AN INTERNATIONAL HELLO

Brazil - Opa

Africa – Hallo

Dutch – Hallo, Goededag

French – Bonjour

Indonesian - Selamat

Italian – Ciao

Korean – annyeonghaseyo

Portuguese – ’Ola

Swedish - Hej / Hallå

Thailand – sà-wàt-dee

Turkey - Alo, Efendim

Arabic – As salam ‘alakum

Chinese – nin hao

German - Guten Tag

Hawaiian - Aloha

Icelandic - Goddag

Italian – Ciao

Israel-Shalom

Japanese – konnichiwa

Norwegian - Goddag

Spanish - ¡Hola!

Polish – HALO/SLUCHAM

Russian - Allo
Marion J. Ball, Ed.D

Senior Advisor Healthcare Informatics
IBM Research,

- Professor Emerita, Johns Hopkins University
- Member, Institute of Medicine
- Member of the Board Of Regents of the National Library of Medicine
- Past President, International Medical Informatics Association (IMIA)

Fellow: American College of Medical Informatics (ACMI), Past Board member and Fellow of the Health Information Management and Systems Society (HIMSS), American Health Information Management Association (AHIMA), Medical Library Association (MLA) and the College of Health Information Management Executives (CHIME), American Academy of Nursing (FAAN)
Panel topic: Personalized Healthcare and Adherence: Issues and Challenges

Session 984 09.
Thursday Aug 22 10:30am-12
Auditorium
Panel on Patient-Centered Care - I
Panel topic: Personalized Healthcare and Adherence: Issues and Challenges

Marion J. Ball
INTRODUCTION

- 10:30-10:40am  Introduction  Marion Ball
- 10:40-11:00am  Vimla Patel presentation
- 11:00-11:20am  Bern Shen presentation
- 11:20-11:40am  Sabrina Hsuehg presentation
- 11:40-12:00  Panel discussion/audience Q&A
Looking back in the rear view mirror to the 1960’s to the early work of Dr. Warner Slack in Wisconsin and to Dr Morris Collen who introduced us to the impotence of empowering the patient as a consumer. ALSO that the computer was an enabling technology that could empower the patient and the consumer. We owe a great debt to these and other wonderful pioneer in our field.
What Do Consumers Want?

• We ask consumers, “What kind of health care do you want?”
  – They answer in terms of quality, access and cost.

• We should ask, “How would you like to interface with the healthcare system?”
  – They would answer in terms of the kind of services and information they want, as they would for Web-based banking or shopping.

JS Parker, Consumer Expectations Demand Client-Focused Technology, in Consumer Informatics, 2005, p 77
Changing Behaviors to help people do what they need!
“Transparency”
The Future is here!

- Where we need to head is to make IT a transparent enabler to provide the care giver and the consumer / patient Information when, where and how they want it to have an effective and efficient Healthcare system.
Lessons Learned

• The importance of re-education is sorely underestimated. This is true for the healthcare provider as well as the consumer.

Thanks to the Department of Health and Aging In Australia, the VA, Rod Kolodner, Barry Weiner, Hans Peterson, and John Tressling.
Lessons Learned

• Need grass roots participation by all levels of health care professionals in developing, implementing and training for the new transformed health care delivery system.

Thanks to the Department of Health and Aging In Australia, the VA, Rod Kolodner, Barry Weiner, Hans Peterson, and John Tressling.
Cultural Change Management

• Approximately 80% of critical success factors for clinical systems installs are people and process related, while 20% are technology related*

*Journal of American Medical Informatics Association
Consumer Technology

The true benefit of these technologies is not in the quantity of data they provide, but in how they transform data into useful information that can make a difference, and improve value and care.
Panel Discussion (1):
Personal Health Care Decision Making by Lay Public

Vimla Patel, PhD, DSc, FRSC
MedInfo – Copenhagen
22 Aug 2013
Vimla L. Patel, PhD, DSc, FRSC

- Senior Research Scientist, The New York Academy of Medicine
- Director, Center for Cognitive Studies in Medicine and Public Health
- Adjunct Professor, Biomedical Informatics, Columbia University, NY
- Adjunct Professor, Public Health, Weill Cornell Medical Center, NY
- Professor of Biomedical Informatics, Arizona State University

- Fellow of the Royal Society of Canada (Academy of Social Sciences)
- Fellow, American College of Medical Informatics
- Associate Editor, Journal of Biomedical Informative (JBI)
- Editorial Boards of Journal of Artificial Intelligence in Medicine (AIM), Advances in Health Science Education (AHSE), Topics in Cognitive Science.

- Past Vice-President (Member services), International Medical Informatics Association (IMIA)
- Past Vice-Chair, AMIA Scientific Program Committee
- Past Editorial Boards: International Journal of Medical Informatics (IJMI), Journal of Medical Decision Making (MDM)
Models of Reasoning

Technical
- Causal
- Descriptive: Explanatory
- Standard of logical consistency between theory and evidence

Lay Public
- Episodic
- Narrative: Explanatory
- Opportunistic
- Difficulties in differentiating theory and evidence

Clinicians use composite models, which are between the technical and lay models
Empirical Studies: How Lay Reasoning Influences Personal Health Decisions

1. What doctor says and what patient hears and decides about personal health care

2. Why some advice to lay public do not lead to desired outcome

3. What medication instructions are intended to be followed and what lay public practice
Example 1

What doctor says and what patient does
Cognition and the Challenge of Communication: Mental Models
Doctor-Patient Interaction

- Eliciting patients’ stories while in the waiting room
- Doctor-patient interaction
- Stories following D-P interaction
- Follow up at home

Scenario for the “Christmas Problem”

The patient was a 72 year old female with past history of heart trouble. Treated with prescription drug Inderal. Previously hospitalized and treated for pneumonia (given antibiotics). She collapsed in a department store while shopping and was taken to hospital but released shortly after being treated. Physician felt that patient’s collapse was due to excessive Inderal. She fell again a week later. EKG indicated that collapse was not due to heart trouble. Patient was asked to stop taking Inderal. One week later, the patient had an angina attack which subsided after she had taken Nitroglycerine. The next day, and approximately three weeks after she was treated for her cold, she visits her physician.
Personalized Healthcare and Adherence: Issues and challenges

Prior Conceptualization: Explaining Illness

Beautiful Day → Go Downtown → Buy Xmas Card

Cond: Wear Heavy Coat
 AND: Wear Scarf
 AND: Wear Knit Cap

Goal: Patient Falls

Patient Representation During D-P Interaction: “The Christmas Problem”

Event 1
- Fluid in Lungs
- Fell 3 Weeks Ago
  - Given Cold Medication
  - Collapsed while Shopping
  - Hospitalized
  - Christmas Shopping not Completed

Event 2
- Dress Too Warmly
- Slipped
  - Fell While Shopping
  - Ambulance/Hospital
  - Stop Inderal
  - Chest Pain
  - Nitroglycerin
  - See Physician

Event 3

Event 4
Personalized Healthcare and Adherence: Issues and challenges

Physician’s Problem Representation of the “Christmas Problem” During D-P Interaction

Pneumonia

Hospital

Home 10 Days

Collapse

Hospital

Recommendation: Go back to Inderal Decrease dosage

Too Warm?

Slipped?

Abrupt Decrease/Cessation in Cardiac Medication (Inderal)

Side Effects: Weakness Fainting

Weakness Fainting

Recommendation: Go back to Inderal Decrease dosage
<table>
<thead>
<tr>
<th>Age</th>
<th>Before Interaction</th>
<th>Physician Diagnosis &amp; Recommendation</th>
<th>After Interaction</th>
<th>Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>27</td>
<td>Stock Broker - Stress</td>
<td>Dx: High blood pressure Type A Personality</td>
<td>Change Profession</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rec: Relaxation Therapy Stop Smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>72</td>
<td>Trouble breathing</td>
<td>Dx: Weight problem</td>
<td>Obesity not from diet</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Water on lungs</td>
<td>Rec: Eat fruits/vegetables Exercise</td>
<td>Afraid of exercise</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obese from surgery</td>
<td></td>
<td>- Fears not breathing</td>
<td></td>
</tr>
<tr>
<td>66</td>
<td>Pain in stomach</td>
<td>Dx: Psychosomatic pain due to high stress</td>
<td>Patient believes she has no Psychological problem</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Believes has ulcer</td>
<td>Rec: See psychiatrist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>72</td>
<td>Dizzy, Weak - Due to cold medication</td>
<td>Dx: Sudden stopping of Inderal</td>
<td>Back on Inderal</td>
<td>Partial</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rec: Continue Inderal - decrease dose</td>
<td>Weakness continues</td>
<td></td>
</tr>
</tbody>
</table>

**Personalized Healthcare and Adherence: Issues and challenges**

**Treatment Adherence**

**Physician Diagnosis & Recommendation**

- High blood pressure
- Type A Personality
- Relaxation Therapy
- Stop Smoking
- Weight problem
- Eat fruits/vegetables
- Exercise
- Psychosomatic pain due to high stress
- See psychiatrist
- Sudden stopping of Inderal
- Continue Inderal
- decrease dose
Interpretation of PatientProblem by Patient and Physician

**Lay Person**

- Illness
- Disrupt Daily Life
- Restore Daily Life
- Wellness, Health

**Physician**

- Disease
- Disrupted Physiology
- Restore Normal Physiology

**Goals:**

- Restore Daily Life
Challenge 1

Understanding What the Patient is Thinking: Listening is Not Enough
Example 2

Healthcare advice that do not lead to desired outcome
Cognition and the Challenge of Communicating across cultures

- Multiple medical systems
- Scientific education + cultural belief systems = ?
Cognition and the Challenge of Communicating across cultures

<table>
<thead>
<tr>
<th>Condition</th>
<th>Causality</th>
<th>No schooling</th>
<th>Primary school</th>
<th>Secondary school</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic PEM</td>
<td>Too little food</td>
<td>55%</td>
<td>83%</td>
<td>84%</td>
</tr>
<tr>
<td>Marasmus</td>
<td>Too little food</td>
<td>31%</td>
<td>10%</td>
<td>31%</td>
</tr>
<tr>
<td>Kwashiorkor</td>
<td>Too little food</td>
<td>11%</td>
<td>7%</td>
<td>19%</td>
</tr>
</tbody>
</table>
Indigestion perceived as primary cause

- indigestion
  - CAU: food to sit in the stomach
  - CAU: no food for arms & legs

- less food (malnourished)
  - CAU: throwing up of food

- enlarged stomach
  - thin arms and legs

- Marasmus
  - CAU:

- Kwashiorkor
  - ASSOC:

“Common sense” explanation for kwash belly
Mother with College Education

Biomedical concepts, but used naively

Cond: skin irritation or victim of burn

ASSOC

"pot belly"

CAU:

Liver complication

CAU: problem in producing enzymes to digest food

COND:

food not digested

some imbalance

Mother with College Education

Kwashiorkor

"pot belly"

Mother with College Education

Kwashiorkor

"pot belly"

Mother with College Education

Kwashiorkor

"pot belly"

Mother with College Education

Kwashiorkor

"pot belly"
Marasmus

Liver problem

Large stomach, big head, arms and legs

Jaundice

Body and eyes become yellow

Food not digested

Take to doctor to give injections

Take to elders for traditional mantras, one per week for 8 weeks

Give strict diet with no oil for one month

Give lemon juice in cooked pulses and carrots

Therapy based on local reasoning
Challenge 2

Working with the power of traditional belief systems which influence decisions about individual health
Example 3

Medication instructions used intuitively by lay public to produce different outcome
Cough Syrup

- Over-the-counter cough medicine used in the treatment of cough associated with common cold
- Correct implementation involves a simple procedure but a complex calculation in determining the proper dosage
- Subjects had to execute a complex quantification for a simple procedure

Pharmaceutical Instructions for Cough Syrup

Each teaspoonful (5ml) contains 15 mg of dextromethorphan hydrobromide U.S.P., in a palatable yellow, lemon flavored syrup.

DOSAGE ADULTS: 1 or 2 teaspoonfuls three or four times daily.

DOSAGE CHILDREN: 1 mg per kg of body weight daily in 3 or 4 divided doses.
Calculation of a Single Dose For a 22-Pound Child

Calculations for a 22-pound child, where \( n = 3 \):

\[
\frac{1/\text{teaspoon}}{5/\text{millilitres}} \times \frac{5/\text{millilitres}}{15/\text{milligrams}} \times \frac{1/\text{milligram/body/weight}}{22 \text{ pounds}} = \frac{10}{15} \text{ teaspoons} = \frac{2}{3} \text{ teaspoon}
\]

\[
\frac{2}{3n} \text{ teaspoon} \times \text{times daily (where } n = 3) = \frac{2}{3 \times 3} \text{ teaspoons, 3 times daily}
\]

\[
\frac{10/\text{kilograms}}{15 \times 3/\text{times/daily}} = \frac{2}{9} \text{ teaspoons, 3 times daily}
\]
Results: Cough Syrup

- The majority of participants (66.5%) were unable to correctly calculate the appropriate dosage of cough syrup.
- Even when calculations were correct, they were unable to estimate the actual amount to administer.
- There were no significant differences based on cultural or educational background (except PhDs).
Dosage Accuracy for Cough Syrup

Percentage

Accuracy

Under dose
Correct dose
Slight overdose
Extreme overdose

English
Indian
Greek
Think-Aloud Quotation #1

One milligram per kilogram of body weight. So 13, 13 daily, 13 milligrams it would be. One milligram per kilogram? 13 kilograms let's say and one times 13 is 13 daily in three or four divided doses. So it would be four doses, I guess, three milligrams each? How many milligrams in a teaspoon? Oh, gosh, I said three milligrams. Each teaspoonful there's five to a teaspoon. Oh, I don't understand. Well, it wouldn't be a full teaspoon it would be more like half a teaspoon, four times a day.
27 kilos, 27 milligrams? 27 milligrams daily. Each teaspoon is 15 milligrams so you want two teaspoons a day divided by four. Hold it, two teaspoons a day divided by three or four doses. So you are talking either one-half to two-thirds a teaspoon, depending on whether it's three or four times a day.
Each teaspoon contains 15 milligrams. Okay, for the children I have to write the weight of the baby, 10 kilograms. I will give him only two teaspoons for the day. Yeah, I give him only two teaspoons, two times a day, because you see here 15 milligrams is one teaspoon. So, one teaspoon is five ml contains 15 milligrams? Yeah, that's it. I give him only two, two teaspoons.
Challenge 3

Designing Instructions for medication adherence taking into account lay public’ intuitive thinking
Summary and Challenges to Personalized Health Care

How we think and make decisions create certain challenges for successful acceptance of personalized health care

- Nature and use of evidence by lay public is different from designers of systems providing care: Understand the users

- Understanding what the patient is thinking: Listening is not enough: Thinking behind behavior (cognition)

- Traditional belief systems are powerful and they influence decisions about individual health: Work within the system rather than against them
Panel Discussion (2): Personalized Healthcare & Adherence: the role of technology

Bern Shen MD
MedInfo – Copenhagen
22 Aug 2013
Bern Shen, MD, MPhil.

- Chief Medical Officer, HealthCrowd
- Member, Band of Angels
- Board of Directors, Clayton Christensen Institute for Disruptive Innovation
- Board of Directors, Univ. of Iowa Research Foundation
- Board of Advisors, Univ. of Iowa College of Public Health
- Adjunct Assoc. Prof., Univ. of Iowa Colleges of Medicine & Business
- Adjunct Asst. Prof., UCSF School of Pharmacy

- Ex-Board Chair, The Health Trust
- Ex-Intel (Chief Healthcare Strategist), Oracle, HP, UCSF, UPMC, Yale
- Ex-Health Practice Lead, Institute for the Future
Agenda

- Personalization
- Adherence
- Some lessons learned from real-world projects
Agenda

• Personalization
• Adherence
• Some lessons learned from real-world projects
Personalized Healthcare and Adherence: Issues and challenges

Healthcare more distributed & differentiated

Personalized medicine

One size fits all (e.g., blockbuster drug, “70kg patient”)
Many ways to personalize

Personalized Healthcare and Adherence: Issues and challenges

- Policies & interventions
  - Biology
    - Physical environment
    - Social environment
- Behavior
- Technology
- Access to quality healthcare
- Health status
Personalized Healthcare and Adherence: Issues and challenges

Logic model

- **Reception**
  - Past behavior
  - Demographics & culture
  - Perceived health threat & susceptibility
  - Perceived benefits & barriers
  - Stereotypes & stigma
  - Personality, moods & emotions
  - Other individual differences
  - Media or intervention exposure
  - ...

- **Acceptance**
  - Poverty
  - Entrenched adversaries
  - Built environment
  - Geographic barriers
  - ...

- **Intentions**
  - Skills & abilities
  - Environmental constraints

- **Action**

**Process & proxy measures**
- Engagement & response rates
- Number & types of health behaviors
- Program completion rates, f/u appointment no-shows
- Health screening, HEDIS measures
- Streamlined workflow

**Behavior change & subjective indices**
- Measures of self-efficacy
- Measures of disease knowledge
- Quality of life, depression
- Productivity, absenteeism

**Clinical & financial outcome metrics**
- Biometrics – e.g., weight, BP, glucose
- Visits to clinic, or ED
- Hospital admissions
- Procedure volumes
- Utilization & cost savings
- Newly enabled business models

**Time frame for impact**
- Weeks
- Months
- Years
Agenda

• Personalization
• Adherence
• Some lessons learned from real-world projects
Why behavior matters

Yet behavior is largely “invisible”
Personalized Healthcare and Adherence: Issues and challenges

Behavior not only individual
Agenda

• Personalization
• Adherence
• Some lessons learned from real-world projects
Personalized Healthcare and Adherence: Issues and challenges

Mobile + Personalization
Rise of mobile phones computing
Evolution of personalization

Dynamic Content
- Static Messages

Targeting & Optimization
- One-size-fits-all

Outcomes Analytics
- No analytics
Take care of those attractive eyes of yours - make an appointment for an eye exam now, then text back SEXY.

Your loved ones are counting on you - if you can call today for an appointment to get your eyes checked, text back FAMILY.

Hey you! It's your eyes - be sure to get me checked this year! Make that appointment, then text back GOTCHA.

What's more important to you than good vision? Please make an appointment to get your eyes checked, then text FOR ME.

Ваши близкие рассчитывают на вас - чтобы записаться на прием и проверить ваше зрение ответьте текстом FAMILY сегодня.
People are different

~40% overall response rate

Individual stopped responding – but still wanted to receive messages

Highlights the importance of the right outcome measures
Timing matters

<1 week: 58% response rate

>2 weeks: 31% response rate
Hypothesis: Can a mobile messaging program reduce dropout & increase program adherence among cardiac rehab patients?

Results: Compared to the control group, patients in the intervention group demonstrated 2x rehab completion, ¼ no-show rate at 3-month follow-up appointment, better exercise tolerance, & lower depression scores.

Analysis: Increased rehab completion rate reduces utilization → meaningful savings.

This analysis was performed using data from our program, supplemented with data from respected sources to estimate cost savings.
"Both builders and users of... systems tend to think of them simply as technical tools or problem-solving aids, assuming them to be value-free. However, ...the reasoning embedded in such systems reflects cultural values and disciplinary assumptions, including assumptions about the everyday world of medicine."

Agenda

• Personalization
• Adherence
• Some lessons learned from real-world projects
Panel Discussion (3):
**Personal Informatics for Wellness:**

*An Interactive Analytics Framework for Computer-Supported Collaborative Prevention*

Pei-Yun Sabrina Hsueh, PhD, MIMS
MedInfo – Copenhagen
22 Aug 2013
Personalized Healthcare and Adherence: Issues and challenges

Pei-Yun (Sabrina) Hsueh, PhD

Research Data Scientist, Wellness Analytics Lead, Health Informatics Research Group
IBM T. J. Watson Research Center

- IBM Invention Achievement Awards, Organization Committee of Academy of Technology Conference & Healthcare and Life Science Distinguished Speaker Series
- Google European Anita Borg Scholar
- Program Committee, ACM HLT, NAACL, EACL, CODATA Chronic Disease Management and Independent Living for the Aged
- Invited Session Chair, AHFE, ISREC, IEEE SOLI, CollaborateCom
- Board of Director, Chinese Institute of Engineers Greater New York Chapter
- National Science Council Merit Award
- Book Chapter/Journal Review: Artificial Intelligence, IGI Global Privacy Protection Technologies in Business Organizations, IEEE Intelligent Systems, Transactions on Knowledge and Data Engineering, Statistical Analysis and Data Mining, IEEE Selected Topics in Signal Processing, Journal of Natural Language Engineering

PhD in Informatics, University of Edinburgh;
Masters in Information Mgmt, University of California, Berkeley;
Bachelor in Computer Science, National Taiwan University
Healthcare becoming Personal

Disruption will involve pushing more medicine into the precision category.
~ Clayton Christensen “The innovator’s Prescription”

Degree of personalization

Degree of collaboration (data dimension)

Empirical Medicine

Intuitive Medicine

Disease-Centric Guideline

Precision Medicine

Data-Driven Evidence

All patients with same diagnosis

Patients receiving alternative treatment

Patients receiving traditional treatment
Personalized Healthcare and Adherence: Issues and challenges

From Genetic Determinants of Health to Personalized Medicine and Prevention

- Personalized Medicine

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>Percentage of Ineffectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension Drugs</td>
<td>10-30%</td>
</tr>
<tr>
<td>ACE Inhibitors</td>
<td></td>
</tr>
<tr>
<td>Heart Failure Drugs</td>
<td>15-25%</td>
</tr>
<tr>
<td>Beta Blockers</td>
<td></td>
</tr>
<tr>
<td>Anti-Depressants</td>
<td>20-50%</td>
</tr>
<tr>
<td>Cholesterol Drugs</td>
<td>30-70%</td>
</tr>
<tr>
<td>Statins</td>
<td></td>
</tr>
<tr>
<td>Asthma Drugs</td>
<td>40-70%</td>
</tr>
<tr>
<td>Beta-2-agonists</td>
<td></td>
</tr>
</tbody>
</table>

Percentage of the patient population for which any particular drug is ineffective.

- Personalized Prevention
Introducing Data-Driven Analytics into Personalized Services: Improved Outcome and Reduced Cost

**Individualized Guideline Improved Clinical Outcomes**

- $\approx 13\%$ absolute risk reduction

**Individualized Guideline Reduced Operational Costs**

- $\approx 6,000$ myocardial infarctions (MIs) and strokes prevented annually * $7,000$ cost savings per person
- $\approx 420M$ US dollars saved in a US provider alone

<table>
<thead>
<tr>
<th>Treatment Strategy</th>
<th>Mls Prevented, $n$</th>
<th>Strokes Prevented, $n$</th>
<th>Net Cost, $\text{$ (millions)}$</th>
<th>Relative Savings Ratio (95% CI)$\dagger$</th>
<th>Relative Benefit Ratio (95% CI)$\ddagger$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Random care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Same benefit</td>
<td>60</td>
<td>65</td>
<td>7.55</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Same cost</td>
<td>14</td>
<td>13</td>
<td>1.63</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>JNC 7 guidelines</td>
<td>60</td>
<td>65</td>
<td>1.63</td>
<td>NA</td>
<td>NA</td>
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<tr>
<td>Individualized guidelines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Same benefit</td>
<td>66</td>
<td>60</td>
<td>$-2.25$</td>
<td>1.65 (1.52–2.79)</td>
<td>–</td>
</tr>
<tr>
<td>Same cost</td>
<td>87</td>
<td>80</td>
<td>1.64</td>
<td>–</td>
<td>1.43 (1.33–1.70)</td>
</tr>
</tbody>
</table>

Source:
http://www.annals.org/content/154/9/627.abstract
Personalized Healthcare and Adherence: Issues and challenges

Holistic View of Determinants of Health to Personalized Services

- **Nature (Endogenous determinant)** (e.g., genetics predisposition)  
  - Personalized Medicine  
  - Delivery (Care flow determinant)  
  - Personalized Care  
  - Nurture (Exogenous determinant) (e.g., environment exposure, behavior pattern, social circumstances)  
  - Personalized Prevention and Disease Management

**Huge opportunity space for risk reduction:**
- **Cancer** (60-69%)  
  (HALE, JAMA 2004; de Lorgeril Arch Intern Med, 1998)
- **Cardiovascular disease** (73-83%)  
  (NHS, NEJM 2000)
- **Type II Diabetes** (58-91%)  
- **Cardiovascular complication** (42-57%)  
  (UKPDS, US EDIC)
- **Eye complication** (76%), **Kidney complication** (50%), **Nerve complication** (60%)

Progress impeded by the lack of efficient personalization and validation techniques
Healthcare becoming both Personal and Collaborative: Two Concepts to be Introduced...

Amazon, Netflix, Pandora, and iTunes v.s. Wellness service providers.
What is the middle ground?
..... Thinking in the line of “Mass Customization”...

What these companies do not have?
..... Thinking in the line of “Personal Informatics”...

Degree of personalization

Degree of collaboration

(data dimension)
Personalized Healthcare and Adherence: Issues and challenges

System Approach to the Personalization Problem

Personal wellness data model + Hospital HIS
Personalized Healthcare and Adherence: Issues and challenges

Core Service Flow (As-Is Process)

Longitudinal record

Clinical Requirement

Guideline

Diabetes
CHF
Cardiovascular
Metabolic

Monitoring

Sensor
Transaction feed
Smart Device App
Compliance feed

Clinical
Activity
Nutrition

Follow-up stage
Value Proposition of Personalized Service

Core Service Flow (As-Is, To-Be)

As-Is Process

- Guideline
- Personal Wellness Record
- Longitudinal record
- Clinical Requirement
- Adherence
- Personalization
- Intervention Portfolio
- Progression Model
- Risk Stratification

Personalized Service

Customer/Patient

Value-adding process

To-Be Process: Personalized Services (Consultation, Follow-Up)

- Risk Stratification Model
- Guideline
- Personal Wellness Record
- Risk Stratification
- Clinical Requirement
- Personalized Service Plan
- User Profile
- Service Recommendation
- Monitoring & Interactive Feedback
- Outcome-driven Adaptation
- Clinical
- Activity
- Nutrition
- Smart Device App
- Transaction Test
- Personalized Compliance Plan

Consultation stage

Theme #1

Follow-up stage

Theme #2

Theme #3
Personalized Healthcare and Adherence: Issues and challenges

Adherence service – snapshot

Three screening service users with different conditions, recommended care guidelines & compliance history:

(User 1) needs chronic care, high HbA1C, use fitness center intensively, not on optimal plan; (had a few hyperglycemia episodes in the past)

(User 2) mainly diets to improve HbA1c control; compliance rate on activity is low for two months

(User 3) uses a premium plan, adheres to personal activity plan

@ PoC, compliance managers use personalization analytics to predict intervention need:

High Risk
High Propensity to Respond

High Risk
Low Propensity

Low Risk
Low Propensity

Determine Compliance Alert; Drive Plan and Campaign Design:

Perform intervention; Update plan according to intervention need options

Issue new personal plan to be suggested in the next visit

No action taken
Personalized Healthcare and Adherence: Issues and challenges

Literacy Interactive Method — Personalize Literacy Portfolio

TTM

Maintenance

Action

Preparation

Contemplation

Precontemplation

Health eating

Being Active

Monitoring

Taking Medication

Problem Solving

Healthy coping

Reducing Risks

AADE 7

Curve A
11/14 Tony
Follow-up Stage

Mary

Tony

Curve B
11/14 Mary
Follow-up Stage
Personalized Healthcare and Adherence: Issues and challenges

Patient Engagement - DMIMF (DM Intelligence Management Framework)

*Adopting engagement model to improve service quality and compliance on lifestyle behavior change*

**Pre-assessment (Outcome-based indicator)**

1-1. [HIS & historical] Patient health profile
1-2. [literacy tools] DM Health literacy
1-3. [literacy tools] Compliance of adopting care plan
1-4. [literacy tools] Feedback of engaging w/ hospital/care team
1-5. [literacy tools] Quiz of patient characteristic (optional)

**Follow-up (DM interaction and literacy)**

2-1. [literacy tools] DM 7 dimensions of self-care
2-2. [literacy tools] Health behavior awareness & maturity
2-3. [literacy tools] Patient goal induction
2-4. [literacy tools] Behavior change readiness

**Post-assessment (Outcome-based indicator)**

3-1. [HIS & historical] Patient health profile
3-2. [literacy tools] DM Health literacy
3-3. [literacy tools] Compliance of adopting care plan
3-4. [literacy tools] Feedback of engaging w/ hospital/care team
3-5 [literacy tools] CX satisfaction test on Physician/health educator/CM

**Potential Patient group - risk screening**

Pre-assessment

Post-assessment

Follow-up

**Team:** Y. Yeh, D. Chao, V. Deng, G. Liao, X. Zhu, P. Hsueh, S. Ramakrishnan
Personalized Healthcare and Adherence: Issues and challenges

Personalization: Core Issues Addressed & Remaining Questions

**Remaining questions in each issue**

1. **Individual difference**
   - How to measure and validate?
   - What are the missing information at individual level?

2. **Actionable recommendation**
   - How to translate dynamically changing, multi-faceted adherence factors into a patient-centric view?
   - How to account for multiple dimensions of wellness decision making?

3. **Adherence risk**
   - How to model incremental response?
   - How to create differential response to adherence exceptions in absence of individual outcome data?

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**Themes**

- **Theme #1**: Personalization for risk stratification (from population to individual evidence)
- **Theme #2**: Personalization for in-context recommendation (from disease-centric to patient-centric)
- **Theme #3**: Personalization for adherence risk mitigation (from status-insensitive to status-sensitive)
### Personalization: Core Issues Addressed & Analytics Components

<table>
<thead>
<tr>
<th>Remaining questions in each issue</th>
<th>Personalization analytics in response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Individual difference</strong></td>
<td>active \characterization\ as a service</td>
</tr>
<tr>
<td>• How to measure and validate?</td>
<td>Quantifiable individual difference</td>
</tr>
<tr>
<td>• What are the missing information at individual level?</td>
<td>Patient-centric outcome-maximizing</td>
</tr>
<tr>
<td><strong>2 Actionable recommendation</strong></td>
<td>Actionable recommendation</td>
</tr>
<tr>
<td>• How to translate multi-faceted disease risks into a patient-centric view?</td>
<td>Lift modeling for proactive risk mitigation</td>
</tr>
<tr>
<td>• How to account for multiple criteria of wellness decision making?</td>
<td>Risk-adverse intervention target</td>
</tr>
<tr>
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</tbody>
</table>
Summary

- Importance of personalization in patient engagement
  - Clinical touch point identification for mass customization
  - Incorporating personal informatics tools for user modeling
  - Innovation opportunities in care delivery and patient engagement models

- Interactive Analytics Scheme for Personalization services
  - PWR + HIS
  - Analytics Engine: Summarization $\rightarrow$ Customization $\rightarrow$ Engagement
  - Interaction Engine: user modeling $\rightarrow$ important attribute solicitation/self-assessment
  - Instant outcome measurement and feedback generation

- Ongoing in-market experiments (pilots)
  - Personalized engagement and customer “stickiness”
  - Invention: Crowd-sourced DB and dynamic accretion of questions based on patient status estimation
  - Sustainable value capture?
Framework to accelerate personalized service design

**Technologies to enhance wellness services**
- Guide the identification of customization points in clinical workflow and deployment of the Analytics and IM offerings
- Create new tools and infrastructure for client engagements
- Explore light-weight approach to connect the components (to prepare for future cloud offerings)

**New solutions and services**
- Bring together clients and researchers to understand clinical touch points
- Demonstrate how to leverage customization points to engage users and possibly improve health literacy and outcomes

**Replicable patterns for patient engagement deployment**
- Create ETL procedures to be repeatedly use in other provider settings
- Explore both hosted and internal deployment possibilities

**Plug-in for other tools**
- Create a recipe from data collection to summarization to customization to engagement to outcome measurement
- Each component can be singled out as a standalone process for other tools