

- 1.
- IPRs and licensing.

“intellectual property” =

“intellectual property” =  
a gaggle of rights...



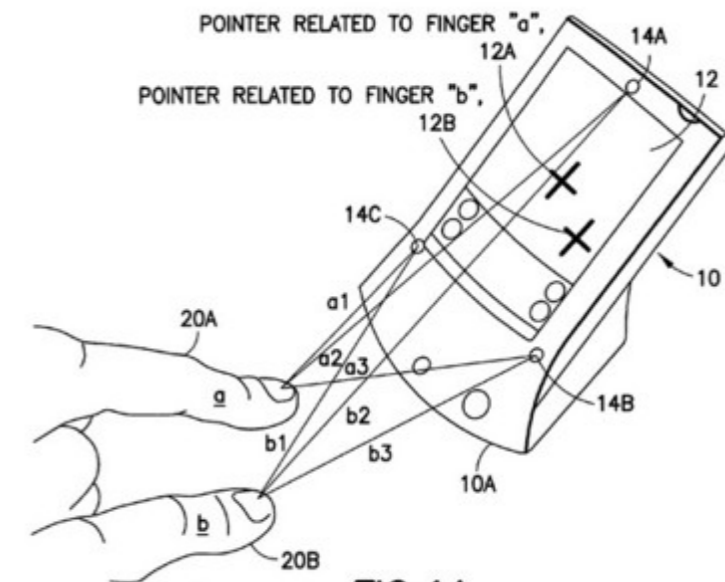
“intellectual property”



“intellectual property”



“intellectual property”





“intellectual property”

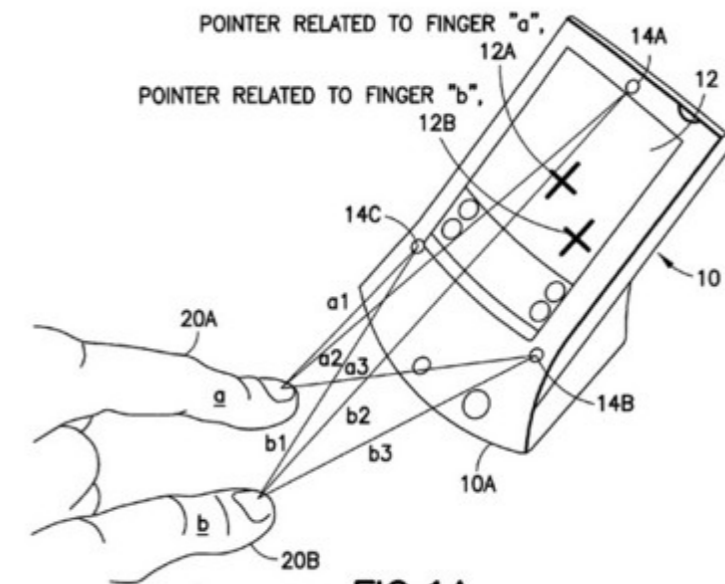


FIG. 1A

not:





not:



not:

$$1 \times \underline{\quad} = 7$$

$$3 \times \underline{\quad} = 12$$

$$9 \times \underline{\quad} = 72$$

$$7 \times \underline{\quad} = 49$$

$$5 \times \underline{\quad} = 30$$

**no (c) on data, generally speaking.**

(not a “creative expression”)





NO PUBLIC

ACCESS





global NGO / non profit organization





PUBLIC  
FOOTPATH



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International ▼

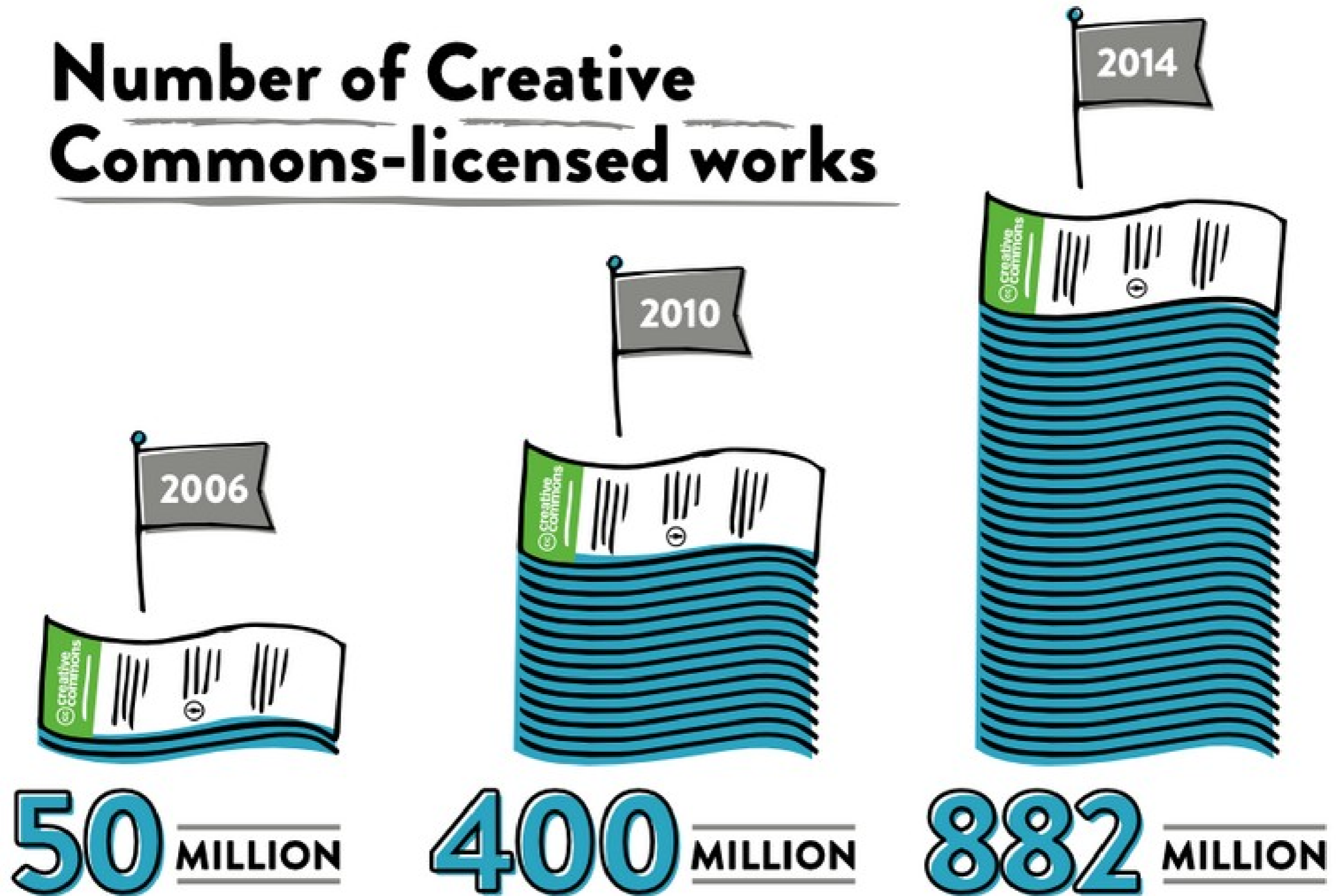
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- 2.
- PCORI and open licenses

- “open access” to research literature



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# When and How to Comply

**1** **Preparing a manuscript** **Address copyright**  
[show me](#)

**2** **Accepted for publication** **Post it to PubMed Central and track it in My NCBI**  
[show me](#)





**3** **Reporting to NIH** **Include PMCID in citations**  
[show me](#)

## Overview:

To advance science and improve human health, NIH makes the peer-reviewed articles it funds publicly available on [PubMed Central](#). The NIH public access policy requires scientists to submit final peer-reviewed journal manuscripts that arise from NIH funds to PubMed Central immediately upon acceptance for publication. [\[more\]](#)

## Show me specific instructions for my publication



- |   |   |                  |   |   |                          |
|---|---|------------------|---|---|--------------------------|
| 1 |  | NIHMS overview   | 3 |  | My Bibliography overview |
| 2 |  | My NCBI overview | 4 |  | Public Access Compliance |



This petition has been responded to by the White House. See the response below.

WE PETITION THE OBAMA ADMINISTRATION TO:

## **Require free access over the Internet to scientific journal articles arising from taxpayer-funded research.**

We believe in the power of the Internet to foster innovation, research, and education. Requiring the published results of taxpayer-funded research to be posted on the Internet in human and machine readable form would provide access to patients and caregivers, students and their teachers, researchers, entrepreneurs, and other taxpayers who paid for the research. Expanding access would speed the research process and increase the return on our investment in scientific research.


The highly successful Public Access Policy of the National Institutes of Health proves that this can be done without disrupting the research process, and we urge President Obama to act now to implement open access policies for all federal agencies that fund scientific research.

Created: May 13, 2012

EXECUTIVE OFFICE OF THE PRESIDENT  
OFFICE OF SCIENCE AND TECHNOLOGY POLICY  
WASHINGTON, D.C. 20502

February 22, 2013

MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

FROM: John P. Holdren   
Director

SUBJECT: Increasing Access to the Results of Federally Funded Scientific Research

**1. Policy Principles**

The Administration is committed to ensuring that, to the greatest extent and with the fewest constraints possible and consistent with law and the objectives set out below, the direct results of federally funded scientific research are made available to and useful for the public, industry, and the scientific community. Such results include peer-reviewed publications and digital data.


Scientific research supported by the Federal Government catalyzes innovative breakthroughs that drive our economy. The results of that research become the grist for new insights and are assets for progress in areas such as health, energy, the environment, agriculture, and national security.

Access to digital data sets resulting from federally funded research allows companies to focus resources and efforts on understanding and exploiting discoveries. For example, open weather data underpins the forecasting industry, and making genome sequences publicly available has





- “open access” to secondary assets


 Download the app

 About this study


 How this Study Works

 Who is Running this Study


 Who is Eligible to Participate

 About this study

rest state

 About this study

hover state

 About this study

selected state

LINKS

**Learn more.**  
rest state  
#EF4360


**Learn more.**  
hover state  
#8250A0

**Learn more.**  
press state  
#6D6E70

**Learn more.**  
visited state  
#F38286

COLORS

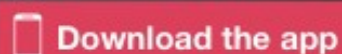
#EF4360 

#231F20 (text) 

#A7A9AB (box outlines) 

# BECOME A RESEARCH PARTNER.

You can help make a difference.

 Download the app

## About this Study

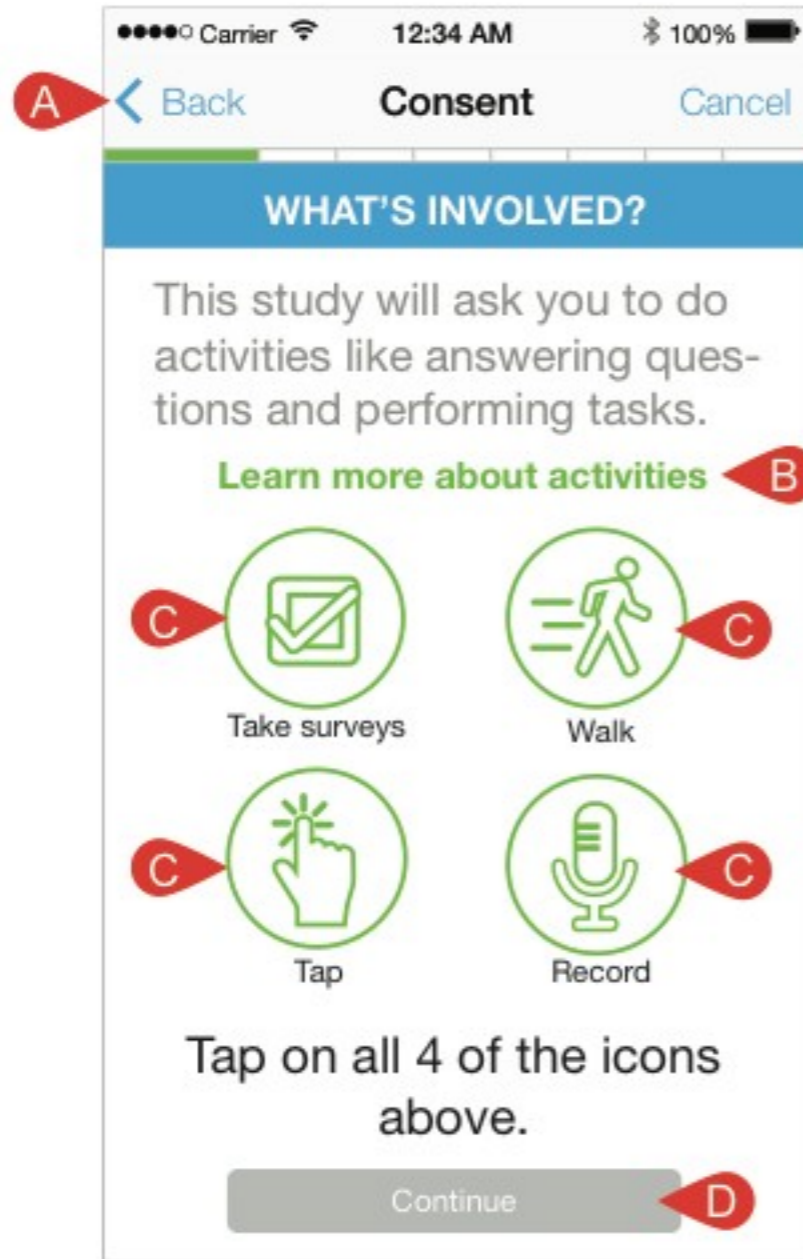
**Become a research Partner:** How can we better manage the symptoms of Breast Cancer treatment together? Sage Bionetworks is proposing a new approach to monitor health in Women treated for Breast Cancer using mobile apps. We want to understand why some Breast Cancer Survivors recover faster than others, why their symptoms vary over time and what can be done to make the symptoms improve. [Learn more.](#)

## How this Study Works



The “Share the Journey” app will use surveys and phone sensor data to collect and track five common symptoms of breast cancer treatment: fatigue, cognitive difficulties, sleep disturbances, mood changes and reduction in exercise performance. Some participants will also be invited to keep a health diary. [Learn more.](#)

 Download the app



- A** Back - Returns the user to the previous step (1).
- B** Learn more about activities - Opens an overlay with more information about the activities (shown on the next page).
- C** The user must tap on each of the 4 task icons to enable the Continue button. Each icon will have a rest, press, and selected state.
 





rest
press
selected
- D** Continue - Takes the user to Step 3. The button is enabled after the user has tapped all 4 task icons.
 

Continue disabled

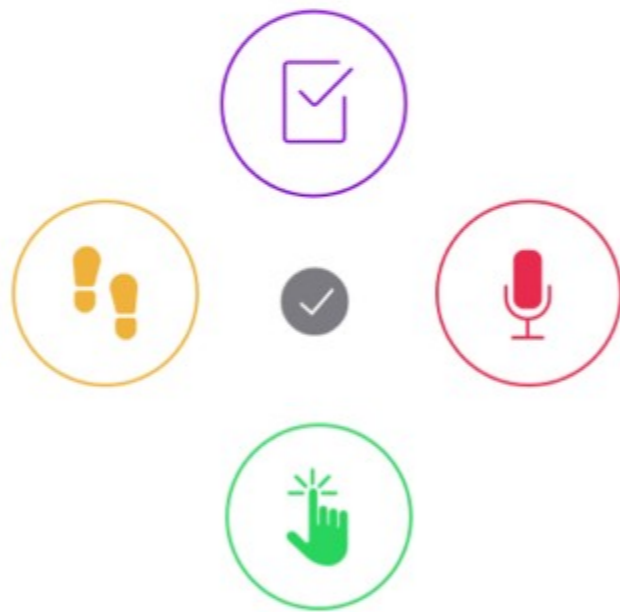
Continue enabled



# What's involved: Activities

This study will ask you to perform tasks and to respond to surveys.

[Learn More](#)



Continue >

Download a mobile app (free) and register an account: You need to have the study app on your phone, register an account and confirm your agreement to participate in this study.

Registration will include entering your name, email address and other general information about yourself to verify your eligibility.

Health Surveys: We will ask you to answer questions about yourself, your medical history, and your current health. You may choose to leave any questions that you do not wish to answer blank.

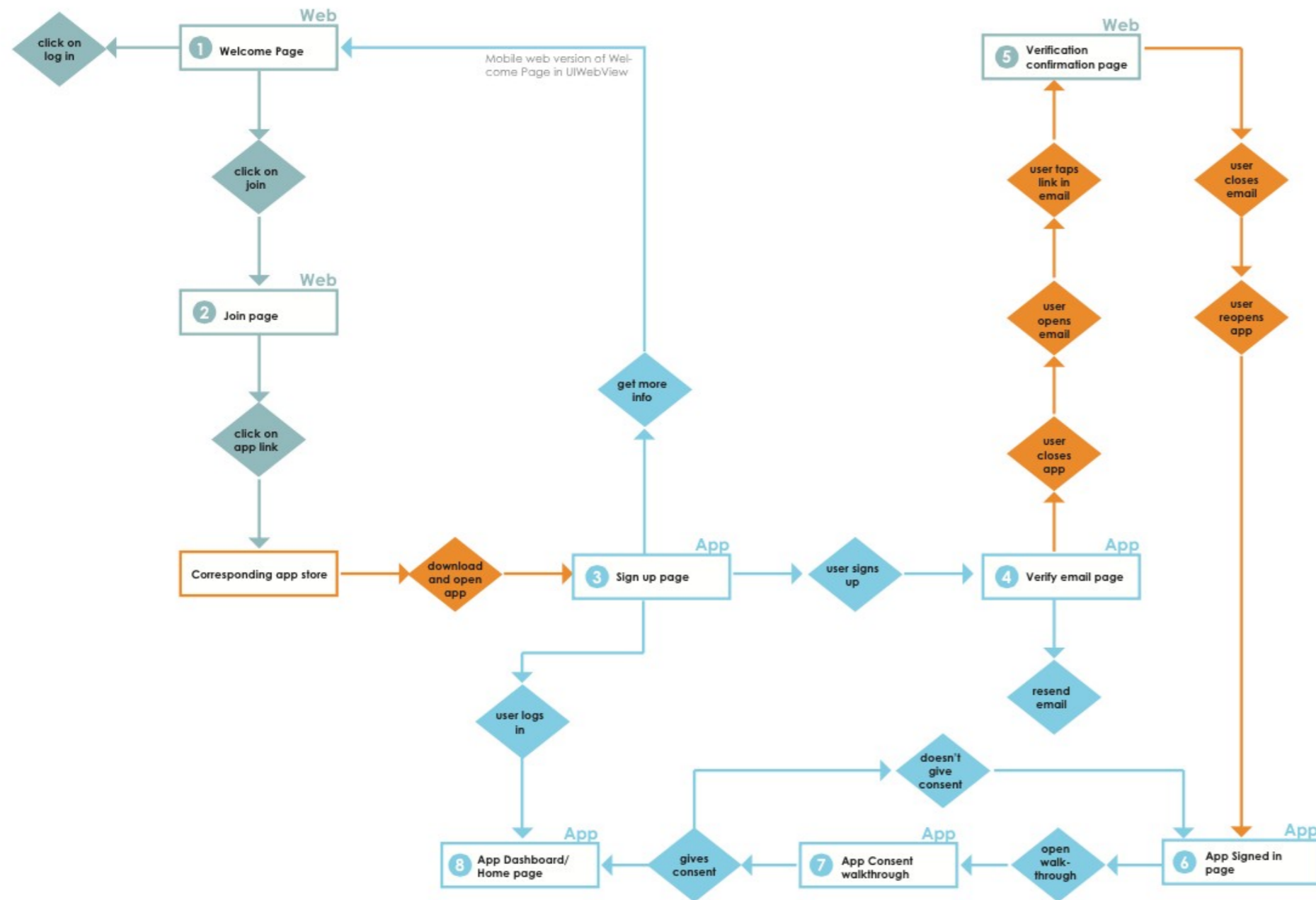
Tasks: We will ask you to perform specific tasks while holding or using your mobile phone and record sensor data directly from your phone. Examples are:

- o to record variations in your voice by saying "aaah" for 10-20 seconds into the microphone of your phone.

- o to hold your phone, walk few steps forward then few steps backward to assess your posture and stability.

- o to tap on the phone screen in a specific way to test your reaction time and dexterity.

- o Additionally, you may be asked for your permission to include some data from third-party fitness devices (like the Fitbit or Jawbone



- 1 Welcome Page**  
 Purpose:
  - Marketing
  - Information about the study (why do it, who are the researchers, etc)
 Main Action
  - Join the Study
 Other actions
  - Log in (not available on mobile web?)
  - Navigation to study information (not available on mobile web?)
- 2 Join page**  
 Purpose:
  - Convey requirements through bulleted list
 Main Action:
  - Download mobile app (links to app for each platform for desktop site, detect user's OS and just display link to corresponding app on mobile web?)
- 3 Sign up page**  
 Purpose:
  - User to set up credentials
 Main Action
  - User to enter email and password
 Other Actions
  - Get more information
  - login link for users that already have accounts
- 4 Verify email page**  
 Purpose:
  - Tells user they need to close the app, go to their email, and click on the link to verify their email
 Main Action
  - None
 Other actions
  - link to resend verification email
- 5 Verification confirmation page**  
 Purpose:
  - Lets the user know their email was verified
  - Directs them to reopen the app
 Main Action
  - None
 Can we directly open the app from a link in email and take them to a confirmation page inside the app, bypassing this page?
- 6 Signed in page**  
 Purpose:
  - confirms the user's email was verified (or not)
  - explains the consent walkthrough
 Main Action
  - User opens consent walkthrough
 Other Actions
  - link to resend verification email
 Does the user have to enter credentials again? Or can the app do a check on the credentials entered previously to detect if the email was verified and display an appropriate message? (your email has been verified -or- your email has not yet been verified -or- return them to sign up page if no credentials detected)
- 7 Consent Walkthrough**  
 Purpose:
  - User understands study
 Main Action
  - User performs 8 steps of consent walkthrough
- 8 Dashboard / Home page**  
 - Somewhere here message to the users that they can now log in on the desktop website to view their data.
  - Show first time user experience (FTUE) tips about the UI. Some FTUE screens will be contextual (ie show the user how to do the tap task as they are asked to do it)

- “open access” to PRO tools



# PROMIS®

Dynamic Tools to Measure Health Outcomes from the Patient Perspective



## PROMIS FAQs

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1 2 3 4 5 6

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**PROMIS - NIH** @promisNIH 9 Oct  
#PROMIS pain item banks will be expanded due to new study funded by @PCORI for PC & PRSE - [bit.ly/1rFHe0K](http://bit.ly/1rFHe0K)  
Expand

## Researchers

Provides efficient, reliable, and valid assessments of adult and child (pediatric) self-reported health

- ▶ [FAQs](#)
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## Clinicians

Provides data about the effect of therapy that cannot be found in traditional clinical measures

- ▶ [FAQs](#)
- ▶ [PROMIS for Clinicians](#)
- ▶ [Select Publications](#)
- ▶ [Computer Adaptive Test \(CAT\) Demonstration](#)



## Patients

Measures what you are able to do and how you feel

- ▶ [More on PROMIS](#)
- ▶ [What Patient Reported Outcomes \(PROs\) Are](#)
- ▶ [PROMIS Measures](#)



- (be very, very careful, especially if using app-based surveys!)





faq

advisors

for researchers

for patients

about us

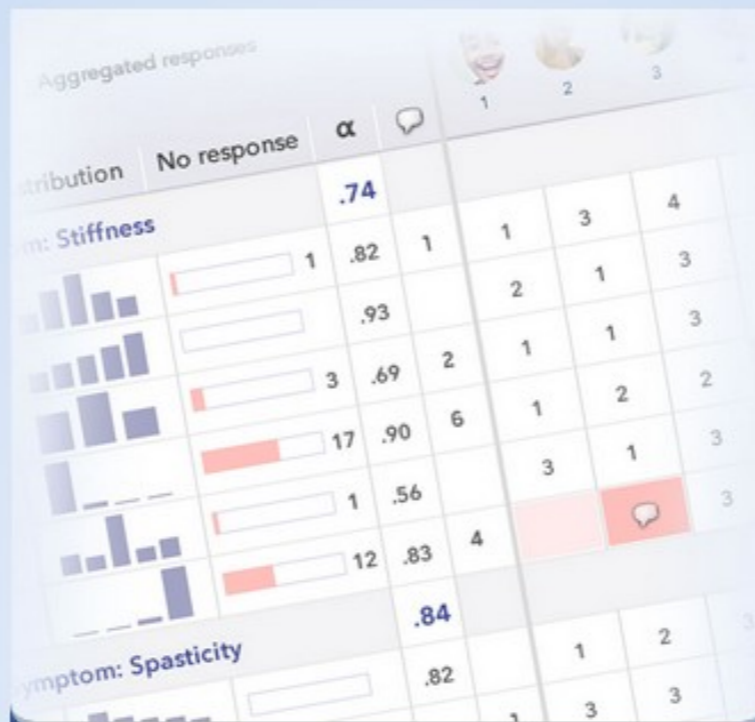
library

researcher login



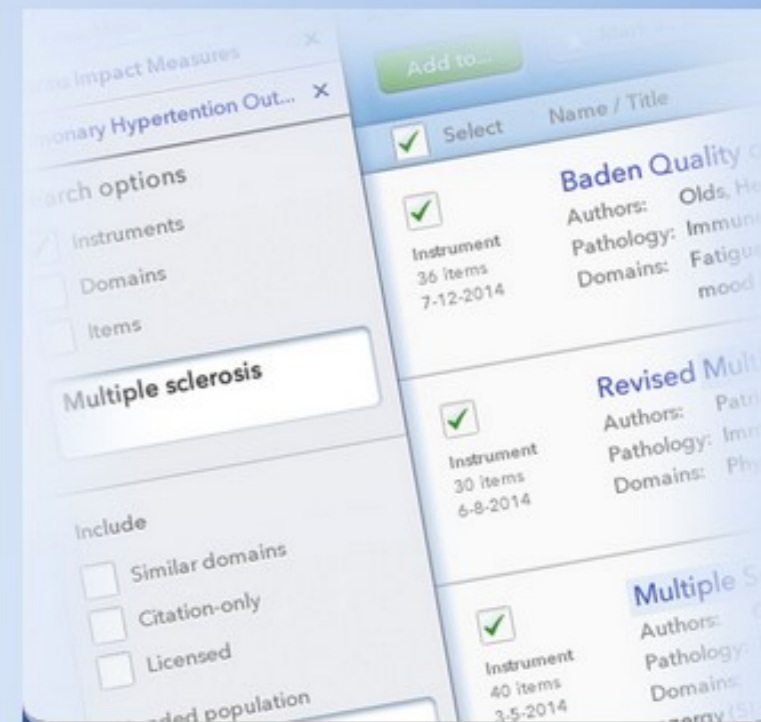
## design

Leverage new, specialized tools to quickly design and field measures.



## test

Access a network of real patients to rapidly test new measures and get feedback on your instrument development.



## share

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- 3.
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```

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under a <a rel="license" href="http://creativecommons.org/licenses/by/4.0/">Creative Commons Attribution 4.0
International License</a>.

```

- attribution via:
  - linkback
  - mention in article
  - mention on website
- mention in “about” text in-app
- preservation of license.txt file

- “automated” attribution



Please note: An account is needed **only** to edit the CC Wiki. If you need an account, please email info at creativecommons.org and we'll make you an account.

# XMP

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- FAQ
- Developers
- ▼ wiki navigation
  - Main Page
  - Community portal
  - Recent changes
  - Random page
  - Help
- Print/export
- Tools

File Type Information	
Supports embedding license URL:	Yes
Supports embedding web statement:	Yes
Supports embedding more permissions:	Yes
Metadata Location:	(unknown)
Metadata Format:	(unknown)

XMP [\(Extensible Metadata Platform\)](#) facilitates embedding metadata in files using a subset of RDF. Most notably, XMP supports embedding metadata in PDF and many image formats, though it is designed to support nearly any file type.



Creative Commons is recommending XMP as the preferred format for embedded metadata, given its [support for numerous file formats](#) and the balkanized state of embedded metadata standards. Others are coming to a similar conclusion; Microsoft has announced support for XMP in Vista applications and Jon Udell [notes](#) "There's also good support in .NET Framework 3.0 for reading and writing XMP metadata." Note that even when embedded with XMP metadata, Creative Commons recommends a licensed document include a visible copyright notice; [format-specific recommendations](#) for visible notices are available.

The Creative Commons [licensing process](#) offers a XMP template which may be used to mark files within XMP-supporting Adobe applications ([step-by-step how-to document](#)). An XMP FileInfo panel is also available.

## Specifying License Information

XMP [defines](#) a rights management schema (see XMP Specification, p. 42). Creative Commons sets the following properties (example values):

- **xmpRights:Marked** — *False* if Public Domain, *True* otherwise.
- **xmpRights:WebStatement** — <http://example.com/pdf-metadata.html> (Replace with URL containing metadata about the XMP-embedded file; this is referred to as the [Web Statement](#).)
- **xmpRights:UsageTerms** — An optional field describing legal terms of use; Creative Commons recommends that when present this take the form *This work is licensed to the public under the Creative Commons Attribution-ShareAlike license* <http://creativecommons.org/licenses/by-sa/2.0/> [verify at](#) <http://example.com/pdfmetadata.html> (Replace URL following 'verify at' with URL containing metadata about the XMP-embedded file; this is typically the





Home » People » Martijn de Boer (NiGiD) » "O Tannenbaum / Oh Christmas Tree"

# O Tannenbaum / Oh Christmas Tree

uploaded: Tue, Dec 23, 2014 @ 8:59 AM

last modified: Tue, Dec 23, 2014 @ 8:59 AM (add)

Stream  
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I Used or Saw "O Tannenbaum / Oh Christmas Tree" In A...

Remix  
Video  
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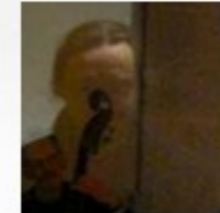
by Martijn de Boer (NiGiD)

featuring Admiral Bob (admiralbob77)

length 2:48

bpm 95

recommends Recommends (9)



Alternate bass for 'O Tannenbaum' by Admiral Bob.

season\_songs, media, remix, editorial\_pick, bpm\_095\_100, trackback, in\_video, sample, ccplus, non\_commercial, audio, mp3, 48k, mono, CBR, flac, VBR, admiral\_bob, admiralbob77, guitar, bass, piano, rhodes, instrumental, blues, bluesy, jazz, jazzy, music\_for\_video, music\_for\_film, tannenbaum, christmas\_tree, holiday, christmas, season, hanukkah, neo\_soul, soul, electric, electric\_guitar, telecaster, les\_paul, drums, saxophone

Play

### Recent Reviews

- Kara Square **Beautiful bass part!**
- Admiral Bob **Nice playing Martijn.**
- Speck **An excellent bass under the tree.**
- texasradiofish **Smooove tree music, MbB**
- keytronic **perfectly played and nice idea for the b...**

[Read all...](#)

Recommended by: Admiral Bob (admiralbob77), Speck, unreal\_dm, texasradiofish, Javolenus, Kara Square (mindmapthat), Alex (AlexBeroza), CSoul, keytronic

"O Tannenbaum / Oh Christmas Tree"  
by Martijn de Boer (NiGiD)

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## Editorial pick

Bask in the beauty of the season with Martijn de Boer's holiday instrumental collab with Admiral Bob. It's the perfect backing track for photo presentations and winter videos.

*Kara Square*



## Uses samples from:

[O Tannenbaum](#) by Admiral Bob  
[Remix History Chart](#)



## Samples are used in:

**Video:** [watch?v=GzOc7kU4sCQ](https://www.youtube.com/watch?v=GzOc7kU4sCQ) by Rufous.tv

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- 4.
- CC licenses and data

**in non-human data, evidence of reuse  
and value creation.**



## Deposited Set 1: 20th May 2010 - GSK TCAMS Dataset (hits from *P. falciparum* whole-cell screening)



Welcome to the Tres Cantos Antimalarial TCAMS dataset. Screening of approximately 2 million compounds in [GlaxoSmithKline's](#) screening library identified inhibitors of proliferation of *P. falciparum* strain 3D7 in human erythrocytes. The dataset contains the structures and screening data for over 13,500 compounds confirmed to inhibit parasite growth by more than 80% at 2  $\mu$ M concentration. The compounds' activity against the multidrug resistant Dd2 strain has also been measured for comparison. In addition, we have included data for a human cell cytotoxicity selectivity screen and also deposited an indication of the 'promiscuity' of the hits (the IFI index) in other high-throughput assays at GSK. Finally, a potential mode of action and predicted *P. falciparum* targets are listed for selected compounds. All efforts have been made to ensure data quality and

accuracy, but users are reminded that these data carry the usual caveats associated with results from large scale screening.

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The chemical structures and the generated data are hereby made public under Creative Commons' CC0 license: <http://creativecommons.org/publicdomain/zero/1.0/> as a resource for antimalarial lead identification and basic research into the druggable genome of *P. falciparum*.

[GSK](#) have committed to provide any corrections, additions and appropriate new annotations or data to ChEMBL-NTD

If you publish on, or wish to reference the GSK TCAMS set please include the link to ChEMBL-NTD ([www.ebi.ac.uk/chemblntd](http://www.ebi.ac.uk/chemblntd)) and adapt the following citation language: Francisco-Javier Gamo, Laura M. Sanz, Jaume Vidal, Cristina de Cozar, Emilio Alvarez, Jose-Luis Lavandera, Dana E. Vanderwall, Darren V. S. Green, Vinod Kumar, Samiul Hasan, James R. Brown, Catherine E. Peishoff, Lon R. Cardon and Jose F. Garcia-Bustos. Thousands of chemical starting points for antimalarial lead identification. *Nature* **465**(7296) 305-310 (2010) [[pdf](#)]

For further information please visit <http://www.gsk.com/responsibility/access/rnd-neglected-tropical-diseases.htm>



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[R&D process](#)
[R&D interviews](#)

### Open access Malaria Box

#### The Malaria Box

Available free of charge, on request, the Malaria Box is a treasure trove of 400 diverse compounds with antimalarial activity. The Malaria Box has been assembled by MMV in a bid to catalyse malaria and neglected disease drug discovery and research. All of the compounds have confirmed activity against the blood-stage of *P. falciparum* and are commercially available. It includes:



- 200 diverse drug-like compounds as starting points for oral drug discovery and development
- 200 diverse probe-like compounds for use as biological tools in malaria research

The final selection, formatted as solutions at 10mM concentration in dimethyl sulfoxide, was distilled from around 20,000 hits generated from an extensive screening campaign of around four million compounds from the libraries of St. Jude Children's Research Hospital, TN, USA, Novartis and GSK. The selection was made to provide the broadest cross-section of structural diversity and, in the case of the drug-like compounds, properties commensurate with oral absorption and the minimum presence of toxicophores.

All that is asked in return of Malaria Box users is for the resulting data to be published and placed in the public domain to help continue the virtuous cycle of research.

[Request the Malaria Box](#)

The Malaria Box has been requested by scientists worldwide.

[Follow-up guidelines](#)
[Results](#)
[Citations and references](#)
[Supporting information](#)
[Terms and conditions](#)
[FAQs](#)

#### Press Releases

- [November 2012](#)
- [July 2012](#)
- [December 2011](#)

[Article in Deutsche Welle  
Drug research: thinking inside the Malaria Box](#)

[Deutsche Welle radio interview](#)

[Scientific poster](#)





# OPEN SOURCE MALARIA

## Looking for New Medicines



### Twitter Activity

@chemraven malarone also nice  
25 Jan 2015 at 12:31

RT @simonihay: Delighted to host c. 250 attendees at the 40th Topics in Infections #RSTMH. If you could not be there all talks will soon be...  
25 Jan 2015 at 12:26

.rebeccamorelle would be great to link directly to the article... Important stuff  
@malarianomoreuk  
@BBCNews  
25 Jan 2015 at 12:21

RT @joycee: love this #openscience model! via @O\_S\_M ! great rules of thumb for life! h/t @jfgm  
http://t.co/WzUNr7HmF2  
23 Jan 2015 at 02:21

RT @MSFsci: Novel Therapeutic Approaches for Neglected Infectious Diseases - special #openaccess issue from @SAGE\_pubs

### Lab Notebook

➔ The Open Source Malaria project is trying a different approach to curing malaria. Guided by open source principles, everything is open and anyone can contribute. [About](#)



### Project Activity

See More

★ 22 Jan 2015 at 07:03 | **Series 3 Synthesis: Modification to sulfonamide group on right-hand side**

I am currently in the process of synthesising the following three Series 3 aminothienopyrimidine molecules with modifications to the sulfonamide group. Starting with 3-bromobenzene sulfonyl chloride, I performed the following three syntheses by reaction with pyrrolidine, methylamine and dimethylamine: ![tf9-1 synthesis]

(<https://cloud.githubusercontent.com/assets/9027414/5855044/d02fb7c6-a22b-11e4-8050-5b814f261b14.png>) ![tf10-1 synthesis]

(<https://cloud.githubusercontent.com/assets/9027414/5855047/d7de95e6-a22b-11e4-90dc-54f0aea80a81.png>) ![tf11-1 synthesis]

(<https://cloud.githubusercontent.com/assets/9027414/5855057/e50f9d1e-a22b-11e4-807d-f27abd5bba9c.png>) [TF9-1]

([http://malaria.oureperiment.org/aminotpsseries/11416/Synthesis\\_of\\_13bromophenylsulfonylpyrrolidine\\_TF91.html](http://malaria.oureperiment.org/aminotpsseries/11416/Synthesis_of_13bromophenylsulfonylpyrrolidine_TF91.html)) yielded an impure white solid, and NMR analysis showed that it was pure enough to take on as-is and use in the next stage of synthesis. [TF10-1]

([http://malaria.oureperiment.org/aminotpsseries/11418/Synthesis\\_of\\_3bromoNmethylbenzenesulfonamide\\_TF101.html](http://malaria.oureperiment.org/aminotpsseries/11418/Synthesis_of_3bromoNmethylbenzenesulfonamide_TF101.html)) and [TF11-1]

([http://malaria.oureperiment.org/aminotpsseries/11420/Synthesis\\_of\\_3bromoNdimethylbenzenesulfonamide\\_TF111.html](http://malaria.oureperiment.org/aminotpsseries/11420/Synthesis_of_3bromoNdimethylbenzenesulfonamide_TF111.html)), however, produced a brown oil and a gooey brown solid (like a melted fruit pastille) respectively - and the NMRs were very messy! We decided the impurity of the products were mainly due to two factors: leaving the reaction mixture stirring overnight, and using some very old amine hydrochlorides (vintage 1999 edition). Instead of wasting time with two columns, I repeated the reactions on the same scale - but instead, used liquid methylamine and dimethylamine, and only left the reactions stirring for 90 minutes: ![tf10-2 synthesis]

(<https://cloud.githubusercontent.com/assets/9027414/5855105/654e5678-a22c-11e4-8148->

### Project Wiki



### Join The Team







# Open Source Malaria Series 4: The Triazolopyrazine (TP) Series

## What's New

This series is currently **active**. (How to respond/input, for example if you want to suggest a molecule that should be made, is described in the [Landing Page](#) under "Join the Team")

[Automatically updated list of to do items in this Series](#) 📄

[Automatically updated list of compounds being made in this series](#) 📄

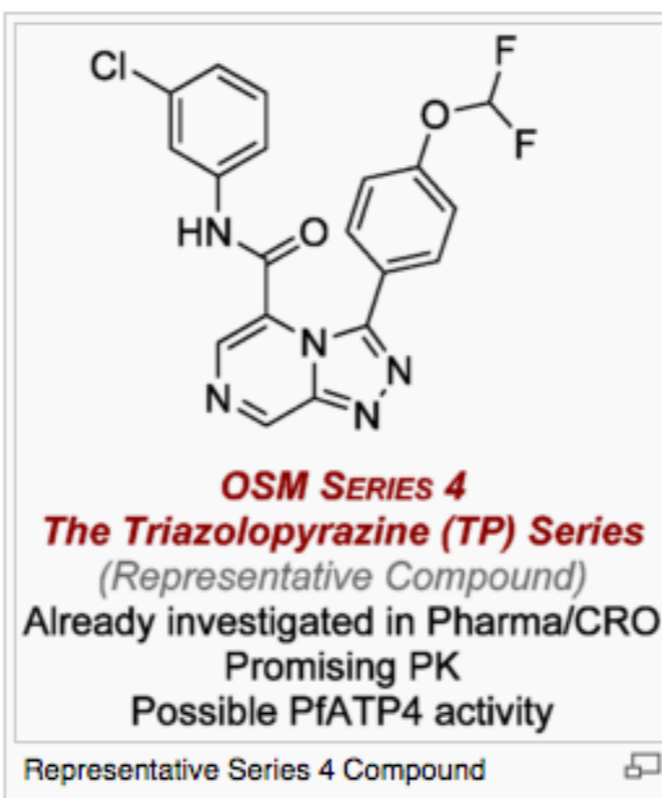
[Most recent online meeting relevant to this series](#) 📄

April 2014 PDF newsletter may be downloaded using [this link](#) 📄. Late 2014 newsletter under construction at GHI [269](#) 📄.

## Introduction

### Preamble

The Triazolopyrazine Series is the newest of the OSM series. It was announced by [MMV](#) and on the OSM blog (*via the briefing document* and as a *general description*) on September 10th 2013 and is sometimes referred to as the *TP Series*, or *OSM Series 4*.



The series arises from industrial work that cannot be fully disclosed which was followed by some hit-to-lead work funded directly by MMV and performed by a CRO which can.

A great deal of exploration of the series has been done, with significant diversity in the core and pendant groups. The series includes many potent compounds, all of which are detailed on this page.

This part of OSM is a lead optimisation project, now aiming to improve solubility, potency and metabolic stability while reducing hERG activity.

As with everything involved in OSM, suggestions can be given in [multiple ways](#).





Over 1 billion people, including 500 million children, in the poorest regions of the world, are affected by neglected diseases that debilitate, disfigure or kill.



**SPOTLIGHT** « »



© Harald Henden

**PAEDIATRIC HIV**

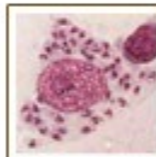
Testimonies of South African mothers: demonstrating the difficulties in administering current treatments for paediatric HIV [More](#)

## DISEASES & PROJECTS

Neglected tropical diseases continue to cause significant morbidity and mortality in the developing world. Yet, of the 1,556 new drugs approved between 1975 and 2004, **only 21 (1.3%) were specifically developed for tropical diseases and tuberculosis, even though these diseases account for 11.4% of the global disease burden.**



**Human African Trypanosomiasis**  
Endemic in 36 African countries with 60 million people at risk, sleeping sickness or...



**Leishmaniasis**  
Occurring in 98 countries with 350 million people at risk worldwide, leishmaniasis...



**Chagas disease**  
Endemic in 21 countries across Latin America and killing more people in the region than malaria...



**Malaria**  
Killing one child every minute in sub-Saharan Africa and approx. 1,300 children every day...



**Paediatric HIV**  
3.2 million children below 15 years of age are living with HIV globally, mainly in sub-Saharan Africa. 700 of them die every day...



**Filarial Diseases**  
120 million people are infected with Lymphatic filariasis (Elephantiasis) and 25 million with Onchocerciasis (River Blindness)...

## DNDI NEWS

20 January 2015

**Speaking of Medicine: "FDA Voucher for Leishmaniasis Treatment: Can Both Patients and Companies Win?"**

29 December 2014

**SLAS Electronic Laboratory Neighbourhood - "Neglected Infectious Diseases: Making Progress, but Burden Remains"**

16 December 2014

**DNDI Receives US\$ 10 Million from USAID to Develop New Drugs for Neglected Filaria Patients**

09 December 2014

**Die Welt - "Tierarznei soll Menschen mit Würmern helfen"**

09 December 2014

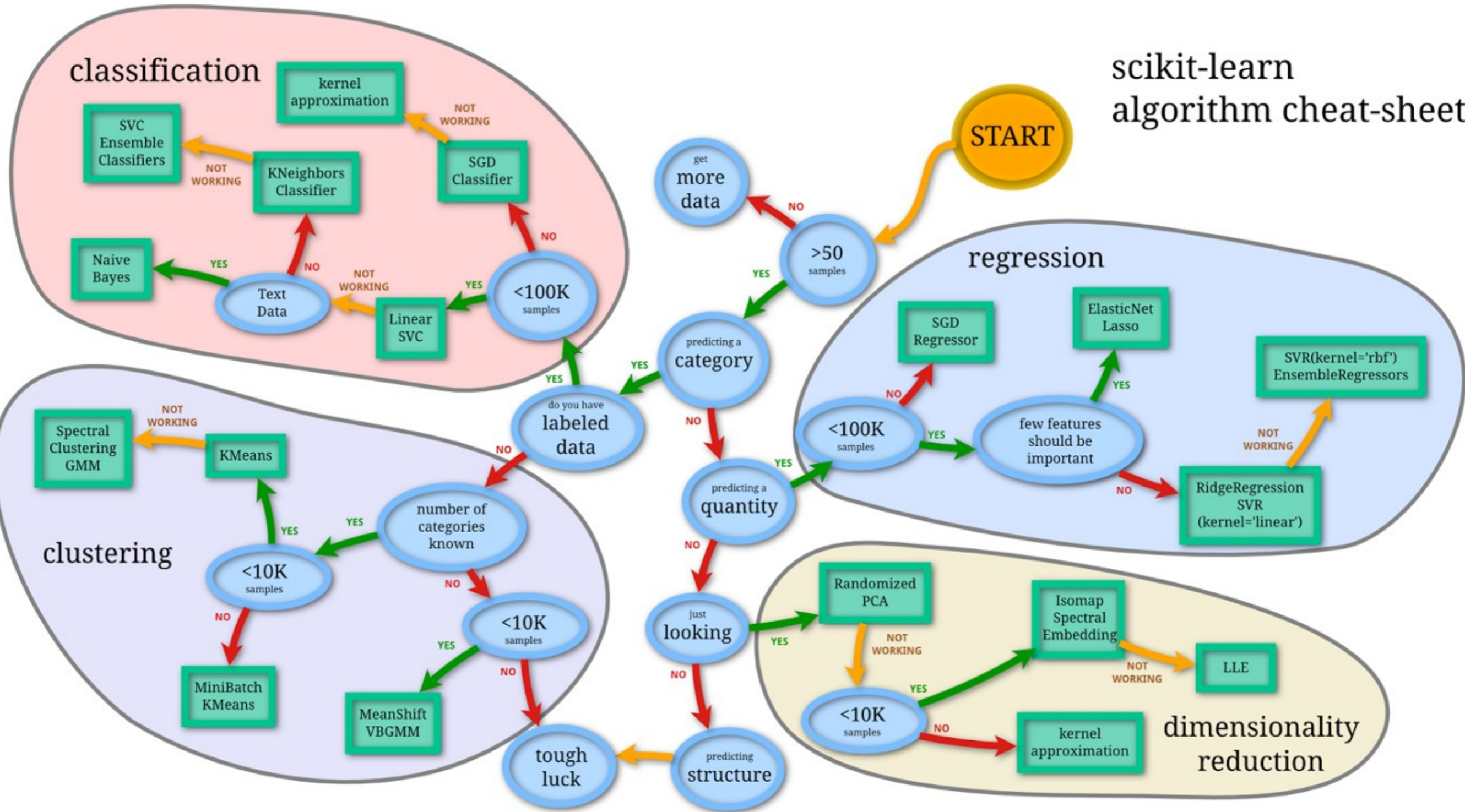
in human data, significant tension between promising control and promising benefits of reuse.







# scikit-learn algorithm cheat-sheet



[Research](#) ▾ [Platforms & Services](#) ▾ [Work with Us](#) ▾

[Synapse](#) [Bridge](#) [Challenges](#) [Governance](#) [E Consent](#)

The Sage Bionetworks governance team works with legal, ethical, and regulatory experts to develop and implement the policies and procedures for appropriate data sharing on each of our collaborative platforms: [Synapse](#) and [BridgeServer](#).

We have a unique set of data governance challenges, as our systems cover the entire life cycle of research data, from generation to analysis and reuse. This necessitates that we develop governance policies and procedures that facilitate the creation of scientific insights while prioritizing the protection and respect of individuals who provide their data.

Our governance process for the Synapse collaborative data platform includes well-documented [Terms and Conditions of Use](#), [guidelines](#) and [operating procedures](#), privacy enhancing technologies, as well as the right of audit and external reviews. Synapse operates as an IRB-approved environment to store, activate, analyze, and collaborate on data. It contains “tiers” of data access based on the nature of the data and the conditions delineated on the consents for the data’s generation, ranging from very wide reuse “Open” to “Controlled” where requests are evaluated before access is granted.

We believe in empowering individuals to contribute their data and insights as research partners on the health problems that matter most to them. We are developing governance mechanisms for the responsible collection and use of digital research assets via web and mobile health applications, that address the concerns for privacy and data protection in a comprehensive manner and manage participant’s preferences.

We generated the [Participant-Centered Consent \(PCC\) toolkit](#) for electronic [informed consent](#), or e-consent. The toolkit is designed for people who are designing clinical studies and who wish to make their informed consent user-centered, rather than document-centered. It contains the building blocks of a visual, interactive approach to informed consent. The PCC toolkit lets its users create visual summaries of consent forms, mapped to key underlying text, for use in software or print.

Last, we build tools to increase the effectiveness of our governance tools. This includes comprehension assessments (for both Synapse users and for clinical enrollment), templates for patient-reported data contribution, tools, and more.

All of our governance policies and processes are available at the links below.



and what we think of as “data” is  
changing, fast.



thank you!

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