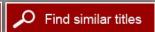


Facilitating Patient Understanding of Discharge Instructions: Workshop Summary

ISBN 978-0-309-30738-3

76 pages 6 x 9 PAPERBACK (2014) Joe Alper and Lyla M. Hernandez, Rapporteurs; Roundtable on Health Literacy; Board on Population Health and Public Health Practice; Institute of Medicine







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Joe Alper and Lyla M. Hernandez, Rapporteurs

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

THE NATIONAL ACADEMIES PRESS Washington, D.C. www.nap.edu

THE NATIONAL ACADEMIES PRESS 500 Fifth Street, NW Washington, DC 20001

NOTICE: The workshop that is the subject of this workshop summary was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

This activity was supported by contracts between the National Academy of Sciences and the Agency for Healthcare Research and Quality (HHSP233200900537P); California Dental Association; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Health Resources and Services Administration (HHSH25034004T); Humana; Johnson & Johnson; Merck and Co., Inc.; Office of Disease Prevention and Health Promotion; and UnitedHealth Group. The views presented in this publication are those of the rapporteur and do not necessarily reflect the views of the organizations or agencies that provided support for the activity.

International Standard Book Number-13: 978-0-309-30738-3 International Standard Book Number-10: 0-309-30738-4

Additional copies of this workshop summary are available for sale from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; http://www.nap.edu.

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

Suggested citation: IOM (Institute of Medicine). 2014. Facilitating patient understanding of discharge instructions: Workshop summary. Washington, DC: The National Academies Press.

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—Goethe



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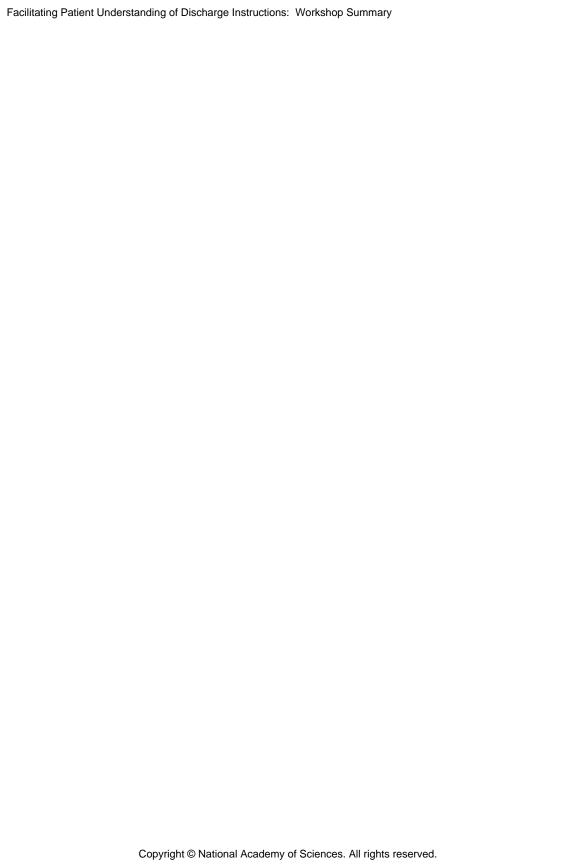
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PLANNING COMMITTEE ON IMPLICATIONS OF HEALTH LITERACY FOR DISCHARGE INSTRUCTIONS¹

- DARREN DEWALT, Associate Professor of Medicine, University of North Carolina at Chapel Hill
- **BENARD DREYER**, Professor of Pediatrics, New York University School of Medicine
- ALEX FEDERMAN, Associate Professor of Medicine, Mount Sinai Hospital
- GEORGE ISHAM, Senior Advisor, HealthPartners, Senior Fellow, HealthPartners Institute for Education and Research
- **RUTH PARKER**, Professor of Medicine, Pediatrics, and Public Health, Emory University School of Medicine

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ROUNDTABLE ON HEALTH LITERACY¹

- GEORGE ISHAM (*Chair*), Senior Advisor, HealthPartners, Senior Fellow, HealthPartners Institute for Education and Research
- WILMA ALVARADO-LITTLE, Director, Community Engagement/ Outreach, University at Albany
- CINDY BRACH, Senior Health Policy Researcher, Agency for Healthcare Research and Quality
- **GEM DAUS**, Public Health Analyst, Health Resources and Services Administration
- BENARD DREYER, Professor of Pediatrics, New York University School of Medicine
- LAURIE FRANCIS, Senior Director of Clinic Operations and Quality, Oregon Primary Care Association
- JILL GRIFFITHS, Vice President, Communications, Aetna
- LORI HALL, Consultant, Health Education, Eli Lilly and Company
- LINDA HARRIS, Team Leader, Health Communication and eHealth Team, U.S. Department of Health and Human Services
- BETSY HUMPHREYS, Deputy Director, National Library of Medicine MARGARET LOVELAND, Senior Director, Global Medical Affairs, Merck & Co., Inc.
- PATRICK McGARRY, Vice President, New Business Inovation and Connected Health, American Academy of Family Physicians
- **RUTH PARKER**, Professor of Medicine, Pediatrics, and Public Health, Emory University School of Medicine
- TERRI ANN PARNELL, Vice President, Health Literacy and Patient Education, North Shore–Long Island Jewish Health System
- KIM PARSON, Consumer Experience Center of Excellence, Humana KAVITA PATEL, Managing Director for Clinical Transformation and
 - Delivery, Brookings Institute
- SUSAN PISANO, Vice President of Communications, America's Health Insurance Plans
- **ANDREW PLEASANT**, Senior Director for Health Literacy and Research, Canyon Ranch Institute
- LINDSEY ROBINSON, President, California Dental Association
- **BERNARD ROSOF,** Co-Chairman, National Priorities Partnership, National Quality Forum
- RIMA RUDD, Senior Lecturer on Health Literacy, Education, and Policy, Harvard University School of Public Health

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- STEVEN RUSH, Director, Health Literacy Innovations, UnitedHealth Group
- PAUL SCHYVE, Senior Advisor, Quality Improvement, The Joint Commission
- ALAN TENNENBERG, Vice President, Global Health Worldwide, Johnson & Johnson
- PATRICK WAYTE, Vice President, Marketing and Health Education, American Heart Association
- WINSTON WONG, Medical Director, Community Benefit Disparities Improvement and Quality Initiatives, Kaiser Permanente

IOM Staff

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MELISSA G. FRENCH, Associate Program Officer
ANDREW LEMERISE, Research Associate
ANGELA MARTIN, Senior Program Assistant
ROSE MARIE MARTINEZ, Director, Board on Population Health and
Public Health Practice

Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

SHARON BARRETT, Health Literacy Staff Consultant, Association of Clinicians for the Underserved

RACHEL BRIGHT, Associate Manager, Changing Diabetes Policy,
Public Affairs Strategy & Public Policy, Novo Nordisk, Inc.

ALLISON LACE, Nurse Manager, St. Joseph Hospital

PATRICIA ROSSLEY, CLAS Coordinator, AmeriHealth Caritas

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Hugh Tilson**, University of North Carolina at Chapel Hill. Appointed by the Institute of Medicine, he was responsible for making certain that an

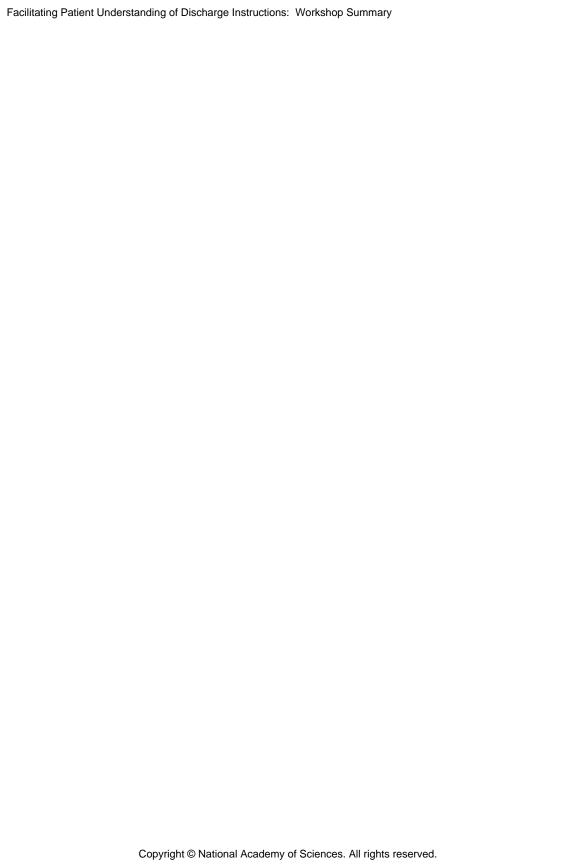
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independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteurs and the institution.

Acknowledgments

The sponsors of the Institute of Medicine Roundtable on Health Literacy made it possible to plan and conduct the workshop Discharge Instructions and After-Visit Summaries, which this report summarizes. Sponsors from the U.S. Department of Health and Human Services are the Agency for Healthcare Research and Quality; Health Resources and Services Administration, and the Office of Disease Prevention and Health Promotion. Non-federal sponsorship was provided by California Dental Association; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Humana; Johnson & Johnson; Merck and Co., Inc.; and the UnitedHealth Group.

The roundtable wishes to express its gratitude to the following speakers for their very interesting and stimulating presentations: John Byrne, Darren DeWalt, Benard Dreyer, Alex Federman, Alice Horowitz, Charles Lee, Man Wai Ng, Michael Paasche-Orlow, Ruth Parker, Joshua Seidman, Avniel Shetreat-Klein, Rachel Solotaroff, and Mark Williams.



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Acronyms

ACA Patient Protection and Affordable Care Act AHRQ Agency for Healthcare Research and Quality

BOOST Better Outcomes by Optimizing Safe Transitions

CMS Centers for Medicare & Medicaid Services
CPRS Computerized Patient Record System

EHR electronic health record

IOM Institute of Medicine

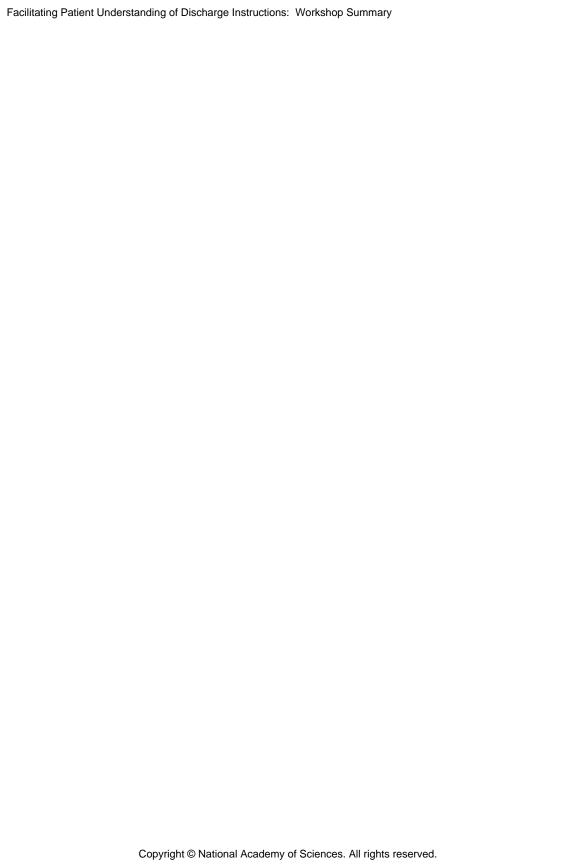
PCP primary care physician

PEMAT Patient Education Materials Assessment Tool

RED Re-Engineered Discharge

SAM Suitability Assessment of Materials

VHA Veterans Health Administration



1

Introduction¹

7ith the implementation of the Patient Protection and Affordable Care Act (ACA), the issue of inadequate health literacy has become even more important. Millions of Americans who had been uninsured became eligible on October 1, 2013, to enroll in health insurance plans, and according to early estimates, some 9.3 million more Americans now have health insurance as of March 2014 (Carman and Eibner, 2014). It is unclear, however, whether these individuals possess the necessary skills to compare and choose the health plan that is best for them, to decide among treatment options, and to understand medication and discharge instructions (Peters et al., 2013). "Discharge instructions are often written beyond the comprehension level of patients, and research has shown repeatedly that many patients do not understand the instructions they receive," said Andrew Pleasant, senior director for health literacy and research at the Canyon Ranch Institute, in his introduction to this workshop. "This is clearly a serious issue that the field of health literacy needs to address."

To explore the aspects of health literacy that impact the ability of patients to understand and follow discharge instructions and to learn from examples of how discharge instructions can be written to improve patient understanding of—and hence compliance with—discharge instructions, the

¹The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the Institute of Medicine (IOM), and they should not be construed as reflecting any group consensus.

Roundtable on Health Literacy held a 1-day public workshop. An ad hoc committee planned and conducted the workshop, which featured presentations and discussions that examined the implications of health literacy for discharge instructions for both ambulatory and inpatient facilities. The Roundtable on Health Literacy brings together leaders from academia, industry, government, foundations, and associations and representatives of patient and consumer interests who work to improve health literacy. To achieve its mission, the roundtable discusses challenges facing health literacy practice and research and identifies approaches to promote health literacy through mechanisms and partnerships in both the public and private sectors.

Examples of the topics covered in this workshop include an overview of the impact of discharge instructions on outcomes, the specifics of inpatient discharge summaries and outpatient after-visit summaries, and case studies illustrating different approaches to improving discharge instructions. The members of the roundtable hoped that this workshop would serve to expand the network of those involved in health literacy innovations and problem solving and that it would foster additional dialogue among existing organizations and individuals about the importance of, and the possibilities for, health literacy efforts at many levels.

ORGANIZATION OF THE SUMMARY

The workshop (see Appendix A for the agenda) was organized by an independent planning committee in accordance with the procedures of the National Academy of Sciences. The planning committee comprised Darren DeWalt, Benard Dreyer, Alex Federman, George Isham, and Ruth Parker. This publication summarizes the presentations and discussions that occurred throughout the workshop, highlighting lessons presented, practical strategies, and potential challenges and opportunities for improving discharge instructions. Chapter 2 provides an overview of why there are rules and regulations governing discharge instructions and how they impact health outcomes. Chapter 3 discusses issues germane to inpatient discharge instructions, and Chapter 4 examines issues specific to outpatient after-visit summaries. Chapter 5 examines different approaches to improving health discharge instructions. Chapter 6 recounts the discussion of roundtable members' comments on lessons learned throughout the workshop.

2

Overview of Issues Involved in Creating Better Discharge Instructions

The workshop's first panel, featuring three speakers, provided background information that would inform the subsequent two panels and the discussions that followed. Joshua Seidman, an independent consultant to the Brookings Accountable Care Organization Learning Network, provided an overview of why rules and regulations about discharge and after-visit summaries were developed and the implications of such policies. Alex Federman, associate professor of medicine at the Icahn School of Medicine at Mount Sinai, discussed what is known about current discharge and after-visit summary materials, and Darren DeWalt, associate professor of medicine at the University of North Carolina at Chapel Hill, addressed the links between discharge and after-visit summaries that are constructed in a health-literate manner and improved outcomes.

DISCHARGE INSTRUCTIONS AND HEALTH LITERACY: POLICIES AND THEIR IMPLICATIONS¹

It is always important, said Joshua Seidman, to think about health literacy in the context of understanding what people say and what people hear, let alone what they remember. He noted that research suggests that 40–80 percent of the medical information communicated by health care practitioners in the doctor's office is completely forgotten by the time

¹This section is based on the presentation by Joshua Seidman, independent consultant to the Brookings Accountable Care Organization Learning Network, and the statements are not endorsed or verified by the Institute of Medicine (IOM).

the patient gets home and that half of the information is recalled incorrectly (Kessels, 2003). In most instances, this failure to communicate is not because the patient is illiterate or unintelligent but because of a mismatch between the background of the person presenting the material and the one receiving it. "I think it is important to understand that information that is being imparted is very much related to someone's background, someone's context," said Seidman.

The discharge planning requirements of the Centers for Medicare & Medicaid Services (CMS) include educating patients and caregivers about postfacility plans. These plans, which are required at discharge from acute care facilities, long-term care facilities, and rehabilitation hospitals, must include written and verbal instructions on postdischarge options, what to expect after discharge, and what to do if issues arise. CMS regulations also require that there be an evaluation of the patient's and caregiver's understanding of needs, though the regulations do not spell out how to evaluate that understanding or how to ensure that that understanding is meaningful. Seidman noted that it is challenging to figure out how to meet those requirements.

Five years ago, the American Recovery and Reinvestment Act created the meaningful use of electronic health records (EHRs) requirement as an incentive to adopt electronic health records and to do so in a way that would be meaningful to the health care system and patients. Seidman explained that the meaningful use requirements included four items relevant to the topic of this workshop. First, patients are entitled to electronic discharge instructions if they want them. Second, patients must be provided with an after-visit summary at the end of every outpatient visit to help address the fact that they forget 40–80 percent of everything they hear in the doctor's office by the time they get home. Also required are patient reminders that are relevant not just to preventive care, such as cancer screenings and immunizations, but also to follow-up care. Patients are also supposed to receive patient-specific educational resources to help put the conveyed information into a context that, together with education, would improve health literacy.

In an ideal world, said Seidman, discharge instructions and patient specific educational resources would account for the language that a patient speaks and whether the patient prefers to receive information in writing, in graphical forms, or even as links to video or audio clips delivered via a mobile device such as a cell phone or tablet. Under provisions of the second stage of the meaningful use requirements, which take effect in 2014, patients are entitled to view, download, and transmit this information and any information in the electronic health record into a form that they find most useful. "But that does not necessarily mean that they are going to understand that information," said Seidman. He added that some organi-

OVERVIEW OF ISSUES 5

zations, such as Healthwise and Krame's, spend a great deal of time thinking about how to make the information mandated by the meaningful use requirements understandable to patients, caregivers, and the like.

The meaningful use provisions also mandate that a certain percentage of patients must actually go online and view, download, or transmit this information. "Just making information available does not mean that it is actually used," said Seidman. "It may even be almost a big secret that this information is available or that you can get your discharge instructions electronically," he explained.

One provision of the meaningful use requirements that is particularly germane to this workshop, said Seidman, pertains to the transition of care summary exchange that is designed to ensure that transitions of care summaries are shared among a patient's many providers. This provision, he explained, "lays the groundwork for further expectations in the future around what shared care plans should be."

To conclude his presentation, Seidman listed some difficult questions that he hoped would stimulate further discussion. The questions included

- What are the biggest policy levers that CMS can use to encourage care providers to do better with their discharge instructions?
- How much "policy" should be driven by the public versus private sectors, and in the public sectors, what is the right balance between federal and state policy levers?
- What is the right balance between ensuring activity is more than "check the box" versus being overly prescriptive, which could stifle innovation?

The last question, he noted, continues to challenge policy makers.

INPATIENT AND AMBULATORY DISCHARGE SUMMARIES²

Noting that little research has been conducted on discharge instructions, Alex Federman discussed two of the few studies on physician-to-patient communication that he was able to find in the literature. The first study examined the use of EHR-integrated treatment cards in a hospital in Geneva, Switzerland (Louis-Simonet et al., 2004). These treatment cards were a tool derived from an EHR that had been modified to enable clinicians to put in patient-specific medications using a series of drop-down menus. When patients were discharged, clinicians would use the cards as

²This section is based on the presentation by Alex Federman, associate professor of Medicine at the Ichan School of Medicine at Mount Sinai, and the statements are not endorsed or verified by the IOM.

prompts and as something that the patients could take with them when they left. In this study, patients who were exposed to the cards and received counseling using the cards were compared 1 week after initially receiving their discharge instructions with patients who did not receive the cards. The results showed that patients who received the cards were able to identify the purpose of their medication, the precautions they needed to take when using the medication, and the potential side effects. "This is not a mind-blowing study by any means," said Federman, "but it does indicate that with counseling and a simple set of instructions about medications, patients will remember some of this information better than if they don't receive such instructions. It points to the potential value of a document that a patient can walk away with after care."

The second study he described was a qualitative examination of discharge summaries from emergency departments (Buckley et al., 2013). The investigators addressed eight patient-identified items that might be missing from discharge instructions:

- Define complex words and concepts with precise terms.
- Present a contextual framework and motivational information that would clearly state the implications of not following the discharge instructions.
- Provide specific, practical information with examples that are meaningful to the patient's everyday experiences.
- Clarify uncertainty and manage expectations about how their condition might evolve after therapy.
- Provide visual aids and pictographs to illustrate key concepts.
- Address inappropriate but common practices and beliefs.
- Use a logical flow of information.
- Emphasize key points using typography (bold versus normal font, for example).

Using an after-visit summary from his own institution that was generated by a widely used commercial EHR system, Federman discussed some of the issues with discharge instructions. First, he noted that the discharge instructions he showed the workshop were 10 pages long. There was a great deal of white space throughout the document, which he said was good for readability. A nice feature of the medication section of the report, he noted, was that it listed both the brand name and generic name of all of the patient's medications. Still, the medication instructions were formatted to fit into a thin column in the report and were inconsistent in terms of daily doses and the time of day that the doses should be taken. A more glaring deficit was the fact that the things that the patient had to do going forward, including information on new prescriptions and when to schedule follow-

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up appointments, do not appear until six pages into this document. The seventh page contains instructions for health conditions that are completely unrelated to the patient's health problems, and the information specific to the patient's self-management needs does not appear until page nine of the discharge report.

In contrast, a discharge instruction from Norway (see Figure 2-1), which was translated into English, provided some examples of useful features not found in the first example (Bergkvist et al., 2009). This report starts with a patient-friendly summary of why the patient had received care and a medication table that listed each drug's dose, the reason why

Landskrona Hospital

SKANE
Department of Medicine, ward 2
Landskrona Hospital

Physician during hospital care: Mats Matsson General practitioner: Olle Olsson

Hospital care: 1 Jan 2008 - 11 Jan 2008

DISCHARGE SUMMARY

Born: 1 Jan 1921

Name: Clara Carlsson

You have been in hospital care because you have experienced dizziness for a period of time and finally you fainted. When you fainted you fell and now suffer from back pain. Your blood pressure was found to be too low and this could explain the dizziness. Your medications have therefore been adjusted and your blood pressure is now back to normal. During your hospital care we also found that you had an infection in the urinary tracts, for which you now are receiving antibiotics.

After discharge, you will return to the nursing home Flower garden. Within three weeks you will have an appointment with your General Practitioner, who will measure and follow up on your blood pressure and back pain.

Medication Report

- · Metoprolol has been decreased from 2 to 1 tablets per day, due to low blood pressure.
- Furosemide has been discontinued since you no longer have a problem with swollen ankles.
- Paracetamol has been added because of the back pain from your fall.
- · Cefadroxil has been added due to a urinary tract infection.

| MEDICINE preparation and dos | e | Effect | Morning | Noon | Evening | Night | Comments |
|---------------------------------|------------|------------------------------------|---------|------|---------|-------|------------------|
| Tabl Metoprolol | 25 mg | Lowers blood pressure | 1 | | | | |
| Tabl Hydrochlorothia | zide 50 mg | Lowers blood pressure | 1 | | | | |
| Tabl Metformin | 850 mg | Against diabetes | 1 | | 1 | | |
| Tabl Paracetamol | 500 mg | Against back pain | 2 | 2 | 2 | 2 | On demand |
| Tabl Cefadroxil | 500 mg | Against urinary tract infection | 1 | | 1 | | Until 13 January |

FIGURE 2-1 Example of a discharge instruction sheet with useful features. SOURCE: Bergkvist et al., 2009, as presented by Federman.

the patient needed to take the drugs, and how many pills the patient should take at specific times of day. "This is a much more low-literacy and patient-centric type of discharge summary," said Federman.

Turning to an ambulatory visit summary, Federman noted that the meaningful use requirements dictate that such a summary be created after every visit and provided in either written or electronic format. The required elements for this summary include the patient's name, clinical office contact information, the date and location of the current visit, an updated patient-specific problem list, a medication list, vital signs, and the reason for the visit, including symptoms. The report must also list all procedures, immunizations, and medications administered during the visit; all ordered tests and results if those results are available at the time of the visit; and a summary of topics covered, the time and location of the next appointment, the list of appointments that the patient needs to schedule with appropriate contact information, and recommended patient decision aids when appropriate.

Federman then presented the results of a study that he conducted in which he and a student did a convenience sampling of 18 primary care practices across the nation and used the Suitability Assessment of Materials (SAM) tool and Patient Education Materials Assessment Tool (PEMAT) to assess understandability and actionability of the ambulatory visit summaries. The summaries from the 18 practices were generated by seven different EHR platforms. The median font size was 10 points, which Federman characterized as fairly small, and the median length was two pages, with a range of one to seven pages. Every summary included patient-specific medication information, but only 78 percent of the summaries provided the primary care provider's name, condition-specific instructions, or appointment information for procedures and consultations. Only two-thirds of the reports included the diagnosis, visit date, or vital signs; about one-half listed the patient's allergies or information on return appointments; and only onequarter of the summaries had a patient problem list or a generalized set of instructions such as what to do in case of emergency. The order in which this information was presented and how it was formatted varied greatly. "What that points to is that nobody is following a particular structure to building these after-visit summaries," said Federman. "There is no common approach."

In most cases, he added, the condition-specific instructions were typed in by the physician using free text. The text typed in by physicians was typically written with less medical jargon than text elsewhere in the documents. Overall, the median reading grade level on these materials was very high across four different reading grade formulas. The SAM tool scored readability as barely adequate, while the PEMAT assessment found that understandability was worse than actionability. Federman noted that the range of scores showed that some of the summaries performed very poorly.

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He concluded his talk by presenting the results of phone interviews conducted with the physicians who participated in the study, which showed that clinicians judged medication lists as helpful but that most other elements were not. One of the major concerns that clinicians voiced was that these summaries should be available in Spanish.

LINK BETWEEN HEALTH LITERATE AFTER-VISIT SUMMARIES AND DISCHARGE INSTRUCTIONS AND IMPROVED OUTCOMES³

Darren DeWalt began the final presentation of the workshop's first panel by commenting that providing discharge instructions is now a part of the workflow in health care thanks to the meaningful use requirements issued by the Office of the National Coordinator for Health Information Technology but that there is still room for improvement. "This is a great opportunity to improve health care or to continue to create more waste," he said. "What I mean by that is that if we are going through the motions or just checking boxes, we are just wasting our time. If we can turn this into a value for our patients and our consumers, then we could substantially improve health care."

The reasons why it is difficult to "get this right," as he put it, are many (Coleman et al., 2013; Makaryus and Friedman, 2005; Parkin et al., 1976). They include, on the patient side, the fact that difficulties arise because patients do not remember details, and they do not feel able to manage their lives and their medical issues because of low self-efficacy. Clinicians, meanwhile, do not understand the limits of their patients' skills and abilities and as a result do not provide a manageable volume of clearly explained instructions and ensure that their patients understand the information they are given. In addition, information systems are not designed to produce discharge instructions in a low-literacy format, as Federman noted, and the content mandated by the meaningful use provisions may be overspecified, leading to the presentation of information that can complicate explanations rather than simplify them.

Health literacy, however, is not the only issue. Several studies have documented a range of between 30 and 43 percent of patients who have a cognitive impairment at the time of discharge that can impact their ability to comprehend or remember discharge instructions (Boustani et al., 2010; Coleman et al., 2013; Lindquist et al., 2011). Cognitive impairment resolves in 1 month in about half of these patients, but rates are even higher

³This section is based on the presentation by Darren DeWalt, associate professor of medicine, University of North Carolina at Chapel Hill, and the statements are not endorsed or verified by the IOM.

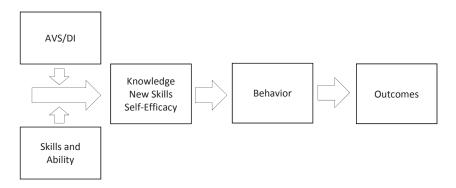


FIGURE 2-2 Mechanistic pathway by which discharge instructions impact outcomes. NOTE: AVS/DI = after-visit summary/discharge instruction. SOURCE: Presented by DeWalt, 2014.

in specific patient populations, such as elderly patients with heart failure, where the rate of cognitive impairment can exceed 50 percent.

The mechanistic pathway by which discharge instructions impact outcomes (see Figure 2-2) starts at the intersection of those instructions with the skills and abilities of the patient. Together, these two components have an effect on knowledge, new skills, and self-efficacy, which leads to behaviors that could produce better health outcomes. "Of course, if this is done poorly, it could lead to lower self-efficacy and worse behaviors and worse health outcomes," said DeWalt.

To illustrate the challenges associated with this mechanistic pathway, DeWalt discussed the cases of two of his patients. One patient, a 60-year-old male admitted to the hospital with chest pain and shortness of breath, had had a heart attack and was hospitalized for 8 days. At the time of his discharge, he was left with substantial cognitive impairment, difficulty with mobility, and an overwhelmed spouse. He also left the hospital with nine pages of discharge instructions that DeWalt stated were "difficult to sort through with a very small font." He added, "I can guarantee you that most of my patients are not referring to this information and that reading something like this is not particularly appealing for a medical patient that is still recovering from illness." Given this patient's status and the nature of the discharge instructions, DeWalt wondered whether the patient or family will make a mistake. He also questioned whether parts of this summary could be left out, and, if so, who should make that decision.

The second case he discussed was that of a 64-year-old female with high

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blood pressure, rheumatoid arthritis, osteoporosis, and a recently ruptured hand tendon whom he had seen in his primary care office. At the time of her visit, her blood pressure was high, and DeWalt needed to increase her medication. She was also planning to have hip surgery soon. Given that she has several different medical problems and several different plans, DeWalt questioned whether she will remember what she needs to do if those plans are not integrated and written. He also wondered whether a medication list alone would have been sufficient at that moment in time and whether the problem list would help her in any way or whether it was just more information that would overwhelm her.

In today's chronic care model, patient discharge instructions done well can be an important part of the productive interactions that can take place between an informed, activated patient and a prepared, proactive practice team and in the end produce good outcomes, DeWalt said. He argued, however, that poorly designed after-visit summary or discharge instructions have little impact on increasing or decreasing knowledge or skills but that they do decrease self-efficacy. "When we present something that is overwhelming, I think it gives patients more of the impression that they are not in control or can't manage this. Consequently, I believe that these could have an adverse consequence of making it more difficult to carry out optimal behaviors," he said.

In contrast, said DeWalt in closing, "I do believe that with good designs, we have an opportunity to improve knowledge skills and efficacy, and behavior and outcomes. I think that is the spirit with which policy makers have come into this, and I believe it is really our job as health systems and as activists, and at the roundtable, to try and help turn this into a win for our patients in our health system." For him, doing so means giving up the idea that this is an information technology problem with an information technology solution. "We need to change how we think, and we need to change how we distill and present instructions," he said. At his institution, the University of North Carolina, medical teams are asked to think about the three things that they want each patient to remember about their self-care and three things they need to do or look out for, and the fact is that most medical teams cannot do that. "We have some work to do in helping reframe how we think about handing this information off to our patients."

DISCUSSION

Rima Rudd, senior lecturer on health literacy, education, and policy at the Harvard School of Public Health, started the ensuing discussion by asking whether it might be acceptable as a policy requirement to absolutely insist on a particular process for the development of these materials; the

process would involve rigorous pilot testing with members of the intended audience and evidence that change has been made based on that pilot testing. Seidman replied that there would be potential trade-offs associated with such a requirement. He said that although pilot testing can be very helpful—he is in fact in favor of increasing the amount of pilot testing done on discharge instructions—it can also slow down the process of developing discharge approaches that might work better. He also noted that such requirements could place a particularly large burden on organizations that have fewer resources to develop better discharge instructions.

In response to the same question, Federman thought that research and development involving focus groups, cognitive interviews, and other research methods could produce best practices for creating after-visit summaries in a way that achieves the goals intended for them. He also noted that one outcome of such research would be greater patient satisfaction, a point with which Seidman and DeWalt agreed. Both Federman and Seidman agreed with a comment from Kim Parson, director of the Consumer Experience Center of Excellence at Humana, who thought that bringing patients into the design phase for discharge summaries might produce a better product.

Patrick McGarry, vice president for new business innovation and connected health at the American Academy of Family Physicians, expressed concern that, during treatment, patients concede locus of control for care, trusting that their clinicians will make appropriate decisions. Yet on discharge, patients are expected to assume control of their own management. Federman responded that much of that shift in locus of control can be facilitated with greater use of personal health records, patient Web portals, and electronic communication, although we are still quite far from having adequate electronic interface with patients. Currently, therefore, hard copies of well-prepared and designed discharge and after-visit summaries are important tools. Seidman added, "There is still just a huge incentive for every clinician to bring every patient into the office in order to get paid. That is going to create a lot of problems around that locus of control." DeWalt said that he believes that "after-visit summaries and discharge instructions, when done right, provide an opportunity to improve the patient's efficacy around their own self-management."

Cindy Brach, senior health policy researcher with the Agency for Healthcare Research and Quality and a roundtable member, asked the panelists if they had any suggestions on how to speed the development of better discharge instructions. Seidman thought that the readmission penalties that Medicare is now levying are already motivating hospitals to think through their discharge instructions. "Now you have thousands of hospitals thinking how to improve their discharge instructions because they have to reduce their readmissions. I think that has created a lot of incentive and a

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lot of positive work," he stated. He also thought that the National Quality Strategy⁴ was a great tool for pushing the development of better discharge instructions. Federman thought that "another driver could be the next iteration of meaningful use criteria if they were to say that the after-visit summary has to have demonstrated impact or has to meet some formatting or other characteristics that makes it health literate."

Winston Wong, medical director for Kaiser Permanente's Community Benefit Disparities Improvement and Quality Initiatives program, said that giving health-literate instructions is critical but that it is also critical to provide support for a patient's transition back home. He then asked if any of the panelists had experience in making discharge instructions more understandable to non-English-speaking patients. Federman, who noted that his clinical practice is in East Harlem, which has a large population of patients who speak only Spanish, said that regulations are needed to address this problem. He said that health care systems want to do something about this because it certainly impacts readmission rates, but their list of things they need to do is so long that addressing language issues becomes less of a priority.

Robert Logan, communication research scientist at the National Library of Medicine, asked what the speakers thought were the challenges of selecting the appropriate information to provide. Seidman said that, from his experience, patients want in-depth information, but they want it to be specific to their situation. The problem is creating systems that can do that. Federman added that when the situation is more complex, we have to bring in tools other than the summaries we are discussing. "In some cases people need navigators, or they need care coaches or other things," he said. Finding the right balance of components is part of the puzzle we are trying to figure out.

Kim Parson pointed out the importance of the principle of co-design of materials. Is the consumer being involved in the creation of discharge and after-visit summaries, she asked? Federman responded that he and his colleagues have a grant to do just that. Seidman pointed out that although co-design is very important, it can present challenges. For example, the

⁴The National Quality Strategy, led by the Agency for Healthcare Research and Quality, has three aims:

^{• &}quot;Better Care: Improve the overall quality, by making health care more patient-centered, reliable, accessible, and safe.

[•] Healthy People/Healthy Communities: Improve the health of the U.S. population by supporting proven interventions to address behavioral, social, and environmental determinants of health in addition to delivering higher-quality care.

Affordable Care: Reduce the cost of quality health care for individuals, families, employers, and government"

http://www.ahrq.gov/workingforquality/about.htm#aims (accessed July 17, 2014).

physician is probably not the best-trained person to do this. Second, from a resource perspective, using co-design can be very time-consuming. A team approach to care might be more able to accomplish this, he said. DeWalt pointed out that in his organization there are separate discharge instructions from physicians, from the nursing team, from the pharmacy team, and from others as well, which "muddies the water even further." There needs to be a way to consolidate these instructions, he said.

Bernard Rosof, co-chairman of the National Priorities Partnership of the National Quality Forum and a roundtable member, asked what drivers should be emphasized as we create health-literate discharge and after-visit summaries. For example, should we think about the National Quality Strategy drivers of patient safety, patient-centered care, care coordination, and decreasing the leading causes of mortality? Seidman responded that the National Quality Strategy priorities could bring focus and guidance to efforts to create health-literate discharge and after-visit summaries.

Margaret Loveland, from Global Medical Affairs of Merck & Co., Inc., said that perhaps as discharge instructions are designed, the most important things should be placed first, things such as in the first two days at home you will do X. She also pointed out that the predischarge process is important, as is postdischarge follow-up. Seidman agreed that the predischarge process and postdischarge follow-up are critical, referring to the work of Eric Coleman on the care transitions model (http://www.caretransitions.org/overview.asp), adding that the ability to engage family caregivers is very important. He said that another critical piece is the dosing of information. "We have got to make sure that we get the right dose, the right frequency, the right duration. All of those things are very similar to medication prescribing," he said.

DeWalt agreed and pointed out that "discharge instructions, in and of themselves, are not going to solve the problem." He pointed out that the current state of discharge instructions reflects a generally disorganized plan put in place for the patients. "Working on how we organize and present the discharge instructions will help the team as they prepare the patient in the predischarge and postdischarge arena," he said.

Laurie Francis, senior director of Clinic Operations and Quality at the Oregon Primary Care Association and a roundtable member, asked how we can move from a focus on physician communication to one that concentrates on patient priorities and uses the care team to provide better care. Federman said, "Payment models." He pointed out that there are many ongoing demonstrations and research studies about engaging community health workers as members of the health care team. It is not enough to tell patients what is needed at the point of discharge or even 1 week after discharge; patients also need to be checked on over time to reinforce what needs to be done, he said.

3

Inpatient Discharge Summaries

The workshop's second panel was structured with one presentation and three reactions to that presentation. In the main presentation, Mark Williams, director of the Center for Health Services Research and professor of internal medicine at the University of Kentucky, described elements that should be included in an inpatient's discharge instruction and the formatting techniques that can improve readability for patients. Benard Dreyer, professor of pediatrics at the New York University School of Medicine; Avniel Shetreat-Klein, assistant professor and associate medical information officer for Epic Operations at Mount Sinai Medical Center; and Man Wai Ng, chief of the Department of Dentistry at Boston Children's Hospital and assistant professor of developmental biology at the Harvard School of Dental Medicine, gave their reactions to that presentation.

KEY ELEMENTS AND FORMATTING DISCHARGE INSTRUCTIONS¹

One recent revision to CMS's Conditions of Participation that health care organizations must meet to participate in Medicare and Medicaid programs was the provision that all hospitals must have, in writing, a discharge planning process that applies to all patients. This requirement, said Mark Williams, is expected to improve the quality of care and reduce the chances

¹This section is based on the presentation by Mark Williams, director of the Center for Health Services Research and professor of internal medicine, University of Kentucky, and the statements are not endorsed or verified by the IOM.

of readmission by creating incentives to provide patients what they need for a smooth and safe transition out of the hospital. The discharge process, according to Medicare's guidelines, should consist of four parts: screening for the risk of adverse health consequences after discharge; evaluation of a patient's postdischarge needs; development of a discharge plan; and initiation of the discharge plan prior to the patient's actual discharge.

Williams noted that any case manager, if asked, will say that hospital discharge planning should begin with hospital admission, but that often does not happen. The Medicare guidelines say that the discharge planning process should include input from medical staff, postacute care facilities, patients, and advocacy groups, but Williams wondered how many hospitals actually integrate all of these inputs into discharge planning. In fact, he said, information and communication deficits at hospital discharge are common, according to the findings of a study he and his colleagues conducted in 2006 (Kripalani et al., 2007). This systematic review found that there was little direct communication between the hospital provider and the community-based care team and that discharge summaries were not commonly available at postdischarge appointments. Even when the summaries are available, the majority lack important information, such as diagnostic test results, a list of tests with pending results, and discharge medications (Were et al., 2009).

In 2009, Williams and a number of colleagues representing several medical societies published a consensus policy statement regarding transitions of care (Snow et al., 2009). One omission from the process that generated this consensus statement, he said, was that patient groups were not involved in creating this consensus statement; nonetheless, he said, it contained a number of principles that are still important and that should drive much of what hospitals do when trying to communicate with patients. These principles include the idea that hospitals should be accountable for what is happening to patients as they transition through the system, taking responsibility to ensure that patients and their families know who is in charge of the patients' care and how to contact that caregiver throughout the process of hospitalization, discharge, and postacute care. Another principle is that there must be coordination of care and family involvement, along with an infrastructure that provides clear and direct communication, including transition records, treatment plans, and follow-up expectations. Finally, Williams said, is the principle that all communication and feedback should be timely and meet national standards and metrics as established by The Joint Commission and the National Quality Forum.

CMS has issued a discharge planning checklist for patients to receive and use prior to hospitalization, and although it is a useful summary of what a patient should expect at discharge, Williams said that it places too much burden on the patient to figure out what should happen instead of being part of a collaborative process among health care providers, patients, and caregivers. He noted that in many years caring for patients and working in many hospitals, he has seen or heard of few cases where patients actually have and used such a checklist. "We certainly don't typically help patients do something like this," said Williams. Nonetheless, he noted that his institution has its own checklist that it provides patients on admission and that there are similar items available from the Agency for Healthcare Research and Quality (AHRQ). Such checklists provide an opportunity for the education of patients and caregivers using a teach-back approach² and could inform what hospitals ought to be doing.

One recent study that Williams participated in looked at what patients actually understand and can execute when they return home (Coleman et al., 2013). Results of interviews with patients after they had gone home showed that health literacy, cognition, and self-efficacy predict successful understanding and execution of discharge instructions. Nevertheless, neither the discharge diagnosis nor the complexity of the instructions was a predictor of success. Williams said that on the basis of these findings, "there needs to be a reliable protocol that identifies patients at high risk for poor understanding and execution of the discharge instructions, and we need to have customized approaches for those patients."

As part of a project funded by AHRQ to develop an effective and easy-to-understand set of discharge instructions, Williams worked with patients to develop what is now called the Discharge Patient Education Tool. This tool is laid out in a structured manner and takes a patient-centered approach to explaining discharge instructions (see Figure 3-1). It explains why the patient was in the hospital and encourages health care providers to explain, in "living room language," definitions of any medical terminology as well as the medical terms. It lists the patient's medical conditions, the tests that were run and their results, the treatments the patient received and the purpose of those treatments, and follow-up information, including appointments and necessary lifestyle changes. All this information fits on two pages, though Williams and his colleagues as part of Project BOOST (Better Outcomes by Optimizing Safe Transitions, www. hospitalmedicine.org/BOOST) developed an even more concise discharge instruction template that hospitals might choose to use.

The fascinating part of this project, said Williams, was that when nurses used these structured patient-centered discharge instructions, the patients reacted very strongly and positively. "A common comment was, 'Why haven't they done this in the past when I was discharged from the hospital,'" said Williams. Still, 7 years later, these simplified forms have

²Teach-back is a method for making sure patients understand what they need to know by asking them to explain back to the provider in their own words.

| • I had to stay in the hos | spital because: | | |
|--|---|--|-----------|
| The medical word for | this condition is: | | |
| I also have these medi | cal conditions | | |
| <u>TESTS</u> | | | |
| While I was in the hospital I | I had these tests: | which showed: | |
| TREATMENT | | | |
| While I was in the hospital with: | I I was treated | The purpose of this treatn | nent was: |
| (initials) Primary Care Doctor: | ospital, I will follow | p up with my doctors. Phone Number: TIME: Phone Number: TIME: : | m |
| DATE. | 20 | TIME. | |
| DATE: | | | m |
| FOLLOW-UP TESTS After leaving the ho | | | _m TIME |
| FOLLOW-UP TESTS After leaving the ho (initials) | ospital I will show t | up for my tests. | |
| FOLLOW-UP TESTS After leaving the ho (initials) | ospital I will show t | DATE | |
| FOLLOW-UP TESTS After leaving the ho (initials) TESTS Call your Primary Care I | ospital I will show t | DATE | |
| FOLLOW-UP TESTS After leaving the ho (initials) TESTS Call your Primary Care I Warning signs LIFE STYLE CHANG After leaving t (initials) | LOCATION Doctor for the follo EES he hospital, I will | DATE wing: make these changes in m | TIME |
| After leaving the ho (initials) TESTS Call your Primary Care I Warning signs LIFE STYLE CHANG After leaving t (initials) Activity: | LOCATION Doctor for the follo EES he hospital, I will | DATE wing: | TIME |

FIGURE 3-1 Discharge Patient Education Tool. SOURCE: BOOST, presented by Williams, 2014.

yet to be integrated into an electronic record despite working with an EHR vendor. In closing, he noted the perversity of this situation given that EHRs can easily generate 30 pages of instructions with no formatting. "While you can come up with something simple and straightforward on your personal computer, we are now obligated to use the EHR, and so we have got to figure out how to get this integrated into EHRs as a standard part of hospital transitional care," Williams said.

When asked by Andrew Pleasant why integration into any vendors' EHR has been so challenging, Williams said that he has been told that it will take 2 to 3 years of reprogramming to finally get this capability implemented, that is, the capability to have infinitely expandable tables and pulling of needed information seamlessly into the patient discharge instructions. "It is impressive how the EHR companies are now controlling so much of what is happening in hospitals as they attempt to meet meaningful use criteria," Williams said.

REACTIONS AND DISCUSSION

Benard Dreyer³

The first issue that Benard Dreyer addressed was information overload, and he proposed several steps to deal with the potential of overwhelming patients with too much information. Clinicians, he said, should think about the most important actions that the patient needs to take and how those actions might differ from the patient's usual behaviors, especially the health-related activities of the patient prior to this admission. This type of information can be lost in the typical discharge instructions. He suggested that a teach-back moment should take place to ensure that the patient truly understands the discharge instructions and that a telephone call should be made to the patient after discharge as an additional check on the patient's understanding. Patients should also be given specific instructions on when and how they should contact their physician after discharge. Regarding the checklists that Williams described, which could incorporate these items as questions that the patient should ask, Drever thought they could be useful but wondered whether they should be given to patients during their admission process rather than ahead of time, when they will likely be forgotten.

Dreyer briefly discussed a few tools that patients could take home. He and his colleagues use simplified written asthma action plans and medication administration and medication-taking tools. He described a low-literacy asthma action plan (see Figure 3-2) that uses illustrations and pictures of medications, along with color-coding and formatting, to convey information in as simple a format as possible. Dreyer also remarked that smartphones, videos, and Web-accessible programs can be valuable tools for communicating with patients. For example, New York University Medical Center has developed a Web-accessible program that providers can access

³This section is based on the presentation by Benard Dreyer, professor of pediatrics at New York University School of Medicine, and the statements are not endorsed or verified by the IOM.

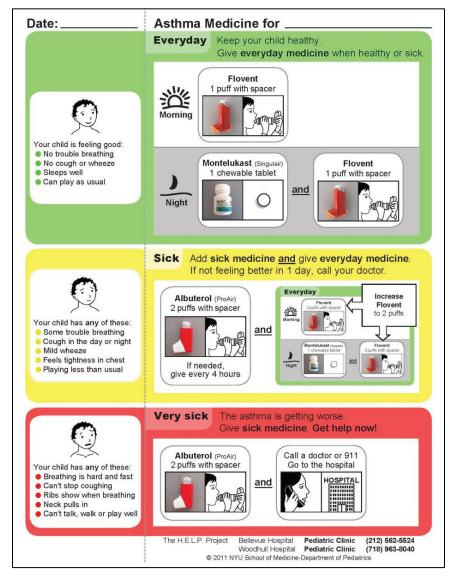


FIGURE 3-2 Asthma medication plan. SOURCE: NYU School of Medicine, 2011, as presented by Dreyer.

to generate interactive patient-specific asthma action plans with embedded video instructions on how the parent and/or child should use an inhaler.

Dealing with unfinished business at the time of discharge can be challenging, said Dreyer. Unfinished business can include laboratory test results that are not back yet at the time of discharge and a list of treatments that need to be arranged after discharge. He noted, too, that patients with certain diseases want to know how their disease will affect them going forward. "We as physicians tend to focus on the short run, but patients want to know what is really going to happen to them in the long run." They also want to know how long it will take for them to return to their normal activities, such as school and work.

In the end, all these concerns come down to one ultimate question, said Drever. "How much of this is our responsibility? If we decide something is not our responsibility, then who is going to be doing that for the patient?" he asked. Things often fall apart, he noted, when patients go home and some important detail was not addressed either by the hospital or by resources in the community. Often, these are simple pieces of information, such as where the pharmacy is located and what its hours of operations are and whether the patients have the money to take care of the drug co-pay. "I often find that the small things that are overlooked cause serious problems when the patient goes home," said Drever, who concluded his comments by noting that the field needs to figure out the easiest ways for patients to get those details once they leave the hospital. He stressed that we need to make sure the patient is ready and prepared for care after discharge, the family and home environment is ready for the patient, and the community and the health care system have the resources and responsibilities necessary for a successful transition.

Avniel Shetreat-Klein⁴

Avniel Shetreat-Klein commented on the difficulty in getting EHRs to produce simplified, readable discharge instructions. Informatics aims to deliver the right information to the right person at the right time. It is doing a good job of giving information for clinical decision support to providers who are working to care for patients. But, Shetreat-Klein said, it is not doing such a great job in terms of the interaction between the EHR and the patient. "Automation—the desire to get the EHR to solve these problems—is to a huge degree what causes these problems," he said. When something is automated, one has as much chance of including bad infor-

⁴This section is based on the presentation by Avniel Shetreat-Klein, assistant professor and associate medical information officer for Epic Operations, Mount Sinai Medical Center, and the statements are not endorsed or verified by the IOM.

mation as including good information. Automated after-visit summaries include medication lists, problem lists, and patient education information that are pulled in automatically from the medical record. As a result, there are errors. For example, one automated after-visit summary included insulin on the medication list four separate times. Presumably that was because the patient was on a sliding scale in the hospital, so there were four different insulin orders—which is its own problem, he said.

Shetreat-Klein noted that the desire to automate, combined with the desire to add in all the information that guidelines recommend, including in discharge instructions, produces exactly the kind of dense, multipage discharge instructions that previous speakers discussed. What needs to change, he said, is not the information that goes into the discharge instructions or the software that organizes that information into a readable form, but the discharge process itself. In fact, Shetreat-Klein argued against trying to integrate discharge instructions into the EHR. Yes, he said, create a one- or two-page form, but keep the physician involved in filling in the patient-specific blanks on that form.

"It is the process of thinking 'what does this patient need?' that provides beneficial information, rather than the garbage-in, garbage-out kind of discharge summary," he said. Williams's example of the BOOST discharge form is great, partly because, he said, "it is not part of the EHR." It changes the process; providers must actually write on the form, which requires a process of thinking about what the specific patient needs.

Although patient checklists can be useful, Shetreat-Klein said, a matching physician checklist should be created in the EHR that would prompt the physician to address all the relevant issues germane to a specific patient. Alternatively, the patient could go over the checklist in the presence of the health care provider, which Shetreat-Klein suspected might make a difference in patient understanding and follow-through. "Removing the automation from the process may help," he said.

Man Wai Ng⁵

Man Wai Ng provided some context for her remarks. She is a pediatric dentist working in a hospital department of dentistry that sees about 28,000 ambulatory patient visits each year. About 750 patients each year receive their dental treatment in the operating room under general anesthesia. The dental service also provides coverage to the emergency department and consultations to patients prior to such treatments as chemotherapy, stem cell transplant, and open heart surgery. Until recently, Ng said, den-

⁵This section is based on the presentation by Man Wai Ng, Harvard School of Dental Medicine, and the statements are not endorsed or verified by the IOM.

tistry has been thought of as a profession that treats cavities (tooth decay) and gum disease. More recently, however, dental caries (or tooth decay) has come to be recognized as a chronic infectious disease that can be prevented and managed. As a result, her hospital has implemented a risk-based disease prevention and management of caries approach that builds on the chronic care treatment model, in collaboration with patients and families, and implementing self-management goals handouts, using pictograms and examining the language used to communicate with patients. Ng noted that electronic dental records are "woefully misaligned" with EHRs. She and her colleagues are challenged to easily provide the educational information that is relevant to patients' oral health concerns and that the patients and their family can access through the hospital's patient portal. The portal is managed as part of the EHR. She also remarked that she believes three processes need to be considered prior to initiating the discharge process for one of her pediatric cases. "One is the need to specify those goals for discharge, two is to assess the child's health care needs, and then three is to identify factors that would influence the child's health upon discharge," Ng explained. The purpose of these three processes, she added, is to screen and identify individual patients for whom a lack of an adequate discharge plan will likely result in unnecessary delay from discharge or impact health after discharge.

The discharge process, she continued, should ideally begin when the child arrives at the hospital, and it should involve all members of the care team. The discharge plan should include teach-back, and it should be delivered with consideration of the parents' English-speaking skills. Ng commented that although online access to discharge instructions and other patient-relevant issues can play an important role in the discharge process, not all patients will have easy access to the Internet. "There needs to be some recognition of this digital divide," she said.

DISCUSSION

During the subsequent discussion, Cindy Brach suggested it was important to distinguish between a discharge summary and a discharge plan or instructions. She also said that she thinks the focus should be on consumerfacing instructions and believes that this should be integrated into the EHR, unlike Shetreat-Klein, even if doing so takes time. Williams agreed that integration into the EHR is critical. Also important are other support tools. The system is not adequately providing information to patients in an understandable manner and supporting their connection to resources after discharge, he said. Tools such as navigators are important to the discharge and postdischarge process.

Shetreat-Klein clarified that his concern about keeping discharge sum-

maries out of the EHR is that once one starts automating the system, instead of having interaction between the provider and the patient about his or her specific problem using common words, one gets a form with all the problems discussed earlier, such as medical jargon, information error, and nonspecific information.

Winston Wong highlighted the importance of patient-centeredness and emphasized the importance of teach-back as a tool to ensure that patients and caregivers understand discharge instructions, and it was noted that teach-back is now becoming widely used across the country. Williams noted that teach-back appears to improve patient satisfaction to a degree that gets reflected on patient satisfaction surveys used by CMS for hospital and physician reimbursement. He added that teach-back needs to be used by all members of the health care team, not just by the last person who sees a patient before discharge. He also noted that combining teach-back with an instrument such as the discharge patient education tool leads to high marks on patient satisfaction. "The patients actually felt that they were receiving attention and [that] the provider cared about them because they were delivering the information in an understandable fashion," he said. Williams said that he is fascinated by what patients tell him. "If I don't know what they are thinking," he said, "then a lot of my conversation is wasted because I have not addressed their concerns up front."

Ng said that when they were thinking about bringing in technology to help patients understand different components around discharge, they asked patient representatives what they thought. The feedback was that technology is great but what they really would rather have are the interactions patients and families have with the care providers. Dreyer then said that he believes that pilot testing is a critical part of developing patient discharge instructions that get at the issues of what patients need and want to know. Rima Rudd noted that pilot testing is not something that should be done on a casual basis. "It is part of the absolute scientific rigor of formative evaluation," she said, "and to the extent that people make excuses, that is totally unscientific and ethically irresponsible."

Terri Ann Parnell, vice president for health literacy and patient education at North Shore–Long Island Jewish Health System and a roundtable member, asked for the presenters' thoughts on the use of texting and audio and video presentations as mechanisms for providing discharge information. And Linda Harris, from the U.S. Department of Health and Human Services and a roundtable member, wondered whether patients, even those with smartphones, have enough bandwidth and data to have meaningful access to health information, which involves the question of who pays. Dreyer said that he did not have any information about the value of audio and video for providing discharge information. As far as the use of texting, Dreyer said that numerous research projects are examining the use of

texting for connecting to patients. Nevertheless, in his opinion, providing adequate discharge instructions requires more than texting. And the issue of who pays is key. Wilma Alvarado-Little suggested that one might consult the deaf community about the use of texting because that is a major communication tool for that community.

Bernard Rosof said he perceives a problem in providing discharge information that is related to the way in which medical care is delivered. Over the past 5 to 10 years, he said, the primary care physician (PCP) presence in hospitals has declined significantly. Patients are given their discharge summaries, but those summaries are not forwarded to the PCP. If, after discharge, something happens that requires primary care intervention, the PCP does not have information about what happened in the hospital or post discharge. Rosof asked how we can ensure that a timely transfer of information to the PCP occurs.

Williams said that this is a critical issue because PCPs need to know if their patients come to the emergency room or are admitted to the hospital; they need to communicate with the hospitalists and, ideally, have access to and be able to react to the electronic medical record. PCPs also need to know when the patient is leaving the hospital and arrange for a follow-up appointment. Lindquist and colleagues (2013) conducted a study that found PCP communication at hospital discharge reduces medication discrepancies.

Shetreat-Klein agreed that the primary care provider is central to the entire process. While we have gotten very good at identifying who patients need to follow up with after discharge, alerting the primary care provider to a hospital admission is something that requires individuals to act on their own to see that it is done, he said. Another major challenge is that sometimes patients do not have a primary care provider or do not know who their PCP is. This situation occurs particularly in the more vulnerable populations, who may be getting care at a clinic where their provider is a resident who changes over time.

Steven Rush suggested that perhaps one might think about discharge preparation rather than focus on discharge instructions, teaching patients while in the hospital how to care for themselves. For example, he said, patients could be taught how to take their medications and what kinds of physical activities in which they could engage. Williams responded that he thinks we should be focusing on patient preparation, but because there is pressure to get patients out of the hospital as rapidly as possible, the system has not be set up to do this kind of training.

As the discussion concluded, Darren DeWalt asked the panelists to provide their recommendations for future actions. Williams said that hospitals need to engage industrial engineers to support the development of better discharge instructions and to integrate electronic medical records into the workflow of the care providers to best serve the patients. Dreyer said that

the field needs to conduct research on patients' understanding of discharge instructions as they are now designed and that it may be necessary to mandate via regulation that hospitals conduct pilot testing. Shetreat-Klein agreed with both of these ideas and added that health care providers need to be brought back into actively designing the discharge process. Ng said that it was critical to think about discharge instructions in terms of systems and that all stakeholders need to be involved in the planning process, with subsequent testing prior to implementation.

4

Outpatient After-Visit Summaries

The workshop's third panel was also structured with one presentation and several reactions to that presentation. In the main presentation, John Byrne, associate chief of staff for education and chief health informatics officer at the VA Loma Linda Healthcare System and associate professor of medicine at the Loma Linda University School of Medicine, discussed the after-visit summary tool that he and his colleagues have developed. Reactions to this presentation came from Rachel Solotaroff, medical director at Central City Concern, and Alice Horowitz, research assistant professor at the University of Maryland School of Public Health.

VA LOMA LINDA HEALTHCARE SYSTEM AFTER-VISIT SUMMARY¹

The Veterans Health Administration (VHA) has more than 8 million enrollees who made some 85 million outpatient visits in 2012, said John Byrne, and it possesses one of the most robust and well-regarded EHR systems (Edsall and Adler, 2011). The EHR system consists of the VHA's EHR, VistA, and its graphical user interface, the Computerized Patient Record System (CPRS). What the VHA does not have, however, is a means of using VistA or the CPRS to generate an after-visit summary, forcing VHA physicians to create their own workarounds, including those using pen and

¹This section is based on the presentation by John Byrne, associate professor of medicine, Loma Linda University School of Medicine, and the statements are not endorsed or verified by the IOM.

paper. It was this situation that spurred Byrne to develop an after-visit summary that was as good as the one he received from his own family physician as far back as 2006.

The goal of this effort, he explained, was to provide patients with a patient-centered clinical summary of their outpatient visits while minimizing the burden on providers by automatically populating the summary with data from VistA but leaving room for customization. After pilot testing the resulting after-visit summary in 2012 and 2013, the VHA has now deployed the summary at six of its sites, including the VA Loma Linda Healthcare System. The development and evaluation process, said Byrne, solicited input and feedback from patients as well as the VHA Medication Reconciliation and the Meaningful Use groups to first create a prototype after-visit summary and then improve the summary through an iterative cycle of field testing and reprogramming. He noted that one challenge that arises from including so much input in the development process is that it can lead to what he called "scope creep." "You end up going beyond the requirements that you had planned for," explained Byrne.

From an operational viewpoint, the after-visit summary is generated by a system that resides outside of the CPRS, which allows it to leverage the data in the VistA EHR and enables it to reach out to other sources on the Internet to expand data and information that is drawn into the summary. A physician, however, creates the summary from the CPRS, using a dropdown menu, and the summary changes in response to items selected for inclusion by the physician. Once the physician opens the summary, it appears in a browser and looks like a PDF document that is going to be printed for the patient. The browser auto-refreshes as the provider enters orders or information into the EHR, minimizing the data entry burden on the health care provider.

The format of the after-visit summary is designed to meet Stage 2 meaningful use criteria and comprises several distinct sections. The patient information section, for example, contains the patient's name, demographic information, smoking status, and language preference. The "Today's Visit" section includes the provider's name and office contact information, the reason for the visit and current problem list, vital signs, a list of diagnostic tests pending, future scheduled tests, immunizations of medications administered during the visit, and referrals to other providers. The "Important Notes" section lists clinical instructions, future appointments, recommended patient decision aids, and remote appointments that account for the fact that many VHA patients spend winters and summers in different parts of the country. Byrne noted that this section also describes the care plan and will eventually include the patient's goals, though it is still unclear how to incorporate those goals into the after-visit summary. "This is more an issue of cultural change rather than a technical issue," Byrne explained.

The "My Ongoing Care" section lists the patient's medications, including those prescribed by physicians outside of the VHA system and those at other VHA locations. This section also includes the names of all the members of the patient's primary care team. Byrne noted that his team is trying to translate the after-visit summary into Spanish and enabling it to be printed out in a larger font size for visually impaired patients. The physician can also include charts for trending clinical data, a feature that patients particularly like, and can call up education sheets based on the ICD-9 codes entered into the CPRS during the patient's visit. This educational material can be incorporated into the after-visit summary, either entirely or in pieces that are copied into specific section of the summary. It can also be printed separately, in which case a note is inserted automatically into the instructions section of the summary informing the patient to read the attached materials. There is also a technical translator built into the system that converts jargon from VistA into patient-friendly language.

Going forward, Byrne and his colleagues plan to conduct an evaluation trial of their after-visit summary. They are also working on a pre-visit summary to provide patients with the list of their medications to facilitate medication reconciliation and an opportunity to write down their concerns for the day. In addition, efforts are under way to make both the pre-visit and after-visit summaries available on patient kiosks that are part of the VA Veteran Portal System.

REACTIONS AND DISCUSSION

Rachel Solotaroff²

Central City Concern, the organization that Rachel Solotaroff works for, is a broad-based social service agency whose mission is to provide comprehensive solutions to ending homelessness and achieving self-sufficiency. As Solotaroff explained, Central City Concern is not a health care organization per se, but there is a high degree of substance abuse and mental illness in the population that it serves, so medical care is an important component of its mission. The population served is 60 to 80 percent homeless, using a fairly broad definition of "homelessness," from chronic homelessness on the streets all the way to transitional housing. Almost all the patients are at 100 percent of the federal poverty level or below, she said.

"Our core product isn't to produce visits, or to reduce hospitalizations," Solotaroff said. "Our core products are to produce hope and to produce safety, in the hope of ultimately influencing the choices that people

²This section is based on the presentation by Rachel Solotaroff, medical director, Central City Concern, and the statements are not endorsed or verified by the IOM.

make." Given the patient population that she and her coworkers treat and the general messiness and ambiguity, as she put it, associated with providing health care for this population, an after-visit summary serves as less of a summary of a visit or as an instructional tool and more of a snapshot in time of where a given individual is, what that individual is hoping for, how the physician can help, and where things might move to over time.

The after-visit summary that she has developed starts with an off-the-shelf product that the health care provider fills in as the visit proceeds. It is a very informal process, so much so that, in Solotaroff's case, she uses a marker to circle the important parts on the printout. She characterized this type of after-visit summary as representing the low-technology end of the spectrum, but one that is highly patient-centric. She starts the process by asking, "What is important to you today, and how can I help?" The patient lists a number of things, and together they try to identify goals to accomplish. Next, Solotaroff spends time checking her understanding of what has been agreed to and then tells the patient that she, too, has some goals, things that she needs to make sure the patient knows about or that they need to address together. Solotaroff said she may ask additional questions, conduct an exam, and look at the discharge summary if the patient has just gotten out of the hospital.

Then, collaboratively, they develop a plan. That is as far as the aftervisit summary goes, that teach-back moment when patients describe what they heard and understand. Solotaroff said she is typing as they have that discussion. For example, when she hears what they say they need to do about swelling ankles, she will write, "for your swelling of your ankles" do such and such. "Or if they have gotten it wrong," she said, "or if they have a misunderstanding, we will reframe it in a way that they can understand it. I type that in as the plan in their own words as we go." She says she tries always to end the summary with a personal sentiment, which may be as simple as "I am thinking about you. Take each day as it comes, and I am amazed at your strength."

Alice Horowitz³

Alice Horowitz described a feasibility study she and her colleagues conducted to determine the user friendliness of community-based dental clinics in Maryland. This project consisted of a health literacy environmental scan of 26 community-based dental clinics using methods developed by Rima Rudd and Jennie Anderson (Rudd and Anderson, 2006) and by

³This section is based on the presentation by Alice Horowitz, research associate professor at the University of Maryland School of Public Health, and the statements are not endorsed or verified by the IOM.

AHRQ (DeWalt et al., 2010). As part of the health literacy environmental scan, Horowitz and her colleagues also conducted a technology assessment of websites and use of EHRs. In addition, they assessed print materials (consent forms, postoperative instructions, and educational materials) that were available in the 26 participating clinics. They also conducted patient interviews and did a mail survey of providers to identify the communication techniques they were using.

This study, said Horowitz, confirmed the feasibility of conducting a health literacy environmental scan in community-based dental clinics and provided guidance for extending the guidelines developed by Rudd and Anderson and by AHRQ into the dental environment. "[The scan could be used] maybe not only just in community-based clinics, but also probably in private practice," said Horowitz. Their survey found that 18 of the 26 clinics used EHRs, though only three of these clinics—all operating under the umbrella of a federally qualified health center—integrated their dental EHR with the patient's medical EHR. "The lack of integration causes terrible barriers, both for the patient and for all kinds of providers," she said, particularly when it comes to decreasing early childhood caries because accomplishing that goal requires the entire health care team (medical and dental) to counsel patients about how to prevent dental caries and how to provide their infants with fluoride varnish treatments. Integration is also important for patients with diabetes, she explained, because controlling periodontal disease has a huge impact on controlling diabetes.

The printed forms, assessed using the SMOG (Simple Measure of Gobbledygook) readability formula, were rated between the 9th and 16th grade level, a long way from the recommended 8th grade level or below. The printed forms tended to use complex dental and legal terminology. These forms, said Horowitz, "were used more to protect the facility or providers than to help the patient understand what was going on." One of the more disturbing findings from this study was that none of the 26 clinics provided after-visit summaries to their patients, though she noted that her personal dentist did not provide after-visit summaries either. "I think we have a long way to go in dental health," said Horowitz. "Despite the availability of guidance for developing after-visit summaries from CMS, dentistry has not exhibited much interest in this potential activity that could make dental facilities and patients more health literate." Horowitz concluded her presentation by saying that the use of after-visit summaries in dental clinics is an exciting new area to explore, develop, and evaluate. Such summaries, if properly prepared, can help dental facilities become

⁴The SMOG formula estimates the level of education a person would need to be able to read and understand a piece of text. See http://www.readabilityformulas.com/smog-readabilityformula.php (accessed July 16, 2014).

more health literate, and they can provide an opportunity for patients to ask questions and providers to remind patients of important information about their appointment and what they need to do next.

DISCUSSION

Laurie Francis pointed out that patient-centeredness is critical to effective discharge planning, yet there are no data in the EHR on patient centeredness. Solotaroff responded that behavioral health is several decades ahead of primary care in terms of understanding patient-centered goals. When her organization was designing its system, it looked at seven domains of an individual's life that lead to self-sufficiency: physical health, substance use, mental health, housing, legal involvement, employment or income, and worldview (a way of getting at the issue of hope). Goals were then developed for each of the domains. When interacting with individuals, if the only thing a person is interested in is housing, then the other domains are set aside. As her organization redesigns its primary care EHR, Solotaroff continued, it will use these domains. The process will be more codified in terms of questions about self-efficacy than the free-form process described earlier in her presentation. There will be questions such as "How confident are you that you will be able to meet this goal?" and "What do you anticipate are barriers to this goal, and what can you use to overcome these barriers?"

John Byrne said that one of his colleagues suggested that the VA system needed a section on goals. It is a great idea, he said, but actually making it work in the EHR and changing the culture to have physicians address patient goals are big obstacles.

Rima Rudd said a common theme is attention to perspective—to the clinician's perspective but also to the patient's perspective. "The idea of dialogue, of truly asking and listening, and engaging those perspectives seems to be the key to successful work," she said.

5

Approaches to Developing Improved Discharge Instructions

The workshop's final panel featured two presentations on two very specific approaches to providing discharge instructions. Michael Paasche-Orlow, associate professor of medicine at the Boston University School of Medicine, discussed Project RED (Re-Engineered Discharge), a nationally recognized model for reengineering the hospital discharge process to improve the safety and efficiency of transitions of care. Charles Lee, president and founder of Polyglot Systems, Inc., spoke about the values and challenges associated with preparing discharge instructions for patients with limited proficiency in English.

PROJECT RED: REENGINEERING THE DISCHARGE PROCESS¹

In his initial comment to the workshop, Michael Paasche-Orlow noted that the issues that had been discussed are relevant to all transitions in the clinical setting when information is being exchanged between a health care provider and a patient. "I hope that as people learn and touch different parts of this elephant, we can share information and really expand together," he said.

Turning to the subject of his presentation, Project RED, Paasche-Orlow began by describing the series of activities that he and his colleagues went through to develop 11 mutually reinforcing components for discharge

¹This section is based on the presentation by Michael Paasche-Orlow, associate professor of medicine, Boston University School of Medicine, and the statements are not endorsed or verified by the IOM.

instructions that formed a RED Checklist. This checklist, which has been adopted by the National Quality Forum as 1 of the 30 "safe practices," includes the following components:

- 1. Make appointments for follow-up care.
- 2. Plan for the follow-up of results from pending tests.
- 3. Organize postdischarge services and equipment.
- 4. Identify the correct medicines and plan for patient to obtain those medications.
- 5. Reconcile the discharge plan with national guidelines.
- 6. Teach a written discharge plan the patient can understand.
- 7. Educate the patient about diagnoses and medicines.
- 8. Assess the degree of the patient's understanding of the plan.
- 9. Expedite transmission of the discharge summary to the primary care physician.
- 10. Provide telephone reinforcement.
- 11. Review appropriate steps for what to do if a problem arises.

After an evaluation and testing phase, including a project to evaluate and expand their thinking about culture competence in the context of Project RED, Paasche-Orlow and his colleagues added a 12th component, which was to ascertain the need for and obtain language assistance.

One challenge that he sees in creating written discharge instructions is dealing with the fact that they are out of date almost from the moment they are created. For example, the discharge instructions may include medication that the patient needs to get after discharge, but perhaps the patient cannot get to the pharmacy to get the prescriptions filled. What happens then? "These things have to be live documents that should be electronically available anywhere the patient goes, on any device," Paasche-Orlow said. "It is crazy that we are not there already."

Rather than thinking of them as a form or a piece of paper, discharge instructions should be viewed as a process that represents a significant cultural shift that, in many organizations, takes work to accomplish. The challenge, he explained, is conveying to an organization's staff that management cares about the work they do with their patients not only when they are within the health care setting but also when they leave. "This is a different type of focus," said Paasche-Orlow, one that goes from "who is taking the next admission" to a perspective that says, "I value the work that you do in preparation for your patient to go home and succeed."

As had been mentioned earlier during the workshop, the electronic systems for producing discharge instructions depend on the quality of the data in EHRs, and it is well known that EHRs are full of bad data. For example, a patient's medication list is often used by the health care provider as a

memory tool to remind him or her that the patient took an antibiotic for an infection 5 years ago. In most systems, though, that outdated information gets dumped in its entirety into the discharge instructions for the simple reason that the medication list in the EHR was not designed to be used to populate a discharge instruction form. Unless someone takes the time to go over the discharge instructions before the health care provider hands those instructions to the patient, and unless the health care provider takes time to review the discharge instructions before talking to the patient about them, the opportunity is ripe for the patient to receive something with little value and for the health care provider to be embarrassed.

Thinking of the care plan as a process instead of a form allows the health care provider to think about every document that goes to the patient in terms of how that document meets an educational agenda, explained Paasche-Orlow. It is important that the health care provider think about how a document will be empowering and activating for a patient and what educational process is required to support that document. Health care systems need to think about what training is necessary for staff and what supervision and monitoring processes are going to be needed for this process to take place. "This really requires that we regard all of the people working in our institutions in a pedagogic role," said Paasche-Orlow.

One of the lessons he and his colleagues learned during the testing and evaluation phase of Project RED was that it is critical to ferret out jargon. For example, everyone on a patient's care team knows what a discharge plan is, but patients relate better when it is called a care plan. Another lesson, Paasche-Orlow said, was the need for a new position, the nurse discharge advocate, who takes responsibility for interacting with the care team, reconciling the medication list, scheduling appointments, facilitating the checklist, and ensuring that the care plan meets national guidelines. The nurse discharge advocate also teaches the care plan and makes sure that the patient understands the details of the plan. The nurse discharge advocate's role is reinforced by the pharmacy staff, a member of whom makes a follow-up phone call 72 hours after discharge that reinforces the care plan and reviews medications.

Following medication instructions is often one of the biggest challenges for newly discharged patients, and the Project RED care plan goes to great lengths to present medication information as clearly as possible. The medication section of the RED care plan breaks down patients' medications according to the time of day they need to take a particular prescription and uses a graphically simple chart format that tells patients why they are taking a specific drug and how many pills to take at each time of the day (see Figure 5-1). The section that lists patients' upcoming appointments also makes use of a simple color-coded chart format that is organized by date and includes the health care provider's contact information, location, and

| Morning | heart | ASPIRIN EC 325 mg | 1 pill | By mouth |
|---------|---------------------------|---|--------------------------|------------------|
| | to stop smoking | NICOTINE 14 mg/24 hr | 1 patch (for 4 weeks) | On skin |
| | Then, after 4 weeks use → | NICOTINE 7 mg/24 hr | 1 patch | On skin |
| | Blood pressure | COZAAR LOSARTAN POTASSIUM 50 mg | 1 pill | By mouth |
| | Infection in eye | VIGAMOX MOXIFLOXACIN HCI 0.5 % soln | 1 drop | In your left eye |
| Noon | Blood pressure | ATENOLOL 75 mg | 1 pill | By mouth |
| | Blood pressure | LISINOPRIL 40 mg | 1 pill | By mouth |
| | Infection in eye | VIGAMOX MOXIFLOXACIN HCI 0.5 % soln | 1 drop | In your left eye |

FIGURE 5-1 Patient medication schedule.

SOURCE: As presented by Paasche-Orlow, 2014.

the reason for the visit. This section is followed by one in which patients can develop an agenda and write down questions for each health care provider at these future appointments.

In his closing remarks, Paasche-Orlow briefly reviewed the results of a randomized controlled trial that he and his colleagues ran to test whether the RED intervention was any better than usual care. The data from this randomized controlled trial of 749 patients showed marked improvements, with a 33 percent reduction in the number of emergency visits and readmissions in the group that received the RED intervention.

DISCHARGE INSTRUCTIONS: PATIENT VALUES AND CHALLENGES²

The mission of Polyglot Systems is to develop practical, affordable multi-language technology solutions to improve access to health care and reduce disparities for underserved patients and those with limited profi-

²This section is based on the presentation by Charles Lee, president and founder of Polyglot Systems, Inc., and the statements are not endorsed or verified by the IOM.

ciency in English. "What we are trying to do is to develop technology-based, scalable solutions to simplify instructions for patients to reduce common avoidable mistakes. The communication areas we currently focus on include reducing medication errors, improving medication adherence, and effective transitions of care," explained Charles Lee, who founded the company in 2001.

His approach is to consider health literacy as a personal skill for gathering, understanding, and then acting on appropriate health information. He mitigates people's low health literacy by consolidating relevant information in a way that enables them to focus on key messages, and by removing clutter and reducing noise. Improving understanding requires getting the reading level to one that is appropriate for most patients and using each patient's preferred language. "Why are we gathering a patient's language preference if we are not going to give them instructions in that language?" he asked. Improving understanding also requires the use of visual aids to reinforce written concepts and the use of font sizes that the elderly and visually impaired can actually read. Lee agreed with Paasche-Orlow that patient discharge is a process, not just a form, and it is essential then that the discharge instructions include specific actionable items presented in a way that is both personalized and encourages dialogue with the health care provider.

As illustrations of how Polyglot Systems is tackling these problems, Lee discussed three examples of the company's work. The medication summary (see Figure 5-2) is organized by time of day in an easy-to-read chart format. The summary that Lee presented was written in Spanish, but the Polyglot system is currently capable of generating the summary in 19 different languages. The summaries contain QR codes that the patient can scan to view video demonstrations, narrated in the patient's language, of complex medications. In the example Lee presented, scanning the QR code took the patient to a website that demonstrated in Spanish how to use a prescribed inhaler. A pilot study of this "Meducation calendar" showed that it reduced medication nonadherence by 56 percent over the first 90 days, compared to a baseline measurement taken prior to using this module (Zullig et al., 2014).

The second example Lee discussed addresses medication safety (see Figure 5-3), and it represents an attempt to take the consumer medication information sheet, which is typically written at a 12th–14th grade reading level and in 6-point font and turn it into something that a patient would read rather than throw away. The result of this project is a medication instruction sheet that is written at a 5th–8th grade reading level and that uses pictograms and other readability tools. These sheets can be generated in one of three font sizes for patients with visual impairments. Each sheet contains a bar code that the user can use at Meducation's free Internet

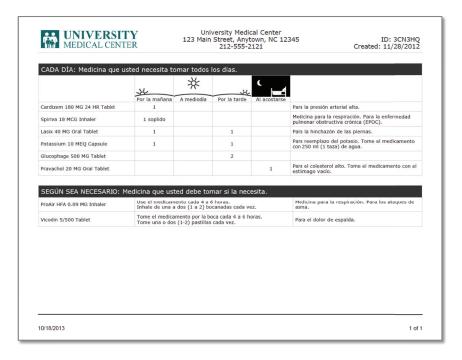


FIGURE 5-2 Medication summary. SOURCE: Polyglot as presented by Lee, 2014.

portal to view in any of the 19 available languages. "If you receive this in Chinese, but I am the caregiver and prefer to read it in English, I can go to the Web portal and download a copy in English," explained Lee. The Web portal also includes demonstrations of how to take complex medications. A pilot test of this tool by the University of Connecticut's John Dempsey Hospital showed that it increased Hospital Consumer Assessment of Healthcare Providers and Systems scores on three medication education measures from the 1st/1st/4th percentiles to the 85th/98th/52nd percentiles.

Lee's final example described a solution for creating customized discharge instructions using a template-based format. This tool allows the health care provider to select a condition, which then populates the system with a list of associated instructions, personalize the instructions available through dropdown menus to make the instructions relevant to the patient, and then print the instructions in English or the patient's preferred language. A pilot study involving 94 bilingual patients found that these discharge instructions were considered the best among all the models from the 18 participating sites. One interesting finding from this small pilot

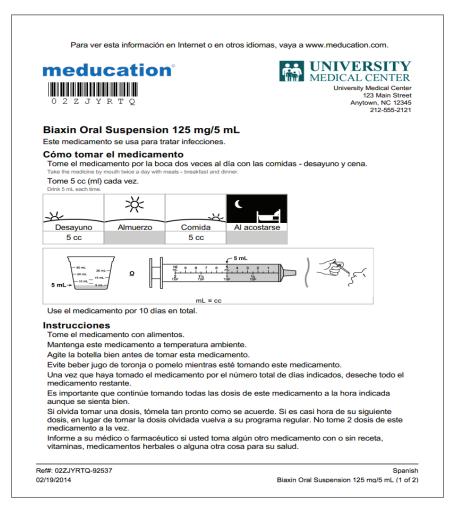


FIGURE 5-3 Medication safety. SOURCE: Polyglot as presented by Lee.

study was that patients and physicians both preferred by a large margin a format that included both English and the second language in a dual-column format. Physicians preferred the dual-column format because they did not like handing out materials they could not read themselves. Patients preferred the dual-column format because it enabled other English speakers in their household to be able to read the instructions. When asked, patients who received the Meducation discharge instructions described the

organizations that used them as caring, considerate, excellent, helpful, professional, responsible, and thoughtful. "The vast majority of patients felt that by receiving these types of documents, they were not being left alone, which is how they often feel when they get sent home from the hospital," said Lee.

He noted that one of the challenges to creating these types of documents is that they need to accommodate both science and art. The science part includes research-based best practices, such as the use of the Universal Medication Schedules; appropriate grade reading level; layouts that are visually pleasing and easy to read; and reinforcements of educational messages. The art part has to do with the intangibles—the key points that need to be included for a specific patient and the presentation for that particular patient given his or her cultural and language background. "You have to be careful how you represent different concepts for patients," said Lee. "For example, how do you represent food? Is it a sandwich, a pizza, or a bowl of rice? That depends on the patient's background."

Another challenge is to sell health literacy to EHR vendors who today are preoccupied with meaningful use certification. "They don't view health literacy as a high priority," said Lee, who added that EHR vendors have reported to him that the market is not asking for these types of products. "That is something we have to work on," he said. There are some positive indicators, though, Lee noted, particularly associated with accountable care organizations and patient-centered medical homes that receive payments on the basis of health outcomes. A key to making inroads, he added, is that these types of tools will have to be integrated into the current workflow. "We need to promote an environment of sharing and sustaining these types of tools and to develop plug-and-play interoperability that makes integrating these types of low-literacy tools easier," said Lee. He added in closing that "we need to stop hoping that patients are going to figure this out by themselves and give them instructions that will get them engaged—instructions that they can actually read, understand, and then act on."

DISCUSSION

During the ensuing discussion, Cindy Brach asked Lee if he had any ideas on how to overcome the market forces that seem to be stymieing adoption of tools for creating better discharge instructions. Lee said that pharmacies might be a good target given that they deal directly with consumers. Paasche-Orlow added that patient satisfaction could be an important lever given that 30 percent of a value-based purchasing score will be based on satisfaction scores. He agreed that pharmacies could be a good leverage point. It was noted that it would be a good idea to bring Walgreens and CVS to a future roundtable workshop.

George Isham said he appreciated the medication instruction sheet with the four-times-a-day regimen for taking medicines. But, he asked, what happens when medications change? How can this medication sheet become a living tool? Also, is there any integration of these instructions with how patients or their family members actually manage the counting out of tablets for each period? Paasche-Orlow responded that a number of issues are involved in trying to turn this into a living tool. For example, the data have to be able to flow and to go to all of a patient's providers. Another problem is that because patients have to pay different out-of-pocket amounts for medications, depending on their insurance coverage, some of them may not fill the prescriptions because of cost. Although there are great difficulties with relying too heavily on information technology, that is how we are going to be able to address these issues, he said.

Benard Dreyer asked Paasche-Orlow what was known about which of the listed 12 steps for reinforcing components for discharge instructions were most important. Paasche-Orlow said the answer is unknown because they did not have a way to differentiate the relative effects of the different components. There is a change in the length of the process, moving from an 8-minute-per-discharge conversation with patients to 45 to 50 minutes of conversation, education, and confirmation of comprehension. And, he said, the follow-up telephone call appears important because about half the time even those individuals who received the full intervention still had something related to medication that needed to be dealt with in the call. It is interesting to note, he said, that about 30 percent of the prescriptions written were still not filled at the time of the follow-up call, a number that shows that there is great need for improvement.

Wilma Alvarado-Little asked Lee what thoughts or ideas he has about adding languages, even languages with less diffusion, as the demographics of the United States change. Lee responded that the development of forms in different languages is market driven. Those with limited English proficiency are the ones first focused on. For example, there are many German speakers in the United States, but they tend to speak English very well. The population of Chinatown, however, which is somewhat isolated from the rest of the city, and the Hmong population have more of an issue with understanding the English language. Once a form has been developed for a particular customer, it becomes instantly available for every other customer, he said.

Given the complex issues involved in pain relief medication and the potential for abuse or unintentional habituation of pain medications, Isham asked, how does one deal with those challenges in discharge instructions for a low literacy population and those with limited English proficiency? Lee responded that it is very complicated and that there is a big difference between unintentional habituation and intentional misuse. Paasche-Orlow

agreed. He cited Massachusetts as an example of a state that has a system any provider can log onto in order to see a patient's history of dispensing of opiates, but this does not address the issue of a patient going across state lines to get medications. Acetaminophen is particularly difficult because not only do prescription products contain the drug but also so do many over-the-counter products. In the end, he said, one has to talk with one's patients because there is only so much a discharge form or an electronic system can do. One must ask oneself whether the patient is a person who is at risk for diversion or for under management of his medications and proceed accordingly.

6

Reflections on the Workshop

The workshop's last session had the members of the roundtable providing their reflections on what they learned over the course of the day's proceedings. Kim Parson said that the entire process has to be thought of in the context of a partnership between health care providers and their patients, a comment reiterated by Betsy Humphries, deputy director of the National Library of Medicine. "If we want these [discharge instructions and after-visit summaries to be of value to patients, we need to engage them in the design of them," said Parson, adding that the work presented at the workshop showed the value of moving away from a checkthe-box mentality. "We need to recognize that one size does not fit all," said Parson. Lori Hall, consultant for health education at Eli Lilly and Company, added that the discharge plan is a tool and cannot replace the human element when educating patients about the various aspects of their care after discharge. She also commented that it is important to remember that information overload is real and that handing a patient a thick booklet of instructions without having a person there to explain important items is likely to lead to more problems than it solves.

Laurie Myers, leader of Health Literacy Strategy for Merck & Co., Inc., thought that the roundtable needs to bring a broader range of people to the table, including pharmacy representatives. Her colleague at Merck, Margaret Loveland, said that the presentations and discussions made it clear that, above all, discharge instructions have to be meaningful, succinct, up to date, and accurate and that they have to account for cultural and language issues specific to individual patients. She also noted that it is important to remember that discharge instructions are not just a document

to hand to the patient. "We have to do education prior to discharge, and we have to follow up postdischarge," she said. Terri Ann Parnell agreed with Myers and added that it is easy to lose sight of the fact that these documents are the patient's and that they have to be created and used with the patient always at the center of the process. Laurie Francis noted, too, that discharge summaries can be an important part of the process that helps patients navigate the system by increasing health literacy.

Cindy Brach remarked that the CMS readmission payment incentives make hospitals a more responsive audience for this work. "I think we have less traction in the outpatient setting, which is where a lot of the care that is delivered keeps patients out of [the] hospital, so we need to think more about that," she said. Brach also reminded the roundtable of another workshop on patient-centered prescription labels at which a speaker challenged the attendees to step up and use the models that had been developed and tested. "U.S. Pharmacopeia stepped up to the plate and proceeded to assemble an advisory group to come up with standards that they then published as recommendations for a patient-centered label," she recounted. "I think that we are at that point with this topic, and I think that the IOM Roundtable on Health Literacy could be moving this forward. Getting vendors, clinician associations, and patients together to help the market realize this opportunity is something where we could make a contribution as a group."

Benard Dreyer said, "I do feel that the train is leaving the station on this issue. EHR vendors and hospitals are well into this, and it is going to be much harder to get them to change once it is established. This is the time to intervene, rather than to wait until it gets solidified. I would urge us to think about how we can do that and maybe have a serious discussion," he said.

Robert Logan said that as someone who approaches health literacy from a nonclinical perspective, the workshop's presentations reminded him of the importance of comprehensive data integration and assessment of a patient's condition. He was reminded, too, that discharge information and health education are a shared responsibility that involves primarily physicians, but also includes nurses, community health workers, and health coaches, and that the design of this tool needs to consider all of these as both sources of information and health educators. He also noted that a key piece of information for many patients is what is new or different about their condition and what to do about that.

Bernard Rosof proposed that there be a framework to discuss the issues of health literacy and discharge summaries that involves the National Quality Strategy and the IOM. "I think we can put this together in terms of patient safety, family- and patient-centered care, care coordination, and decreasing the leading causes of mortality in a framework of a learning health system; then we will accomplish a lot of what we have said around the table," Rosof stated.

Andrew Pleasant noted that he heard a concern about the balance between regulation of these documents and the information they contain but that this concern disappeared when the conversation shifted to one focusing on learning what the patient wants first. He noted that "even the best document process, if it is in a misaligned system, will be limited in its effectiveness. To just focus on the document or to just focus on the process without also focusing on the larger system and the culture that supports that system would be an incomplete solution." Champions, he added, are going to be important for accomplishing the system and culture changes that are needed to create a health-literate system that is more effective for patients.

Pleasant added that he did not hear much at the workshop about the role of theory in informing the design of discharge instructions and aftervisit summaries. "There is a true role for theory so that you know why you are doing what you are doing. It's called the scientific process, and it works pretty well," he said. Patrick McGarry was concerned that there was no mention at the workshop of how the Health Insurance Portability and Accountability Act affects the transmission of electronic data in EHRs. He also echoed the concern of his roundtable colleagues that the effectiveness of these documents to truly inform a patient must be demonstrated. "If people don't understand what is in those documents, they are going to go to the Internet. That is where they are going to get their information, which may or may not be accurate," he said.

Rima Rudd was encouraged by the signs that the field is turning a corner. "We are moving away from a myopic focus on the patient's capability of accessing information. Instead, we are focusing on our creation of accessible information," she said. She, too, was worried that scientific rigor might suffer in the haste to develop better discharge instructions. "We are too accepting of shortcuts when it relates to information exchange. We have to insist on scientific rigor," she said. Part of being scientifically rigorous is to build on accumulated knowledge, something that the field needs to do better. As a result, she said that she was coming away from this workshop as a stronger supporter of regulations than ever before. "Not regulations on the content of what goes into the after-visit protocol but on the process of how these are developed," said Rudd.

Steven Rush, director of the Health Literacy Innovations Program at UnitedHealth Group, cautioned that in the rush to ask patients to use websites, portals, smartphones, and other forms of electronic communication, it is important to teach them how to use these valuable tools. He mentioned research showing that unless there is a personal touch that goes along with these electronic tools, many people will stop using them in about 2 weeks.

Making the final comments, George Isham said that he was struck by the fact that the after-visit summary is only a fragment of what the patient

needs in order to achieve good health. "I can't get away from that thought that the after-visit summary is part of something larger, or ought to be part of something larger, in terms of what we are trying to do to help the patient get information, access services, and so forth." He also acknowledged the frequently voiced concern that health care providers and health care systems are overwhelmed by the information they have to convey as much as patients are overwhelmed by the information they need to absorb. "That is a sign that our health systems need to approach patients differently in the modern age. You cannot do it the same old way with the same old technology and the same old professional skills in the complex modern world and not feel overwhelmed," said Isham. "That means the way we are going about it is wrong, not that we need to dumb down the approach."

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Appendix A

Workshop Agenda

Institute of Medicine Roundtable on Health Literacy

Discharge Instructions and After-Visit Summaries: A Workshop March 17, 2014

The objective of the workshop is to provide information that will facilitate development of clearer, more understandable discharge instructions for both inpatient and outpatient facilities.

OPEN SESSION ROOM 100

8:30-8:45 Welcome, Workshop Overview, and Introduction of First

Panel

George Isham, Roundtable Chair

8:45–10:15 PANEL 1: Background

8:45–9:05 Why Were Rules and Regulations for Discharge Instructions Developed, and

What Are the Implications of These

Policies?

Josh Seidman, Ph.D. Independent Consultant Brookings Accountable Care Organization Learning Network

9:05–9:25 An Overview of What We Know About Current After-Visit Summaries and Hospital Discharge Summaries Instruction Materials

> Alex Federman, M.D., M.P.H. Associate Professor of Medicine Icahn School of Medicine at Mount Sinai

9:25–9:40 The Link Between Discharge and After-Visit Summary Constructed in a Health Literate Manner and Improved Outcomes Darren DeWalt, M.D., M.P.H. Associate Professor of Medicine University of North Carolina at Chapel Hill

9:40-10:15 Discussion

10:15-10:30 BREAK

10:30–12:15 PANEL 2: Inpatient Discharge Summaries

10:30–10:35 Panel Introductions George Isham

10:35–10:55 Presentation: Key Elements and Formatting for Discharge Instructions

Mark Williams, M.D., FACP

Director, Center for Health Services

Research

UK Healthcare

10:55-11:40 Reactions

10:55–11:10 Benard Dreyer, M.D.
Professor of Pediatrics
New York University School
of Medicine

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11:10–11:25 Avniel Shetreat-Klein, M.D., Ph.D. Assistant Professor Associate Medical Information Officer—Epic Operations Mount Sinai Medical Center

11:25–11:40 Man Wai Ng, D.S.S., M.P.H. Harvard School of Dental Medicine

11:40-12:15 Discussion

12:15-1:30 LUNCH

1:30–3:15 PANEL 3: Outpatient After-Visit Summary

1:30–1:35 Panel Introductions *George Isham*

1:35–1:55 Presentation: Key Elements and Formatting for Outpatient After-Visit Summaries

John M. Byrne, D.O.

Associate Professor of Medicine

Loma Linda University School of

Medicine

1:55-2:40 Reactions

1:55–2:10 Rachel Solotaroff, M.D., M.C.R. Medical Director, Central City Concern Portland, Oregon

2:10–2:25 Ruth Parker, M.D.
Professor of Medicine
Emory University School of
Medicine

| 52 | FACILITATING PATIENT | UNDERSTANDING OF DISCHARGE INSTRUCTIONS |
|----|----------------------|---|
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| | | 2:25–2:40 | Alice M. Horowitz, Ph.D. Research Associate Professor University of Maryland School of Public Health | |
|-----------|---|--|--|--|
| | 2:40-3:15 | Discussion | | |
| 3:15-3:30 | BREAK | | | |
| 3:30-4:45 | Approaches | | | |
| | 3:30–3:35 | Introductions George Ish | pam | |
| | 3:35–3:55 | Project RED (Re-Engineered Discharge) Michael Paasche-Orlow, M.D., M.A., M.P.H. Associate Professor of Medicine Boston University School of Medicine | | |
| | 3:55–4:15 | Discharge Instructions: Patient Values and Challenges Charles Lee, M.D. President and Founder Polyglot Systems, Inc. | | |
| | 4:15-4:45 | Discussion | | |
| 4:45-5:15 | Discussion and Roundtable Member Reflections on the Day | | | |
| 5:15-5:30 | Audience Comments and Questions | | | |
| 5:30 | ADJOURN | | | |

Appendix B

Biographical Sketches of Workshop Speakers

John M. Byrne, D.O., is the associate chief of staff for education (ACOS/E) at the VA Loma Linda Healthcare System (VALLHCS). As a practicing general internist, Dr. Byrne has been involved with graduate medical education for the past 20 years as clinician-educator, associate program director, ACOS/E, and associate professor of medicine at Loma Linda University School of Medicine. Dr. Byrne has also served as general internal medicine section chief at VALLHCS. Currently, Dr. Byrne is also chief of the Clinical Informatics Section and the Designated Learning Officer at VALLHCS. His research interests are resident supervision, evaluation of the trainee learning environment, medical informatics, and primary care education. Dr. Byrne and his VA colleagues developed and tested the Clinical Supervision Index (CSI), a tool to quantify attending physician supervision and measure residents' progression toward independence. Through a VA Health Services Research and Development, the CSI was tested and shown to be feasible and reliable in clinical settings at VALLHCS. With a VA Innovations grant, the CSI has been instantiated in software and has been deployed at VALL-HCS through the VA electronic health record, the Computerized Patient Record System. Other areas of research include evaluating the resident learning environment through trainee perceptions and using technology to monitor resident duty hours. With another VA Innovations grant, Dr. Byrne and his colleagues have developed and tested the After-Visit Summary, a tool designed to provide patients with a summary of outpatient visits. He recently received a grant from a VA Patient Aligned Care Team Demonstration Site to test providers' and patients' satisfaction with the After-Visit Summary, Recently, he collaborated with the Internal Medicine Residency

and VALLHCS on an educational innovation award through the VA to develop the Primary Care Interprofessional Patient-Centered Quality Care Training curriculum for internal medicine residents, postdoctoral psychology fellows, and pharmacy residents.

Darren A. DeWalt, M.D., M.P.H., is associate professor in the division of general internal medicine at the University of North Carolina (UNC) at Chapel Hill. He is board certified in pediatrics and in internal medicine. He has been a member of the American College of Physician Foundation Programs Committee for 5 years and is incoming chair of the Programs Committee. Dr. DeWalt actively researches self-management interventions for patients with low literacy and focuses on chronic diseases such as diabetes, heart failure, chronic obstructive pulmonary disease, and asthma. His focus is on patient-physician communication and health system design to achieve better outcomes for vulnerable populations. His work in health literacy includes epidemiological studies, systematic reviews, communication tool development, and clinical trials. He is currently principal investigator on a practice-based intervention to reduce hypertension disparities, work funded by the National Heart, Lung, and Blood Institute. He is the lead author of the Agency for Healthcare Research and Quality Health Literacy Universal Precautions Toolkit.

Dr. DeWalt led the design team and is currently a national improvement advisor for the Improving Performance in Practice (IPIP) program for the boards and specialty societies of internal medicine, family medicine, and pediatrics. IPIP is a program to help practicing primary care physicians improve care systems through working in improvement networks, measuring and sharing performance data, and receiving improvement education and training. He is the principal investigator at the UNC research site for the Patient Reported Outcomes Measurement Information System (PROMIS). PROMIS is developing advanced tools for measurement of symptoms, function, and quality of life. Dr. DeWalt is interested in the use of self-report measurements among vulnerable populations, particularly those with low literacy. Dr. DeWalt is a former Robert Wood Johnson Foundation Clinical Scholar at the UNC at Chapel Hill. He completed his residency in internal medicine and pediatrics at UNC at Chapel Hill, where he also served as chief resident in internal medicine. He received his medical degree from the Vanderbilt University School of Medicine.

Benard P. Dreyer, M.D., FAAP, is professor of pediatrics and director of Developmental-Behavioral Pediatrics at New York University School of Medicine. He is co-chair of the American Academy of Pediatrics (AAP) Health Literacy Program Advisory Committee and the immediate past president of the AAP New York Chapter 3. He is a member of the AAP Council

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on Communications and Media and a liaison member of the Committee on Pediatric Research. He is also active in the Academic Pediatric Association (APA) and is presently president of the APA. Dr. Dreyer's research group has been instrumental in documenting the improved outcomes seen in children exposed to early literacy programs such as Reach-Out-and-Read and has been in the forefront of studying ways to improve communications between providers and families with lower literacy/health literacy and limited English proficiency. He is co-editor of the book *Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics*, which was recently published by the AAP. Dr. Dreyer earned his medical degree from New York University School of Medicine and completed his residency in pediatrics at Albert Einstein College of Medicine.

Alex Federman, M.D., M.P.H., is an aging-focused health services and behavioral health researcher and associate professor of medicine at the Icahn School of Medicine at Mount Sinai. Dr. Federman obtained his bachelor of arts degree in biochemistry from the University of California, Berkeley, in 1988, his medical degree from the State University of New York, Brooklyn, in 1996, and a master of public health degree from the Harvard School of Public Health in 2001. He completed an internship and residency in primary care internal medicine at the Montefiore Medical Center of the Albert Einstein College of Medicine in 1999. He was a health services research fellow in the Department of Health Policy at Harvard Medical School from 1999 to 2001. He joined the faculty of the Mount Sinai School of Medicine in September 2002 and served as chief of the Division of General Internal Medicine there in 2011 and 2012. Dr. Federman was awarded a Robert Wood Johnson Foundation Generalist Physician Faculty Scholarship in 2004 and a Paul B. Beeson Career Development Award in Aging Research from the National Institute on Aging in 2006. His research addresses issues of chronic illness self-management with a focus on health literacy, cognition, and health-related beliefs. He leads two large National Institutes of Health (NIH)-funded cohort studies examining chronic illness self-management in older adults, as well as a Patient-Centered Outcomes Research Institute-funded randomized controlled trial of self-management support for older people with asthma. Dr. Federman also serves on the board of governors of Mount Sinai Care, the accountable care organization of the Mount Sinai Medical System. Dr. Federman provides primary care to adult patients in the Internal Medicine Associates practice in East Harlem, New York.

Alice M. Horowitz, Ph.D., R.D.H., is a research associate professor at the University of Maryland School of Public Health. Formerly she was a

senior scientist in the Division of Population and Health Promotion Sciences at the National Institute of Dental and Craniofacial Research. She was a primary architect of the Maryland State Oral Cancer Prevention and Early Detection coalition. She initiated both state and national research on what health care providers and the public know and do about oral cancer prevention and early detection. She has initiated statewide research on what the public knows and does about preventing dental caries and their perceptions of communication skills of dental providers and on health care provider (physicians, nurse practitioners, dentists, and dental hygienists) reported use of recommended communication practices. She served as the NIH lead for the Healthy People 2010 Oral Health Chapter and worked on Healthy People and Healthy People 2000. She organized the National Institute of Dental and Craniofacial Research's workshop on oral health literacy and co-authored the resultant findings. She has published more than 125 scientific papers and book chapters and is the recipient of numerous awards. Dr. Horowitz holds a Ph.D. in health education from the University of Maryland, College Park.

Charles Lee, M.D., is founder and president of Polyglot Systems, Inc., in Morrisville, North Carolina. Dr. Lee founded Polyglot in 2001 with a mission to develop practical, affordable multi-language technology solutions to improve health care access and reduce disparities for underserved and limited-English-proficient patient populations. He is an internal medicine physician and past National Library of Medicine fellow in medical informatics at UNC at Chapel Hill/Duke University. He has extensive experience in medical software product development as well as health literacy, user interface, and instructional design. Dr. Lee is a past recipient of the Tibbetts Award from the U.S. Small Business Administration for his work in health care and technology. Dr. Lee has received Small Business Innovation Research phase I and II grants for four separate projects through the National Institute on Minority Health and Health Disparities and the National Cancer Institute. Some areas of Dr. Lee's multi-language research and development include (1) applications for health insurance coverage, (2) reduction of medication errors, (3) medication reconciliation and adherence intelligence, (4) discharge instructions, and (5) emergency triage.

Man Wai Ng, Ph.D., is chief of the Department of Dentistry at Boston Children's Hospital and assistant professor of developmental biology (pediatric dentistry) at the Harvard School of Dental Medicine. Dr. Ng received her D.D.S. degree from the State University of New York at Stony Brook and her M.P.H. degree from the Harvard School of Public Health. She has been in full-time hospital dentistry and has served as residency director of pediatric dentistry at two children's hospitals. She is a member of the Review

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Committee of the Commission on Dental Accreditation and the Examination Committee of the American Board of Pediatric Dentistry. She was a member of the board of trustees of the American Academy of Pediatric Dentistry and the Advisory Committee on Training in Primary Care Medicine and Dentistry of the Health Resources and Services Administration.

Michael Paasche-Orlow, M.D., M.A., M.P.H., is associate professor of medicine, Boston University School of Medicine. Dr. Paasche-Orlow is a general internist and a nationally recognized expert in the field of health literacy. Dr. Paasche-Orlow is currently a coinvestigator with five funded grants that examine health literacy, including two intervention studies evaluating simplified information technologies for behavior change among minority patients with a range of health literacy levels. Dr. Paasche-Orlow is a member of the Project RED (Re-Engineered Discharge) research team, a nationally recognized model to reengineer the process of hospital discharge to improve the safety and efficiency of transitions of care. Dr. Paasche-Orlow's work has brought attention to the role that health literacy plays in racial and ethnic disparities, self-care for patients with chronic diseases, end-of-life decision making, and the ethics of research with human subjects. Dr. Paasche-Orlow is the associate program director for the Boston University School of Medicine's General Internal Medicine Academic Post-Doctoral Fellowship Program and the associate section chief for research for the Section of General Internal Medicine in the Boston University School of Medicine's Department of Medicine.

Ruth Parker, M.D., is a professor of medicine and public health at Emory University School of Medicine. She developed one of the first measurement tools to quantify patients' abilities to read and understand health information—the Test of Functional Health Literacy in Adults (TOFHLA)—and co-wrote the definition of health literacy that is used by Healthy People and the NIH and in the Institute of Medicine (IOM) report *Health Literacy:* A Prescription to End Confusion. She is also the developer of a model of health literacy that is achieving growing recognition in the United States and internationally. Dr. Parker worked to define medication labels as an issue at the intersection of health literacy and patient safety, and she cowrote the seminal white paper on the topic, which was presented to the IOM at a workshop on standardizing medication labels. This led to pivotal work by the U.S. Pharmacopeia, where Dr. Parker worked on an expert panel to create standards for improved medication labels. This standard has now been published by U.S. Pharmacopeia.

Dr. Parker also works with the Food and Drug Administration as a scientific expert/special government employee regarding medication labels and with the Nonprescription Drug Advisory Committee as an expert in

consumer understanding of medication labels. Dr. Parker is also a strong advocate for health literacy and its importance to health. She has worked tirelessly with professional societies, federal and state agencies, and congressional staff to inform them about health literacy issues and to encourage them to recognize health literacy as a priority issue.

Joshua J. Seidman, Ph.D., is a consultant to the Brookings Accoutable Care Organization Learning Network, supporting physician-led accountable care organizations in using data better to manage population health. For more than 23 years, Dr. Seidman has focused on delivery system transformation through quality measurement and improvement; patient engagement; participatory medicine; and the intersection of e-health and health services research. Dr. Seidman also oversaw quality and performance improvement at Evolent Health, which supports the nation's leading providers in their population health and care transformation efforts. He previously served as director of meaningful use for the U.S. Department of Health and Human Services, where he was responsible for the Office of the National Coordinator for Health Information Technology's policy development around the meaningful use of electronic health records and e-quality measures. Previously, Dr. Seidman was the founding president of the Center for Information Therapy, which advanced the practice and science of using health information technology to deliver tailored information to consumers to help them make better health decisions. He has also served as director of Measure Development at the National Committee for Quality Assurance and has conducted research and analysis related to providers at the American College of Cardiology and the Advisory Board Company, Dr. Seidman earned a Ph.D. in health services research and an M.H.S. in health policy and management from Johns Hopkins Bloomberg School of Public Health and earned a B.A. in political science from Brown University. In a volunteer capacity, Dr. Seidman currently serves as president of the Society for Participatory Medicine and previously served for 5 years as president of Micah House, a transitional house for homeless women in recovery from substance abuse.

Avniel Shetreat-Klein, M.D., Ph.D., is associate medical information officer at the Mount Sinai Medical Center, a 1,300-bed, Davies-award-winning academic medical center. Dr. Shetreat-Klein is board certified in physical medicine and rehabilitation as well as in clinical informatics. In addition to an active clinical practice specializing in the rehabilitation of individuals with spinal cord injury, he leads a team of clinicians who provide clinical input into decisions affecting the information systems at the medical center, focusing heavily on the use of the electronic medical record and associated systems to drive quality, safety, and regulatory initiatives.

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Rachel Solotaroff, M.D., M.C.R., is medical director at Portland, Oregon's Central City Concern, an agency whose mission is to provide comprehensive solutions to ending homelessness and achieving self-sufficiency. She works as a general internist at Central City Concern's Old Town Clinic, a designated Healthcare for the Homeless program. In the past 8 years, Dr. Solotaroff has also overseen the transformation of the Old Town Clinic into a patient-centered primary care home, with an emphasis on providing integrated care for individuals with complex social, medical, and behavioral health conditions, including chronic pain, addiction, trauma, and homelessness. In the current environment of health care transformation, Dr. Solotaroff devotes most of her nonclinical time to co-creating an integrated and seamless continuum of care for vulnerable individuals at Central City Concern and within the Portland community.

Mark V. Williams, M.D., FACP, M.H.M., is director of the Center for Health Services Research and professor and vice-chair of the Department of Internal Medicine at the University of Kentucky. Dr. Williams graduated from Emory University School of Medicine and completed a residency in internal medicine at Massachusetts General Hospital. He also completed a Faculty Development Fellowship in General Medicine at UNC at Chapel Hill, the Woodruff Leadership Academy at Emory, the Program in Palliative Care Education and Practice at Harvard, the Advance Training Program in Health Care Delivery Improvement sponsored by Intermountain Healthcare's Institute for Health Care Delivery Research, and the Business for Scientists Program at the Kellogg School of Management at Northwestern University.

Dr. Williams established the first hospitalist program at a public hospital in 1998 and built two of the largest academic hospitalist programs in the United States at Emory University (1998-2007) and Northwestern University (2007-2013). A past president of the Society of Hospital Medicine (SHM) and the founding editor of the Journal of Hospital Medicine, Dr. Williams actively promotes the role of hospitalists as leaders in the delivery of health care to hospitalized patients. He has been quoted in the New York Times, the Wall Street Journal, and Consumer Reports. He also serves as principal investigator for SHM's Project BOOST (Better Outcomes by Optimizing Safe Transitions). With grant funding from the John A. Hartford Foundation, BlueCross BlueShield of Illinois, and other foundations, Project BOOST has been disseminated to more than 180 hospitals across the United States. Dr. Williams has more than 100 peer-reviewed publications, including work in such journals as the Journal of the American Medical Association, the New England Journal of Medicine, and the Annals of Internal Medicine. His research focuses on quality improvement, care transitions, teamwork, and the role of health literacy in the delivery of health care.

