

White Paper

TALKING THE PATIENTS' LANGUAGE

The importance of effective, health literate, patient-centered engagement

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EXECUTIVE SUMMARY

FOSTERING POSITIVE HEALTH BEHAVIORS

This white paper explores evidence that improving patient engagement leads to positive outcomes for all healthcare system stakeholders. The clinical encounter is at the core of patient engagement, supporting and fostering positive health behaviors. This engagement can be amplified by patient support programs designed using the principles of behavior change, adult learning, health literacy and instructional design. Based on multimodal instructional design, such programs can enhance engagement of patients with different learning styles, using a range of modalities – print, video, digital, mobile, or face-to-face training. Behaviorally driven mobile health interventions are of particular interest, potentially offering an interactive channel to address pathways linked to sustained behavior change, although the benefits of face-to-face interaction should not be underestimated.

INTRODUCTION: USING PATIENT ENGAGEMENT TO OPTIMIZE HEALTHCARE OUTCOMES

Effective patient engagement and empowerment – driving patients' involvement in their own healthcare and decision making – has potential to improve treatment adherence, health outcomes and patient quality of life. However, while engagement is critical for better patient outcomes, as many as 56% of healthcare consumers in the United States show little or no engagement in their health.¹

Over the past decades, clinical practice has gradually been increasing its focus from an "authoritative/paternal" model to a more "collaborative/consumer" model. This shift often calls on patients as consumers to become more active in their own healthcare decisions, and to move from "adherence" to "self-management" where they have a full

PATIENT ENGAGEMENT IS DEFINED BY THE AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ) AS

"The involvement in their own care by individuals (and others they designate to engage on their behalf), with the goal that they make competent, well-informed decisions about their health and healthcare and take action to support those decisions."²

understanding and belief in their treatment plan. As the number of chronic disease patients is growing significantly across the world, the healthcare industry has responded to the call for increased "patient engagement," with governments also supporting this trend. This response aligns with a growing body of evidence demonstrating that patient-reported and quality outcomes and patient experience are improved when patients become more actively involved in their own healthcare.

The rise in patient engagement activities represents a shift in approach within the current values and outcomes era. This increase in patient engagement accompanies the changes in long-term disease prevalence and therapies, an aging population, the presence in individuals of multiple chronic medical conditions (multimorbidity), simultaneous use of multiple drugs to treat a single ailment or condition (polypharmacy), and cancer increasingly becoming a long-term condition rather than a terminal disease.

Pharmaceutical company pipelines are also shifting, placing a new emphasis on patient identification, and patient education and training. The regulatory environment continues to evolve, with requirements to demonstrate that patient engagement activities meet a need, are non-promotional, and support patient autonomy. There is also increasing interest in use of eHealth (healthcare practice supported by electronic processes and communication) and mHealth (the use of mobile phones and other wireless technology in medical care).

An awareness of current policymaker agendas is essential. Of equal importance is the need to show value of a product if costs are increased, a push for greater citizen engagement, changes in the healthcare workforce, and availability of supporting technology.

DRIVING PATIENT ENGAGEMENT, LEARNING AND RETENTION

The clinical encounter is at the heart of interactions between patients and the healthcare system, and this drives patient engagement, supporting and fostering positive health behaviors (Figure 1).

It is now widely recognized that increasing someone's level of involvement in the learning process is a key consideration when designing patient engagement services.³ This moves us away from just providing passive content to considering ways in which people can engage and "be involved." In addition, multimodal programs incorporate multiple learning approaches to cater to the many learning styles that adults bring to training environments (Figure 2).

> Good patient engagement strategies using multimodal design can help enhance learning by building engagement through a variety of formats, which can benefit patients with many different learning styles.

Figure 1: Patients actively participating in their own healthcare can achieve positive outcomes

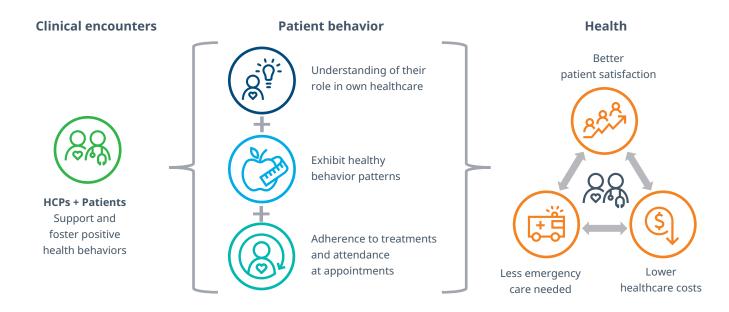
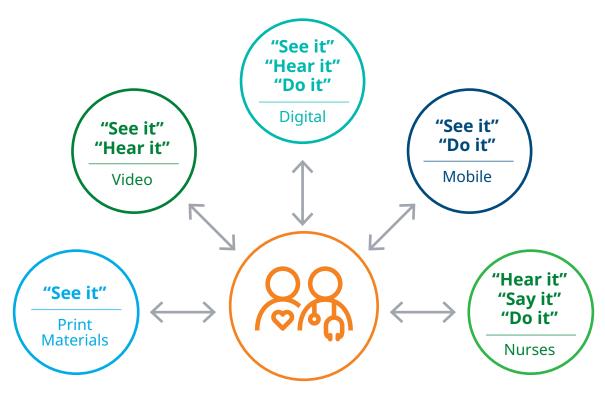


Figure 2: Considering different styles of learning



Good patient engagement strategies using multimodal design can help enhance learning by building engagement through a variety of formats – print, video, digital, mobile and face-to-face training with healthcare providers (Figure 3). Varied formats can enable engagement of patients with many different learning styles. For example, informational content can be delivered via printed materials ("see it"). Patient stories and emotional engagement can be delivered via videos ("see it, hear it"). Action planning, goal setting and tools can be delivered to patients via digital channels, including the Internet and apps ("see it, hear it, do it"). Symptom trackers and text reminders are good examples of these channels, and allow patients to be prompted ("see it, do it"). Live discussions can take place through nurse educator or pharmacist contact, in person or through a call center ("hear it, say it, do it").

Figure 3: Using multimodal design to enhance learning



"See it, hear it, say it, and do it"

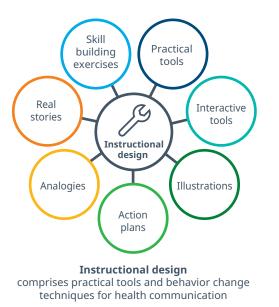
DEVELOPING EFFECTIVE CONTENT FOR PATIENT ENGAGEMENT PROGRAMS

Effective content can be developed for patient engagement programs by using the principles of behavior change, adult learning and health literacy (Figure 4). Instructional design takes advantage of elements such as skill-building exercises, practical and interactive tools, illustrations, action plans, analogies and real stories. Behavior change models – taking account of patient knowledge, attitudes/beliefs and skills – have been applied to almost every disease state. In addition, incorporating evidence-based behavior change techniques into content, such as action planning and self-monitoring of behavior, increases the likelihood of effecting meaningful change.⁴

The 3 pillars of instructional design, behavior change and health literacy models can be a powerful combination to help engage patients, and should form the foundations of any patient support program. This combination provides:

- Tools to address values, beliefs, attitudes, emotions
- **Education** to address gaps and barriers, and justify the patient engagement program or product
- **Practical training** to increase self-efficacy, confidence and skill
- **Materials** that leverage the entire support network (HCPs, nurses, dieticians, physician assistants, pharmacists, advocacy, family)
- **Resources** to support access and overcome cost barriers
- Action plans that offer a linear path, showing the various steps the patient needs to follow (Figure 5)
- **Multimodal design** to accommodate multiple learning styles

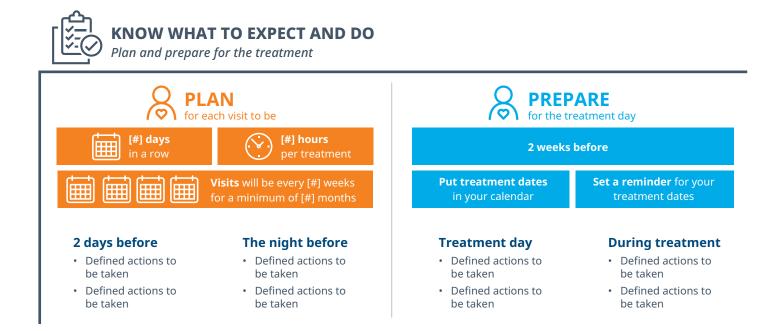
Figure 4: Developing effective engagement content



Using the principles of instructional design, behavior change and health literacy



Figure 5: Action plans: Applying the theory to patient materials



THE IMPORTANCE OF HEALTH LITERACY

Health literacy is much more than being able to read. Patients need to be able to find information in print materials, online and through health and advocacy organizations. They can use this information to manage their health condition(s) by:

- **Understanding** treatment choices and recommendations, including risks and benefits
- Interpreting information for example, risks for disease recurrence or progression – that may use numerical concepts such as percentages and probability
- **Asking questions** for clarification; and managing appointments and insurance-related tasks.

Health literacy is one of the strongest predictors of health status and outcomes, with low health literacy being associated with incorrect use of medicines, less knowledge of disease prevention and self-care strategies, more hospitalizations and emergency visits, and higher levels of illness.^{5,6} Health literacy is a stronger predictor of health status than income, education, employment status, or racial or ethnic group.

HEALTH LITERACY IS DEFINED AS

"The ability to find, understand, and use basic health information and services needed to make appropriate health decisions."⁷

Despite its importance, health literacy remains a major problem around the world.^{8,9} In Europe, fewer than 1 in 8 adults have excellent health literacy and one-half of adults have problematic or inadequate health literacy. In the United States, fewer than 1 in 10 adults have proficient health literacy, and more than one-third of adults have basic or below-basic health literacy.

PRINCIPLES FOR ENSURING **CLEAR COMMUNICATION**

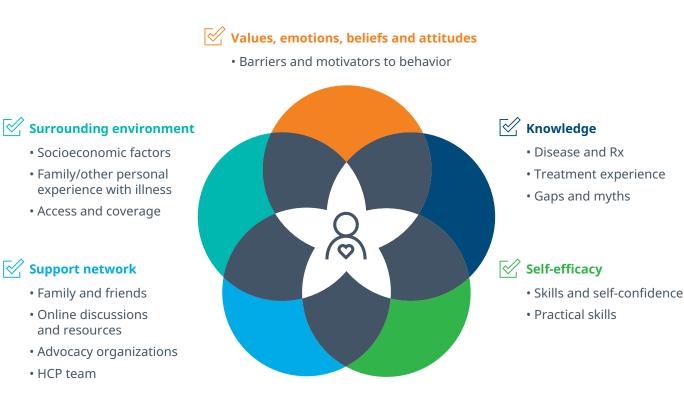
To ensure clear communication, it is helpful to adopt proven principles for developing materials that are easy for patients to understand and use. Health literacy principles from the U.S. Centers for Disease Control and Prevention include:10-12

Providing content that solves problems, based on knowledge about the intended audience (Figure 6), by ensuring that the writer:

- · Makes the purpose of the piece evident
- Validates patient/caregiver challenges
- Limits the number of concepts to what can reasonably be learned in the time allowed
- Focuses on behaviors, rather than medical facts
- For data/statistics, uses ratios with (or instead of) percentages
- Reviews key takeaways.

Figure 6: Characteristics of the intended audience

HCP team



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Writing and editing content for easy reading,

including using an active voice, choosing common words that are a good fit, and being consistent with word use, are all essential approaches, which also facilitate the process of translating patient materials into other languages. New terms should be defined within the text, abbreviations spelled out at the first mention, and context provided when offering new information. Writing should be tailored to 6th to 8th grade reading level (U.S.) or 7th to 9th grade reading level (Europe), or lower, using the Fry readability assessment.¹³ Subheads should be used, and information subdivided with bullet points, with no more than 7 items in a bulleted list.

Barriers to applying health literacy principles may exist, including Institutional Review Board (IRB) and Ethics Committee (EC) requirements, branding guidelines, the need for age-specific design (e.g. pediatrics), production specifications due to budgetary issues, and client preferences. Many companies and regulatory bodies, such as the FDA, are increasingly recognizing the importance of health literacy, and in some cases providing recommendations and requirements for material reading levels.

Designing for easy reading, using a general checklist:

• Provide adequate white space around the text and graphics. This helps keep the design simple and enables readers to focus on the main feature and message. White space helps readers feel less overwhelmed when trying to focus on content. • Ensure that design is appropriate for the patient demographic (age, ethnicity, etc.), and provides consistency in layout from page-to-page, with an appropriate font style and size, left-justified body text, and limited use of italics and underlining.

Using color with purpose, providing contrast between text and background, and using blocks of color to highlight key messages in a "Tips" section or glossary. Dark text on a light background can be easier to read than white text on a dark background.

Using visuals for emphasis, to explain information, reinforce important content, and provide relief from large areas of text. Photos and illustrations can help demonstrate desired behaviors, with images chosen to represent the target audience. Tables, charts and diagrams should be used to explain information. Readers with low literacy levels might rely on pictures to help them understand information and what they need to do. Placing these images close to copy describing the desired behavior, as well as providing captions to the visuals, helps readers comprehend the information and, hopefully, moves them toward engaging in the positive action that is being depicted.

Involving the reader by validating the challenges that patients and caregivers face, and using a positive and friendly tone. Opportunities to interact with the material – via checklists, action plans, Q&A sections or notes pages – can help readers understand, absorb and apply the information.

AN EXAMPLE IN PRACTICE: THE BIOPSYCHOSOCIAL ASSESSMENT MODEL

When designing materials and methods to engage patients it is important to move beyond the medication and intentional non-compliance and consider psychosocial barriers. In many clinical situations, unintentional adherence barriers and treatment decisions are driven by psychosocial concerns. One example in practice, the Biopsychosocial Assessment Model,¹⁴ provides a holistic view of patient and caregiver needs in 7 key areas (Figure 7). The IQVIA approach to digital innovation challenges the assumption that behavior change can be established through simple reminders, tracking and alerts, and supports the idea that behaviorally driven mobile health interventions can address multiple pathways associated with sustained behavior change.

Figure 7: The Biopsychosocial Assessment Model

Ensures that we know the needs, drivers and barriers of the audience



Figure 8: The Biopsychosocial Assessment Model applied to chronic pain

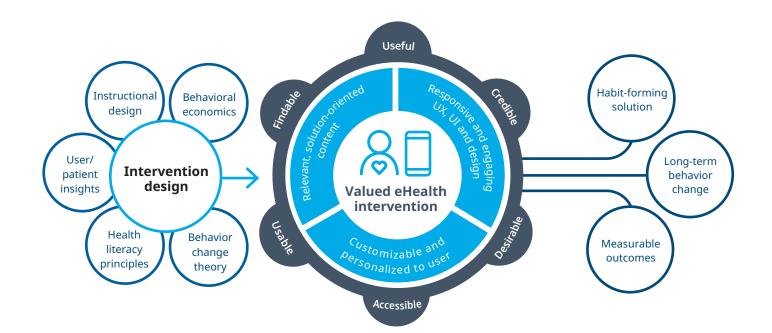


As an example, effective patient engagement material can be designed for the patient with chronic pain having first considered all relevant factors within this assessment model (Figure 8). This will include content, style and mode of delivery, which all need to be considered against the background of the assessment model results.

DIGITAL SOLUTIONS DRIVING ENGAGEMENT AND SUSTAINED BEHAVIOR CHANGE

Digital innovations may enable a nimble approach based on patient needs, helping to initiate and track behaviors, and encourage longer-lasting behavior changes and best practices. The IQVIA approach to digital innovation challenges the assumption that behavior change can be established through simple reminders, tracking and alerts, and supports the idea that behaviorally driven mobile health interventions can address multiple pathways associated with sustained behavior change (Figure 9).

Figure 9: Opportunities for digital innovation to drive engagement and efficiency



CONCLUSION: FACE-TO-FACE INTERACTIONS AND TECHNOLOGY CAN OPTIMIZE CARE AND OUTCOMES

Successful patient engagement programs depend on a tailored combination of face-to-face interactions and technology – including behaviorally driven mobile health approaches – with oversight from healthcare professionals. These programs need to respond to ongoing changes in disease prevalence, R&D pipelines, the regulatory environment and policymaker agendas. Based on best practices in supporting health literacy, such programs can prove their worth in enabling pharmaceutical and biotech companies to help optimize patient care and outcomes, while clearly demonstrating the benefits of their therapies. Continuing to talk the patients' language – through effective, patient-centered engagement – will build on this success in years to come.

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John leads our patient engagement, medical affairs, medical communications and market access businesses across Europe where he works with clients to address practical barriers to the uptake and use of medicines and medical devices. John's business focuses on building innovative and creative solutions through strong design and development capabilities alongside ensuring excellence in delivery from outsourced teams of nurses, Medical Scientific Liaison and pathway redesign specialists. He took up this position in September 2017 after two years as Senior Director for Global Service Development in Integrated Market Access.

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Clare provides oversight and strategic direction for patient, caregiver and healthcare professional programs to promote health related behavior change as well as behavioral science thought leadership and product design. A health psychology specialist with a strong academic and commercial skill set, Clare has extensive experience in health behavioral research, intervention design and evaluation. For over 8 years, Clare has designed and overseen the delivery of global patient support services across a wide range of therapeutic areas and led strategic product design to promote sustained health behavior change.

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