# MY DATA JOURNEY TO HEALTHBANK

Sophia Turner

# I WANT MY DATA TO HELP RESEARCH

Find the cause

Find a treatment



## Participant Information Sheet

REC Reference Number: **BDM/14/15-57**

**An investigation of dietary intake and perceptions of food groups following breast cancer treatment**

We would like to invite you to participate in this original research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being conducted and what your participation will involve. Take time to read the following information carefully and discuss it with others if you wish. Please contact us on the email address below if you have any queries or if you would like further information.

# I WANT TO SHARE MY DATA WITH OTHERS

## The **Cancer** Forums

7/12 DX **stage 3** pan can (adenocarcinoma) @ 65 - borderline resectable
8/12 - 10/12 Chemo (GTX) & Stereotactic Radiation
12/12 Whipple - R0 margins, 2/29 nodes pos.
1/13 - 5/16 Vaccine clinical trial - randomized to control group - vaccine showed no benefit
2/13 - 8/13 Gemzar for 6 months
Quarterly scans - no evidence of disease to 10/14 - spot on lung being watched - possible infection 2 month
on antibiotics
3/15 - spot larger - probable met - surgery planned
4/15 - PET prior to surg - recurrence & lung mets - Surgery cancelled - EUS w/ FNA showed adenocarcinoma
**Stage 4**
5/15 - 9/15 Folfirinox @ reduced dosage - Stopped treatment after 11 infusions due to neuropathy
10/15 - 8/16 maintenance 5-fu every other week
8/16 - stable disease on both CT and PET/CT - chemo holiday while other treatments explored
9/16 - lung biopsy confirms pan can met,
10/16 -NanoKnife to pancreatic bed -PET after Nano showed new met in hilar lymph nodes - SBRT to both
lung & lymph

Still open to immuno-oncology trials (vaccines or checkpoint inhibitors) if I find one I'm eligible for.

"Graveyards of user-generated data"

| | |
|---|---|
| Join Date: | Mar 2014 |
| Location: | Bonita Springs, FL. |
| | USA |
| Posts: | 1,479 |

## CancerCommons    Donate Your Data

Cancer Commons is based on a set of core principles acknowledging thousands of lives can be saved with collaboration and rapid knowledge sharing across patients, caregivers, providers and the field of research. Our patient-facing programs are designed to facilitate and accelerate getting the right knowledge, to the right patient at the right time keeping patient goals around overall survival and quality of life at the forefront.

# I WOULD LIKE INTERNATIONAL TREATMENT COMPARISONS



FLATIRON

CancerLinQ connects and analyzes real-world cancer data from almost any electronic record source—to improve the quality and value of care for all.

CancerLinQ combines the expertise of the country's leading oncologists with big data analytics technology.

Fighting cancer with organized data.

We started Flatiron Health for one simple reason: to make a difference in the fight against cancer.

*"We want to consider international data sources….We have to consider regulatory, privacy and security issues"*
Rich Ross - CSO

*"Cancer care is so complex that the EHRs haven't caught up to the level of complexity. In fact it's getting more complex every day because of genomics and immunotherapy and the EHRs are getting further behind"*

# I WOULD LIKE THE DATA THAT HEALTH IT COMPANIES HAVE ABOUT ME

## DNAnexus

Looking for an easier way to manage your genomic data? Start focusing on the opportunities, not the obstacles. Here's how DNAnexus can help.

### Upload your data to the cloud quickly

- Multiple upload methods provided: Command-line upload, upload via the web platform, fetch from a URL, or direct upload via DNAnexus API
- Upload Agent: Multi-threaded data upload from any stage in the pipeline, including multiplexed data directly from the sequencing instrument
- Automatic checksum to ensure data integrity

"...more researchers are adopting a systems biology approach, combining genetic data with phenotypic data, such as patient records and clinical information, along with metabolomoics and epigenomics".

## SOPHIA GENETICS

## SOPHiA™

SOPHiA is the most advanced artificial intelligence AI for Data-Driven Medicine. A state-of-the-art technology, SOPHiA continuously learns from thousands of patients' genomic profiles and experts' knowledge to improve patients' diagnostics and treatments.

" Professor Miguel Angel Moreno-Pelayo, Head of Genetics at the Hospital Ramón y Cajal, Madrid: "With such advanced and cost-effective DNA sequences analysis technology, clinicians are unlocking a new era of personalised medicine where patients can be diagnosed faster and more accurately." "

# I WOULD LIKE ANECDOTAL DATA TO BE ANALYZED AND PUBLISHED

- Powered observational studies
- Compare with Breakthrough recall bias / biobank

**Can Observational Data Replace Randomized Trials?**

McGale P. et al, (2016), Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 34, 3355 - 3357

# SO, WHY AM IN INTERESTED IN HEALTHBANK?

Rethink ownership of health data – away from traditional models of ownership

Governments

Hospitals

Health IT companies

→

**healthbank**

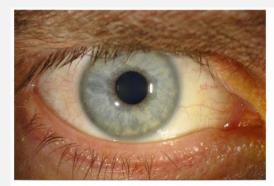CONSUMERS WILL OWN AND STORE THEIR DATA – AND GET SOME FORM OF RETURN TO INDIVIDUALS AND SOCIETY

# CONSUMERS TO OWN AND STORE THEIR DATA

- BANK

- All your healthcare data will be in one place: eye, wearables, genetic, health records, 360 assessments, vaccinations, orthodontal, MRI scans etc

- OWNERSHIP

- It's yours:

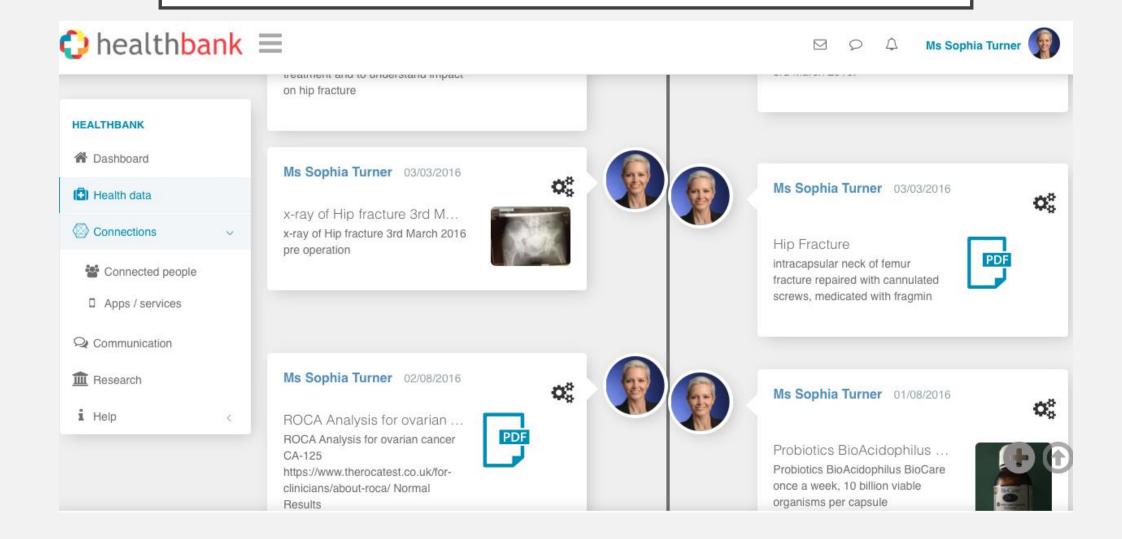- you can access it

- you can share it

- you choose whether and when it's used for research



Dr. Ian Crozier survived Ebola, only to have his normally blue left eye turn green because of inflammation. Though the rest of his body was Ebola-free, his eye was teeming with the virus.

# MY HEALTHBANK

# AND BEYOND…