



Data Dashboards

Edinburgh Open Research Conference
2023

DAVID PERRY 16TH MAY 2023



Data Dashboards

The advantages of having access to data insights when conducting large scale citizen science 'direct to public' research projects.

Exemplar Project - DecodeME

<https://www.decode-me.org.uk/>



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Join the world's largest ME/CFS study

We aim to find genetic causes of why people become ill with myalgic encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS) with our groundbreaking research. [Take part](#) from your home.

[Take part](#)

DecodeME Background



Sign-Up



Survey



Scoring



Selection



Sampling



Problem Statement

The advantages of having access to data insights when conducting large scale citizen science 'direct to public' research projects.

- ▶ **Large Scale**
- ▶ **Direct to Public**
- ▶ **Process Automation**
- ▶ **Management Overview**

Large Scale

- ▶ 25,000 Samples Sought
- ▶ How many participants need to be approached to achieve this goal?

Direct to Public

- ▶ Citizen Science
- ▶ Engagement
- ▶ Communications
- ▶ Managing Expectations



Process Automation

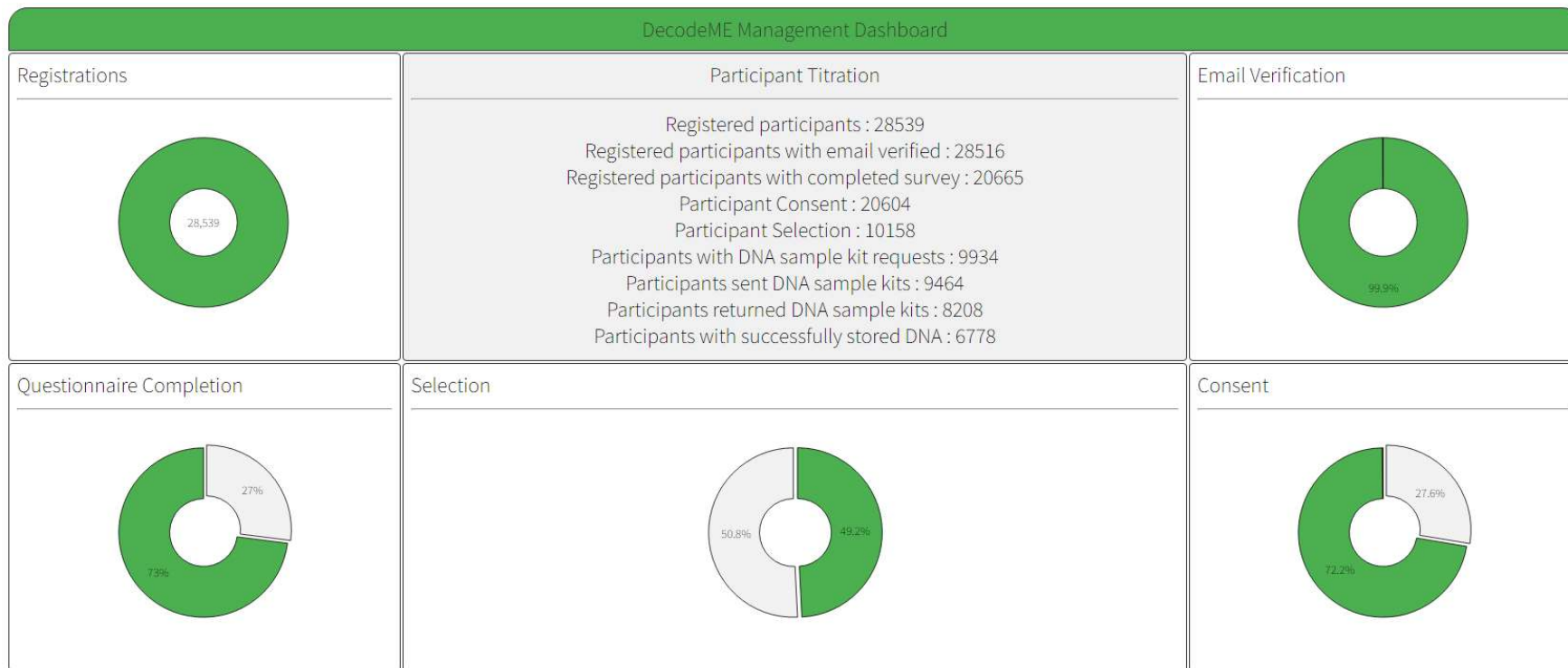
- ▶ Data Workflows
- ▶ Database Schemas
- ▶ Project Partners and Data Exchange
 - ▶ Gemini Print
 - ▶ UK BioCentre
 - ▶ ThermoFisher Scientific
- ▶ Emails, Text Messages, and Paper Letters

Management Overview

- ▶ Data Dashboard Visualisations
- ▶ Data Driven Insights
 - ▶ Project Progress
 - ▶ Participant Titration
 - ▶ Key Performance Indicators
 - ▶ Resourcing
 - ▶ Issue Highlighting
 - ▶ Reports for Funders

DecodeME Management Dashboard Live Demo

Live demonstration of dashboard...





DecodeME Dashboard

[Home](#) [Dashboard](#) [Registrations](#) [Questionnaires](#) [Timings](#) [Demographics](#) [Samples](#) [Marketing](#) [IMD](#) [CSV Data](#) [Login](#) [Contact](#)

Decode
The ME/CFS Study

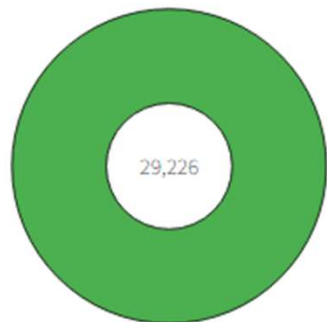


DecodeME Dashboard

- Please choose an action from the links above.

DecodeME Management Dashboard

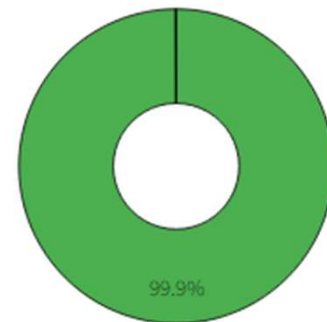
Registrations



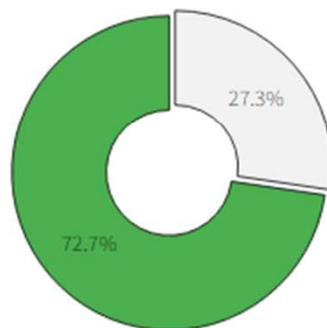
Participant Titration

Registered participants : 29226
Registered participants with email verified : 29201
Registered participants with completed survey : 21082
Participant Consent : 21018
Participant Selection : 10314
Participants with DNA sample kit requests : ██████████
Participants sent DNA sample kits : ██████████
Participants returned DNA sample kits : ██████████
Participants with successfully stored DNA : ██████████

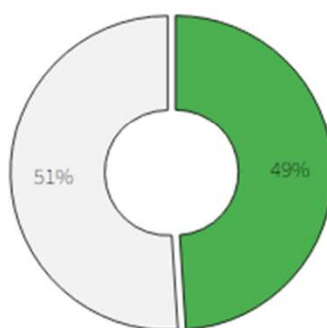
Email Verification



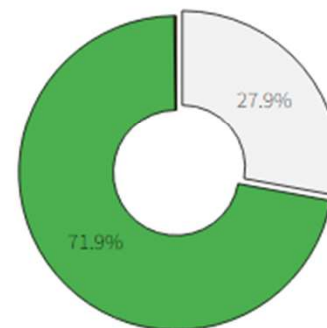
Questionnaire Completion



Selection



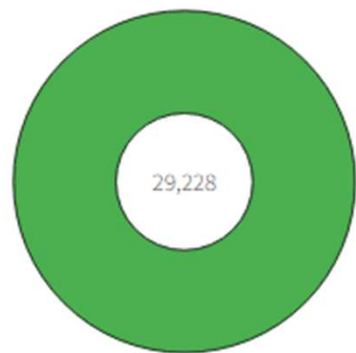
Consent





DecodeME Management Dashboard

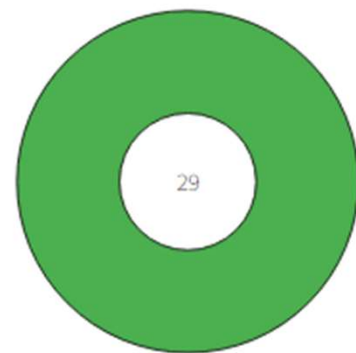
Registrations Total



Registrations by date

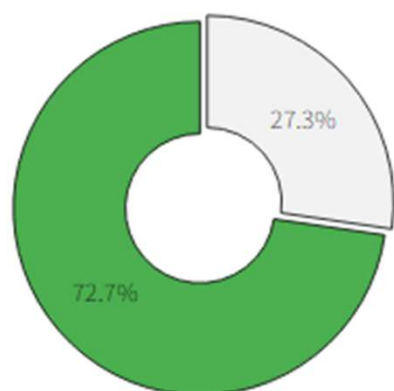
Date	Registrations
15/05/2023 - Monday	29
14/05/2023 - Sunday	95
13/05/2023 - Saturday	102
12/05/2023 - Friday	81
17/09/2022 - Saturday	312
16/09/2022 - Friday	706
15/09/2022 - Thursday	1025
14/09/2022 - Wednesday	980
13/09/2022 - Tuesday	2696
12/09/2022 - Monday	6636
11/09/2022 - Sunday	0

Registrations Today



DecodeME Management Dashboard

Questionnaire Completion



Incomplete Questionnaires

Delay	Count
Up to 3 days	1
3 to 10 days	1
10 to 21 days	1
21 days or more	1
Total	4

Questionnaires Completed per Week

Week	Count
15th May - 21st May 2023	11
8th May - 14th May 2023	513
1st May - 7th May 2023	248
24th Apr - 30th Apr 2023	249



DecodeME Management Dashboard

Average Time

15m:56s

Median Time

12m:53s

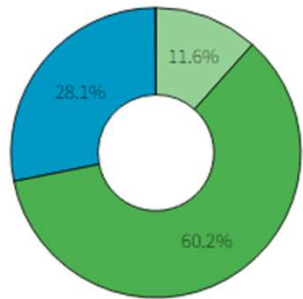
Time to complete questionnaire by self reported disease severity

Severity	Mean	Min	Max	StDev	50th Percentile	90th Percentile	Count
Mild	14m:13s	2m:9s	161m:45s	9m:16s	11m:49s	23m:24s	
Moderate	16m:28s	1m:59s	337m:56s	12m:33s	13m:22s	27m:43s	
Severe	18m:48s	2m:10s	497m:43s	19m:57s	14m:14s	32m:57s	
Very severe	19m:7s	2m:37s	121m:11s	17m:56s	13m:22s	37m:3s	
Not collected	0m:52s	0m:6s	4m:29s	0m:49s	0m:37s	1m:52s	
All	15m:56s	0m:6s	497m:43s	12m:49s	12m:53s	27m:0s	

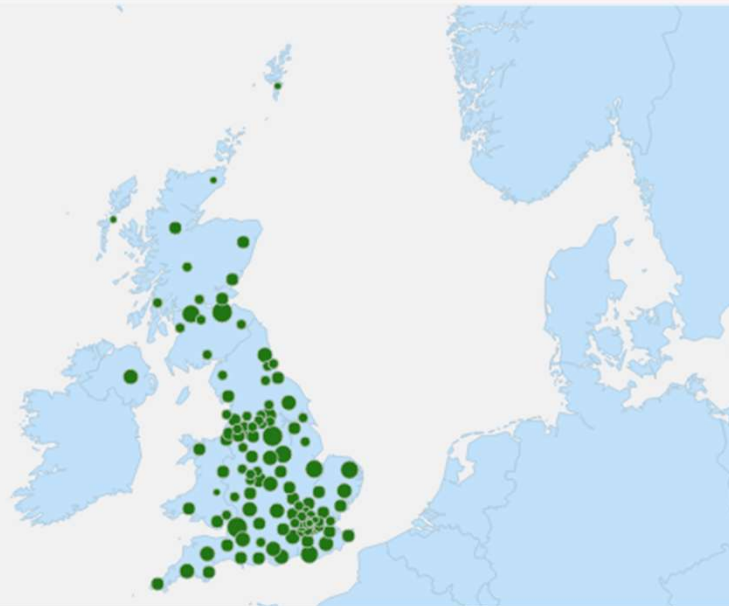


DecodeME Management Dashboard

Sex at Birth



Location by Postcode Area



Location by UK Region

UK Region
Scotland
Wales
Northern Ireland
England, North West
England, North East
England, West Midlands
England, East Midlands
England, East of England
England, South West
England, South East
England, Greater London
Unknown
Total




DecodeME Management Dashboard

Participant distribution over IMD rank deciles per country

Country	Decile 1	Decile 2	Decile 3	Decile 4	Decile 5	Decile 6	Decile 7	Decile 8	Decile 9	Decile 10	Count
England	5.9%	6.9%	8.3%	10%	10.6%	11.6%	11.7%	11.5%	11.5%	11.9%	
Northern Ireland	7.4%	7.1%	5.1%	10.5%	11.3%	8.1%	8.8%	11.8%	14.5%	15.4%	
Scotland	5.2%	6.5%	7.7%	9.6%	10.2%	11.4%	12.2%	12.6%	12.3%	12.3%	
Wales	6.1%	6%	7.1%	8.8%	11.1%	12.3%	13.9%	12.4%	12.6%	9.6%	
Unknown											

Decile 1 is most deprived.



How did you hear about DecodeME?

Description	Count	Percentage
None	7,700	17.4
Email Invitation	6,112	13.8
Website	2,896	6.6
Twitter	1,257	2.8
Facebook	12,072	27.3
Instagram	2,213	5
Online Advertisement	1,034	2.3
Newspaper or Online News Article	1,818	4.1
Radio	634	1.4
Television	445	1
Support Group	1,522	3.4
Family or Friend	3,208	7.3
Other	1,111	2.5

Dashboard Software

- ▶ Google Chart API's
- ▶ PowerBI
- ▶ Tableau
- ▶ Dash (Plotly with Python)
- ▶ Office365 Tools (Excel or Access)
- ▶ ...and many others...

Considerations

- ▶ Live Data vs Snapshots
- ▶ Data query performance
- ▶ Cybersecurity
 - ▶ Data Location
 - ▶ Data Access
 - ▶ Authentication & Authorisation

Thank You & Questions

