

THE ROLE OF DATA AND TECHNOLOGY IN PATIENT ENGAGEMENT

DIGITAL TOOLS FOR THE NEW REALITY

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MPN Voice Background

Our organization was formed in 2003 by a small group of patients and clinicians around the practice of Dr Claire Harrison at St Thomas' Hospital in London

MPN Voice now has nearly 3000 members across the UK and in many other countries throughout the world

Our mission is to provide clear and accurate information and emotional support to MPN patients and their families/friends.

We advocate for the MPN community in the UK and Ireland and were a founding member of MPN Advocates Network

Digital Engagement

Engagement with the MPN community started with small face-to-face meetings but rapidly became an online presence with a website, which is now in its 4th iteration. We have gradually adopted a range of Social Media platforms:

- Facebook
- Twitter
- Instagram
- YouTube
- HealthUnlocked



Health Unlocked is a global social networking platform that hosts over 700 online health communities with discussion forums
MPN Voice has an HU community of 7500 members and over 10,000 posts.

The MPN Voice HU forum is moderated by patient volunteers and specialist clinicians

How we responded to the COVID pandemic

By May 2020, all of our face-to-face activities (patient meetings and fundraising events) were effectively prohibited, so we were forced become a fully digital organization:

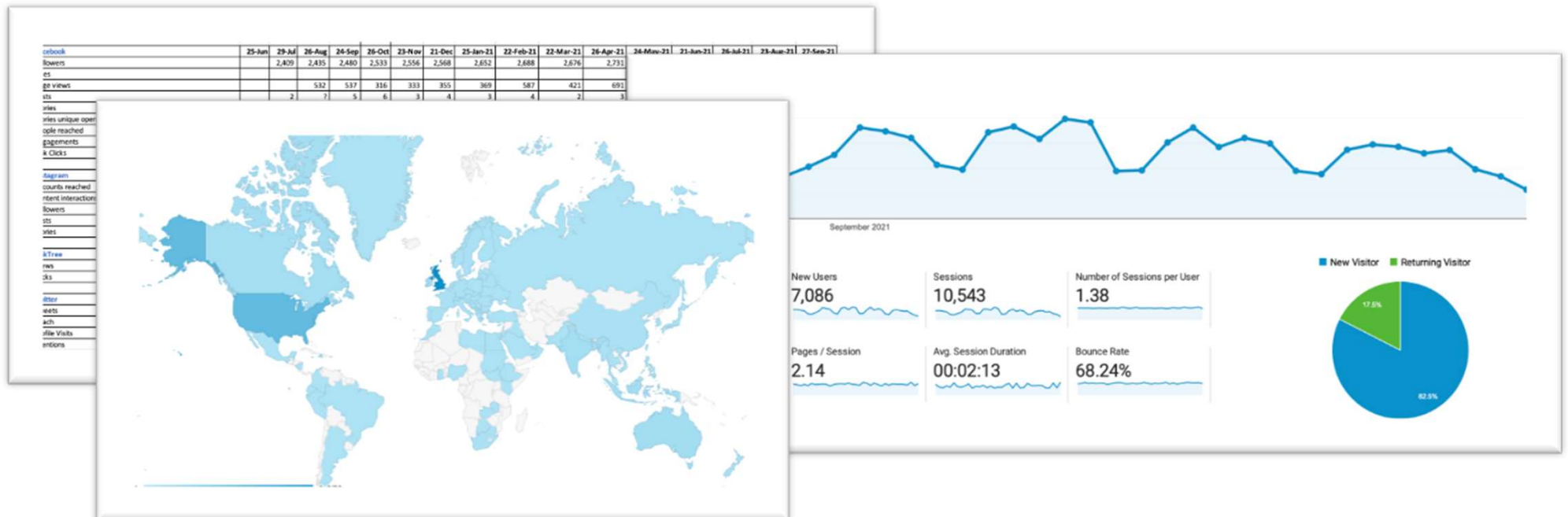
- *All patient meetings became ‘virtual’ using Zoom or equivalent technologies*
 - *We used a combination of do-it-yourself video conferencing, commercial services and services provided by Guy’s Hospital*
- *Use of Social Media has increased and become more systematic*
 - *A dedicated volunteer Social Media Manager took responsibility for maintaining a regular Facebook, Twitter and Instagram presence*

Engagement Data

On a monthly basis, we gather and review usage data from the website, social media platforms and HealthUnlocked.

We are able to judge:

- how many users we are reaching in different regions
- what content is most popular
- other data like popular times and days of the week



What we have learned

Digital engagement reaches more people but delivers a less rich experience

Digital engagement is a process, not a project. It needs ongoing commitment, monitoring and review

Digital skills are necessary, but also knowledge and understanding of the medical terminology, writing and design skills

In order to be more agile and reactive, we formed a small executive team that met at least monthly

In Conclusion

The pandemic has permanently changed MPN Voice:

- Our digital presence will be an important part of our work*
- Our management process is much more proactive and rigorous*

*I would like to acknowledge and thank **Maz Campbell-Drew** for her amazing work over the past several years but particularly the last 18 months, and also **Mark Taylor**, a volunteer MPN patient who took on the Social Media Management role about 6 months ago and has helped us transform MPN Voice in the ways I've described*