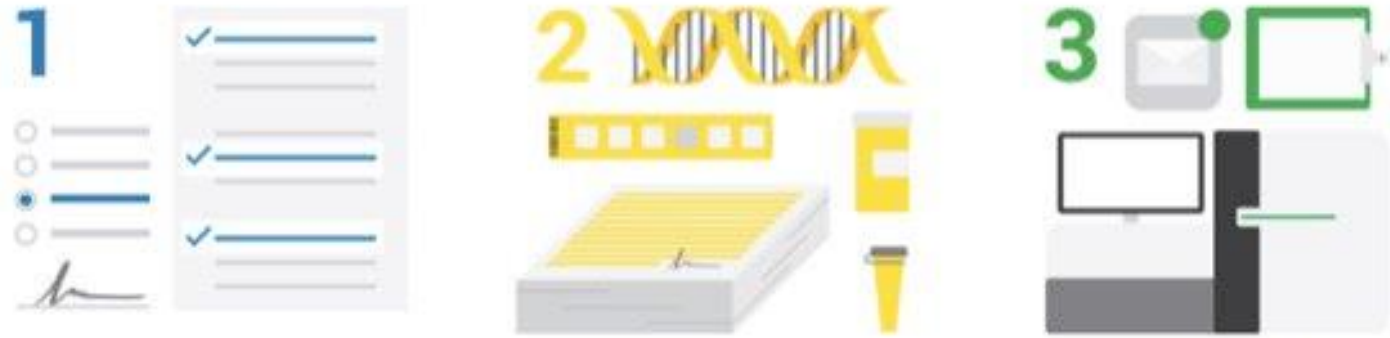
Learn More

count me in

Become part of the research movement. Have a direct impact on the future.

By saying "Count Me In", you will partner with leading research institutes, hospitals, and patient advocacy groups by sharing part of your stored tumor tissue and copies of your medical records.

Here's how you can participate



Step 1. Tell us about yourself

Click "Count Me In" and complete a simple online form to tell us about yourself and your cancer. Our goal is to perform many different studies within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us design future

Step 2. Give us permission to collect your samples and data

When we start a study that matches what you have told us about yourself, we will ask you to fill out an online consent form that requests your permission to obtain copies of your medical records and some of your stored tumor tissue. We will do the rest - we'll contact

Step 3. Learn with us along the way

We are excited to learn with you! Throughout the project, we will provide you with regular updates about the status of the project and share any discoveries that you have enabled us to make. We also may ask you additional questions about your experience to help with

INSTITUT JULES BORDET INSTITUUT

Source: www.mbcproject.org

ULB iris

“Count Me In”









“I want to live and watch my children grow up, but if I can’t, then I want to leave a legacy and a cure.”
—Houston, TX

“As someone who does not live near a research center and therefore cannot easily participate in trials, I finally feel like I can contribute.”
—Lake Tahoe, CA

“Amazing how happy that little box makes you feel! I felt like a 2 year old. Let me help! I feel a sense of pride and belonging because of this.”
—Minneapolis, MN

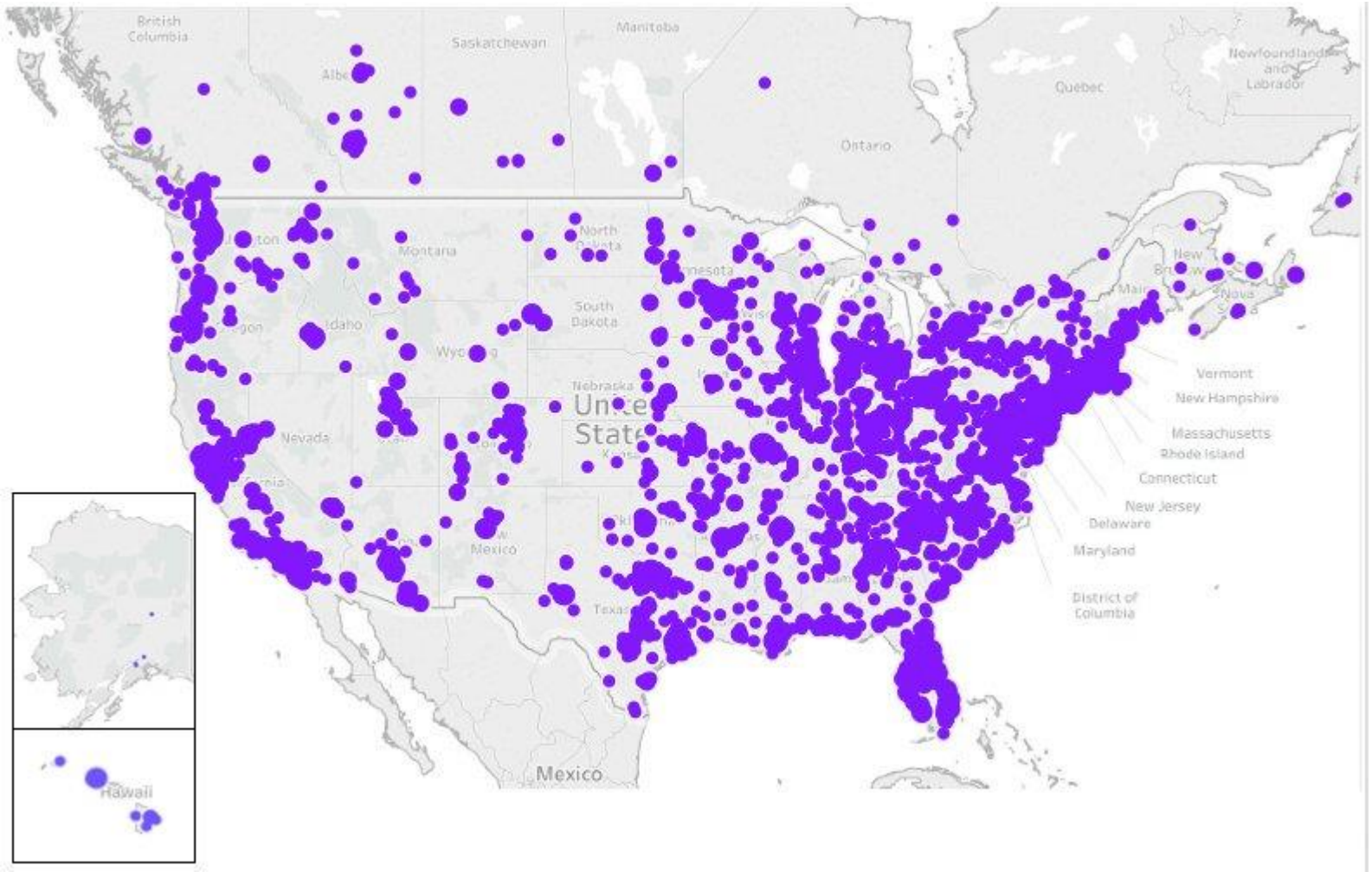
“Giving us HOPE for the future and if not for some of us, for our families.”
—Scottsdale, AZ

INSTITUT
JULES BORDET
INSTITUUT

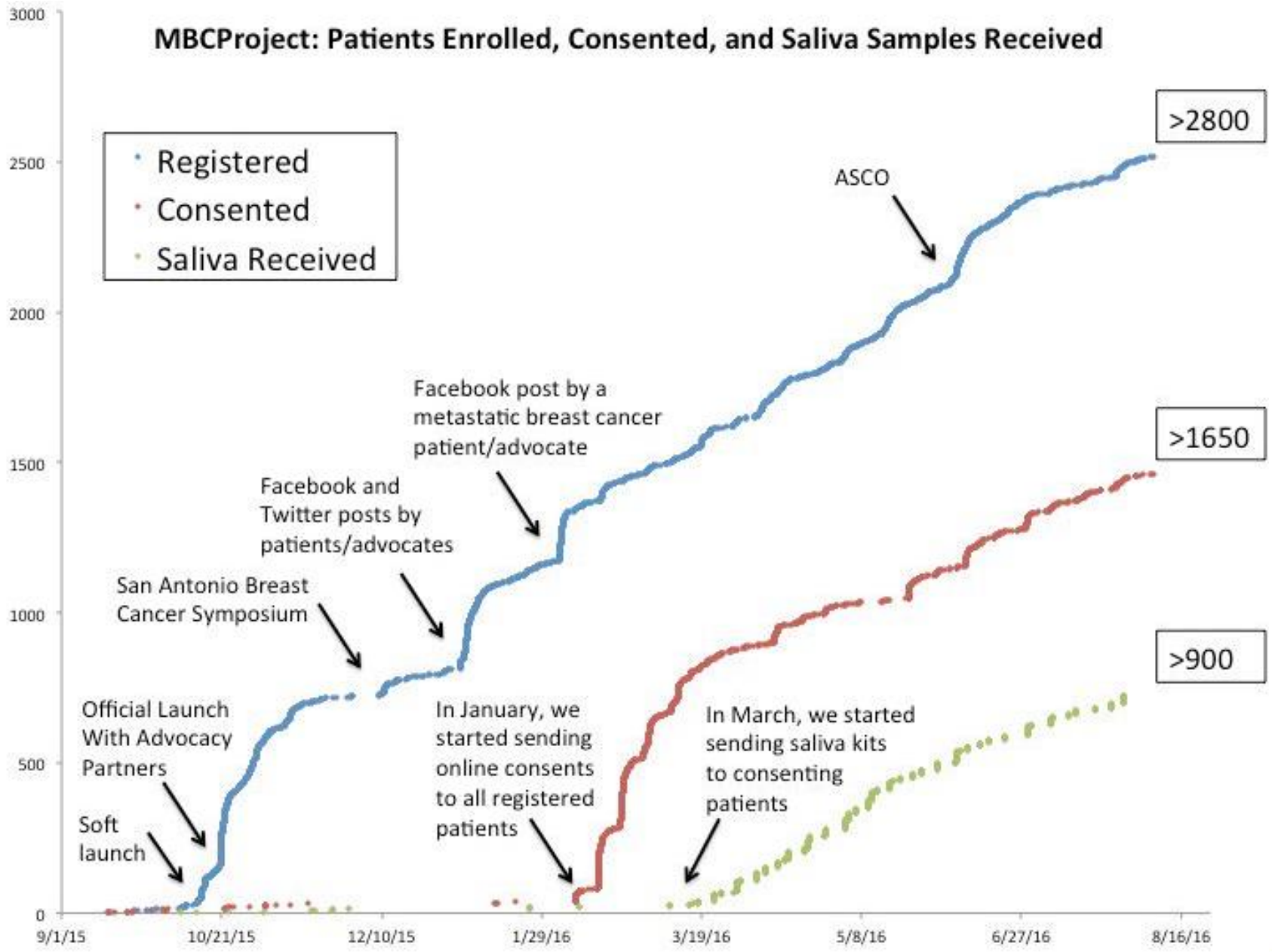
Source: www.mbcproject.org

ULB iris

Over 5000 patients recruited in 3 years

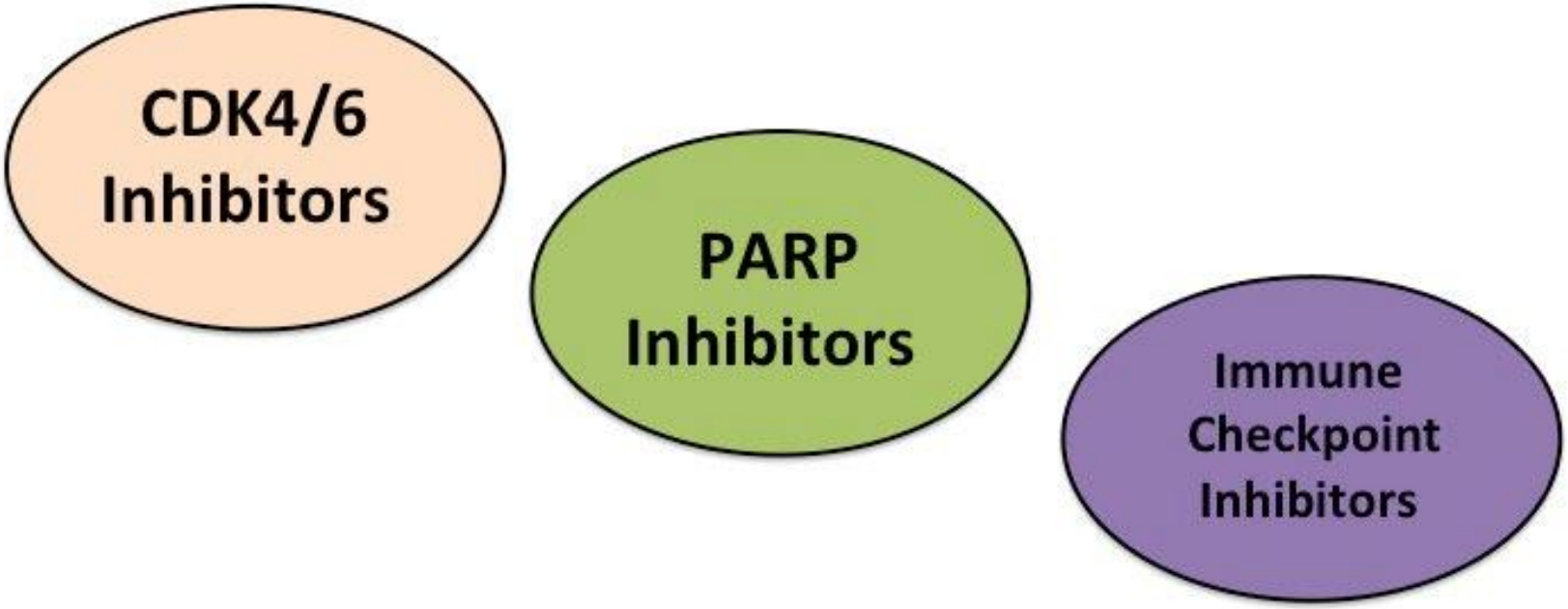


Source: www.mbcproject.org



Source: www.mbcproject.org

Response and Resistance to Specific Drugs



Ability to ask patients for additional data allows identification of specific cohorts of patients prior to medical record abstraction

INSTITUT JULES BORDET INSTITUUT

Source: www.mbcproject.org

ULB iris

cBioPortal FOR CANCER GENOMICS

Data Sets | Web API | R/MATLAB | Tutorials | FAQ | News | Visualize Your Data | About

The Metastatic Breast Cancer Project (Provisional, October 2017) Query this study

The Metastatic Breast Cancer Project is a patient-driven initiative. This study includes genomic data, patient-reported data (pre-pended as PRD), medical record data (MedR), and pathology report data (PATH). All of the titles and descriptive text for the clinical data elements have been finalized in partnership with numerous patients in the project. As these data were generated in a research, not a clinical, laboratory, they are for research purposes only and cannot be used to inform clinical decision-making. All annotations have been de-identified. More information is available at www.mbcproject.org. Questions about these data can be directed to data@mbcproject.org.

Study Summary | Clinical Data | Mutated Genes | Copy Number Alterations

Selected: 103 samples / 78 patients | query genes - click to expand | Query | Select cases by IDs | Add Chart

Cancer Type Detailed	#	Freq
Breast Invasive Ductal ...	67	65.05%
Invasive Breast Carcinoma	16	15.53%
Breast Mixed Ductal and...	11	10.68%
Breast Invasive Lobular...	9	8.74%

Search...

Mutated Genes (103 profiled samples)

Gene	# Mut	#	Freq
TP53	30	30	29.13%
PIK3CA	29	27	26.21%
TTN	27	24	23.30%
OBSCN	13	12	11.65%
RYR1	11	10	9.71%
CDH1	9	9	8.74%
KIAA1109	10	9	8.74%
KMT2C	9	9	8.74%
ACAN	8	8	7.77%
SYNE1	8	7	6.80%
APOB	7	7	6.80%

Search...

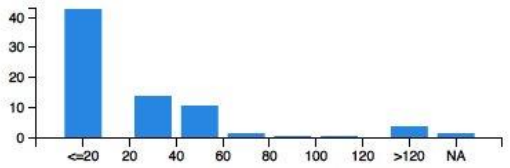
CNA Genes (103 profiled samples)

Gene	Cytoband	CNA	#	Freq
CCND1	11q13.3	AMP	38	36.89%
NDRG1	8q24.22	AMP	34	33.01%
FGF19	11q13.3	AMP	33	32.04%
ERBB2	17q12	AMP	32	31.07%
FGF4	11q13.3	AMP	31	30.10%
FGF3	11q13.3	AMP	31	30.10%
IKZF3	17q12-q...	AMP	31	30.10%
CDK12	17q12	AMP	29	28.16%
RAD21	8q24.11	AMP	29	28.16%
MUC1	1q22	AMP	28	27.18%
PDPK1	16p13.3	AMP	27	26.21%

Search...

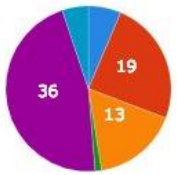
MedR Age at Diagnosis

With Mutation Data

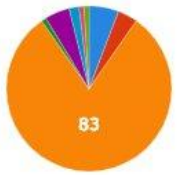


MedR Time to Metastatic Diagnosis (Calculated Months)

MedR Stage at Diagnosis

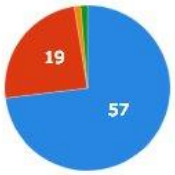


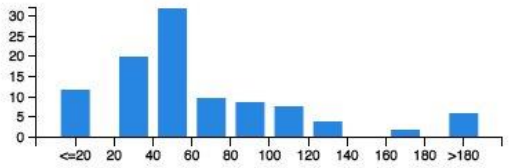
PATH Procedure Location



With CNA Data

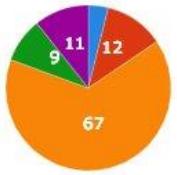
# of Samples Per Patient



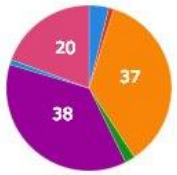


Mutation Count

PATH Sample Histology



PATH Sample Grade



iris

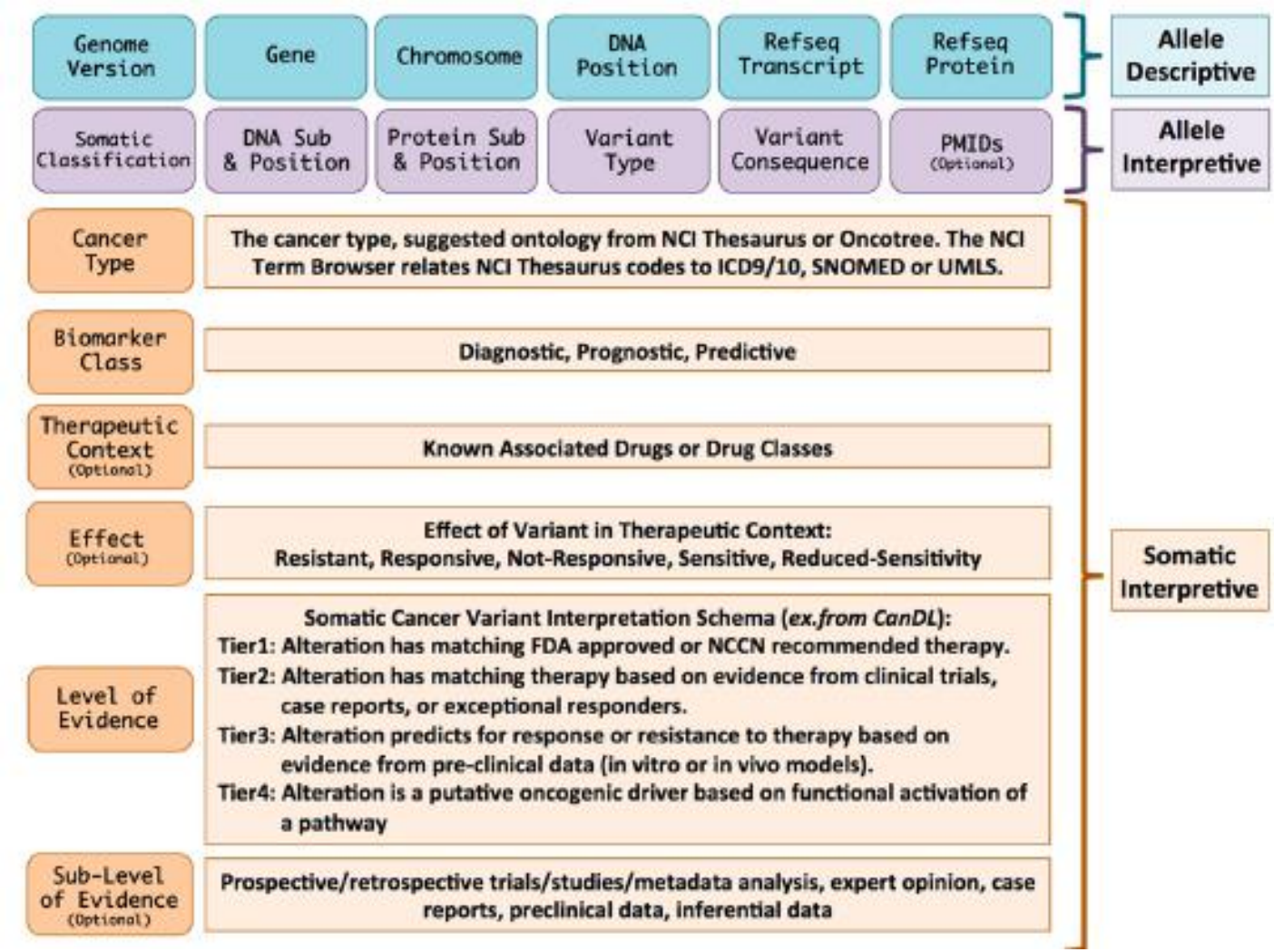
INSTITUT
JULES BORDET
INSTITUUT

Data Sharing: what perspectives?

- Homogeneisation
- Big Data
- Patient privacy protection and the GDPR

ULB iris

Standardization efforts for genomic data
(Minimum Variant Level Data MVLD)



Ritter D et al. Genome Medicine 2016.

Structuration of clinical data

How Can We Encode Unstructured Eligibility Criteria?

1. Eligibility criteria is communicated in a variety of forms, including free text, lists, and tables.
2. Great need for a mechanism to structure eligibility information.

Clinical Trial Markup Language (CTML): A human-readable programming language for describing clinical trial eligibility criteria. CTML currently supports genomic, clinical, and demographic criteria, and can be expanded to encompass any desired eligibility criteria.

INSTITUT JULES BORDET INSTITUUT

Presented by C. Del Vecchio Fitz at AACR 2018

ULB iris

CTML: Example

A

Subject Inclusion Criteria

In order to be eligible for participation in this trial, the subject must:

1. Have a histologically confirmed diagnosis of advanced (unresectable Stage III) or metastatic (Stage IV) melanoma or a histologically or cytologically-documented, locally-advanced or metastatic solid malignancy, and have at least one measurable lesion as defined by RECIST 1.1 on imaging studies (CT or MRI).
   - Mucosal or ocular melanoma are excluded.
2. Be willing and able to provide written informed consent for the trial. The subject may also provide consent for Future Biomedical Research. However, the subject may participate in the main trial without participating in Future Biomedical Research.
3. Be ≥ 18 years of age on day of signing the informed consent.
4. Have BRAF mutation testing as determined at a local laboratory and either:
   a. Have a BRAF mutation-positive (V600 E or K) tumor to be eligible for treatment with MK-3475+trametinib+dabrafenib, trametinib+dabrafenib or MK-3475+dabrafenib (if this part of the study is performed). If a subject's initial specimen does not test BRAF mutation-positive, a newly obtained specimen (different from the sample previously submitted) may be submitted for testing. If the newer specimen tests BRAF mutation-positive, the subject meets this eligibility criterion.
   b. Have a BRAF mutation-negative (wild type) tumor to be eligible for treatment with MK-3475+trametinib

B

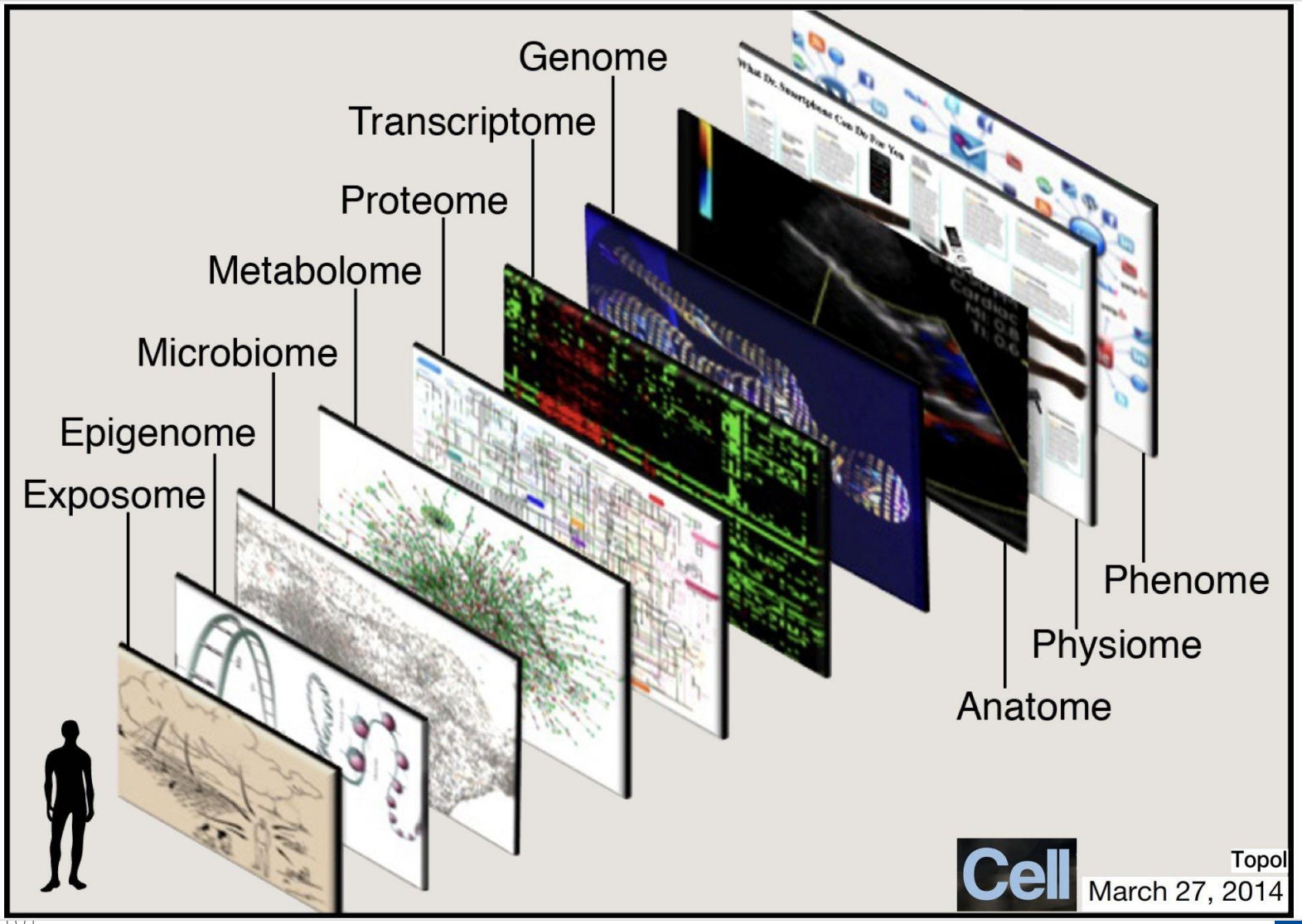
```
age: Adults                                                    Trial
curated_on: December 13, 2016
last_updated: September 01, 2017
long_title: A Phase I/II Study to Assess the Safety and Efficacy of
  MK-3475 in Combination with Trametinib and Dabrafenib in Subjects
  with Advanced Melanoma.
nct_id: NCT02130466
phase: I/II
protocol_no: 14-355
protocol_type: Treatment
short_title: MK-3475+TRAMETINIB+DABRAFENIB IN ADV MELANOMA
status: Closed to Accrual
treatment_list:                                          Treatment List
  - arm:
    - arm_description: 'DOSEM: BRAF MUTANT DOSE LEVELS'
      arm_suspended: N
      match:
        - and:
          - or:                                  Genomic Match Criteria
            - genomic:
                hugo_symbol: BRAF
                protein_change: p.V600E
                variant_category: Mutation
            - genomic:
                hugo_symbol: BRAF
                protein_change: p.V600K
                variant_category: Mutation
          - and:
            - clinical:                          Clinical Match Criteria
                age_numerical: '>=18'
                oncotree_primary_diagnosis: Melanoma
            - clinical:
                age_numerical: '>=18'
                oncotree_primary_diagnosis: '!Ocular Melanoma'
            - clinical:
                age_numerical: '>=18'
                oncotree_primary_diagnosis: '!Uveal Melanoma'
            - clinical:
                age_n                    '>=18'
```

INSTITUT JULES BORDET INSTITUUT

Presented by C. Del Vecchio Fitz at AACR 2018

ULB iris

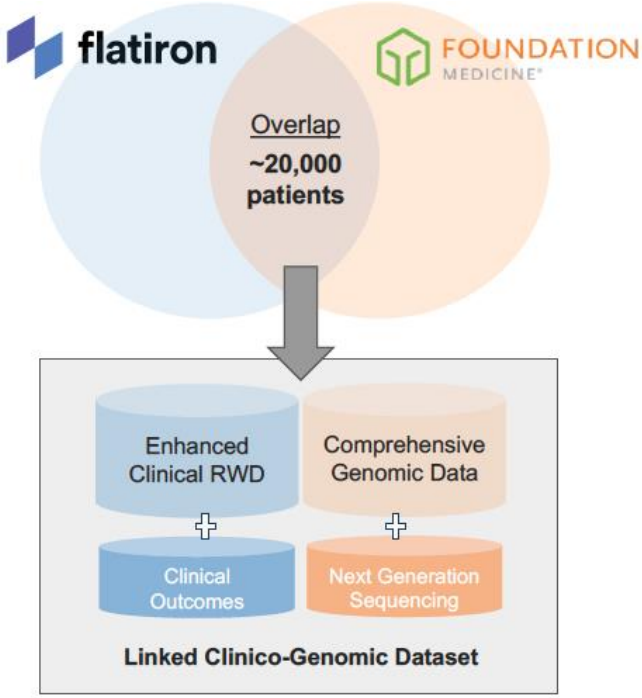
From genomic data to Big Data



Building a Transformative Database

Generation of a Clinico-Genomics Database (CGDB) Using "Real-World" Data

- More than 20,000 oncology patients from community practices were identified who were both sequenced by Foundation Medicine and for whom electronic health records were available for abstraction by Flatiron; 2139 of these patients have non-small cell lung cancer (NSCLC)
- The information was linked in a HIPAA-compliant fashion through a third party to create the database which is updated quarterly
- Tumor sequencing defines genomic alterations in over 300 genes and global tumor mutation burden (TMB, mutations / Mb)



All Patients in Flatiron Network
1,673,125

↓

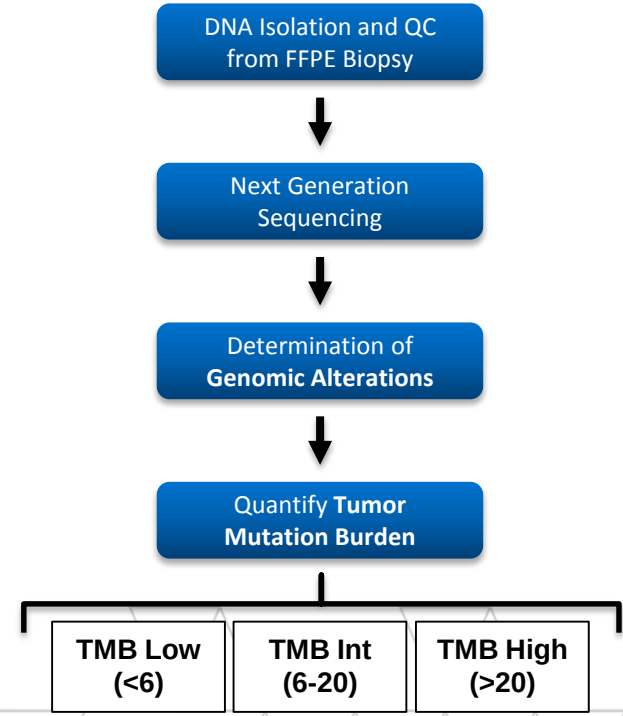
Patients who underwent tumor profiling by Foundation Medicine
20,022

↓

Lung Cancer ICD code with at least 1 visit on or after Jan 1, 2011
3,364

↓

Chart-confirmed NSCLC with NGS testing of this tumor
2,139



Courtesy Singal G

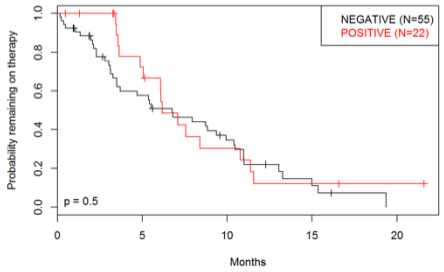
Singal G et al. ESMO 2017.

Tumor Mutation Burden And Response to CIT

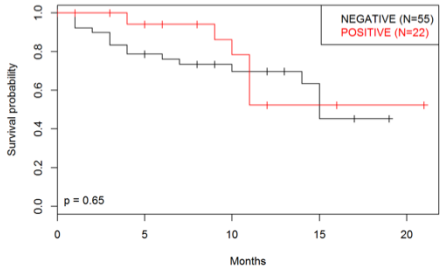
Incorporating Tumor Mutation Burden as a Biomarker for Response to CIT

PD-L1 Status Does Not Predict Response to Nivolumab

PD-L1 Status does not Correlate with Duration on Therapy

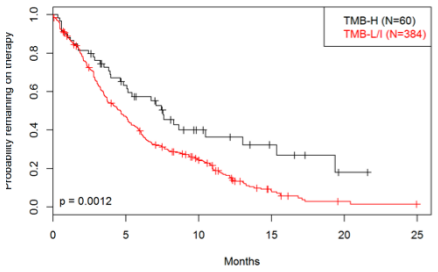


PD-L1 Status does not Correlate with Survival from Therapy Start

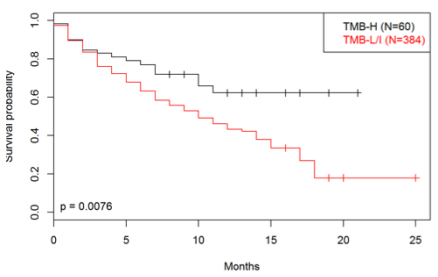


High TMB (>20 mutations/Mb) Predicts Response to Nivolumab

High TMB Correlates with Duration on Therapy

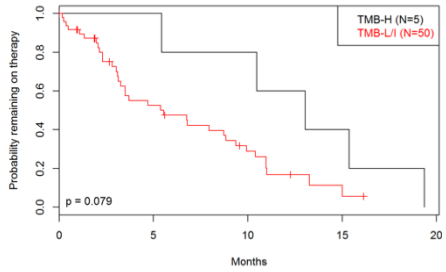


High TMB Correlates with Survival from Therapy Start

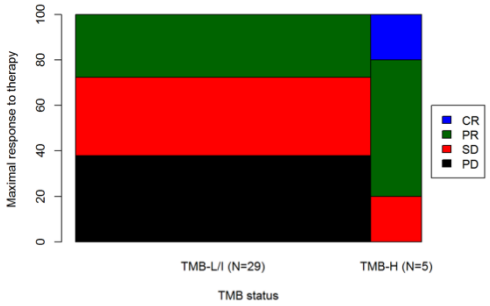


High TMB Predicts Response to Nivolumab in PD-L1 Negative Group

High TMB Correlates with Duration on Therapy in PD-L1 Negative Group



High TMB is Associated with Response to Therapy in PD-L1 Negative Patients



Cox Proportional Hazards Model Confirms association of TMB with Duration on Nivolumab and may suggest additional genomic biomarkers

Variable	p-value	HR	95% CI
TMB	**0.00285**	**0.9798**	**0.9667-0.993**
BRAF: WT/Mut	**0.02822**	**2.2763**	**1.0918-4.746**
STK11: WT/Mut	0.10595	0.7539	0.5353-1.062
KRAS: WT/Mut	0.12782	1.2516	0.9376-1.671
Histology: Other/Adeno	0.14161	0.7808	0.5613-1.086
Race: Other/Asian	0.25766	1.547	0.7268-3.293
EGFR: WT/Mut	0.51532	0.8652	0.5595-1.338
ALK: WT/Mut	0.56517	0.755	0.2897-1.967
Race: Black/Asian	0.7201	0.8582	0.3717-1.981
Race: White/Asian	0.72533	1.1299	0.5717-2.233
ROS1: WT/Mut	0.79441	1.1696	0.3601-3.799
Age at Adv Diag	0.83411	1.0015	0.9876-1.016
Stage: II/I	0.84572	0.9331	0.4647-1.874
Histology: SqCC/Adeno	0.85058	1.0382	0.7026-1.534
First Line Number	0.85946	0.9913	0.9002-1.092
Stage: III/I	0.88323	1.0474	0.5643-1.944
Gender: M/F	0.91417	1.0142	0.7845-1.311
Smoking: No/Yes	0.92386	1.0174	0.713.9-1.45
Stage: IV/I	0.9969	0.9988	0.5568-1.792

Courtesy Singal G

Singal G et al. ESMO 2017.

INSTITUT
JULES BORDET
INSTITUUT

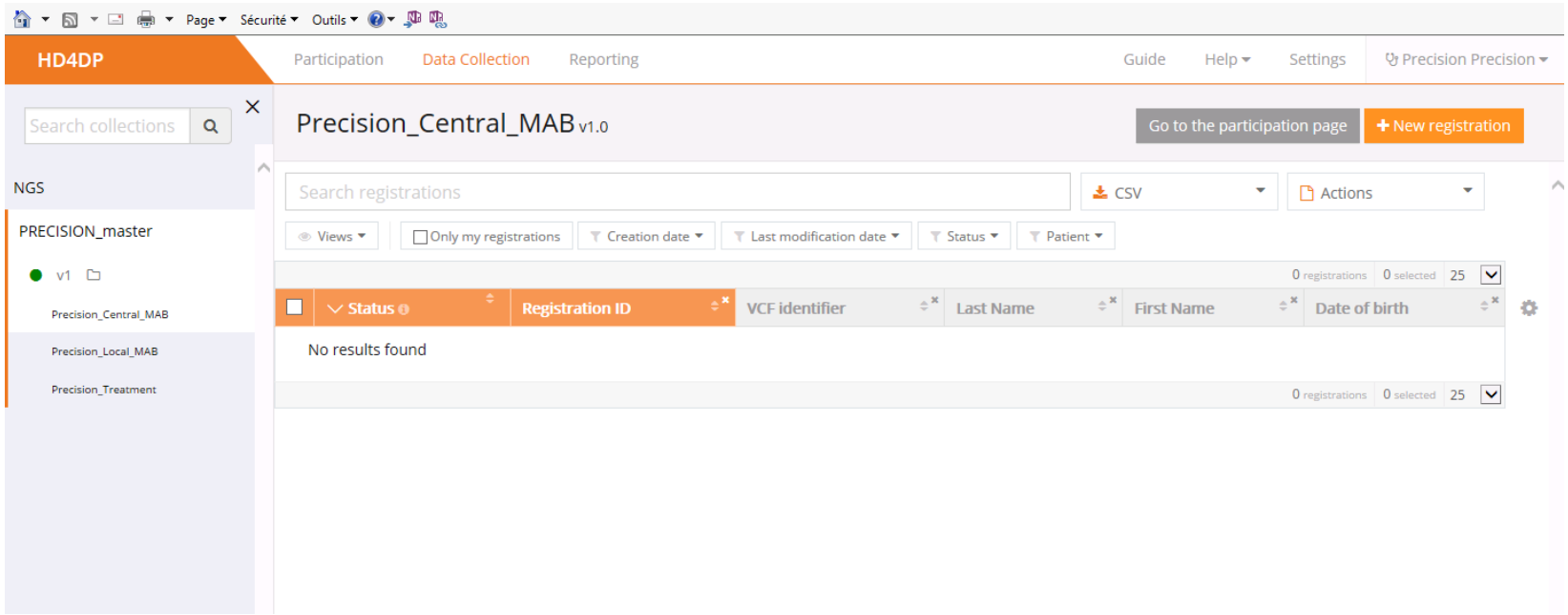
Belgian point of view

The reimbursement of NGS will be linked to data sharing (VCF files) on the national HealthData platform

ULB iris

Precision 1

healthdata.be



INSTITUT
JULES BORDET
INSTITUUT

ULB
iris

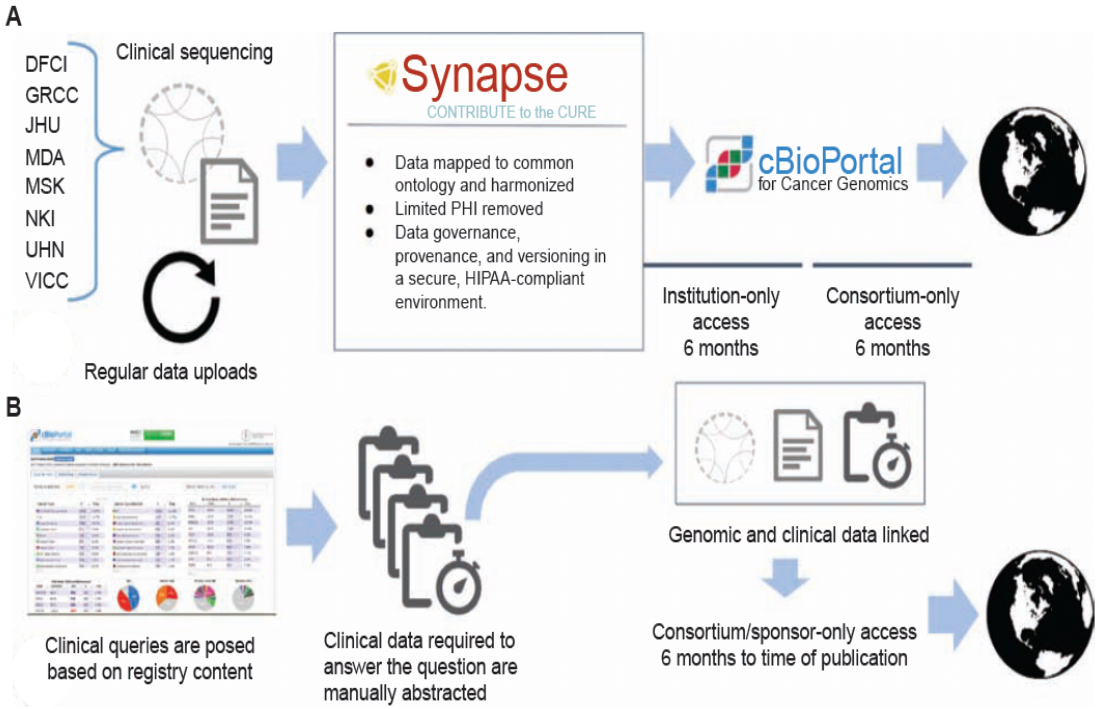
AACR American Association for Cancer Research

FINDING CURES TOGETHER℠

PROJECT GENIE

Genomics Evidence Neoplasia Information Exchange

Center abbreviation	Center name
DFCI	Dana-Farber Cancer Institute, USA
GRCC	Institut Gustave Roussy, France
JHU	Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, USA
MDA	The University of Texas MD Anderson Cancer Center, USA
MSK	Memorial Sloan Kettering Cancer Center, USA
NKI	Netherlands Cancer Institute, on behalf of the Center for Personalized Cancer Treatment, the Netherlands
UHN	Princess Margaret Cancer Centre, University Health Network, Canada
VICC	Vanderbilt-Ingram Cancer Center, USA



INSTITUT JULES BORDET INSTITUUT

AACR Project GENIE Consortium. Cancer Discov 2017.

ULB iris

Patient privacy protection

Science AAAS

Identifying Personal Genomes by Surname Inference
Melissa Gymrek *et al.*
Science **339**, 321 (2013);
DOI: 10.1126/science.1229566

Consent of the patient in case of identification risk but…

RESEARCH

GENETIC PRIVACY

Identity inference of genomic data using long-range familial searches

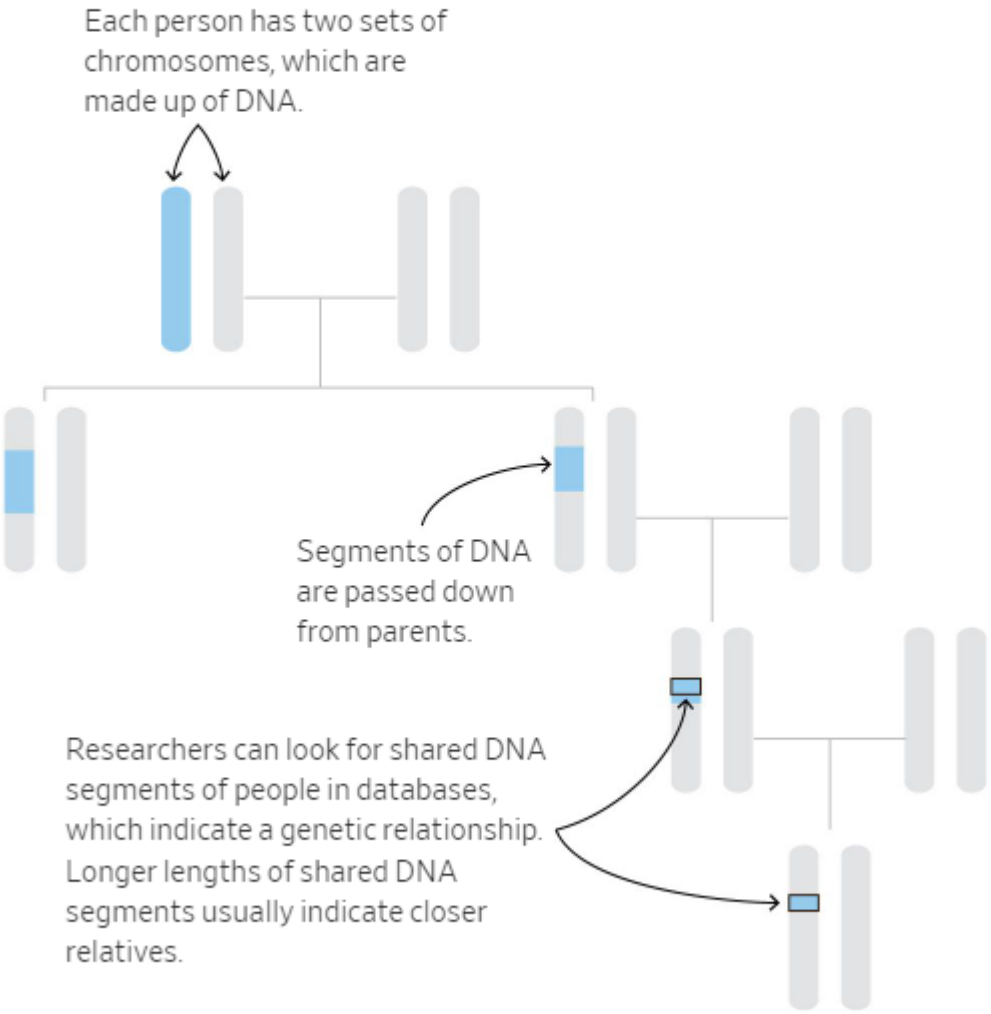
Yaniv Erlich[1,2,3,4]*, Tal Shor[1], Itsik Pe'er[2,3], Shai Carmi[5]

« Objective factors», (such as the cost of the identification and time needed, the availability and evolution of the technologies at the time of treatment), should be taken into consideration when deciding the qualification of the data*.

Making Matches

As more people upload DNA results into public databases, it will get easier to identify relatives beyond the immediate family. One way to find relatives is by locating shared DNA segments that people have inherited from common ancestors.

How it works



Sources: Science; Yaniv Erlich

The Washington Post
Democracy Dies in Darkness

Public Safety

To find alleged Golden State Killer, investigators first found his great-great-grandparents

SACRAMENTO — Detectives had searched for four decades for the clue that would unlock the identity of the Golden State Killer, the predator who terrorized California top to bottom with a string of horrific rapes and homicides in the 1970s and '80s.

Holes used DNA recovered from a crime scene to find the killer's great-great-great grandparents, who lived in the early 1800s. Branch by painstaking branch, he and a team created about 25 family trees containing thousands of relatives down to the present day.

Making sense of GDPR

- The GDPR is a complex piece of legislation. That complexity is increased by the often vague terms
- The GDPR does not equate data processing for healthcare and research with that of social media such as Facebook
- The GDPR also introduced huge fines for infringements on the GDPR which may have contributed to a sometimes overcautious interpretation
- As follows from the Breyer decision of the European Court of Justice in October 2016, the risk of re-identification does not need to be zero
- A strong call to liaise with patient organisations and the public at large

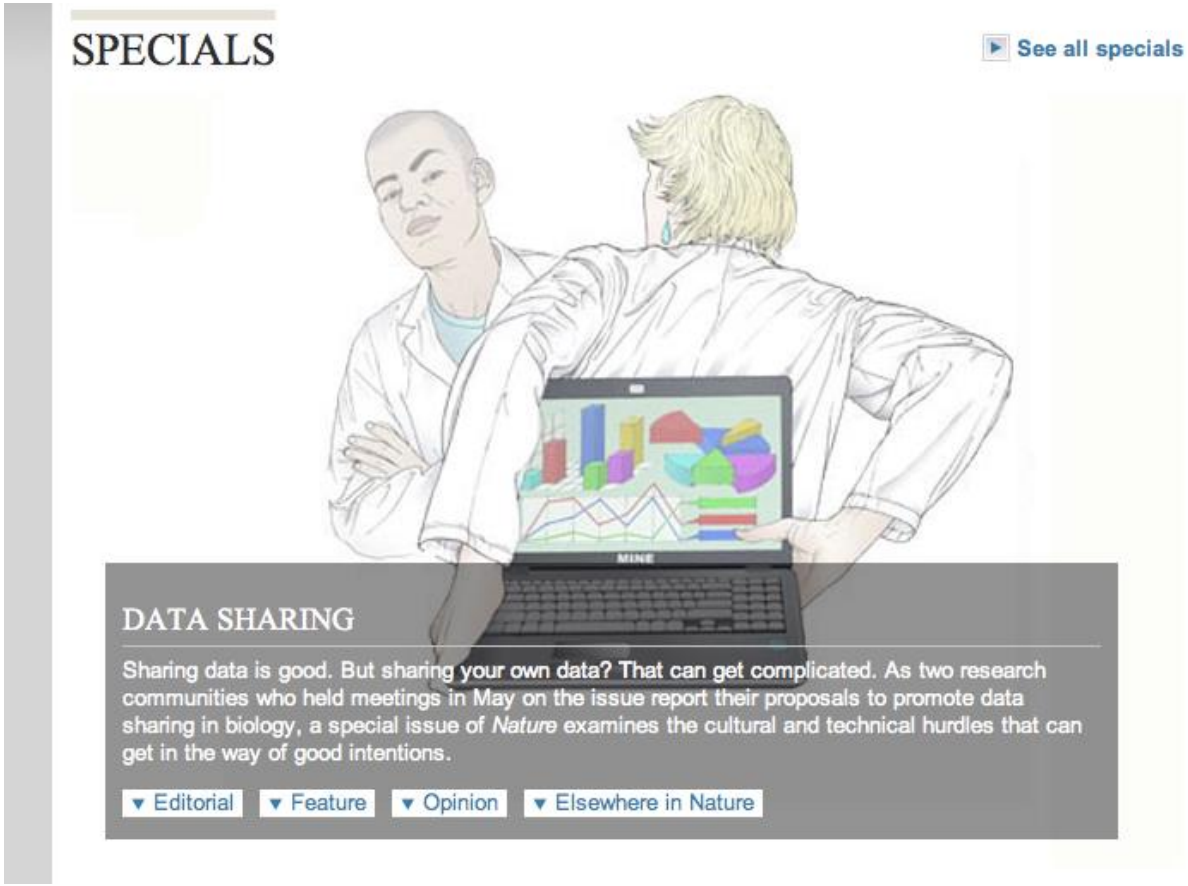
Van Veen EB et al. Eur J Can 2018.

facebook

Cambridge Analytica

INSTITUT
JULES BORDET
INSTITUUT

ULB iris



philippe.aftimos@bordet.be

@aftimosp

INSTITUT JULES BORDET INSTITUUT

ULB iris