The Office of the National Coordinator for
Health Information Technology

Patient-Centered Care

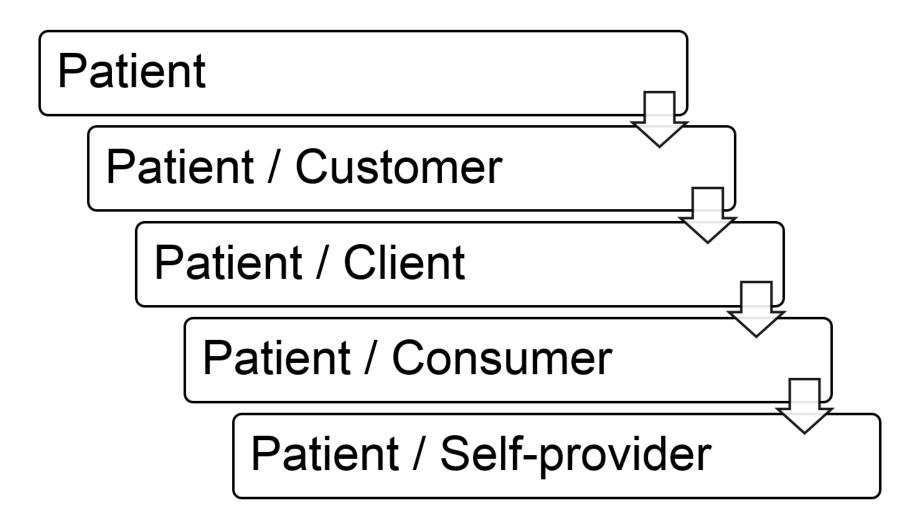## Activated Patients

Lecture a: Do-It-Yourself Medicine

Activated Patients
Learning Objectives

- Bring a global perspective to Do-It-Yourself (DIY) medicine/describe factors influencing expansion

- Discuss the impact of DIY medicine on both clinical practice and clinical research

- Discuss the potential promise and peril of the changes that DIY medicine will bring to healthcare

- Discuss the role of the Quantified Self & mobile health applications in patient-centered care

Do-It-Yourself (DIY) Medicine

Patient

Patient / Customer

Patient / Client

Patient / Consumer

Patient / Self-provider

Do-It-Yourself (DIY) Medicine 2

- Increasingly common due to:
  - Availability of online or remote diagnostic and treatment methods
  - More sophisticated consumer health products
  - Digital health/mobile health medical apps
  - Community based support/education groups
  - Digital clinical research tools/ Crowdsourcing

Online or Remote Diagnostic and Treatment Modalities

- Telemedicine
  - Diagnose
  - Monitor
  - Treat
- Telehealth
  - Improve self-care
  - Education
  - Support systems

Remote Diagnosis and Treatment Example

- HealthTap
  - Virtual concierge practice
    - Patients communicate directly to physicians
  - HealthTap U
    - Medical student resource
  - RateRx
    - Physician ratings of drug effectiveness
  - Curbside Consult
    - Online forum

Telehealth Examples

- Partners HealthCare congestive heart failure study:
  - In-home monitoring with use of decision support
  - Targeted nurse interventions
  - 3 to 4 nurses per 250 patients
  - Hospital readmissions reduced 44%
  - $10 million in savings over 6 years

Telehealth Examples (2)

- Veterans Administration Care Coordination/ Home Telehealth program:
  - Participants with 6 chronic diseases
    - 17,025 initially
    - 120,000 by 2012
  - High patient satisfaction
  - 25% decrease in bed days
  - 19% decrease in hospital admissions
  - Savings of almost $2,000

Consumer Health Products

- 23andMe
  - Consumer driven genetic service
    - Meets FDA clinical and scientific standards
  - Provides services directly to patients
    - Carrier status report
    - Ability to compare reports with other users
    - Allows participation in research

Connected Health

- Digital health and mobile health
  - Accessing online information
  - Software and wearable sensor technology
    - Track and achieve healthcare goals
- Increasing rates of adoption
  - Two-thirds of Americans use smartphones
  - 2018 sales estimate - $50 billion
  - Underrepresented populations

Source: (www.rockhealth.com)

Mobile Health Apps

- Online health information - WebMD
- Online provider scheduling/ratings - ZocDoc
- Mobile health tracking - MyFitnessPal
- Wearables/sensors – FitBit, Jawbone, etc.

Community Based Support & Education Groups

- Patient Communities

- Support

- Education

- Biobanks

- Clinical data repositories

Patient Community Examples

- PatientsLikeMe (PLM)
- Creaky Joints & ArthritisPower1 Patient Powered Research Network (PPRN)
- CureTogether
- PXE International
- Mayo Clinic Database and Biobank
  - Spontaneous Coronary Artery Dissection (SCAD)

Source:	(The author has worked with CreakyJoints and leads development of the ArthritisPower app as part of a PCORI funded PPRN.)

Digital Clinical Research Tools & Crowdsourcing

- Fair Access to Science and Technology Research (FASTR) Act
- Public data repositories
  - Developed by universities, healthcare centers, pharmaceutical companies and patients
  - Aims to spur scientific advances
- Public data commons
  - Collaborative research
  - New methods of data analysis

Examples of Data Repositories

- Personal Genome Project (Harvard, 2005)
- Patient-Centered Clinical Research Network (PCORnet)
  - Formed in 2010
  - Multiple aims
    - Streamline clinical trials
    - Empower patients
- PatientsLikeMe (PLM)

Source: (NIH 2013)

DIY Medicine – Benefits

- Increased access to data for patients and researchers

- Collaborative crowd-sourced discovery

- Empowered patients

- Increased funding for research

- Increased benefits to patients from research

DIY Medicine − Risks

- Healthcare costs
  - May decrease but may also increase
- Integration of new sources of data into healthcare processes
- Research
  - Crowdsourced research needs new standards

Activated Patients
lecture a – Summary

- Trends
  - Availability of diagnostic & treatment methods
  - More sophisticated consumer health products
  - Digital health/mobile health medical apps
  - Community based support/education groups
  - Digital clinical research tools & crowdsourcing
- Outcomes
  - Empowered, knowledgeable consumers
  - Effecting change in healthcare

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Images

Slide 3: Patient to Self-Provider. UAB.

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