Engaging Patients and Families Through Transparency

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Drivers of High Cost, Poor Quality Care

- Mistakes
- Unjustified variation
- Fragmented systems
- Perverse incentives
- Patients-Families as passive recipients of healthcare
- Supply-demand mismatch
- Failure to anticipate and prevent

Time Required for Primary Care of Patients

Hours per day needed by a family practitioner to provide all acute, preventive and chronic disease care to a panel of 2500 patients:

18-21 hours per day

Am J Public Health. 2003 April; 93(4): 635–641.
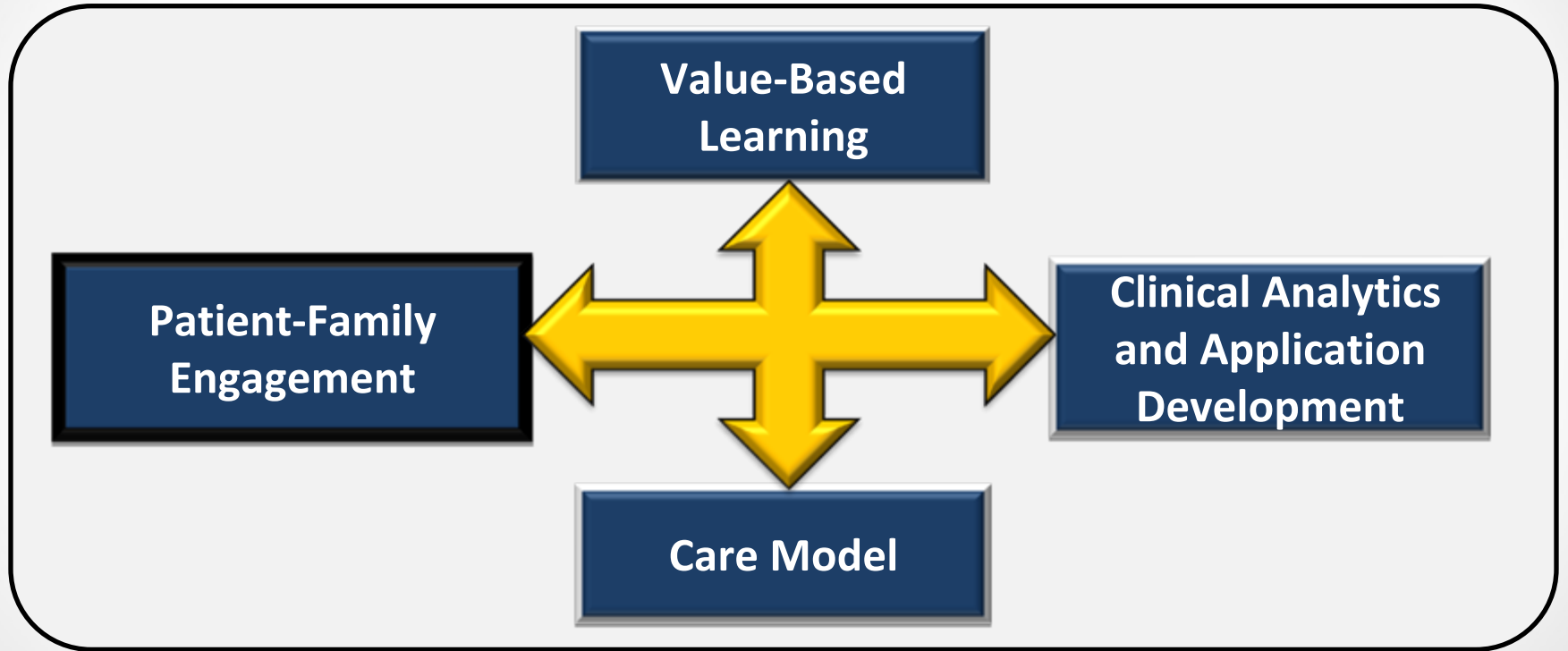Ann Fam Med May 1, 2005 vol. 3 no. 3 209-214

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Traditional Change Efforts…

… May Not Always Be Effective
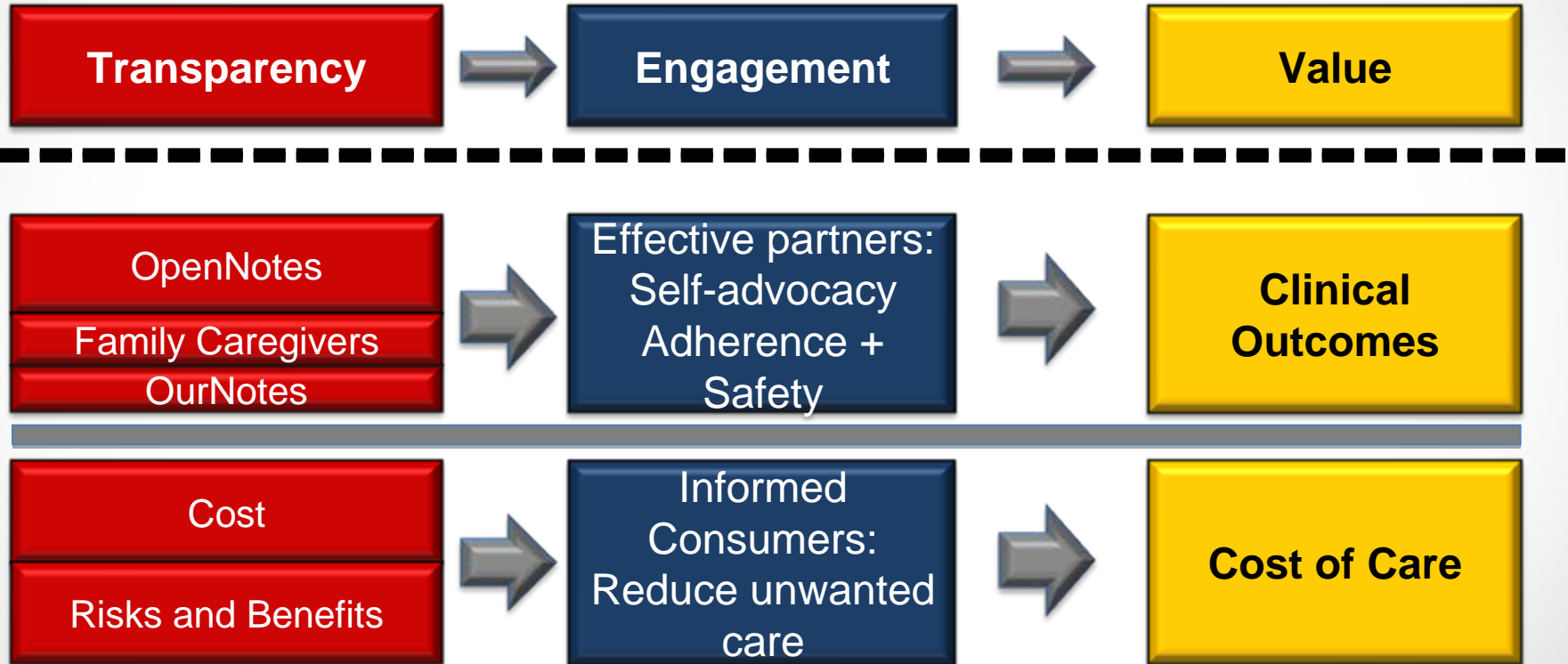
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Center for Clinical Innovation

Patient-Family Engagement and Transparency: Background and Rationale

- Changes in US Healthcare (cottage industry to integrated systems of care, adoption of electronic health records, complexity of insurance) have the potential to disengage patients-families

- Engaging patients-families as partners in care and as consumers will enhance value

- Health information technology-enabled transparency has the potential be an enabler of engagement

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Transparency as an Enabler of Value

Transparency	→	Engagement	→	Value

OpenNotes Family Caregivers OurNotes	→	Effective partners: Self-advocacy Adherence + Safety	→	**Clinical Outcomes**
Cost Risks and Benefits	→	Informed Consumers: Reduce unwanted care	→	**Cost of Care**

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Patient Engagement Through Health Information Technology: OpenNotes

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What is OpenNotes?

In OpenNotes, doctors use a secure Internet portal to invite patients to review notes following an office visit

The heart of OpenNotes is to:

•Involve patients far more actively in all aspects of care

•Improve communication between the doctor and patient

•Encourage patients to share information with others – especially the ones who care for them

•Help prevent mistakes

OpenNotes Demonstration

- 12-month project that started in the summer of 2010

- 105 Primary Care Physicians (PCPs) and over 19,000 patients

- Beth Israel Deaconess Medical Center, Boston
  - 39 PCPs
  - 10,300 patients

- Geisinger Health System, Pennsylvania
  - 24 PCPs
  - 8,700 patients

- Harborview Medical Center, Seattle
  - 45 PCPs
  - 270 patients

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Central Questions

- Does OpenNotes help patients become more actively involved in their care?

- Will OpenNotes be the straw that breaks the doctor's back?

- After a year, did doctors and patients want OpenNotes to continue?

Study Conditions

- Providers could drop out at any time

- Providers could exclude any patient prior to the study and could exclude a patient at any time during the study

- Notes were made available to patients only on a prospective basis

- Patients received reminders that a note was available to read after a visit and prior to an upcoming visit

Doctors and OpenNotes

Participating Doctors' Main Concerns: Predictions vs. Experiences

OpenNotes would lead to:	Pre % BIDMC | GHS	Post % BIDMC | GHS
Longer visits	23 | 32	3 | 5
More time addressing patient questions outside of visits	49 | 45	8 | 0
More time writing notes	46 | 36	21 | 14
Less candid documentation	33 | 32	28 | 9

Doctor Comments

*"I think patients believe something I write in the chart more completely than when verbally communicated **– I think it's more real** to them."*

*"My fears: Longer notes, more questions, and message from patients. In reality, **it was not a big deal."***

*"**I felt like my care was safer,** as I knew that patients would be able to update me if I didn't get it right."*

*"I think this had **no impact whatsoever."***

Patients and OpenNotes

Patients Looking at Their Notes

Of patients who had an OpenNotes visit, the percentage from Geisinger who opened their notes:

- 58% of patients opened all of their notes
- 82% of patients opened at least one note

Patient Reports: Post-Intervention Survey

Patients reported that they:	Patients % BIDMC	Patients % GHS
Understood their health and medical conditions better	88	77
Took better care of themselves	74	71
Remembered the plan for their care better	87	76
Were better prepared for their visits	77	69
Felt more in control of their health care	89	77
Were more likely to take medications as prescribed (of patients taking medications)	61	78

Patient Reports: Post-Intervention Survey

Patients reported that they:	Patients % BIDMC	Patients % GHS
Shared notes with someone else	19	21
Shared notes with a lawyer	0	0
Found notes more confusing than helpful	2	4
Worried more	6	8
Felt offended	2	2

Patient Comments:
Post-Intervention Survey: Engagement

*My reading them in private **helped me understand** without office tenseness.*

*Weeks after my visit, I thought, "Wasn't I supposed to look into something?" **I went online immediately.** Good thing! It was a precancerous skin lesion my doctor wanted removed (I did).*

*In his notes, the doctor called me "mildly obese." This prompted immediate enrollment in Weight Watchers and daily exercise. **I'm determined to reverse** that comment by my next check-up.*

Patient Comments:
Medical Errors

*She referred to several issues that I knew were wrong, and when I told her about them she admitted she **confused me with another patient.** Also on one occasion she made a statement about increasing the dose on a medication that I never took. **Those type of errors concern me.***

*If this would have been available years ago I would have had my **breast cancer diagnosed earlier**, as a previous doctor had written in my chart and had marked the exact area but never informed me…So this potentially could save lives.*

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The Bottom Line

- After one year, 74% of BIDMC PCPs, 83% of GHS PCPs and 81% of HMC PCPs want patients to continue to see visit notes online

- After one year, 99% of BIDMC patients, 99% of GHS patients, and 99% of HMC patients want to continue to see their visit notes online

- When choosing doctors or health plans in the future, 86% of BIDMC patients, 85% of GHS patients and 89% of HMC patients say availability of OpenNotes would affect their decisions

- As of May 2015, over 1400 Geisinger providers are live on OpenNotes, impacting over 220,000 patients

- As of May 2015, over 5,000,000 patients have access to OpenNotes

Family Caregivers

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Family Caregivers

- Family caregivers are friends or family members who assist patients with their medical care, transportation, and other activities of daily living

- More than 34 million ill or disabled adults are cared for by unpaid caregivers (AARP, 2008)

- Caregiving strain negatively impacts family caregiver health, and in turn affects their ability to provide care (NAC, 2006)

- Better support of family caregivers is an effective strategy to improving undesirable outcomes of patients (Mittelman, JAMA)

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Family Caregiving Network, Health Care Team and the Electronic Health Record

- Family caregivers, in the EHR landscape, are generally an under-recognized, invisible workforce

- Documentation of the family caregiving network including their roles, privileges, capabilities and status rarely performed

- Care team often unclear with regards as to who to call, what consents have been provided with regards to the sharing of information and medical decision making

- Reasonable concerns regarding privacy of health information, abusive relationships and concordance with care planning abound

Family Caregiving Network and Supportive Health Information Technology

- Proxy function for patient portals do exist but are rarely used

- HIPAA frequently cited by family caregivers as a barrier to getting needed information

- Family caregivers often use patient credentials to access information or contact care team

- Family caregivers as the "human information exchange"

- Limited consumer technology that fully integrates with electronic health records to meet family needs

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Vision - Family Caregivers

Patients and Family Caregivers will:

•understand who is taking care of the patient and who to go to for questions or concerns

•understand why procedures, therapies and tests) are being performed

•anticipate risks and side effects including financial solvency and be prepared for contingencies

•be in control of logistics of care (e.g., coordinated travel)

•manage their medical information wherever the patient is receiving care

•communicate with the health care team efficiently and effectively

•connect to appropriate community resources and social support

Family Caregiver Initiatives

- OpenNotes and Proxies
- Caregiver identification and health literacy of the dyad
- Family Caregiver Application

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Patient Engagement Through Health Information Technology: OurNotes

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OurNotes: Co-Generation of Notes

INTRO: You are scheduled for an appointment to discuss [insert primary dx code associated with visit] with [provider's name].

Q1: What health issues would you like to discuss with me today? Please tell me a bit about your health problems (if any) and how they are impacting you and your life.

OurNotes

I saw a commercial on TV for this new med i want to try. Is it right for me? my current pill costs too much. I'm concerned that my sugar has been high recently.

The benadryl my doc told me to take for allergies makes me very tired during the day. Can I take something else?

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OurNotes Pilot

- Patient Exit Survey and Interviews (n = 64)
  - 77% reported less than 2 minutes to complete
  - 64% reported being 'very comfortable' with technology
  - 70% reported that OurNotes made them feel more involved in their care
  - 83% reported that OurNotes allowed for focused time with provider to review health goals
- Provider Interview
  - Ensured focus on patients' agenda
  - Added to visit efficiency

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OurNotes: Theme

"Sometimes I don't remember things. When I go into my doctor's visits, I have to write down all my notes … I carry it in my purse for a week, so it looks like all tattered and everything. *If I could have a "notes" section* *that I could send to my doctor beforehand of topics I want to discuss with him, that would be really sweet."*

OurNotes: Theme

"I use messaging to the doctor for my mother. She will not tell you she fell twice this week but I just wanted to give you a heads up. Right? I could do things like that."

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Transparency as an Enabler of Value

| Transparency | ➡ | Engagement | ➡ | Value |

| OpenNotes / Family Caregivers / OurNotes | ➡ | Effective partners: Self-advocacy Adherence + Safety | ➡ | **Clinical Outcomes** |

| Cost / Risks and Benefits | ➡ | Informed Consumers: Reduce unwanted care | ➡ | **Cost of Care** |

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