

Africa Health  
digital summit 2019



# ePatients in a sustainable eHealth system

Vanessa Carter

## Nothing to disclose

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Please tag posts using



the handle **@\_FaceSA**



Healthcare Communications  
and Social Media South Africa



Stanford University  
Medicine X  
ePatient  
Scholar

Antibiotic  
Resistance  
Activist

Founder of  
#hcsmsA

Vanessa Carter



[www.vanessacarter.co.za](http://www.vanessacarter.co.za)



# BECOME AN ANTIBIOTIC GUARDIAN

Choose a Pledge  
[AntibioticGuardian.com](http://AntibioticGuardian.com)  
/South-Africa

Keep  Antibiotics Working



#AntibioticGuardian

#ProtectAntibioticsZA



The Honorable Minister Aaron Motsoaledi signs the pledge for Antibiotic Guardian South Africa



[www.healthcaresocialmedia.co.za](http://www.healthcaresocialmedia.co.za)

- **CPD WORKSHOPS**

First CPD accredited course about ePatients and healthcare communications and social media

- **GROUP AND INDIVIDUAL TRAINING**

For the effective use of social media for health and science communication

- **MONTHLY TWITTER CHAT**

Moderate a monthly Twitter chat on #hcsmsA as well as for external organisations to help crowdsource data

- **SOCIAL MEDIA INFLUENCER PROGRAMS**

Implement social media influencer programs



**UNMASK  
STIGMA**



All stakeholders welcome  
Transcript by Symplr



## How can we take a Sustainable Approach to end TB in South Africa?

[CLICK HERE](#) to read more about the #hcsmsa Twitter chat on 21 March 2019



**FIND**   
Because diagnosis matters

VOICES FOR DIAGNOSIS AWARD  
72nd World Health Assembly 2019

ePatients in a sustainable  
eHealth system?

Listen to stories first.

Video Credit: Stanford University Medicine X



Ten years of surgeries. Two years of infection during 2010 - 2012 that wouldn't go away.



**2 surgeries  
8 months  
later**

One or two ways  
the internet  
played a major  
role towards my  
recovery

- I could send a compiled electronic medical record to a specialist overseas.
- Finding a doctor online. Very few had websites and social media accounts locally making it almost impossible for me to navigate the system and find the right experts, resulting in extra surgeries.
- A video consultation with the craniofacial expert in Boston enabled me to coordinate my team at home and make better decisions.
- The understanding of what MRSA was through online research so I could take a greater part in participating to manage infection (e.g. IPC at home and in hospital, medication adherence, making sure I had fewer surgical interventions and complications by choosing my surgeons more carefully).

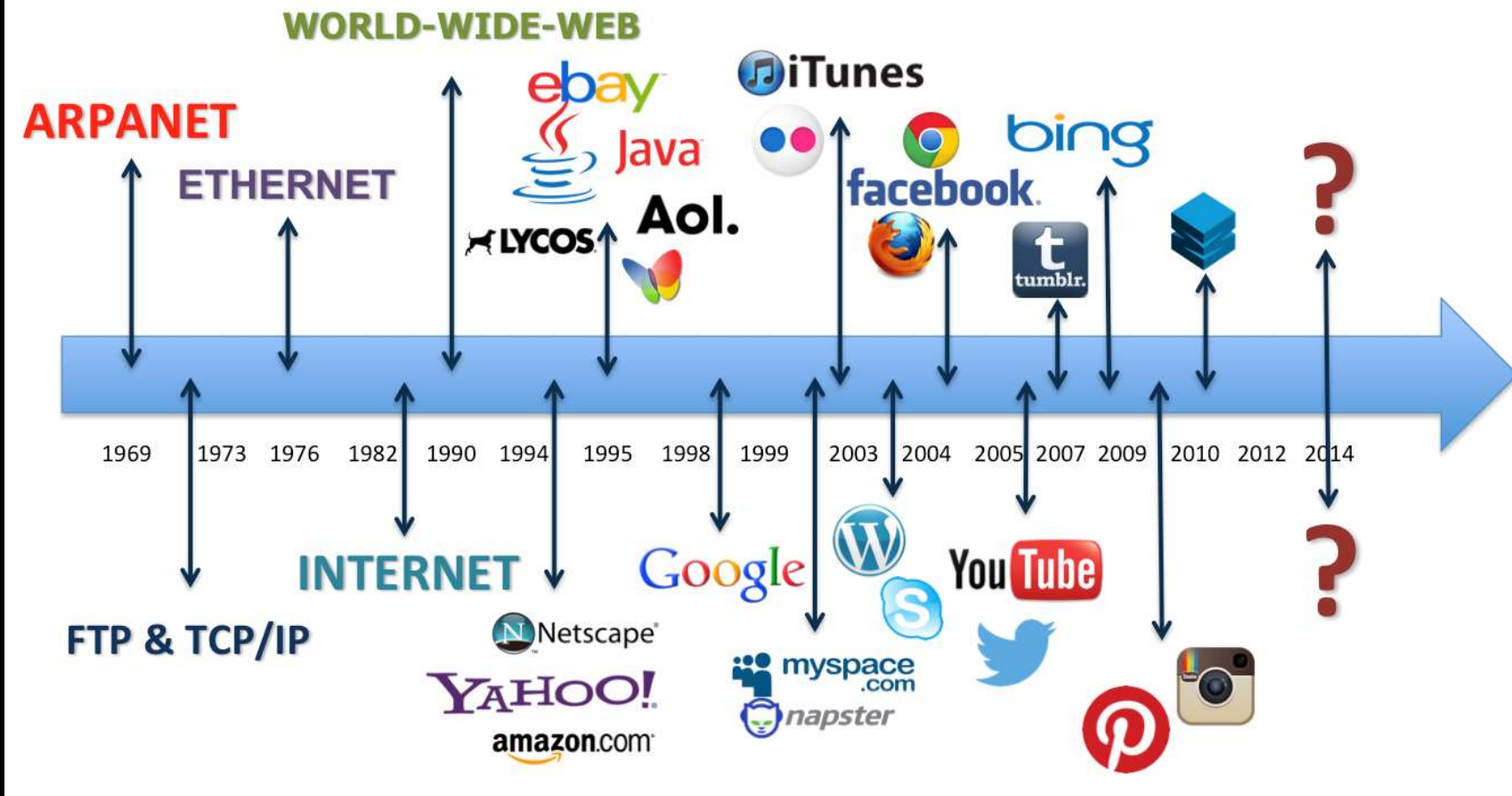
Patients can't  
do this!

It was not me  
directing my  
recovery

Patients are  
not intelligent  
enough

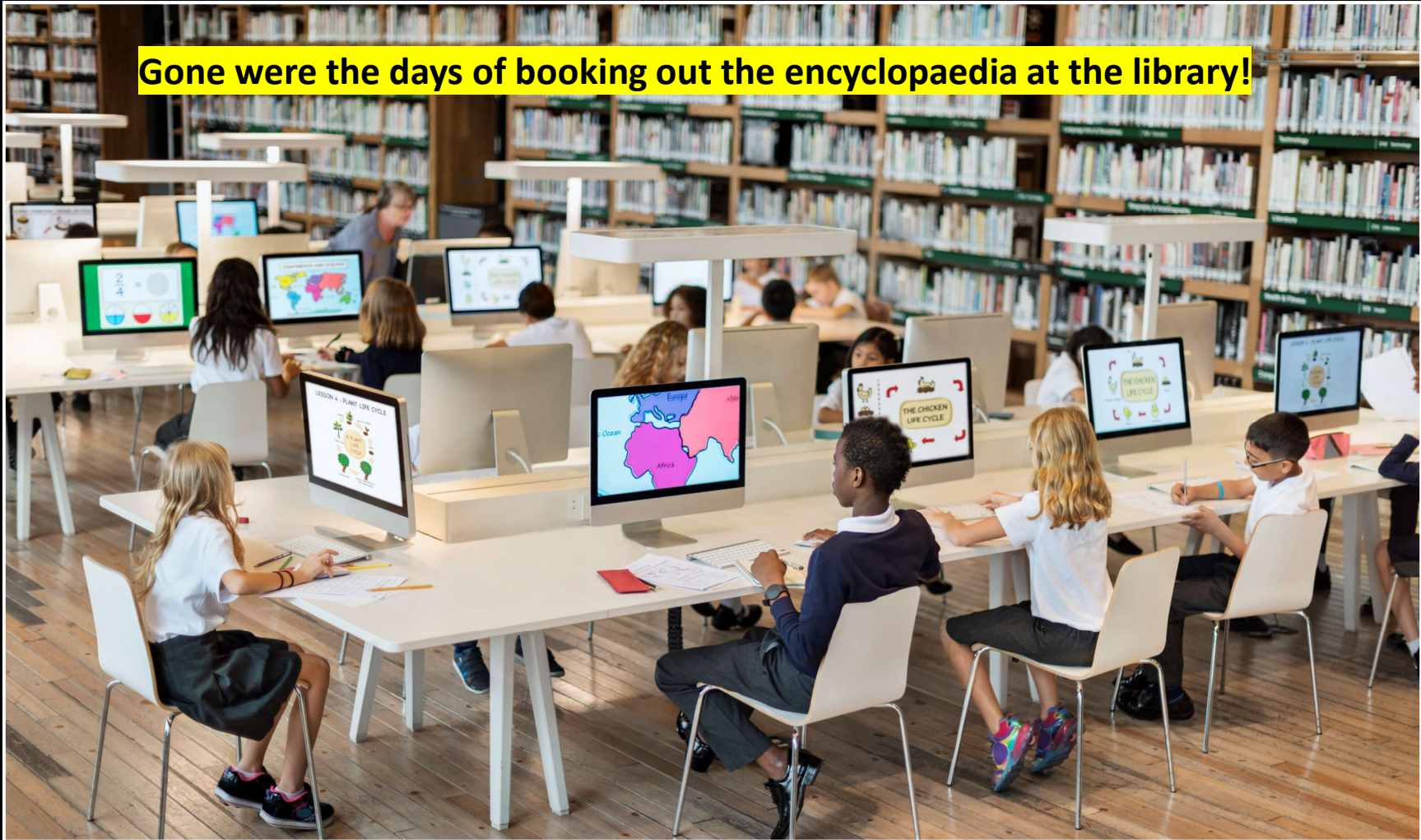
The general consensus is that patients aren't able to manage their health and any access to data should remain forbidden, however my story is an example of what the internet already offered in 2012.

What is an ePatient?



The internet was first made publicly available in 1991.

**Gone were the days of booking out the encyclopaedia at the library!**



The internet gave everyone at all ages access to an information highway!  
Any information we needed became a few clicks away!



Yet, almost 3 decades later healthcare still believes that patients having access to information to educate and empower themselves is a burden on the system



Patient self-diagnoses himself!

# Cyberchondriac

A woman with long, wavy brown hair and a shocked expression is looking at her smartphone. The background features a world map with glowing blue dots and white dashed lines representing data connections. The word "Cyberchondriac" is written in large, white, bold letters across the top of the image.

Because of this phenomenon in the 90's, the term cyberchondriac was coined

## IT WAS DOCUMENTED IN THE OXFORD DICTIONARY

“A person who compulsively searches the internet for information about particular real or imagined symptoms of illness.”

The term was in fact derived from two words as the internet emerged in medicine back in the 1990's which was cyber and hypochondriac.

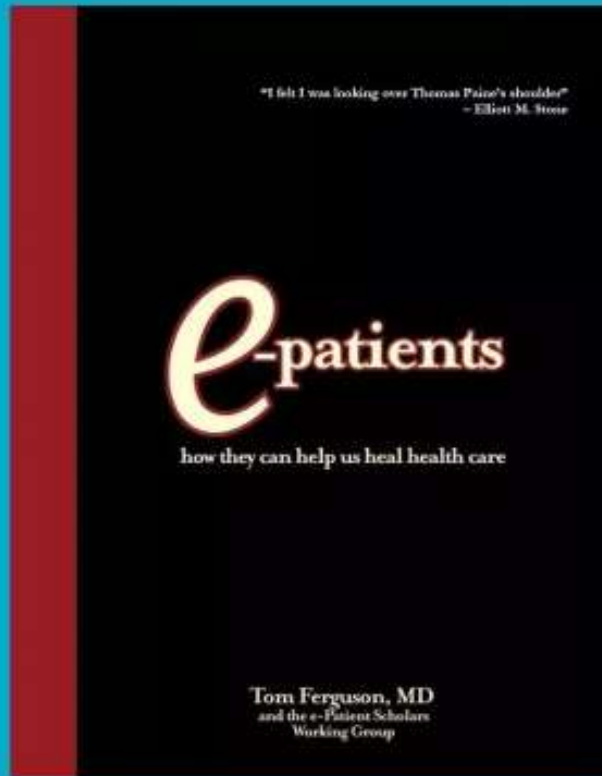


## **Dr Tom Ferguson**

**American Researcher and Doctor  
1943 - 2006**

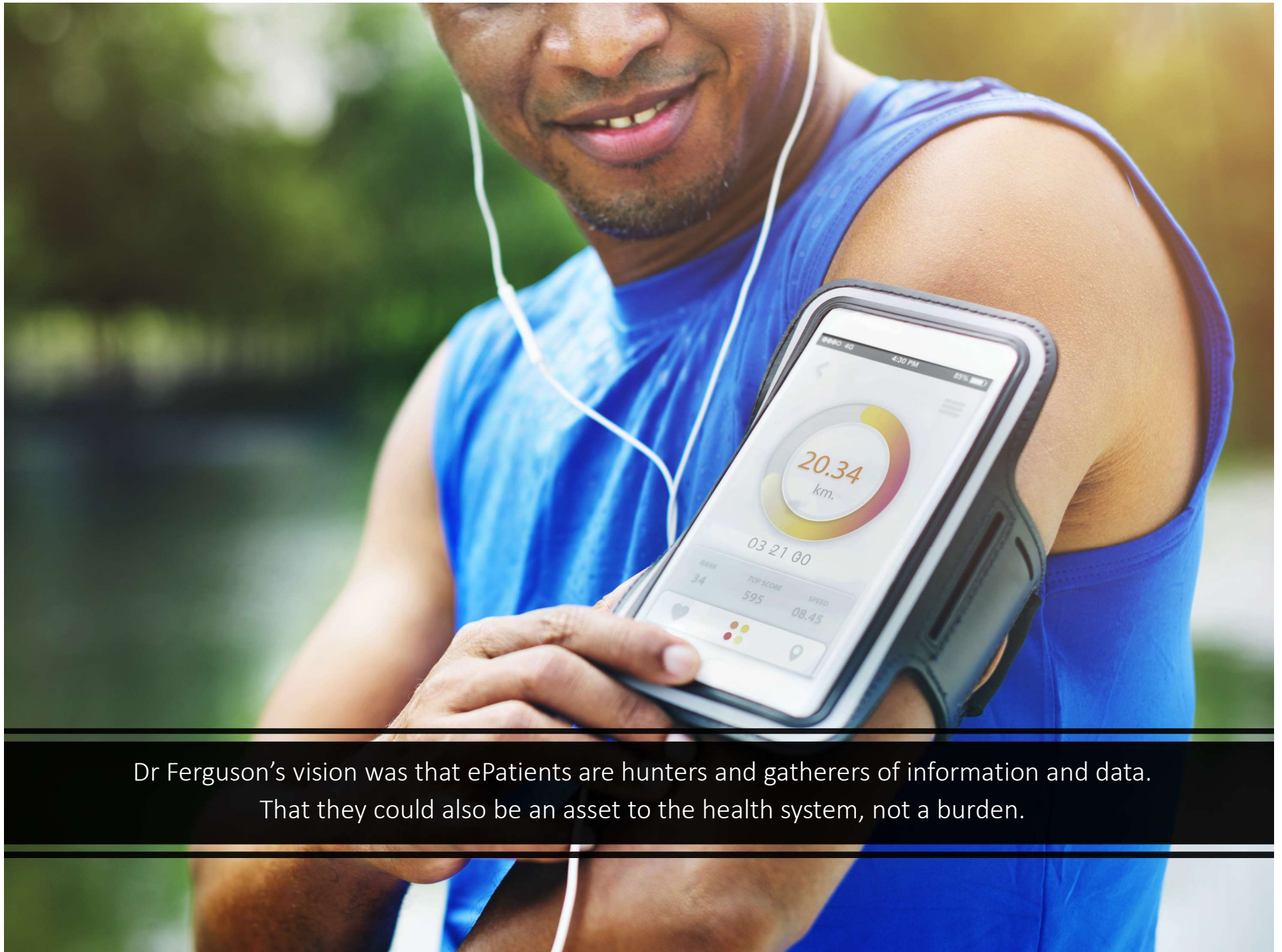
Started working on research and a white paper to study these new digital patients and coined the term **ePatient**.

He was an early advocate for patient empowerment urging patients to assume control of their own health and believed that the internet and other digital technologies could be a way to do that.

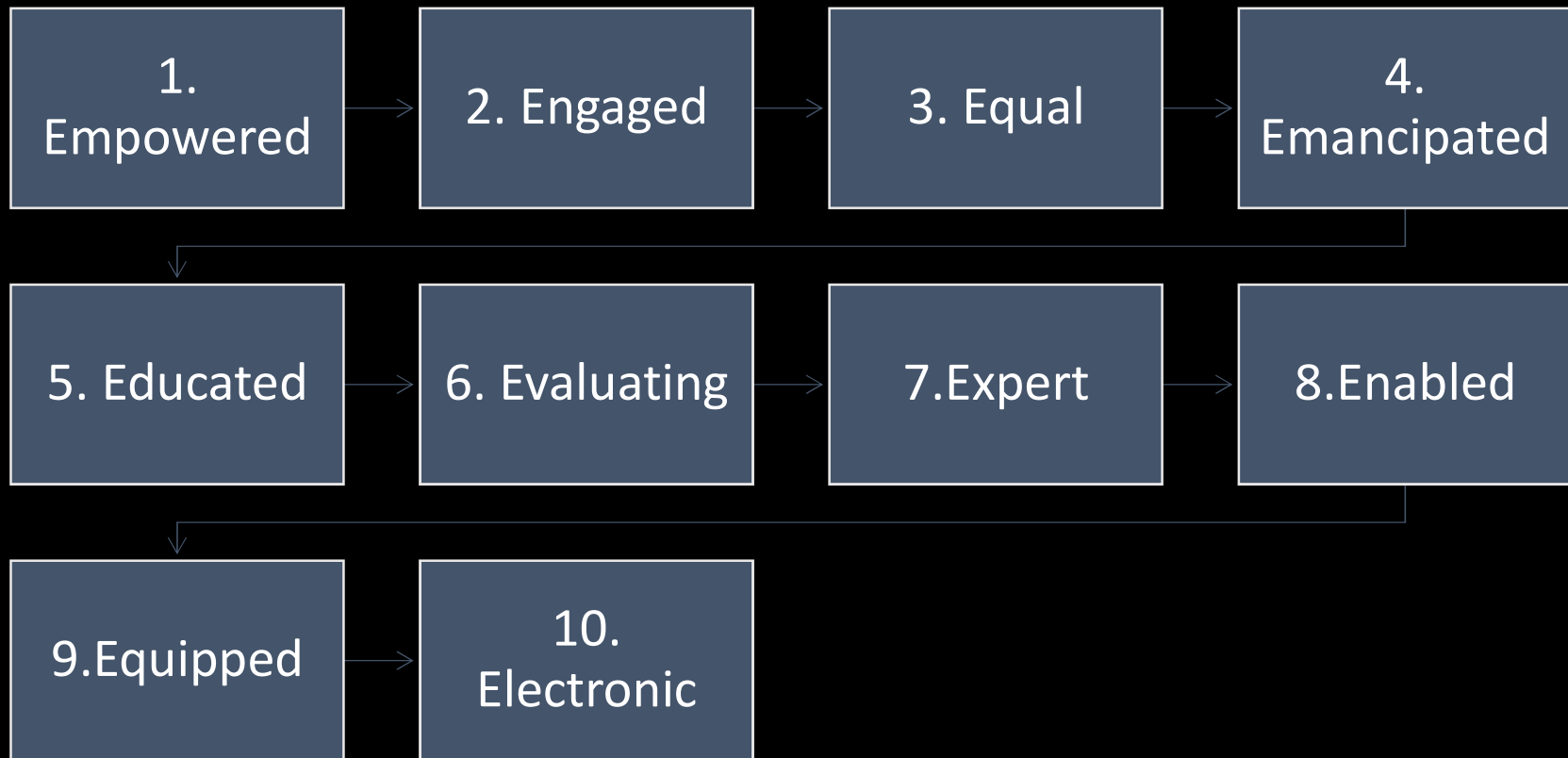


## e-Patient Whitepaper

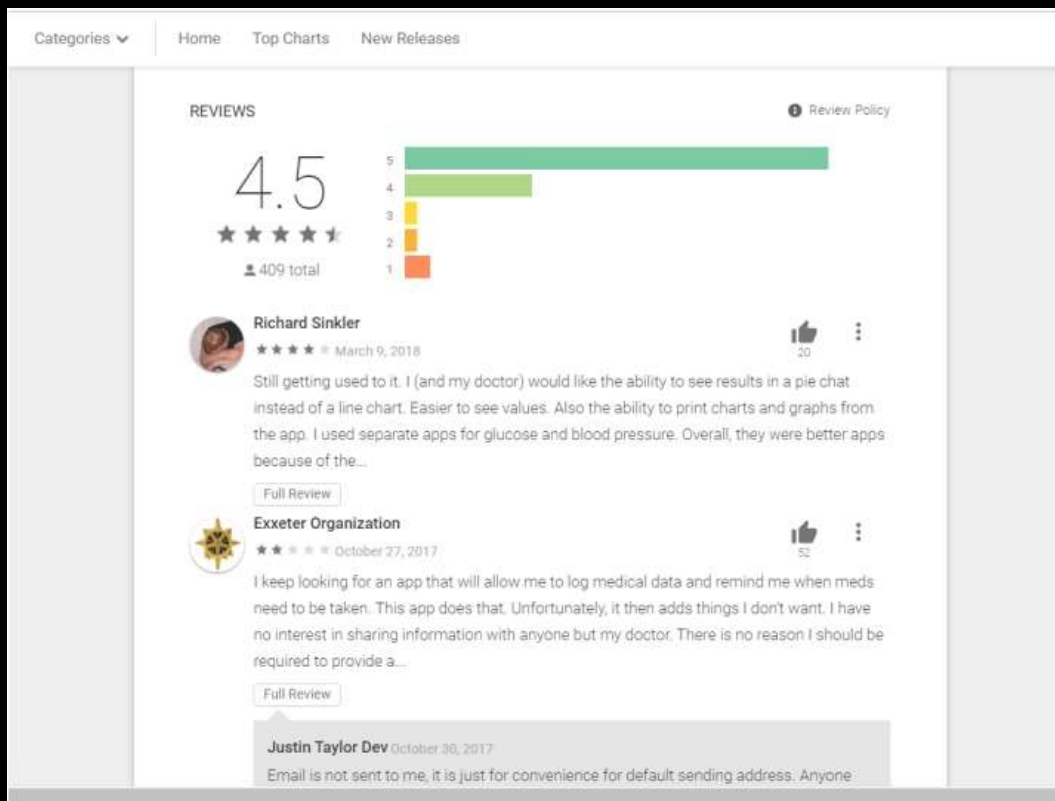
[www.participatorymedicine.org/e-patients-white-paper](http://www.participatorymedicine.org/e-patients-white-paper)



Dr Ferguson's vision was that ePatients are hunters and gatherers of information and data. That they could also be an asset to the health system, not a burden.



The 10 e's of an ePatient



## Evaluating ePatient

An evaluating patient uses various techniques to evaluate online resources or understands that data may not always be accurate

E.g.: Consumers use mobile application reviews before making a purchase. This helps them to evaluate a product or service provider. Patient communities, social media conversations and forums are another way they evaluate information.



## Engaged ePatient

An engaged ePatient is a patient that participates fully in using the technology to generate quality data.

Good quality data input means good quality output.

E.g.: Virtual and other types of immersive technologies increase engagement through providing solutions that improve the patient's experience or meet their direct needs. Much of this is established through using user-centered design methods

## Paternal healthcare

Limited access to online information. Patient is provider dependent

## web 1.0

Patients start to search for healthcare information online using search engines

## web 2.0

Patients start to use social media and web 2.0 tools to find information and grow their network

## web 3.0

Patients use web 2.0 and data generated from their connected objects and electronic health records



Patient 1.0

Patient 2.0

Patient 3.0

**PATIENTS CAN EVOLVE WITH TECHNOLOGY**

But can technology create ePatients alone? No.

# IS IT ENOUGH FOR PATIENT JUST TO BE DIGITAL?

FEATURES	CYBERCHONDRIAC	E-PATIENT
<b>Use digital technologies in their health management</b>	yes	yes
<b>Use the internet with strategy</b>	no	yes
<b>Can deal with large volumes of information</b>	no	yes
<b>Relationship with their doctor. Ask doctors opinion about online research before self-diagnosing</b>	no	yes
<b>Can evaluate information</b>	no	yes



Could patient-centered design make a difference? Yes  
Good design can improve engagement, education and empowerment etc.



Doctor to patient relationship.

Could telling patients not to collect information and gather data electronically to manage their health be counterproductive to eHealth?



Patients need to understand why their participation matters to collecting quality data. They are active participants using digital devices.



Smart Cities  
collecting  
quality  
data from  
citizens for  
eGovernment

ePatient  
or  
cyberchondriac?

Are patients online in  
South Africa?

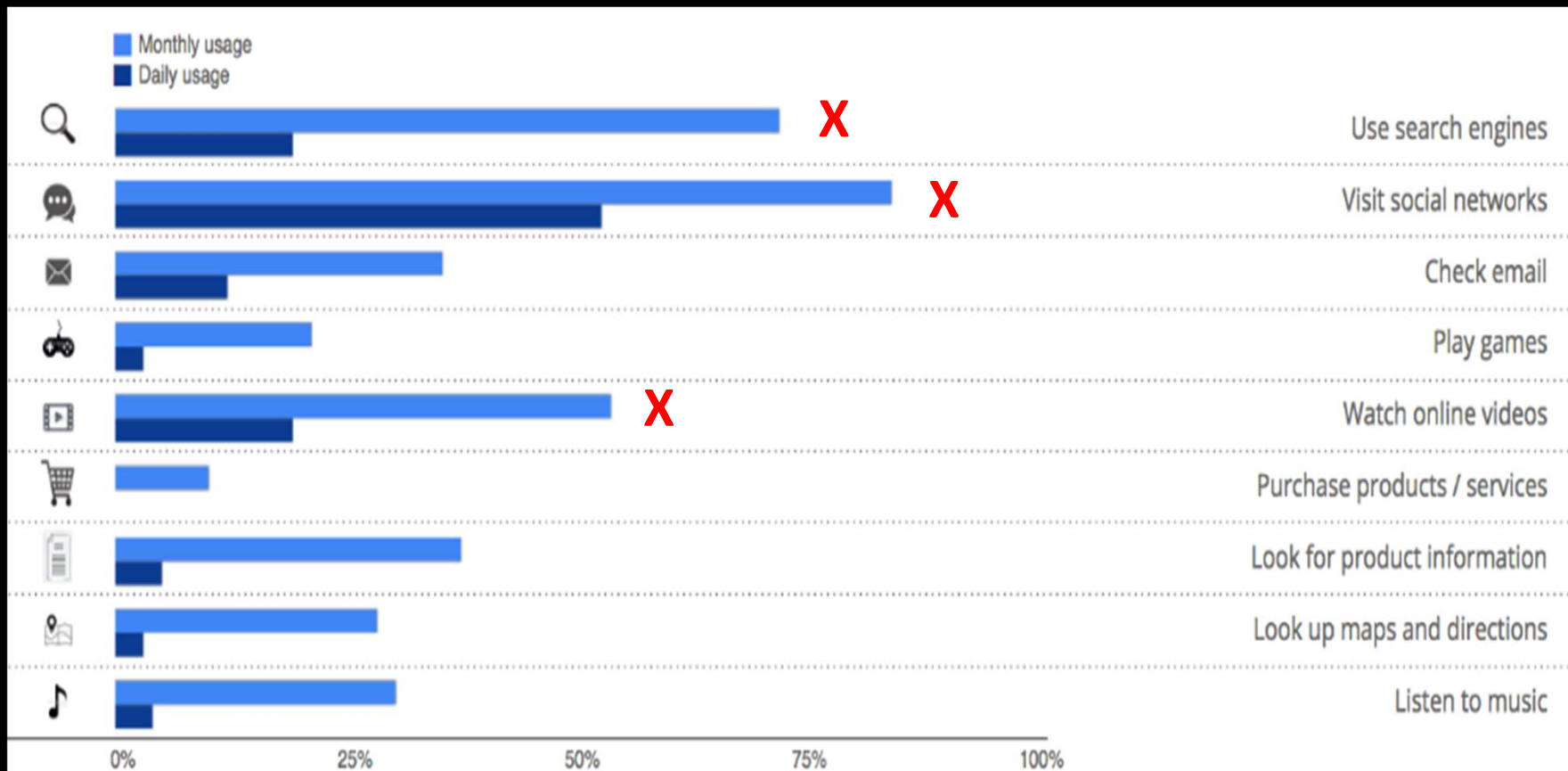


#FEES  
MUST  
FALL

If students can mobilize a protest in a few days which reaches global proportions through a single hashtag, we have to admit the internet is a powerful tool

Image credit: <https://doc-research.org/2018/03/digitalisation-of-the-media-in-africa-prospects-for-change/>





Question asked: QIA1\_N [How often do you do the following activities online, via any device, via app or browser?]  
 Base: Online users 16 years and older // n (Local) = 646  
 Source: Connected Consumer Study 2017

KANTAR TNS, | Google Market Insights | ZA - 20-

South African citizens are social with close to 80% of the internet time spent on social media.

The argument still remains that South Africans don't have access to video, however it's the third most popular online activity according to Google Market Insights.

Image resource: [www.themediaonline.co.za/2017/11/changing-behaviour-of-online-consumers-across-generations](http://www.themediaonline.co.za/2017/11/changing-behaviour-of-online-consumers-across-generations)

Can the internet be used to  
crowdsource patient ideas  
so we can improve  
design research?



## DEFINING SUSTAINABLE HEALTH SYSTEMS FOR CANCER PATIENTS IN SOUTH AFRICA

Click to read the #hcsmsa Twitter chat blog and questions for 1 November 2018



Supporting  
organisations



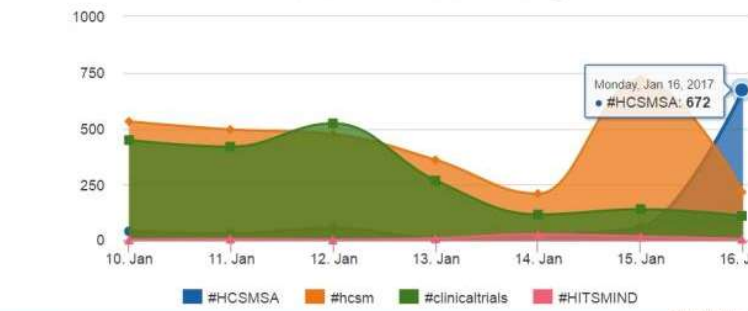
THE  
*Pink Parasol*  
PROJECT



Tweetchats are only one example of how social media can be used. Twitter is open source



TT Mobile US @TTMobile\_us  
#hcsmsA is now trending in USA, ranking 41  
Retweeted by HealthSocMed #hcsmsA  
#HCSMSA and Related Hashtags



P. F. Anderson @pfanderson  
I love that #hcsmsA is trending in MICHIGAN! #hcsmsA pic.twitter.com/m6AbK5xoil

- @msharmas RT @innonurse: T5: Plan around your users, their experience, and deploy security models to support your requirements. -->...
- @facesa @innonurse @FaceSA My pleasure Danielle, look forward to seeing you soon!! #hcsmsa
- @yawampoma Retweeted Nick van Terheyden (@drnic1): @yawampoma thanks for joining #hcsmsA
- @yawampoma RT @drnic1: @yawampoma thanks for joining #hcsmsA
- @msharmas RT @nxsttop1: T4/5 Patient ID Tied to More Security & Privacy>> Why Ireland has a National PT Identifier...by @danmunro https://t.co/Ogp3...

#HCSMSA content from Twitter

The Numbers

- 5,792,508 Impressions
- 733 Tweets
- 121 Participants
- 20 Avg Tweets/Hour
- 6 Avg Tweets/Participant

Tweet Like



Data can be sorted by users, hashtag, geolocation, relationships with others etc.

## Healthcare Hashtag Project

Healthcare Hashtag Project, a free open platform for patients, caregivers, advocates, doctors and other providers that connects them to relevant conversations and communities.

## The Community by the Numbers

2,000,000,000+ Tweets

16,617 Topics

18,866 Hashtags

6,274 Contributors

### Tweet Chats

TRENDING

1. #BCSM
2. #HCLDR
3. #LCSM
4. #BTSM
5. #HITsm
6. #hpm
7. #DCDE
8. #MMSM
9. #JACR
10. #ourD
11. #hcsmsA
12. #MedEd
13. #NephJC
14. #wedns
15. #AskASN

NEW

- #BIDChat
- #NHSautomation
- #IDSchat
- #Improve4Patients

### Conferences

TRENDING

1. #HeartFailure2019
2. #EAPC2019
3. #APSA50
4. #ASCO19
5. #DDW19
6. #CAEP20
7. #WE2012
8. #ATS2019
9. #ESOC2019
10. #EuroPCR
11. #SLIPE2019
12. #SER19
13. #37VicenzaCourse
14. #promOT
15. #SEAP2019G

NEW

- #SPAFALL19
- #CCAS20
- #AEDVSOMOSTODOS
- #SPABAH20

### Diseases

TRENDING

1. #BCSM
2. #LCSM
3. #Lymphoma
4. #GERD
5. #BTSM
6. #hidradenitissuppurativa
7. #MERS
8. #BreastCancer
9. #Diabetes
10. #Schizofrenie
11. #AFib
12. #pwme
13. #Migraine
14. #OVCA
15. #MMSM

NEW

- #DiabeticRetinopathy
- #CKD
- #BehcetsDisease
- #albuminuria

### Other

TRENDING

1. #NNM
2. #hcsm
3. #SpringTestingWeek
4. #WHIS
5. #digitalhealth
6. #opioid
7. #MedTwitter
8. #pharma
9. #RespEd
10. #gecb
11. #CTD2019
12. #PedsID
13. #EuroTestWeek
14. #ALS
15. #hcsmeu

NEW

- #ROedu
- #RadOncDiversity
- #cahypox
- #RadNTT

Patient and professional communities indexed by hashtag. Image credit: Symplur.com



**Bhekisisa M&G Health** @Bhekisisa\_MG

11 hours ago

Can #NewsMedia assist public health experts to counter #antivaxxers? Find out at our @MiaMalan's keynote TODAY at the @africahealthxb Public Health Conference at the Gallagher Centre at 10am. MT @PublicHealthSA #AfricaHealthEXB <https://t.co/M652PikHrl>



**Mia Malan** @miamalan

10 hours ago

RT @Bhekisisa\_MG: Can #NewsMedia assist public health experts to counter #antivaxxers? Find out at our @MiaMalan's keynote TODAY at the @af...



**Bhekisisa M&G Health** @Bhekisisa\_MG

10 hours ago

Our @MiaMalan will be talking about why #PublicHealth experts need to know how to use #SocialMedia in her @africahealthxb @PublicHealthSA Conference keynote TODAY at 10am. #AfricaHealthEXB <https://t.co/7ONvFphSbl>



**Dr Shakira Choonara** @ChoonaraShakira

10 hours ago

Will check in soon! @africahealthxb on this week, catch all the updates @PublicHealthSA @moeketsimodise1 @miamalan @MahlabaK @AUYouthProgram @AYUCorg @AfricaCDC #AfricaHealthEXB



**Bhekisisa M&G Health** @Bhekisisa\_MG

8 hours ago

The #DigitalRevolution: Why everyone now has their own printing press and why public health officials should use theirs. Catch our @MiaMalan's keynote on this at the @africahealthxb Public Health Conference at the Gallagher Centre NOW. MT @PublicHealthSA #AfricaHealthEXB <https://t.co/HNJfy8m7IP>



**Andreas Pflieger** @Pflieger\_A

8 hours ago

#Africa #Health #Expo 2019: Things are already in motion and we are ready to help you meet #Austria's #innovation #leaders in #medical #equipment and #technology - come visit us at exhibiton stand 2E.33A in Hall 2. #AfricaHealthExb @wko\_aw @Austria\_in\_SA <https://t.co/hnHfoaoO06>



**Bhekisisa M&G Health** @Bhekisisa\_MG

8 hours ago

.@miamalan at @PublicHealthSA #AfricaHealthEXB: The digital revolution has given everyone their own printing press in the form of a website or social media — and public health officials should use theirs. <https://t.co/Fb6qKeWEAS>



**Kesentseng Jackson Mahlaba** @MahlabaK

8 hours ago

RT @ChoonaraShakira: Will check in soon! @africahealthxb on this week, catch all the updates @PublicHealthSA @moeketsimodise1 @miamalan...



Event transcripts like those at #AfricaHealthExb can be recorded in real-time with a hashtag!

Image credit: Symplur.com

“The most underutilised resource in all of health care is the patient.”

— Dave deBronkart



[www.vanessacarter.co.za](http://www.vanessacarter.co.za)