

# ONLINE ENGAGEMENT PRACTICES OF THE TRANSFORMING GENETIC MEDICINE INITIATIVE

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## Introduction

### The Transforming Genetic Medicine Initiative

The Transforming Genetic Medicine Initiative (TGMI) is a multi-disciplinary group of scientific and clinical experts from the ICR and other institutes, launched in 2016.

The goal of the TGMI is to design, develop, and deliver foundational resources to enable genetic medicine to be safe and effective.

### Communication and engagement are core goals

In addition to the development of tools and processes, the TGMI is committed to ensuring that these foundational resources are used.

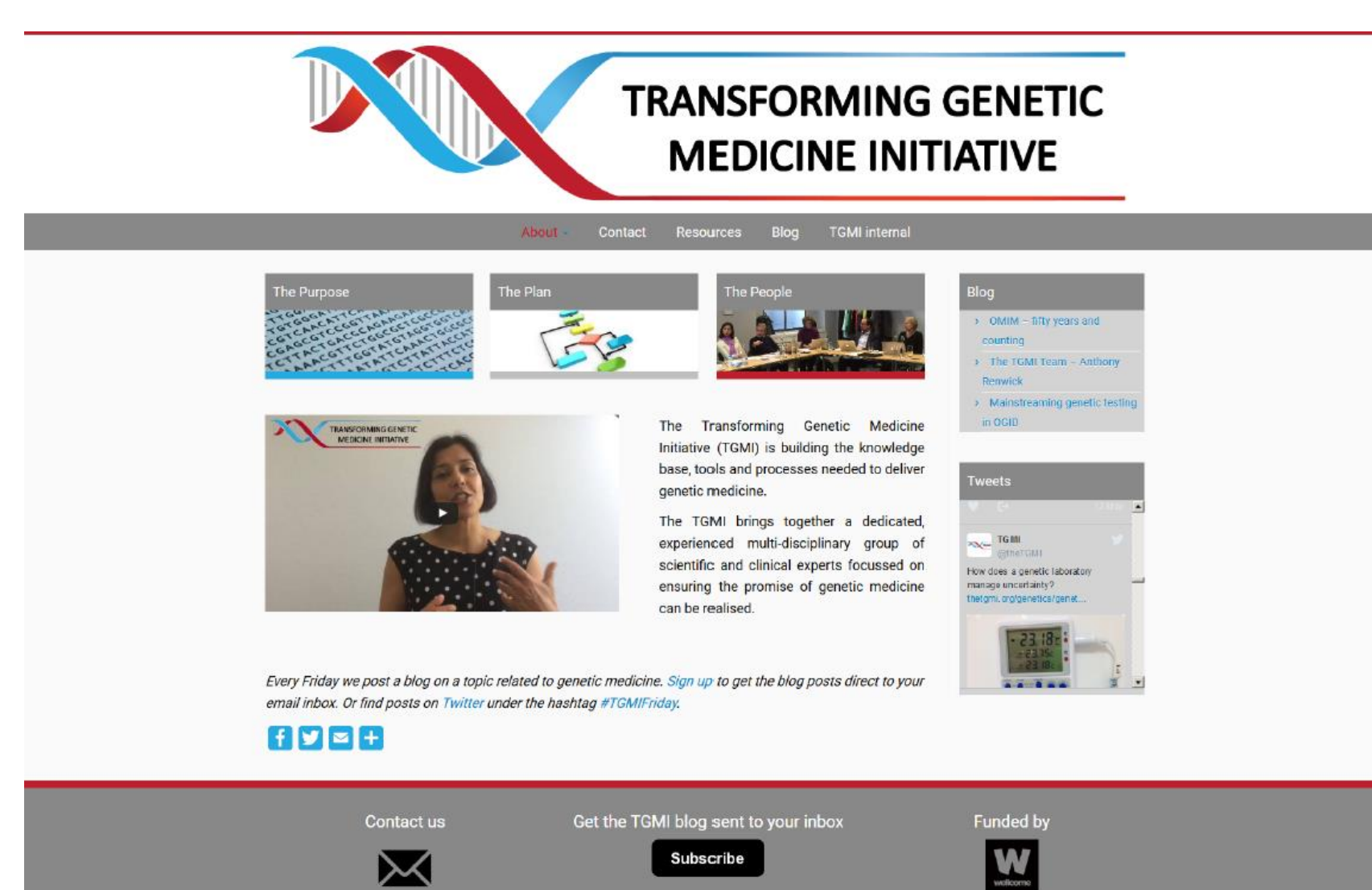
To encourage input, discussion and feedback during all stages of the TGMI's work, communication has been made a priority since the start of the programme, with an early emphasis on online engagement.

## What the TGMI is working on

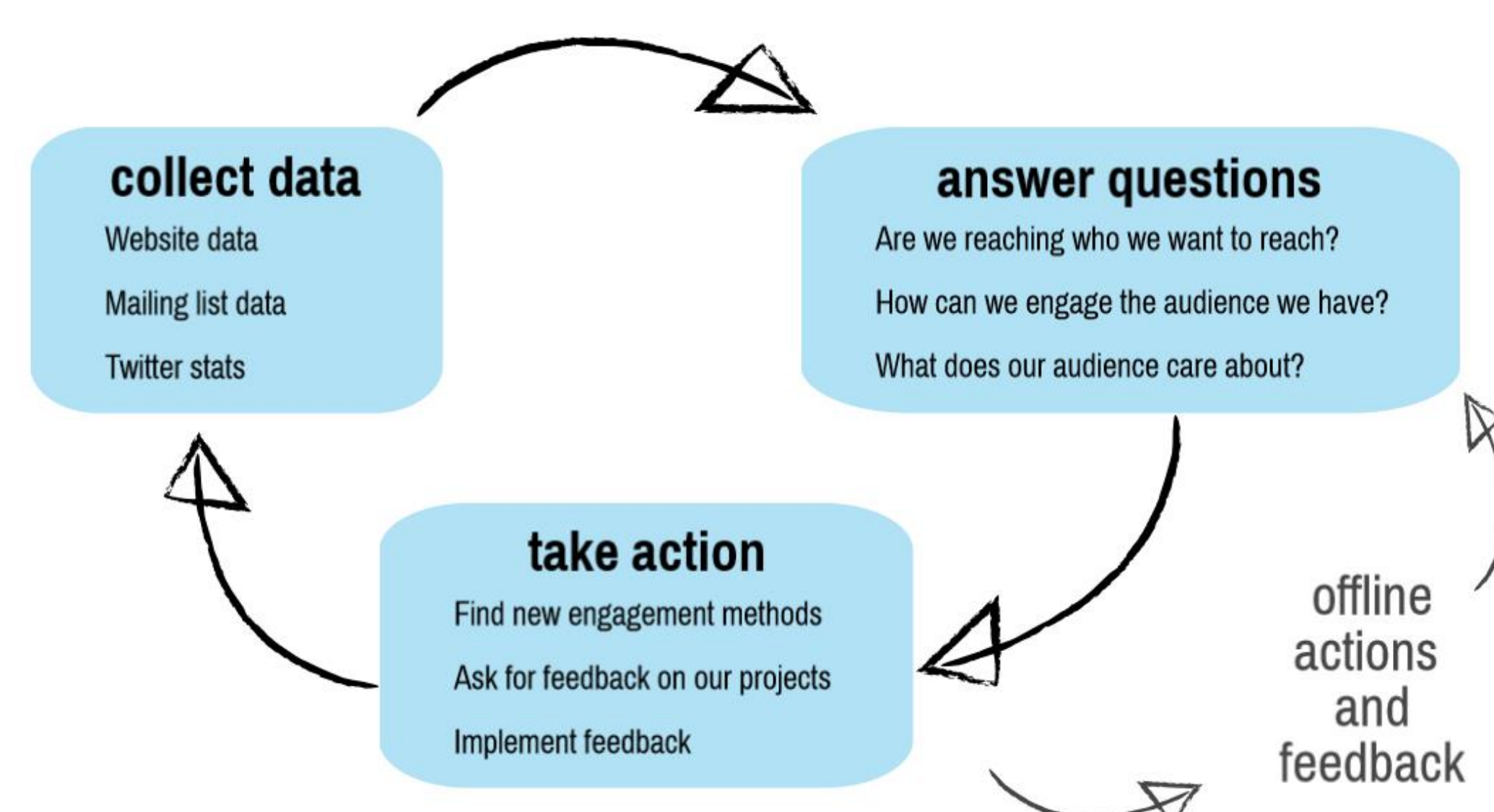
1. Gene-Disease Map, to provide information on the association between genes and human disease.
2. Clinical Annotation Reference System (CARS) to provide standardised frameworks for consistent annotation and reporting of gene variation.
3. Integrated approaches to deliver fast and automated gene variation interpretation.
4. Develop and validate flexible processes and pipelines that maximise the research and clinical utilities of genetic testing.

## TGMI's online engagement methods

- TGMI website with a weekly updated blog.
- Mailing list to receive weekly updates by email. (Automated).
- Twitter account for daily engagement.
- All of the TGMI's research output is available online through open access articles and repositories.



## Measuring online engagement



## Different online engagement for different projects



### Mainstreaming Cancer Genetics

Started 2013, at Royal Marsden and ICR. Since 2017, expanding to international collaborations as MCG-I

Initial project: Mainstreaming BRCA testing for breast- and ovarian cancer patients at Royal Marsden.

Initial audience: Well-defined by interests and location

Website with blog updated about once a month with project updates.

Twitter updated about once a week.

Training materials aimed at geneticists and clinical teams are available on the MCG website and on YouTube. Targeted, often offline, engagement works well.

Online engagement serves to spread information further. With expansion to MCG-I, online engagement is becoming more important.

### Transforming Genetic Medicine Initiative

Started 2016, as a collaboration between researchers and clinicians at several institutes throughout the UK

Initial projects: Several simultaneous projects (see box "What the TGMI is working on")

Initial audience: Broad. Anyone working in or interested in genetic medicine.

Website with blog updated once a week, with news about the team, TGMI projects, or topics related to problems that TGMI addresses.

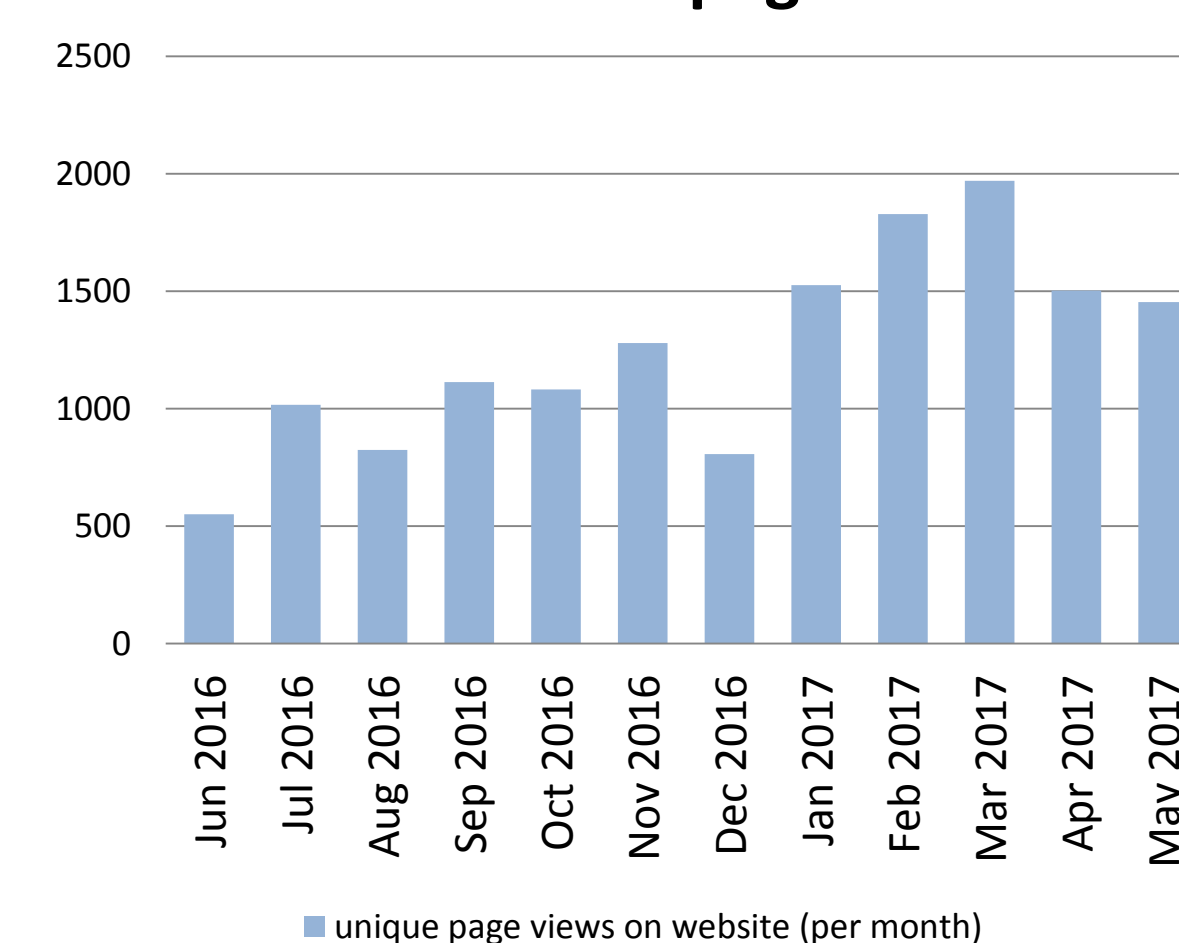
Twitter updated daily.

Resources and tools are made available via the TGMI website as they become available. This section of the website is expanding as new resources are being developed.

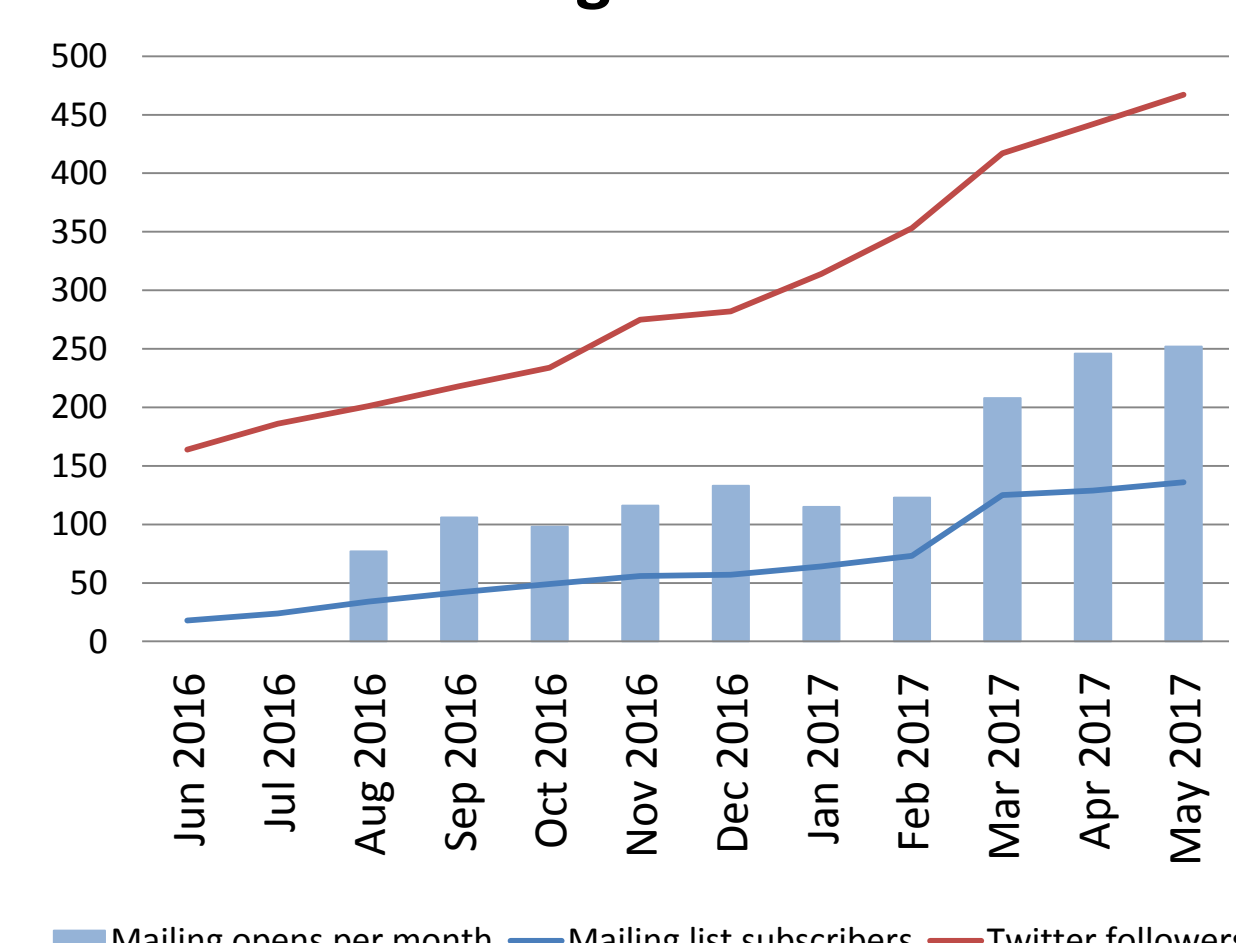
Online engagement initially serves to introduce the TGMI to a new and broad global audience. The TGMI is also soliciting community feedback on ongoing projects via its online channels.

## Growing TGMI's visibility online

TGMI website page views



TGMI mailing list and Twitter



Left: Monthly page views on theTGMI.org website since June 2016.

Right: Monthly mailing list subscribers (blue line), email opens (blue bars), and Twitter followers (red line) since June 2016

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