the power of social in health & healthcare
Exploring Digital Health Trends
Report #1: The Power of Social

At Microsoft Innovation Center Vlaanderen we are convinced that healthcare is at the cusp of radical change, driven by a number of converging technologies and digital trends, such as sensors, mobile technologies, Big Data & analytics, gaming technology, online education and social networks.

In a series of reports we explore key digital health trends and related opportunities for technology companies, healthcare providers and patients-consumers. We take both an international and Flemish perspective, the latter based on interviews with local stakeholders. In this report we focus on social networks.

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About Microsoft Innovation Center Vlaanderen

Our mission is to stimulate ICT-related innovation and entrepreneurship in Flanders, with a particular focus on healthcare. We do so by supporting high-potential technology startups. MIC Vlaanderen has two operational offices in the cities of Genk and Kortrijk, Belgium.

www.micvlaanderen.be
AGENDA

Why does social matter?

How are providers responding?

Startup Mechanics I
Connecting Patients

Startup Mechanics II
Connecting Patients and Caregivers

Obstacles & Barriers

Startup Mechanics III
Connecting Caregivers

A Word of Advice
First, what is “Social”?  
The social “platforms”, obviously
social defined

Also, the thousands of niche social tools

dribbble
untappd

cafemom
goodreads
In fact, any application (public or organisational) can have ‘social’ features.
social defined

1. Social = Social Networks, Social Media, ‘social’ features of any application
2. User generated content
3. Community
4. Collaborative endeavour & crowdsourcing
5. Decentralised reach & distribution
Why does social matter?
Note the **generational shift**

90% of young people (aged 18-24) in the U.S. would engage in health activities or trust information found via social media. This while less than half of people aged 45-64 would share via social media.

It’s happening faster than you think

- 42% of U.S. consumers have used social media to access health-related consumer reviews.
- 25% have posted about their health experiences.
- 20% have joined a health forum or community.

Patients are inspiring millions

“Clouds”, a song by Zach Sobiech released on YouTube about his battle with cancer, went viral and has achieved close to 10 million views.
Cancer survivor Dave deBronkart and other activist “e-patients” are reaching global audiences and helping to transform the healthcare system, especially with regard to patient empowerment and the accessibility of healthcare information to patients.
How are providers & pharma responding?
They’re opening up

The pioneer & benchmark: The Mayo Clinic began using social media in 2005. Ranked as the most social media friendly hospital in the US.
PROVIDER CASE  Social Media Strategy at Providers

www.mayoclinic.org
US-based leader in medical care, research & education

“More than 3,300 physicians, scientists and researchers from Mayo Clinic share their expertise to empower you.”

Sharing Mayo Clinic = blog & social network where patients share stories

490,000 Facebook fans & 690,000 Twitter followers

15,000 YouTube subscribers, 11 million views

Regular podcasts and Q&A sessions with Mayo doctors
In Feb, 2013, the hospital live-tweeted a caesarean section, from prep to aftermath, sharing video (GoPro camera), photos, information and responding to questions via Twitter.

83,000 people watched live, and millions saw stories online, on TV and print.

2000 comments sent to the Dr.
Why are providers using social media?

- **It’s where patients are**
- Facebook, Twitter, YouTube, etc are free to use
- Hospitals can prepare patients for their stay using accessible videos, and thus create a better experience
- Providers can offer a trusted place for patients to share their stories, creating word-of-mouth recommendations
- It enables rapid dissemination of news about specific diseases and treatments, keeping patients informed and attracting new ones


“Applying social media in healthcare isn't just inevitable: it's the right thing to do in the interests of patients”

Lee A. Aase, Director
Center for Social Media, Mayo Clinic
Social media & Flemish hospitals? ...missed opportunity!

Source: Zorgnet Vlaanderen Survey 2012
PROVIDER CASE  Social Media Strategy at Providers

www.zol.be
Hospital that is pioneering social media use in Flanders

Successful social media use on a shoestring (no dedicated staff)

Lighter ‘infotainment’ channel, 4000 likes. Goal: 20-30,000 users.
Mix of press videos, ‘how to’ videos for healthcare professionals and information for patients
Used mainly to communicate with press & influencers
Pharma laggards?

The pharmaceutical sector is a laggard in the use of social media (due to regulatory risk), but this is changing thanks to new FDA guidelines. In 2014, IMS Health ranked the top 10 pharma companies in terms of social media reach, relevance & relationships. Johnson & Johnson came out on top by a wide margin.
www.jnj.com

Global consumer health company

Engaging the world using social media

Johnson & Johnson uses social media for branding (e.g. 5-minute videos about “fatherhood”), for corporate communication (annual report), for health communication (e.g. baby care), and for corporate social responsibility (e.g. a social media hub to cover UN events on the Millennium Development Goals)
3 Core Models:
I. Connecting Patients
II. Connecting Patients with Caregivers
III. Connecting Caregivers
STARTUP MECHANICS 1

Connecting Patients for Mutual Gain
PatientsLikeMe, a pioneering social network for patients, has doubled its number of users since 2011, reaching more than 200,000 users covering approximately 2,000 diseases.
The value in connecting patients

**SUPPORT** - People who have gone through what you have often are very knowledgeable about the disease, symptoms and treatment options, and can offer useful advice (and emotional support)

**INSIGHT** - As a group, if all are willing to share detailed information about symptoms and response to treatment, useful data can be gathered for generating insights and for medical research

**PERSONALISED SERVICE** - By sharing detailed information about yourself, providers can offer highly targeted information and services (such as information about clinical trials)
Challenge #1

Matching patients and facilitating support

“Will community members really understand my situation and be able to offer genuine support?”

“How can I help fellow community members?”
STARTUP CASE  Connecting Patients

I HAD CANCER™ beta
www.ihadcancer.com
A social network for cancer patients

Advanced community search tool

I HAD CANCER lets users search community members using a range of filters, including demographic data, location, disease type, and whether they’re currently ‘fighting’ the disease, have survived the disease or supported someone with the disease.

BROWSE COMMUNITY.

Name or Zip Code

SEARCH

Survivors
Fighters
Supporters

VIEW BY
LOCATION
PEOPLE

Age:
10 20 30 40 50 60 70

Gender:
Female Male

Year Diagnosed:

Type of Cancer:
Breast Cancer

FILTER →
Esperity invites users to keep a structured medical diary (for insights into how their quality of life evolves) and analyses that data for matchmaking purposes.

Esperity also has a built-in translation tool so users from different countries can easily communicate.
Meddik invites users to track their health using a Health Timeline. The tool forces users to use a common health language describing conditions & treatments. It relies on this to calculate a clinical similarity index to connect users. Each entry in the timeline is an opportunity to connect users with relevant people and information.
Challenge #2

Capturing data and creating valid insight

“Why should I share information?”

“Can we trust this information?”

“Is there enough data to generate real insight?”
Generating insight from a user’s own data

Esperity’s medical diary allows users to track their progress in a structured way and thereby discover patterns and trends in how medication is making them feel. Esperity will also allow users to contribute to medical research by sharing their data.
STARTUP CASE  Connecting Patients

www.meddik.com
Platform for collaborative health

Socially curated health information

Meddik facilitates structured discussions and reviews of relevant information (e.g. studies, reports, articles) concerning specific conditions and treatments.
STARTUP CASE  Connecting Patients

PatientsLikeMe is one of the largest patient social networks and a pioneer in community-driven research.

It launched the Open Research Exchange, a platform where patients and researchers collaborate to design, test and share better ways to measure health outcomes.

Bringing methodological rigour to community-driven research
23andMe acquired CureTogether

Expanding the dataset to include genotype & phenotype

23andMe Makes First Acquisition, Nabs To Double Down On Crowdsourced Gen

Founded in 2006, 23andMe set out with an ambitious goal: To one day make the human genome searchable by becoming the go to resource for personal genetic information. Leveraging DNA analysis technology and web-based interactive tools, the company developed a “Personal Genome Service” that allows anyone and everyone to access and better understand their genetic data, including their ancestry and predisposition to certain diseases. But the company believes that its true differentiation and value proposition today derives from a novel research model. Along with providing users with 200+ health and traits reports and ancestry info, the service enables users to opt into sharing their medical and family history, lifestyle and other phenotypic data, contributing to genetic research or participating directly in studies and surveys.

So, when 23andMe was recently awarded its first patent for determining a user’s risk for Parkinson’s Disease, it was naturally seen as the validation for its crowdsourced and...

Genetic testing provider 23andMe used crowdsourced research to determine a user’s risk for Parkinson’s Disease (earning it a patent).

In 2012 the company acquired CureTogether, one of the pioneers in community-driven research, and thereby vastly expanded its dataset.
Sickweather scans social networks for indicators of illness, allowing users to scan maps for illness, akin to how one would check for rain.

The tool lets users track illnesses, compare symptoms and see which viruses are making the rounds in your area.
Challenge #3

Offering services & making money while protecting privacy

“How will you protect my privacy?”

“How do you make money?”
Selling data to partners

“We take the information patients like you share about your experience with the disease and sell it to our partners (i.e., companies that are developing or selling products to patients). These products may include drugs, devices, equipment, insurance, and medical services.” - PatientsLikeMe

Leader of the pack, PatientsLikeMe, is upfront about their business model: they sell user contributed data to commercial partners. However, they are transparent about the types of data they sell (“shared data”) and don’t sell (“restricted data” such as names & addresses).
Esperity and I Had Cancer are keeping their options open regarding potential commercial partnerships but are more hesitant about actually selling user data. Options here are to offer targeted promotional/advertising opportunities to companies or offering ‘white label’ sections of the site.
STARTUP TIPS Connecting Patients

Differentiate through smart matchmaking (recommendation engine) and make communication safe & convenient.

Offer tools that stimulate sharing (protect privacy, match people correctly) and generate valid/trustworthy insight (e.g. template questionnaires, tips/education). Also try to bring in data from other relevant sources.

No easy business models. Selling data to commercial providers is an option but clashes with privacy issues.
STARTUP MECHANICS 2

Connecting Patients & Caregivers for Mutual Gain
The value in connecting caregivers & patients

MATCHMAKING – patients find the right doctor, doctors attract more patients

INSIGHT - crowdsource answers to medical questions by getting doctors & patients talking to each other at internet scale

COLLABORATION - help caregivers, patients and families coordinate the care process better.
Challenge #1

Intelligent matching of patients & providers

“How do I find a healthcare professional who I can trust/has the right expertise/is affordable/is accessible at my convenience?”

“How can I, as a provider, attract more patients and build my practice/business?”
ZocDoc (and its many competitors) offers a web-based platform for finding and booking a doctor online. Doctors can be searched according to location, speciality, review score and availability. Doctors pay a monthly fee and in return attract new patients and are spared the hassle of taking calls & managing their agenda.
Boekeenafspraak.be is a Belgian Zocdoc clone for beauty and non-medical care services. For example, cancer patients can find beauticians, dieticians, wellness coaches and hairdressers who have experience working with cancer patients.
Atendi tackles the Belgian problem of waiting lists for care homes. Families can use Atendi to register on multiple waiting lists and track their position on those waiting lists. Care providers can manage their waiting list via a SaaS solution and more easily communicate available space.
Challenge #2

Capturing data and creating valid insight

“Why should I invest my time and expertise contributing to this community?”

“Why should I trust this information?”
Matchmaking & insight through a Q&A platform

Pioneer in the doctor-patient Q&A area, HealthTap lets patients find answers to medical questions and doctors build their reputations. The company is adding new services continuously such as video Q&A, doctor-recommended health apps, private conversations and HIPAA compliant storage of your health activity.
Are you a medical detective? CrowdMed invites patients to submit their unresolved symptoms, and subsequently lets anyone (doctors, non-medical people) try to solve the case by coming up with the right diagnosis. CrowdMed offers premium (professional assessment) services.
Crowdsourcing disease prevention methods

Connects patients, clinicians, NGOs & pharma to raise awareness about dengue fever and to crowdsource & identify successful prevention methods. Uses Facebook (160k followers) to spread news and Twitter to activate opinion leaders.
Mining external data sources

Healthmap aggregates data from disease surveillance institutes and news sites for disease outbreak monitoring and real-time surveillance of emerging public health threats.
Facilitating improved and viable collaboration

“How will this service simplify the patient-provider relationship and create a win-win situation for both parties?”

“Is this new way of working at all possible given current reimbursement systems and regulation?”
Cloud-based EHR provider PracticeFusion developed a patient portal (Patient Fusion), which gives patients access to their medical record, but also lets them find, rate & book doctors, and communicate with their existing doctor.
PatientsKnowBest, a UK-based provider of a Personal Health Record platform, lets patients organise their “circle of care” (clinical team and family members) by giving them access to their web-based personal health record and conduct online consultations with their doctor.
HealthTap launches online consultations service

Doctors are making house calls again

HealthTap now offers a subscription based online consultation service to patients

Launch Special!  Try it now >
STARTUP CASE  Connecting Patients & Caregivers

www.hetfamilienet.nl

Care collaboration tool for elderly care

Facilitating communication among caregivers & family

Familienet is a collaboration platform where the family and the caregivers of an elderly person in residential care can easily communicate and coordinate the care process.
Challenge #4

Building a viable business model

“Who pays?”
STARTUP CASE  Connecting Patients & Caregivers

Provider pays: Doctors pay ZocDoc a monthly fee and in return attract new patients and are spared the hassle of taking calls & managing their agenda.

Patient pays: HealthTap charges patients a fee for its ‘concierge medicine’ service (online consultations)

Third party pays: PatientFusion charges pharmacies and labs for convenient access to doctors. Pharmaceutical companies pay to analyse data for prescribing patterns.
Clever matchmaking tools are a potential differentiator, especially for patients, but often not sufficient from a business model perspective (doctors pay for tools that save/make money).

Providers need robust incentives if they are to share medical expertise freely. Use 3rd party data sources.

Collaboration tools must help providers save time, reduce costs, increase revenue and/or improve customer satisfaction – all within current reimbursement/legal frameworks.

Viable models exist to charge providers, patients and third-party partners.
Connecting Caregivers for Mutual Gain
The value in connecting caregivers

**CAREER NETWORKING** - professionals network LinkedIn style for career advancement

**INSIGHT** - doctors help each other out answering questions and developing knowledge resources

**COLLABORATION** - easier communication & workflow concerning medical reports, referrals, EHR, etc
The value in connecting caregivers

Matching caregivers in a trustworthy, fast, & relevant way

“Are these people really doctors?”

“I don’t have time for this.”

“What’s the value in networking online?”
Social network Doximity relies on a database of registered doctors to ensure legitimate membership. The tools offers its users a convenient way to manage their online reputations, network with peers for career advancement, receive curated literature updates and send faxes via smartphone or the web.
The value in connecting caregivers

Generating reliable insight that is easy to contribute to and easy/fast to use

“I need point-of-care access to the right information”

“I need simplicity. I don’t have time to take on a complex tool”
SharePractice is a mobile app that lets doctors access and contribute to a library of treatment insights. Users can quickly discover and rate treatments for specific disorders. Users can also organise their favourite bits of information and protocols in one place. The app also serves as a networking tool, organised around content.
The value in connecting caregivers

Finding practical benefits in connecting providers

“Will this tool save me time and money?”
www.getrefferalmd.com

ReferralMD lets users track referral sources (and thus the effectiveness of their marketing), manage/build a referral network, and makes it easier to manage the referral process (referral forms, keep track of referrals)
An EHR with network effects

PracticeFusion wins customers because it lets its users (doctors) easily share information and manage referrals. As the company grows its user base, so does the strength of the network effect. The company also offers an analytics product, analysing prescribing behaviour of its user base.
Back up your social network using formal registries of clinicians to ensure legitimate membership and easy searching based on structured data.

Compete on the basis of how quickly you can generate, deliver and prioritise insight for your users.

There are multiple ways in which social tools can deliver practical benefit, such as easing communication and earning Continuing Education credits.

The best tools succeed in delivering multiple value propositions, including networking, insight and practical benefits, in a single tool. Most of these tools are free but the winners have huge captive audiences that can be commercialised to pharmaceutical companies and others.
Obstacles & Barriers
What are the issues?

**Accuracy** and reliability of information. Users rely on advice and information gained via social health tools to make medical decisions. What measures do providers take to make sure such information is accurate and in line with clinical practice and science?

Shared health data may be revealed to **unintended audiences** (fake accounts, data sold to 3rd parties, etc), and could be misused for non-medical purposes (could have an impact on a user’s reputation, career, relationships, insurance)

**Privacy control.** Users typically have little control or knowledge over how their data is used & stored, or how they can (if at all) change their privacy settings

**Data security.** A single hack can compromise the personal data of thousands of users.
“Quality was variable”

A study of 10 diabetes-related social networks highlighted serious quality & safety problems:

“Gaps in medical disclaimer user....”
“Gaps in external review approaches.”
“Transparency was missing...”
“Technological safety was poor....”
“Privacy policies’ poor readability...”

Who’s data is it?

Many social health platforms (try to) commercialise user data for medical research or even marketing purposes.

Pioneers CureTogether and PatientsLikeMe have succeeded in this but simultaneously have focused heavily on their core values such as putting patients first and promoting transparency.

In contrast, 23andMe (which recently acquired CureTogether) has faced serious PR issues in its attempts to commercialise user data.

“Gene Patent Stirs Controversy: A genetic testing company fields concerns that their latest gene patent goes against their ‘core beliefs’ regarding access to genetic information”

June 4, 2012 headline in The Scientist
A word of advice
Some recommendations on privacy


- Patients should share the minimum amount of personal data to accomplish the intended purpose. The more data they share, the bigger the risk.

- Get patients engaged in protecting their privacy, for example by offering multiple levels of privacy, and keep default setting at maximum level of privacy. Also educate users about privacy risks. And be fully transparent about the uses of their data.

- Build privacy and security in the design of the site. E.g. encrypt data, automatically remove personal identifiers, secure data storage, etc.

- Be accountable. New legislation is needed to hold providers accountable for violating privacy and abusing data. Providers must give users control over how their health data is used, especially for non-medical purposes.
A final word of advice

• **Consumers & patients:** There are some exceptionally useful social tools out there, especially for social support, for finding information about your health concerns and for keeping motivated in your lifestyle choices. But take care, you and your personal data are often the ‘product’.

• **Providers** (hospitals, caregivers, public health entities, etc): It's unstoppable. It's the right thing to do for your patients, and it makes business sense too. Think strategically about the opportunities.

• **Startups:** There should be plenty of room to innovate in the core mechanics of what all the current social health tools do, i.e. connect people for mutual gain and facilitate collaboration for mutual gain. Also, take issues of trust, privacy and security very seriously. These will only gain in importance.
Thanks!

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