



Consistent follower engagement on social media can grow your audience and raise awareness of rare diseases

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Abstract

Medics4RareDiseases (M4RD) is driving an attitude change towards rare diseases amongst medical students and doctors in training in order to improve the patient experience and reduce the diagnostic odyssey. In 2019 M4RD used Instagram Stories as a platform to reach a global medical audience with a feature known as #MysteryDiseaseMonday (#MDM). Each week M4RD involved a different patient group (PG) to help produce content for a Story about a specific rare condition. M4RD followers were also able to answer a poll asking whether they had or had not heard of that particular condition. 34 different rare diseases were polled in 2019. Haemophilia was the most heard of condition with 90% of voters choosing "yes" whereas none of the voters had heard of neuroferritinopathy. The aim of #MDM was to raise awareness of rare conditions and the pivotal role of PGs. However an exciting bi-product of MDM was the audience growth that M4RD received.

Introduction

M4RD targets rare disease awareness activities at medical professionals in order to reduce the diagnostic odyssey. The activities of the charity do not usually focus on a specific rare disease, rather it focuses on the key message of "rare diseases are collectively common". It is unfeasible for any individual to know the details of over 7000 rare disease. Instead M4RD wants clinicians to understand the relevance of rare disease to their everyday practice and #DareToThinkRare. However an exception to this rule is #MDM - an audience engagement feature that M4RD ran on its Instagram Story throughout 2019. This focused on a specific condition each week and then brought the message back to the common challenges that those with rare diseases face and the need for doctors to #DareToThinkRare.

Methods

1. Recruit a patient group (PG) to take part
2. The PG provides information and media for #MDM which they confirm they have permission to share
3. Provide a date for the #MDM to take place so the PG can share and take part on the day
4. On the set Monday create a 'poll' on Instagram
5. After 2-3 hours start posting information about the condition that was provided by the PG
6. Credit the PG by including its logo, tagging its Instagram handle & including its website URL
7. After 24 hours the Instagram Story disappears
8. The next day post the result of the poll
9. Create a highlight out of the Instagram Story posts

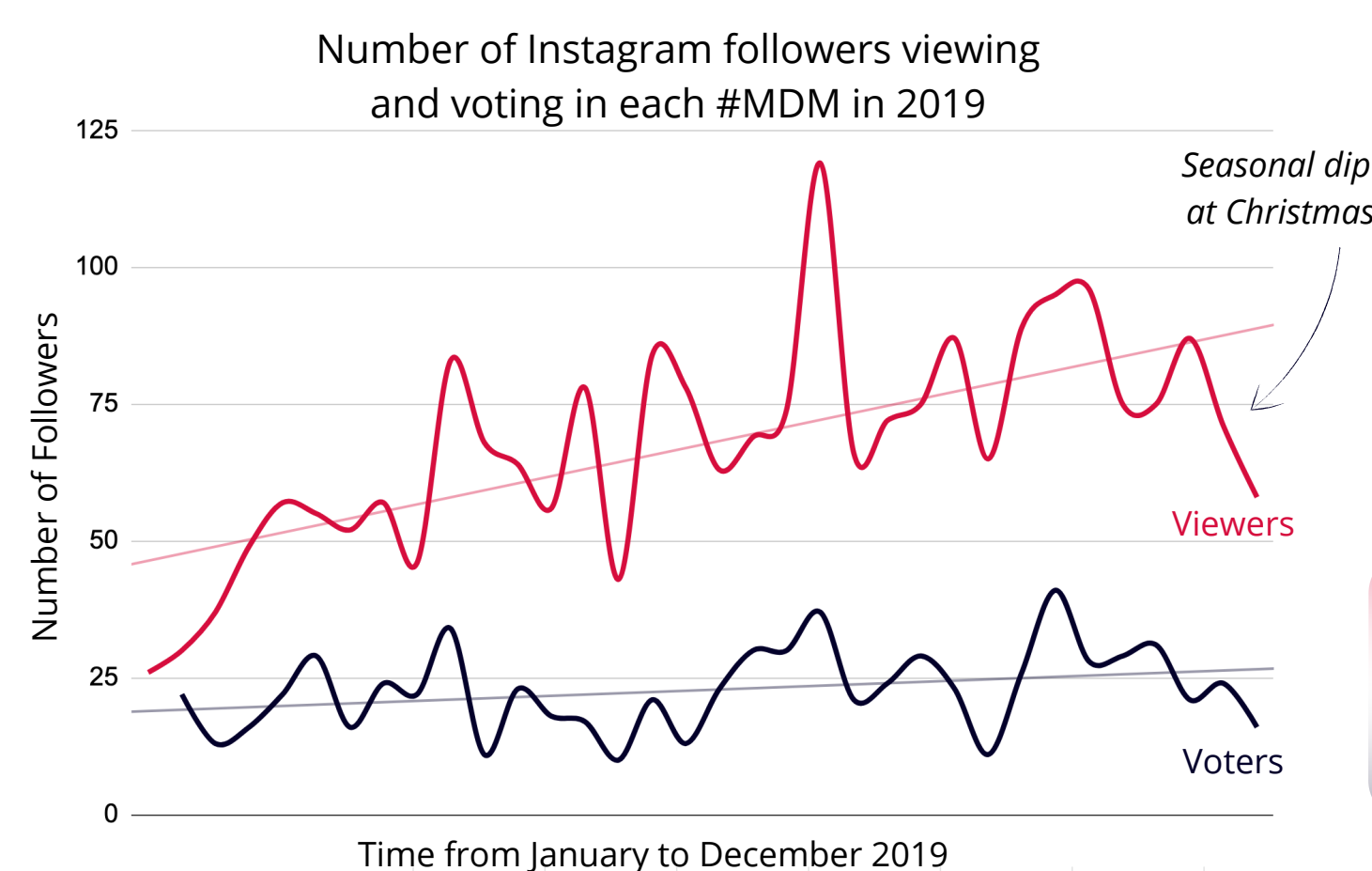
Conclusions

The poll is open to everyone using Instagram so we suspect the true awareness of each condition amongst medical professionals is lower than the results suggest. This is because: 1. Instagram users who have the featured condition often answer "yes", making the result look a lot more promising than we suspect the reality is 2. Viewers of the Story are not obliged to vote in the poll and it has been anecdotally noted that often followers known to be doctors will only vote if they can answer "yes"!

However we can conclude that consistent and interactive engagement with our audience helped grow our Instagram followers significantly in 2019.

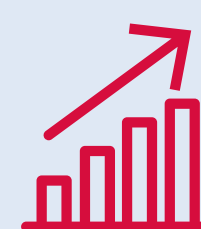
M4RD is a UK Registered Charity
Number 1183996
In 2019 M4RD was sponsored by
BioMarin, Inventiva and Sobi
[M4RD.org](https://www.m4rd.org)

Results



34 different conditions polled in 2019

Most heard of
Haemophilia Type A
Fragile X Syndrome
Bone Sarcoma
DDX3X Syndrome
Fibular Hemimelia
Neuroferritinopathy
Least heard of



Instagram following increased by ~325%



Total number of views = 2299
Total number of votes = 733

Voters had heard of the condition	Number of conditions	Conditions in each category
91-100%	0	
81-90%	3	Haemophilia type A; Fragile X, Bone sarcoma
71-90%	5	Kawasaki disease; Hypoparathyroidism; NF1; Spinal CSF leak; Ataxia
60-69%	2	Rett syndrome; 22q Deletion syndrome
50-59%	3	PKU; Cranial CSF leak; Acromegaly
40-49%	4	Gaucher; Cholangiocarcinoma; Pompe; Moyamoya
30-39%	2	Fibromuscular dysplasia; Medulloblastoma
20-29%	7	Wyburn Mason Syndrome; Stiff Person Syndrome; Isolated Congenital Asplenia; SCAD; Acute Necrotizing Encephalopathy; CSID
10-19%	5	Kikuchi-fujimoto; Alström syndrome; CSID; Dyskeratosis; CAPS; Arachnoiditis
0-9%	3	Pitt Hopkins; Fibular hemimelia; Neuroferritinopathy; DDX3X



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