



Empowering citizens in the digital health society

Digital capacity-building: how patients and patient groups are changing health priorities, policy and service delivery



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Director

myhealthapps.net/PatientView



About PatientView

- UK-based research, consulting and publishing company
- **Collects and analyses the viewpoints of thousands of patient groups (and their members) worldwide** – since 2000
- Has the capacity to reach out to about **100,000 patient organisations worldwide**, covering over 1,000 health specialties
- Launched **myhealthapps.net** in November 2013 to help patients, carers, and health-conscious consumers find apps that have been tried and trusted by people like them



Where we are today...

- Over 450 apps
- Covering **150+ health specialties**
- Apps in **50 languages**
- **Reviews** by over **650 patient organisations worldwide**
- **Transparency**: info on and links to app developer, who funded the app, whether it was developed with a medical adviser, if it has regulatory approval (if necessary)
- **Neutral platform**: only apps recommended by patient, carer or health advocacy groups included. *Myhealthapps.net/PatientView takes no money from app developers or app downloads*

www.myhealthapps.net



Languages: English

Countries of use: Any in which the user is familiar with English

Cost: Free in many locations (sign-up required) – offered as a self-management tool by health authorities in the UK, Canada and New Zealand

Developer: Big White Wall, UK
(Based in United Kingdom)
<http://www.bigwhitewall.com>

Funder: Same as technical developer

Medical Adviser: Clinical Director, Dr Simon Wilson

BigWhiteWall

Summary

“Big White Wall is its community of members, who support, help each other and share what’s troubling them in a safe and anonymous environment. The site is available 24 hours a day, 7 days a week, 365 days a year – no need to wait until morning, the next business day or for a doctors’ appointment. You can find support simply by logging on.

To ensure safety and anonymity, the site is monitored by clinically trained ‘Wall Guides’, who are online 24/7. We know that finding help when you’re distressed can be hard, so our Wall Guides are also there to help you feel welcome and guide you on how to get the most from our services.”

What it offers

Community Support • Anonymity • Creative Outlets • Focused Courses • Safety • Self-Improvement Tools • Assessments • Personalised Suggestions

<http://myhealthapps.net/app/details/323/Big-White-Wall>

Co-creating services with healthcare systems and providers

Epilepsy Commissioning Toolkit

Epilepsy Action and **Epilepsy Society** in the UK have worked with nine Clinical Commissioning Groups (CCGs) [NHS England] to create a single access point of resources to support effective commissioning for children and adults with epilepsy. The resource includes nine sections which guide commissioners through the whole commissioning process. Each section can be accessed individually to meet commissioners' specific needs.

Focus on **co-production of services** - involving patients and communities working with professionals in the commissioning, design and review of services to “get a better deal which includes better health outcomes.”

See other examples on Wellbeing Our Way: www.nationalvoices.org.uk/wellbeing-our-way/about

National Voices is the coalition of charities that stands for people being in control of their health and care.

Our mission: person-centred care. We want person-centred care: people having as much control and influence as possible over decisions that affect their own health and care – as patients, carers and members of communities. We want people to be partners in the design of services and partners in research, innovation and improvement.

Initiating and improving medical research

In the USA, the **American Sleep Apnea Association (ASAA)** used ResearchKit for their Sleephealth study app, launched in 2016, offering two linked benefits for patients:

- a personalised tool designed to help people better understand the link between their sleep habits and general well-being
- an opportunity to share sleep data on a large scale.

Results: One year from launch, it had nearly 20,000 users. Whilst at its peak 47% of these opted in to take part in the sleep study.

65% had never taken part in medical studies before.

The ASAA puts a lot of emphasis through its website and forum on the benefits of becoming what it calls ‘**citizen researchers**’:

- receiving support
- sharing insights
- helping direct future research
- improving their knowledge of what our medical system does and how it works.

<https://www.sleepapnea.org/sleephealth-app-celebrates-first-anniversary/>



“This really represents a new way of doing medical research...We are in the beginning stages of learning how to do it.”

One of our goals is to spread the word about the importance of taking part in research...we want interested individuals to not just participant in a single research study, but to consider joining our community as well, and be part of the research movement.”

*Carl Stepnowsky
Chief Science Officer
American Sleep Apnea Association*



National
Multiple Sclerosis
Society

Coalition-building to secure research funds

MS activists urge Congress to support **federal MS research funding** through the National Institutes of Health and the MS Congressionally Directed Medical Research Program.

Hashtags: [#MSresearch](#) and #NIH / @NIH or #CDMRP / @CDMRP

Example messages:

.@publicofficial please support \$10 mil for the MS @CDMRP in FY 2016 #MSresearch

.@publicofficial please support \$32 bil for the @NIH in FY 2016 #Msresearch

NB using a full stop in front of an @mention ensures that all of your followers see the tweet.

If your member of Congress signed onto the MS research funding letters, thank him/her:

Thank you to @publicofficial for supporting #MSresearch through the MS @CDMRP

Thank you to @publicofficial for supporting #MSresearch through the MS @NIH



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