

# SCIENTIFIC DATA

Data descriptors to enhance utility and utilization of data sets



## **Stefan Wiemann**

Division Molecular Genome Analysis  
German Cancer Research Center  
Member Editorial Board, Scientific Data

## **Andrew L. Hufton**

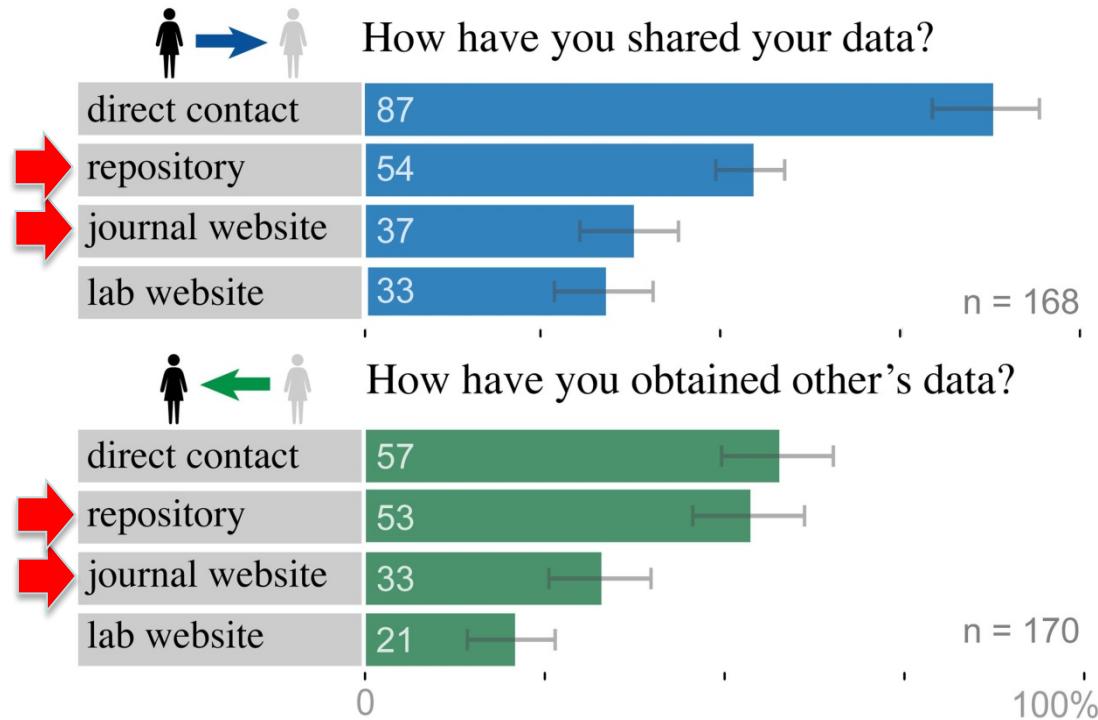
Managing Editor, Scientific Data  
Nature Publishing Group  
[andrew.hufton@nature.com](mailto:andrew.hufton@nature.com)

Helmholtz Open Science Webinars on Research Data  
Webinar 35 – 3 / 9 May 2016

**It's about sharing,  
utility & utilization of research data  
(in this webinar)**

## The current situation

- Most researchers are sharing data, and using the data of others
- Direct contact between researchers (on request) is a common way of sharing data
- **Repositories are second most common method of sharing, followed by papers (supplements)**



Kratz JE, Strasser C (2015) Researcher Perspectives on Publication and Peer Review of Data. *PLoS ONE* 10(2): e0117619.

## Comprehensive molecular portraits of human breast tumours

The Cancer Genome Atlas Network\*

We analysed primary breast cancers by genomic DNA copy number arrays, DNA methylation, exome sequencing, messenger RNA arrays, microRNA sequencing and reverse-phase protein arrays. Our ability to integrate information across platforms provided key insights into previously defined gene expression subtypes and demonstrated the existence of four main breast cancer classes when combining data from five platforms, each of which shows significant molecular heterogeneity. Somatic mutations in only three genes (*TP53*, *PIK3CA* and *GATA3*) occurred at >10% incidence across all breast cancers; however, there were numerous subtype-associated and novel gene mutations including the enrichment of specific mutations in *GATA3*, *PIK3CA* and *MAP3K1* with the luminal A subtype. We identified two novel protein-expression-defined subgroups, possibly produced by stromal/microenvironmental elements, and integrated analyses identified specific signalling pathways dominant in each molecular subtype including a HER2/phosphorylated HER2/EGFR/phosphorylated EGFR signature within the HER2-enriched expression subtype. Comparison of basal-like breast tumours with high-grade serous ovarian tumours showed many molecular commonalities, indicating a related aetiology and similar therapeutic opportunities. The biological finding of the four main breast cancer subtypes caused by different subsets of genetic and epigenetic abnormalities raises the hypothesis that much of the clinically observable plasticity and heterogeneity occurs within, and not across, these major biological subtypes of breast cancer.

4 OCTOBER 2012 | VOL 490 | NATURE | 61

**Supplementary Information** is available in the online version of the paper.



### **PDF files**

#### 1. [Supplementary Information \(14.1M\)](#)

This file contains Supplementary Figures 1-20, Supplementary Methods 1-15 (with additional figures and tables) and Supplementary References.

### **Zip files**

#### 1. [Supplementary Tables \(1M\)](#)

This zipped file contains Supplementary Tables 1-8. *This file was replaced on 15 November 2012 to correct an error in Supplementary Table 5.*

**information is often “hidden” in supplements**

# Part of supplementary Table 1 – patient data

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z
1	Complete TCGA ID	Gender	Age at Initial Pathologi	ER Status	PR Status	HER2 Final Status	Tumor	Tumor-T1 Coded	Node	Node-Coded	Metastasis	Metasta-sis-Coded	AJCC Stage	Converted Stage	Survival Data Form	Vital Status	Days to Date of Last Contact	Days to date of Death	OS event	OS Time	PAM50 mRNA	Sign	Unspec	ed n		
2	TCGA-A2-A0T2	FEMALE	66	Negative	Negative	Negative	T3	T_Other	N3	Positive	M1	Positive	Stage IV	No_Conversion	follow up	DECEASED	240	240	1	240	Basal-like					
3	TCGA-A2-A04P	FEMALE	36	Negative	Negative	Negative	T2	T_Other	N3	Positive	M0	Negative	Stage III	No_Conversion	follow up	DECEASED	547	547	1	547	Basal-like					
4	TCGA-A1-A05K	FEMALE	54	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	DECEASED	594	967	1	967	Basal-like					
5	TCGA-A2-A0CM	FEMALE	40	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	DECEASED	754	754	1	754	Basal-like					
6	TCGA-AR-A1A8	FEMALE	50	Negative	Negative	Negative	T1	T1	N2	Positive	M0	Negative	Stage III	Stage III	enrollment	DECEASED [Not Available]	523	1	523	Basal-like						
7	TCGA-B6-A0WX	FEMALE	40	Negative	Negative	Negative	T3	T_Other	N1	Positive	M0	Negative	Stage III	No_Conversion	follow up	DECEASED	653	653	1	653	Basal-like					
8	TCGA-BH-A1FO	FEMALE	80	Negative	Indeterminate	Negative	T1	T1	N1	Positive	M0	Negative	Stage II	Stage II	enrollment	DECEASED [Not Available]	785	1	785	Basal-like						
9	TCGA-B6-A016	FEMALE	49	Negative	Negative	Not Available	T1	T1	N1	Positive	M0	Negative	Stage II	No_Conversion	follow up	DECEASED	991	997	1	997	Basal-like					
10	TCGA-BH-A18V	FEMALE	48	Negative	Negative	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	No_Conversion	enrollment	DECEASED	1555	1555	1	1555	Basal-like					
11	TCGA-BH-A18Q	FEMALE	56	Negative	Negative	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	No_Conversion	enrollment	DECEASED	1692	1692	1	1692	Basal-like					
12	TCGA-BH-A18K	FEMALE	46	Positive	Positive	Negative	T1	T1	N0	Negative	M0	Negative	Stage I	Stage I	enrollment	DECEASED	2547	2762	1	2762	Basal-like					
13	TCGA-BH-A0H1	FEMALE	56	Positive	Positive	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	No_Conversion	follow up	LIVING	72	NA	0	72	Basal-like					
14	TCGA-BH-A0E0	FEMALE	38	Negative	Negative	Negative	T3	T_Other	N3	Positive	M0	Negative	Stage III	No_Conversion	follow up	LIVING	133	NA	0	133	Basal-like					
15	TCGA-BH-A0R9	FEMALE	59	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	170	NA	0	170	Basal-like					
16	TCGA-A7-A13D	FEMALE	46	Negative	Positive	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	267	NA	0	267	Basal-like					
17	TCGA-BH-A0E9	FEMALE	68	Negative	Negative	Negative	T1	T1	N0	Negative	M0	Negative	Stage I	Stage I	follow up	LIVING	292	NA	0	292	Basal-like					
18	TCGA-A0-A0J4	FEMALE	41	Negative	Negative	Negative	T1	T1	N0	Negative	M0	Negative	Stage I	Stage I	follow up	LIVING	294	NA	0	294	Basal-like					
19	TCGA-A7-A0CE	FEMALE	57	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	303	NA	0	309	Basal-like					
20	TCGA-A7-A13E	FEMALE	62	Positive	Negative	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	No_Conversion	follow up	LIVING	326	NA	0	326	Basal-like					
21	TCGA-A7-A0DA	FEMALE	62	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	373	NA	0	373	Basal-like					
22	TCGA-D8-A142	FEMALE	74	Negative	Negative	Negative	T3	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	425	NA	0	425	Basal-like					
23	TCGA-D8-A143	FEMALE	51	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	431	NA	0	431	Basal-like					
24	TCGA-AQ-A04J	FEMALE	45	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	499	NA	0	499	Basal-like					
25	TCGA-A2-A0H1	FEMALE	67	Positive	Positive	Negative	T1	T1	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	516	NA	0	516	Basal-like					
26	TCGA-A2-A0T0	FEMALE	59	Negative	Negative	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	No_Conversion	follow up	LIVING	533	NA	0	533	Basal-like					
27	TCGA-A2-A0Y6	FEMALE	48	Negative	Negative	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	No_Conversion	follow up	LIVING	553	NA	0	553	Basal-like					
28	TCGA-A2-A0YJ	FEMALE	39	Positive	Negative	Negative	T3	T_Other	N2	Positive	M0	Negative	Stage III	No_Conversion	follow up	LIVING	565	NA	0	565	Basal-like					
29	TCGA-A2-A0D0	FEMALE	60	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	643	NA	0	643	Basal-like					
30	TCGA-A2-A0U4	FEMALE	47	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	670	NA	0	670	Basal-like					
31	TCGA-A2-A0J6	FEMALE	61	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	775	NA	0	775	Basal-like					
32	TCGA-A2-A0YM	FEMALE	67	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	964	NA	0	964	Basal-like					
33	TCGA-A2-A0D2	FEMALE	45	Negative	Negative	Negative	T2	T_Other	N0	Negative	M0	Negative	Stage II	Stage II	follow up	LIVING	1027	NA	0	1027	Basal-like					
34	TCGA-BH-A0B3	FEMALE	53	Negative	Negative	Negative	T2	T_Other	N1	Positive	M0	Negative	Stage II	Stage II	No_Conversion	follow up	LIVING	1203	NA	0	1203	Basal-like				
35	TCGA-A2-A0QD	FEMALE	48	Negative	Negative	Negative	T1	T1	N0	Negative	M0	Negative	Stage I	Stage I	follow up	LIVING	1275	NA	0	1275	Basal-like					
36	TCGA-A2-A0SV	FEMALE	48	Negative	Negative	Negative	T1	T1	N0	Negative	M0	Negative	Stage I	Stage I	follow up	LIVING	1288	NA	0	1288	Basal-like					
37	TCGA-A2-A0SV	FEMALE	48	Negative	Negative	Negative	T1	T1	N0	Negative	M0	Negative	Stage I	Stage I	follow up	LIVING	1288	NA	0	1288	Basal-like					

A need of proper description/annotation of that data to facilitate re-use!

# How do you make your data useful?

Open data is about more than disclosure –  
it must be “FAIR”

- Findable
- Accessible
- Interoperable
- Re-usable

Wilkinson et al. **The FAIR Guiding Principles for scientific data management and stewardship**  
*Scientific Data* **3**, Article number: 160018 (2016) <http://dx.doi.org/10.1038/sdata.2016.18>

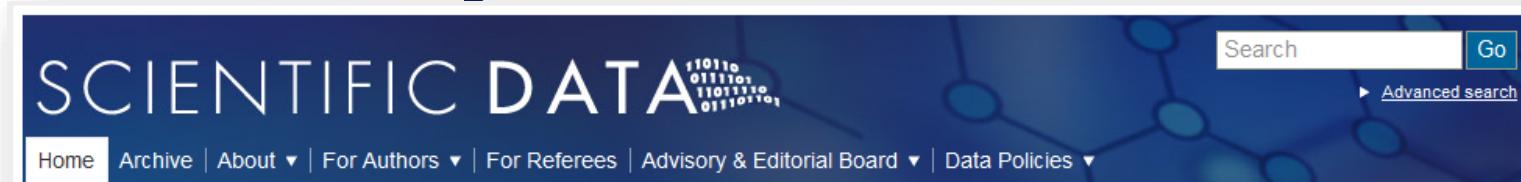
# the data paper

– a link between original paper and the data



i.e., annotation of data set(s)

# Launched in May 2014



The screenshot shows the homepage of the **SCIENTIFIC DATA** journal. The header features the journal title in large white letters, with a small binary sequence (10110 01110110 110110110 011101101) overlaid on the letter 'A'. On the right, there is a search bar with a 'Go' button and a link to 'Advanced search'. Below the header is a navigation bar with links to 'Home', 'Archive', 'About', 'For Authors', 'For Referees', 'Advisory & Editorial Board', and 'Data Policies'. The main content area is titled 'Featured Data Descriptor' and shows a photograph of a scuba diver examining a coral reef. To the right of the image is a summary of a paper: 'Systematic global assessment of reef fish communities by the Reef Life Survey program' by Graham J. Edgar and Rick D. Stuart-Smith, published on 27 May 2014 with doi: 10.1038/sdata.2014.7. Below this summary is a text block stating: 'Founded in 2007, the Reef Life Survey uses volunteer divers to assess biodiversity on ocean reefs around the world. Here, the authors release and describe the data collected by this project in detail, opening up this important citizen-science dataset to the wider scientific community.' The sidebar on the right is titled 'About Scientific Data' and describes the journal as an open-access, peer-reviewed publication for descriptions of scientifically valuable datasets. It highlights the 'Data Descriptor' article type. Below this text are links for 'E-alert', 'RSS', 'Facebook', and 'Twitter'. At the bottom of the sidebar is a 'Submit manuscript' button. The footer of the page includes the 'nature OUTLOOK' logo, a note about support from Otsuka Pharmaceutical Development and Commercialization, Inc., and a small image related to schizophrenia.

## Featured Data Descriptor



**Systematic global assessment of reef fish communities by the Reef Life Survey program**  
Graham J. Edgar and Rick D. Stuart-Smith  
27 May 2014 | doi: 10.1038/sdata.2014.7

Founded in 2007, the Reef Life Survey uses volunteer divers to assess biodiversity on ocean reefs around the world. Here, the authors release and describe the data collected by this project in detail, opening up this important citizen-science dataset to the wider scientific community.

## Latest content

Data Descriptor | 27 May 2014

**microclim: Global estimates of hourly microclimate based on long-term monthly climate averages**  
Kearney *et al.*

Data Descriptor | 27 May 2014

**miRNA expression atlas in male rat**  
Minami *et al.*

Data Descriptor | 27 May 2014

**A high-resolution 7-Tesla fMRI dataset from complex natural stimulation with an audio movie**  
Hanke *et al.*

Data Descriptor | 27 May 2014

**Time-resolved gene expression profiling during reprogramming of C/EBP $\alpha$ -pulsed B**

## About Scientific Data

*Scientific Data* is an open-access, peer-reviewed publication for descriptions of scientifically valuable datasets. Our primary article-type, the **Data Descriptor**, is designed to make your data more discoverable, interpretable and reusable.

 E-alert

 RSS

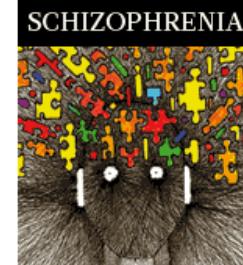
 Facebook

 Twitter

 Submit manuscript 

**nature OUTLOOK**

Produced with support from Otsuka Pharmaceutical Development and Commercialization, Inc.



## Announcements

Scientific Data Updates



## Get Credit for Sharing Your Data

Publications will be indexed and citeable.



## Open-access

Articles are published by default under a Creative Commons Attribution licence (CC BY). Each publication supported by CC0 metadata.



## Focused on Data Reuse

All the information others need to reuse the data; no interpretative analysis, or hypothesis testing



## Peer-reviewed

Rigorous peer-review focused on technical data quality and reuse value



## Promoting Community Data Repositories

Not a new data repository; data stored in community data repositories

# The “Data Descriptor” article-type

**Does not contain tests of new scientific hypotheses  
(no Results, no Discussion)**

## Sections:

- Title
- Abstract
- Background & Summary
- **Methods**
- **Data Records** ←
- **Technical Validation**
- **Usage Notes**
- Figures & Tables
- References
- **Data Citations**

### Data Records

All the samples used in this study are summarized in Table 1. Consistent identifiers are used in Tables 2 and 3 to allow mapping between the proteomic and transcriptomic data outputs.

#### Data Record 1

The raw data, peaklists (.mgf), ProteomeDiscoverer result files (.msf) and ProteomeDiscoverer workflow files (.xml) have been uploaded to ProteomeXchange (<http://www.proteomexchange.org/>) with the following accession number PXD000134 (ref. 67; Table 2).

#### Data Record 2

Microarray data are available at the NCBI Gene Expression Omnibus (GEO) database under the accession numbers GSE26451 (ref. 68) and GSE26453 (ref. 69; Table 3).

#### Data Record 3

The peptide and protein identification data sets have been annotated by The Global Proteome Machine at <http://gpmdb.thegpm.org/>

#### Data Record 4

The peptide and protein identification data sets have been annotated by the StemCellOmicsRepository (SCOR) at <http://scor.chem.wisc.edu/>

- + All articles supported by machine-readable metadata in the ISA-tab format

# Sample case

The screenshot shows the homepage of the **SCIENTIFIC DATA** journal. The header features the journal title in large white letters, with a small binary code graphic (1101110 0111101 11011110 011101101) to the right. A search bar with a 'Go' button is in the top right. The main navigation menu includes Home, Archive, About, For Authors, For Referees, Data Policies, and Collections. Below the header, a breadcrumb trail shows the current page: Home > Data Descriptors > Data Descriptor. The main content area displays an article titled "An open access pilot freely sharing cancer genomic data from participants in Texas". The article is authored by Lauren B. Becnel, Stacey Pereira, Jennifer A. Drummond, Marie-Claude Gingras, Kyle R. Covington, Christie L. Kovar, Harsha Vardhan Doddapaneni, Jianhong Hu, Donna Muzny, Amy L. McGuire, David A. Wheeler & Richard A. Gibbs. Below the title, there are links for Affiliations, Contributions, and Corresponding author. The footer contains links for E-alert, RSS, Facebook, and Twitter, along with a "Submit manuscript" button. The page is identified as **Scientific Data 3, Article number: 160010 (2016) doi:10.1038/sdata.2016.10**.

SCIENTIFIC DATA | DATA DESCRIPTOR **OPEN**

An open access pilot freely sharing cancer genomic data from participants in Texas

Lauren B. Becnel, Stacey Pereira, Jennifer A. Drummond, Marie-Claude Gingras, Kyle R. Covington, Christie L. Kovar, Harsha Vardhan Doddapaneni, Jianhong Hu, Donna Muzny, Amy L. McGuire, David A. Wheeler & Richard A. Gibbs

Affiliations | Contributions | Corresponding author

Scientific Data 3, Article number: 160010 (2016) | doi:10.1038/sdata.2016.10

Submit manuscript

# Data descriptors to increase utility of data



The screenshot shows the homepage of the journal *SCIENTIFIC DATA*. The header includes a search bar with 'Search' and 'Go' buttons, and a link to 'Advanced search'. Below the header is a navigation bar with links to 'Home', 'Archive', 'About', 'For Authors', 'For Referees', 'Data Policies', and 'Collections'. The main content area shows a article titled 'An open access pilot freely sharing cancer genomic data from participants in Texas'. The article is authored by Lauren B. Becnel, Stacey Perei, Covington, Christie L. Kovar, H., Amy L. McGuire, David A. Wheeler, and others. The abstract discusses the challenges of sharing genomic data while protecting participant privacy. A red arrow points to a specific sentence in the abstract: 'genetic data from 7 human cancer cases with matched normal are freely available without requirement for data use agreements nor any major restriction except that end users cannot attempt to re-identify the participants (<http://txcrb.org/open.html>).'

SCIENTIFIC DATA

Home | Archive | About ▾ | For Authors ▾ | For Referees | Data Policies ▾ | Collections ▾

Home > Data Descriptors > Data Descriptor

SCIENTIFIC DATA | DATA DESCRIPTOR OPEN

An open access pilot freely sharing cancer genomic data from participants in Texas

Abstract

Lauren B. Becnel, Stacey Perei, Covington, Christie L. Kovar, H., Amy L. McGuire, David A. Wheeler, et al.

Affiliations | Contributions | Cited by | References | Data Records | Technical Validation | Usage Notes | Additional Information | References | Data Citations | Acknowledgements | Author information

Scientific Data 3, Article number: 160010

Abstract

Genomic data sharing in cancer has been restricted to aggregate or controlled-access initiatives to protect the privacy of research participants. By limiting access to these data, it has been argued that the autonomy of individuals who decide to participate in data sharing efforts has been superseded and the utility of the data as research and educational tools reduced. In a pilot Open Access (OA) project from the CPRIT-funded Texas Cancer Research Biobank, many Texas cancer patients were willing to openly share genomic data from tumor and normal matched pair specimens. For the first time, genetic data from 7 human cancer cases with matched normal are freely available without requirement for data use agreements nor any major restriction except that end users cannot attempt to re-identify the participants (<http://txcrb.org/open.html>).

# Access to the data

<http://txcrb.org/open.html>

The Texas Cancer Research Biobank (TCRB) was created to bridge the gap between doctors and scientific researchers to improve the prevention, diagnosis and treatment of cancer. This work occurred with funding from the [Cancer Prevention & Research Institute of Texas](#) (CPRIT) from 2010-2014.



## Click Here to Access Data

By clicking this button you agree to never attempt to re-identify these participants and to abide by our Conditions of Use



## Access the Clinical Data Annotations by Specimen Label

The table below contains a list of the data available through the BCM-HGSC SFTP server.

**To access this data, you must first register for an account and verify that you have read the Conditions for Data Use.**

## [Register for SFTP account](#)

Once you have registered, you can download the data through the [web interface](#) or [SFTP](#). Please refer to the [download instructions](#) for more information.

Case #	Sex/ Age/ Race/ Ethnicity	Prior treatment	Tumor % cellularity/ TNM	Disease Morph./ Anatomic Site	Tumor Grade
1	M/ 51-60/ White/ Not Hispanic or Latino	No	10%/ T3 N1 M0	8500/3: infiltrating duct adenocarcinoma/ Head of pancreas	II
	F/				

# There is room for detailed Methods

## Methods

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[Abstract](#) • [Background & Summary](#) • [Methods](#) • [Data Records](#) • [Technical Validation](#) • [Usage Notes](#) •  
[Additional Information](#) • [References](#) • [Data Citations](#) • [Acknowledgements](#) • [Author information](#)

### Obtaining informed consent

All work was carried out as part of an IRB-approved protocol (BCM IRB H-32711), which utilized a main consent document for general participation in TCRB with an opt-in consent addendum for OA data release. Of 194 TCRB participants offered the option of signing the opt-in addendum participating in OA sharing out of >2,500 total participants, more than half agreed to open access data sharing at time of consent. Annotated TCRB specimen and data collection consent and the OA opt in consent documents are available at <http://txcrb.org/resources.html>. To address concerns about whether patients can provide truly informed consent regarding the potential risks of genomic data sharing, a subset of the OA participants ( $n=37$ ) were educated on risks and societal benefits of data sharing. The educational materials are available at <http://txcrb.org/privacy.html>. Participants were surveyed to assess their comprehension, risk tolerance, and subjective comfort with OA data release. Each participant was again queried, post-survey, to reconfirm their choice to take part in the OA data sharing option. The majority demonstrated adequate understanding of the possible privacy and discrimination risks, yet still elected to allow their data to be openly shared. The work described in Pereira *et al.*<sup>9</sup> is one clear example that many, though not all, cancer patients indeed desire to participate in activities that could have broad-reaching, positive impacts to public health for reducing cancer mortality and morbidity, and have the capability to make an informed choice.

# Data sets are comprehensively described

## Data Records

[Abstract](#) • [Background & Summary](#) • [Methods](#) • Data Records • [Technical Validation](#) • [Usage Notes](#) • [Additional Information](#) • [References](#) • [Data Citations](#) • [Acknowledgements](#) • [Author information](#)

FASTQ reads and BAM data records for tumor (T) and normal (N) specimens from each case are freely available along with their conditions of use are freely available on the Texas Cancer Research Biobank website, <http://txcrb.org/open.html> (Data Citation 1: TCRB Open Access Repository TCRBOA1). Clinical annotations available for these cases are defined in Table 1. Other than a click-through agreement to acknowledge the conditions of use, requirement to create an access account for auditing purposes, and include these conditions within any re-sharing of the data, there are no additional barriers to data access on this portal. User accounts are valid for 30 days and can be renewed. All or some of these data may be downloaded, shared and redistributed for research and educational purposes in accordance with their conditions of use.

To ensure sustainable availability of the data, they are also deposited within SRA. We created the Texas Cancer Research Biobank Open Access Data Sharing Umbrella Project (Accession: PRJNA285925) under which two platform-specific projects were created—the subproject entitled the Texas Cancer Research Biobank Open Access Data Sharing: Exome Project (Data Citation 2: NCBI Sequence Read Archive [PRJNA284596](#)) that includes all seven cases and the subproject entitled

# Means of validation having been applied

## Technical Validation

[Abstract](#) • [Background & Summary](#) • [Methods](#) • [Data Records](#) • [Technical Validation](#) • [Usage Notes](#) • [Additional Information](#) • [References](#) • [Data Citations](#) • [Acknowledgements](#) • [Author information](#)

The TCRB utilized a secure, database-backed web application called Acquire<sup>30</sup> (code available at <https://github.com/BCM-DLDCC/Acquire>) for tracking specimens and their annotations. Through its modules, it supports the full lifecycle of biobanking operations, from collections to quality control testing. Public researchers can use the specimen request module to electronically search for and request available specimens. Acquire greatly facilitated non-OA TCRB donations to the TCGA and ICGC.

As TCRB tissue advocates at sites across the state of Texas consented patients, collected specimens, and entered data into Acquire. The system automatically assigns a barcode and UUID (universally unique identifier) to each specimen, aliquot and derivative. These identifiers are completely masked and contain no PHI or other data that can be mapped back to participants, such that the system's administrators held the mapping for the UUIDs to participant identifiers acted as the TCRB honest broker. All specimens underwent initial review by expert pathologists for disease diagnosis at the Texas hospital or clinic at which the patients were consented. The TCRB's own

# Usage Notes – here: ethical constraints...!

## Usage Notes

[Abstract](#) • [Background & Summary](#) • [Methods](#) • [Data Records](#) • [Technical Validation](#) • [Usage Notes](#) •

[Additional Information](#) • [References](#) • [Data Citations](#) • [Acknowledgements](#) • [Author information](#)

By downloading or utilizing any part of this dataset, end users must agree to the following conditions of use:

- No attempt to identify any specific individual represented by these data or any derivatives of these data will be made.
- No attempt will be made to compare and/or link this public data set or derivatives in part or in whole to private health information.
- These data in part or in whole may be freely downloaded, used in analyses and repackaged in databases.
- Redistribution of any part of these data or any material derived from the data will include a copy of this notice.
- The data are intended for use as learning and/or research tools only.
- This data set is not intended for direct profit of anyone who receives it and may not be resold.
- Users are free to use the data in scientific publications if the providers of the data (Texas Cancer Research Biobank and Baylor College of Medicine Human Genome Sequencing Center) are properly acknowledged.

## Some problems with sharing upon request

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- Relies heavily on trust (have you tried “cloning by phoning”?)
- Data associated with published works disappears at a rate of ~17% per year

(Vines et al. 2014, *Current Biology* 24(1), 94–97, 2014. doi:10.1016/j.cub.2013.11.014)

- Datasets not referenced in a manuscript are essentially invisible (a.k.a “Dark data”)
- Data producers do not get appropriate credit for their work

# **Stability of databases is another problem!**

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**New Project -> collection of data)**



**Database developed -> paper written)**



**End of project**



**Death of database  
-> loss of data!**

# Where to deposit data?



Browse our recommended data repository online.

- *We currently list more than 60 repositories, across the biological, physical and social sciences*
- *We advise authors on the best place to store their data*

# Some recommended Data Repositories

## Omics

### Functional genomics

Functional genomics is a broad experimental category, and *Scientific Data*'s recommendations in this discipline likewise bridge disparate research disciplines. Data should be deposited following the relevant community requirements where possible.

Please refer to the [MIAME](#) standard for microarray data. Molecular interaction data should be deposited with a member of the [International Molecular Exchange Consortium \(IMEx\)](#), following the [MIMIx recommendations](#).

For data linking genotyping and phenotyping information in human subjects, we strongly recommend submission to dbGAP or EGA, which have mechanisms in place to handle sensitive data.

<a href="#">ArrayExpress</a>	<a href="#">view BioSharing entry</a>
<a href="#">Gene Expression Omnibus (GEO)</a>	<a href="#">view BioSharing entry</a>
<a href="#">GenomeRNAi</a>	<a href="#">view BioSharing entry</a>
<a href="#">dbGAP</a>	<a href="#">view BioSharing entry</a>
<a href="#">The European Genome-phenome Archive (EGA)</a>	<a href="#">view BioSharing entry</a>

# Broad scope of Scientific Data

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## View data repositories

- Biological sciences:
  - nucleic acid sequence; protein sequence; molecular & supramolecular structure; neuroscience; omics; taxonomy & species diversity; mathematical & modelling resources; cytometry; organism-focused resources
- Health sciences
- Chemistry & chemical biology
- Earth and environmental sciences
- Physics, astrophysics & astronomy
- Social sciences
- Generalist repositories
- Institutional or project-specific repositories

# Other use cases: Screening data

SCIENTIFIC DATA

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SCIENTIFIC DATA | DATA DESCRIPTOR [OPEN](#)

Parallel genome-scale loss of function screens in 216 cancer cell lines for the identification of context-specific genetic dependencies

Glenn S Cowley, Barbara A Weir [...] William C Hahn

Affiliations | Contributions | Corresponding authors

Scientific Data 1, Article number: 140035 (2014) | doi:10.1038/sdata.2014.35  
Received 20 May 2014 | Accepted 22 August 2014 | Published online 30 September 2014

Changes have been made to this article:  
Corrigendum (11 November 2014)

[PDF](#) [ISATab](#) [Citation](#) [Reprints](#) [Rights & permissions](#) [Article metrics](#)

**Abstract**

Abstract • Background & Summary • Methods • Data Records • Technical Validation • Usage Notes • Additional information • References • Data Citations • Acknowledgements • Author information • Supplementary information

Using a genome-scale, lentivirally delivered shRNA library, we performed massively parallel pooled

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**Associated Links**

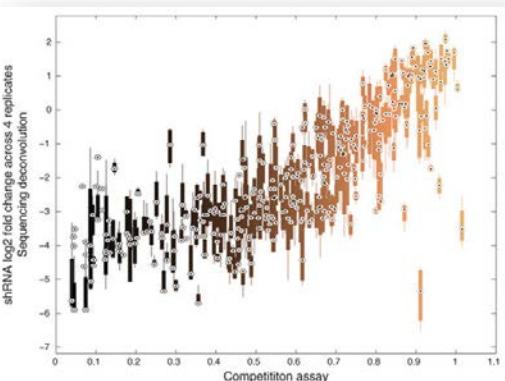
*Cancer Discovery* | Article  
Essential Gene Profiles in Breast, Pancreatic, and Ovarian Cancer Cells  
by A. Buzina *et al*

*Proceedings of the National Academy of Sciences* | Article  
Highly parallel identification of essential genes in cancer cells  
by A. Subramanian *et al*

*Proceedings of the National Academy of Sciences* | Article  
Systematic investigation of genetic vulnerabilities across cancer cell lines reveals lineage-specific dependencies in ovarian cancer  
by A. East *et al*

doi:10.1038/sdata.2014.35

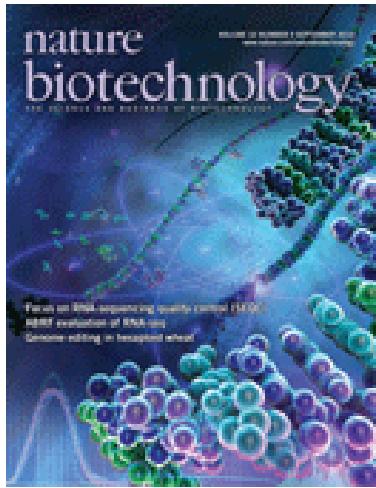
- **Screen results and in-depth analysis published in 2011 at *PNAS***
- **Full screen data published at *Scientific Data* in 2014**
- **Data at [figshare](#)**
- **Data Descriptor cited 26 times according to Google Scholar!**



# Publish alongside: major consortium

See the Focus on RNA sequencing quality control (SEQC)

In the September 2014 issue of *Nature Biotechnology*



**A comprehensive assessment of RNA-seq accuracy, reproducibility and information content by the Sequencing Quality Control Consortium**

SEQC/MAQC-III Consortium | doi: 10.1038/nbt.2957

**The concordance between RNA-seq and microarray data depends on chemical treatment and transcript abundance**

Wang et al. | doi: 10.1038/nbt.3001

## SCIENTIFIC DATA

**Cross-platform ultradeep transcriptomic profiling of human reference RNA samples by RNA-Seq**

Xu et al. | doi: 10.1038/sdata.2014.20

**Transcriptomic profiling of rat liver samples in a comprehensive study design by RNA-Seq**

Gong et al. | doi: 10.1038/sdata.2014.21

# Earth sciences

SEARCH

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Home ▶ Data Descriptors ▶ Data Descriptor

SCIENTIFIC DATA | DATA DESCRIPTOR [OPEN](#)

A Southern Indian Ocean database of hydrographic profiles obtained with instrumented elephant seals

Fabien Roquet, Guy Williams, Mark A. Hindell, Rob Harcourt, Clive McMahon, Christophe Guinet, Jean-Benoit Charrassin, Gilles Reverdin, Lars Boehme, Phil Lovell & M. Fedak

Affiliations | Contributions | Corresponding author

Scientific Data 1, Article number: 140028 | doi:10.1038/sdata.2014.28  
Received 23 May 2014 | Accepted 04 August 2014 | Published online 02 September 2014

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[Article metrics](#)

Deployment on land

CTD Profiling Data compression

ARGOS transmission Geo-localization

Reception in CLS Argos, Toulouse

Example of salinity profile comparison

Distribution to ocean data centers

Post-processing of CTD data

Data extraction Storage at SMRU Distribution to GTS

- Data in at **BODC/NERC**
- Builds on previous article at *Nature Geoscience*

## Global integrated drought monitoring and prediction system

Zengchao Hao, Amir Aghakouchak, Navid Nakhjiri & Alireza Farahmand

Affiliations | Contributions | Corresponding author

Scientific Data 1, Article number: 140001 | doi:10.1038/sdata.2014.1

Received 12 November 2013 | Accepted 10 January 2014 | Published online 11 March 2014

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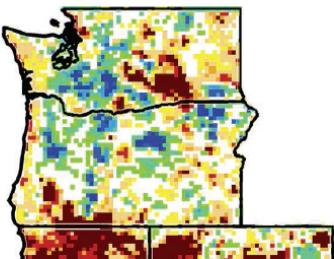
Associated Links

## LETTERS

edited by Jennifer Sills

### Australia's Drought: Lessons for California

MOST OF CALIFORNIA IS SUFFERING FROM AN extreme drought, and storage levels in the major reservoirs are well below historic levels. For the past several months, an unusually stubborn ridge of high pressure off the West Coast of the United States has been blocking normal winter storms and the rain they carry. California's history of drought has led to statewide strategies to save water, but Californian residents and policy-makers can do even more: They can look to the story of Australia's experience with a drought so intense and long-lasting



sumptuous activities, watering and car washing, efficient water management for shutoffs, those temporary restrictions grew, still restrict daytime most relevant for how the Australian changes. Studies of goodwill and cooperation of stress of drought (6).

AMIR AGHAKOUCHAK,<sup>1\*</sup> DAVID FELDMAN,<sup>2</sup>

MICHAEL J. STEWARDSON,<sup>2</sup> JEAN-DANIEL

SAPHORES,<sup>1</sup> STANLEY GRANT,<sup>1,2</sup> BRETT SANDERS<sup>3</sup>

The Henry Samueli School of Engineering, University of California, Irvine, Irvine, CA 92697, USA. <sup>2</sup>Melbourne School of Engineering, The University of Melbourne, Parkville, VIC 3010, Australia.

\*Corresponding author. E-mail: amir.a@uci.edu

#### References

1. A. J. Dijk *et al.* *Water Resources Res.* **49**, 1040 (2013).
2. Z. Hao *et al.* *Sci. Data* **1**, 1 (2014). 2
3. S. Dolnicar, A. I. Schauer, *J. Environ. Manage.* **90**, 888 (2009).

- **New Dataset**
- **Data in figshare**
- **Code in figshare**
- **Integrated figshare data viewer**

*Cited 47 times,  
according to Google  
Scholar!*

## Who benefits from enhanced re-use of data:

- Individual researcher -> citations
- Scientific community -> access to valuable data
- Society -> progress in research
- Funding agencies -> justification of funding
- Tax payer -> output per € / \$ / Yen...  
-> funding for new research

# SCIENTIFIC DATA

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### Managing Editor, Scientific Data

Andrew L. Hufton

[andrew.hufton@nature.com](mailto:andrew.hufton@nature.com)

### Honorary Academic Editor

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