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# Patient Engagement in Neuroradiology: A Narrative Review and Case Studies

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## ABSTRACT

**SUMMARY:** The field of patient engagement in radiology is evolving and offers ample opportunities for neuroradiologists to become involved. The patient journey can serve as a model that inspires patient engagement initiatives. The patient journey in radiology may be viewed in 5 stages: 1) awareness that an imaging test is needed, 2) considering having a specific imaging test, 3) access to imaging, 4) imaging service delivery, and 5) ongoing care. Here, we describe patient engagement opportunities based on literature review and paired with case studies by practicing neuroradiologists.

**ABBREVIATION:** OOPC = out-of-pocket cost

**P**atient engagement refers to the desire by, and capability of, patients to actively participate in their own health care journey, in a way uniquely appropriate to the individual, through collaboration with a care provider or health care institution, with the aim of improving health outcomes and enhancing the overall patient experience.<sup>1</sup> The idea of patient engagement emphasizes treating patients as active participants in their health care rather than passive recipients of medical advice. Neuroradiologists play a crucial role in patient care, and understanding patient engagement can substantial impact the way we interact with and provide care to our patients.

When adapted to neuroradiology practice, patient engagement includes giving access to the information and resources patients need to make decisions related to neuroimaging studies. This can include explaining the purpose, benefits, and potential risks of a particular imaging test or procedure to patients, addressing their concerns, and ensuring they have a clear understanding of the results and their implications. Fundamental principles in patient engagement comprise empowering patients to ask questions and express their preferences, recognizing that patients have unique perspectives and knowledge about their

own bodies, and allowing them to let their personal circumstances influence their health care choices.<sup>2</sup> By embracing patient engagement, neuroradiologists can create a patient-centered approach to care that can improve patient satisfaction, compliance with recommended treatments, and overall health outcomes.<sup>3</sup>

Here, we performed a narrative review of patient engagement opportunities in diagnostic neuroradiology or radiology by using a patient journey framework (Online Supplemental Data).<sup>4</sup> Additionally, members of the ASNR Quality, Safety, and Value Committee provided examples of initiatives from their own practices. Patient engagement is still a “young” movement in health care; because of a paucity of neuroradiology-specific examples in the published literature, some relevant adaptations were made from radiology in general or from medicine at large.

## The Patient Journey Framework

A simple and intuitive way to identify opportunities for patient engagement comes with patient journey mapping, where patients describe in sequence each step, point of contact, and each experience along their care journey.<sup>4</sup> Patient journey mapping is a visual representation of the patient’s points of engagement with the health care system as a linear path. This can be used as a tool to identify opportunities for improvement, for example, how radiology could meet a patient’s needs at each stage of this journey (Online Supplemental Data).

In general, there are 5 steps in this journey that have been described in medicine, which can be summarized as Awareness, Consideration, Access, Service Delivery, and Ongoing Care<sup>4</sup> and which we adapted to radiology. The journey starts with the patient’s Awareness that they need medical care, and it usually involves information gathering through online searches, review

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sites, marketing campaigns, networking, and community involvement. During the Consideration stage, patients decide whether a health system can meet their needs by contemplating factors, such as referrals, coverage and benefits, recommendations, access, and ratings and reviews. Once decided, the Access stage refers to scheduling and preparing for a visit with a health care professional or service, which entails a variety of communications as part of the scheduling and patient acquisition process, as well as any information regarding getting to the location and how to prepare for the visit. The following Service Delivery stage extends from checking in to checking out, and includes admission, discharge, and billing. The final stage is Ongoing Care with a goal of attaining and maintaining wellness and/or continued care management. Here, we adapt these journey stages to radiology as follows: 1) awareness that an imaging test is needed, 2) considering having a specific imaging test, 3) access to imaging, 4) imaging service delivery, and 5) ongoing care (Online Supplemental Data).

### **Patient Engagement in Neuroradiology/Radiology**

In the following, we present a narrative review of patient engagement in neuroradiology by using the patient journey (Online Supplemental Data). When available, the content was enriched by case studies in neuroradiology that may not be available in the published literature and that highlight successes and barriers.

#### **Stage 1: Awareness**

**Definition.** Patient awareness of needing medical imaging involves information gathering (eg, online searches, review sites, marketing campaigns, networking, community involvement).<sup>4</sup>

**Narrative Review.** At this stage of the patient's journey, the key intervention to improve engagement is communication with the purpose of education, for example, through written information or through visuals, such as infographics or videos. Educational materials for patients become relevant and may change in content depending on the stage of the patient's journey.

Based on research in medicine, during the Awareness stage, patients mostly look for information on commercial websites (.com) (~70%), followed by using a search engine (~10%), or searching academically affiliated sites (.edu) (~10%) and government-sponsored websites (.gov) (5%).<sup>5</sup> Nonprofit organizations (.org) were not an important source of information.<sup>5</sup> The main issue with seeking information from commercial sites is that it can be challenging to differentiate useful health information from marketing and promotional materials. Accordingly, patients experienced higher levels of frustration when using search engines, and search engines required more effort, as well as raised concerns regarding the content quality.<sup>5</sup>

RadiologyInfo.org is a patient-facing website that is accessible at no charge and sponsored by the Radiological Society of North America and the American College of Radiology. The site explains various imaging modalities, including CT and MR imaging, and mentions specialties like mammography, women's and men's imaging, nuclear medicine, and radiation therapy, but does not explain other radiology subspecialties, such as neuroradiology. Among the conditions that are addressed on the site are

several neuroradiology entities, such as carotid artery stenosis, dementia, epilepsy, head and neck cancer, head injury, headache, parathyroid disease, and stroke. Entering the search terms "neuroradiology" or "neuroimaging," however, yields no results for patients who may have heard these terms and are looking for more information. RadiologyInfo.org has undergone revisions to improve language levels, but language levels remain very high, both for the English and Spanish language versions.<sup>6,7</sup>

ImageGently.org is mostly geared toward radiologists and promotes decreasing patient exposure to ionizing radiation, especially in children. ImageGentlyParents.org, while having its own website, contains currently very limited information for parents. It offers an option for submitting inquiries, but it is unclear who these messages are being sent to and what type of response to expect.

The American Society of Neuroradiology has dedicated a web page to patient information ([www.asnr.org/patientinfo](http://www.asnr.org/patientinfo)) and represents a great opportunity for neuroradiologists to become involved and collaborate with patients on adding meaningful and patient-centered content. Such efforts could alleviate patients' online search frustrations and offer curated and reliable content.<sup>5</sup> Linking neuroradiology-specific information to larger efforts, such as RadiologyInfo.org, could potentially increase the traffic on this website. Ideally, commercial patient-facing websites should promote content that was generated and/or curated by radiologists and neuroradiologists. Overall, this represents a great opportunity for neuroradiologists to develop content and enhance the field's visibility and value to patients.

There were no case studies for this section.

#### **Stage 2: Consideration**

**Definition.** Patients decide whether having an imaging test can meet their needs; involves weighing factors, for example, referrals, insurance coverage/out-of-pocket cost (OOPC), recommendations, access, ratings, and reviews.<sup>4</sup>

**Narrative Review.** To aid with the decision whether an imaging test would be useful, clinicians can use Clinical Decision Support systems. These systems typically relate to a specific clinical scenario, are evidence-based, and are intended to increase the appropriateness of imaging utilization.<sup>8</sup> Informed patients, however, may choose not to follow the recommendations that arise from the use of evidence-based guidelines because those do not incorporate patients' personal preferences.<sup>9</sup> Shared decision-making has evolved as an approach where clinical providers enable patients to make decisions that take into consideration both the clinical and scientific evidence, as well as the patient's personal context, goals, values, and preferences for health care.<sup>9</sup> Shared decision-making occurs continually along the patient journey, and radiology plays a role in deciding whether an imaging test is the best choice, which imaging test is most appropriate, and what to do with the imaging results. Patient decision aids can be used to convey scientific evidence, list trade-offs, and to elucidate patient preferences when deciding whether imaging is the best choice, such as for lung cancer screening.<sup>10</sup> There is currently a scarcity of patient-decision aids for imaging decisions, which represents a huge opportunity for neuroradiologists to get involved.

Patients often select providers that have been suggested to them by another health professional, and they may use comparative information when there is a specific health outcome they have in mind, or when they do not trust in their health provider.<sup>11</sup> Patients consider the following characteristics when choosing a provider: Availability under the existing insurance plan, accessible in a convenient location, affiliated with an academic center, certified/qualified physicians and staff, friendly and understanding communication style, provides updates, and more.<sup>11</sup>

An example of a publicly available site that offers comparable information on health care providers is Medicare's Care Compare,<sup>12</sup> and rankings performed by specific organizations, such as U.S. News or Leapfrog's Safety Grade. Of note, none of these sources include imaging services quality metrics in their scoring and ranking systems. Medicare's tool permits searching for and comparing radiologists on a limited number of features, such as distance from the patient, telehealth services, specialties, board certification, education and training, affiliations, etc. While accreditation status of an imaging facility may be a publicly available indicator of service quality, there is currently no list of features or metrics that could be used to better define and measure neuroradiology services quality.

Another opportunity for patient engagement at this stage lies with providing information regarding billing and OOPC. Starting in January 2021, the Centers for Medicare and Medicaid Services required that hospitals provide clear and accessible information regarding pricing for items and services.<sup>13</sup> Radiology practices can offer patient-friendly price transparency tools to estimate personalized OOPC, which patients may perceive as a benefit.<sup>14</sup> Of note, these estimates may vary over time and can be inaccurate.<sup>14</sup> For example, patients from the same insurance company can each have different OOPCs, and those insurance contracts change over time. An important aspect of offering price transparency tools is to couple access with explanations of differences in service when paying more.<sup>15</sup> For example, patients with severe back pain listed among services and features that they would pay more for: improved imaging results accuracy, an imaging facility that was recommended by the provider, or a facility with a higher online star rating.<sup>15</sup> As neuroradiologists, we are aware that patients who pay more do not necessarily receive higher quality care. There is an opportunity to engage patients in jointly defining quality indicators and jointly raising awareness of neuroradiology service quality metrics that are worth paying more for.

A case study *A Patient Decision Aid (PDA) for Imaging Pediatric Headache* has been added for this section (Online Supplemental Data).

### Stage 3: Access

**Definition.** Scheduling and preparing for an imaging test; involves communications (eg, scheduling), patient acquisition process, directions to the imaging location, and test preparation.<sup>4</sup>

**Narrative Review.** Allowing patients to book their own appointments increases patient engagement, as indicated by a reduction in the number of missed appointments.<sup>16</sup> Self-scheduling also allows patients to schedule appointments so that relatives can join them.<sup>17</sup> While many radiology practices offer online scheduling

for patients, many academic imaging centers that use centralized scheduling have difficulty in offering this service to their patients.<sup>18</sup> There is a huge opportunity to advocate for patient self-scheduling in neuroradiology, understanding that this may require elaborate algorithms to help patients schedule the examination on a scanner in the system that is best suited to deliver the image quality required for their clinical indication, for example, ability to perform functional MR imaging before neurosurgical interventions or perfusion imaging for patients with brain tumors. Commercial applications are evolving.<sup>19</sup> Patients may want to reach out to the imaging facility with questions ahead of their appointment, which could be addressed by offering a number to call or by giving access to a blog site that shows answers to frequently asked questions.<sup>20</sup> Of note, offering self-scheduling can create disparities for patients, which could be mitigated by pairing this service with efforts of facilitating portal use for all patient populations.<sup>21</sup>

At this stage in the patient journey, it would be appropriate to provide patients with information regarding items to bring to the appointment, patient preparation instructions, an explanation of the check-in process, navigation and wayfinding, and checklists before CT and MR imaging examinations.<sup>22</sup> Such information can easily be shared through electronic patient portals, mobile applications, or websites.<sup>21</sup>

The concept of helping patients prepare for an imaging study may differ between radiologists and patients. Radiologists naturally focus on preparing patients to assure the images can be acquired without complications and will be of diagnostic quality. Examples include limiting PO intake before a fluoroscopy examination of the upper gastrointestinal tract or advising patients not to use deodorant before a mammogram. Patient-centered preparation, on the other hand, may include explanations of the imaging modality and technique, and any discomfort or risks associated with it, such as lying on a hard MR imaging table for a prolonged period, exposure to ionizing radiation in CT, need for sedation in MR imaging, physical effects of IV contrast injections, and risks associated with a variety of IV contrast agents. Patients may feel uncomfortable thinking they have to undress for an examination and an explanation on why, how, and where to undress can help alleviate anxiety ahead of time. Infographics and leaflets can be effective in providing patients with the information they seek at an accessible language level and are typically reinforced by visuals.<sup>22,23</sup> Virtual reality applications have also proved useful, particularly in preparing patients for MR imaging scans.<sup>24</sup>

Wayfinding can be improved by sharing maps and images of sites, parking options, and entrances before the appointment.<sup>22</sup> It is important to include patients in the process of developing these materials, to assure they meet patients' needs.<sup>22</sup> Neuroradiologists could examine their patients' ability to find imaging sites and advocate for more effective wayfinding design, which may include wayfinding kiosks or apps in addition to design features that include color coding, landmarks, room and elevator labeling, and signage.<sup>25</sup>

A case study *Our Pediatric Radiology Website* has been added for this section (Online Supplemental Data).

#### Stage 4: Service

**Definition.** Having the imaging test; involves participation (eg, checking in), following instructions, enduring discomfort, discharge, billing.<sup>4</sup>

**Narrative Review.** Delays can be avoided if patients are informed ahead of time what information they will need upon check-in. Facilitated by the COVID-19 pandemic, some imaging practices continue to offer remote check-in to their patients,<sup>26</sup> which can conceivably save time and create a sense of privacy. Of note, the check-in process provides an opportunity to let patients know about access to patient portals.<sup>20,27</sup>

Patients are generally motivated to cooperate with instructions for successful image acquisitions unless they cannot physically comply. There is a paucity of scripts that could help radiology technologists and nurses communicate to patients how they can cooperate.<sup>28</sup> Neuroradiologists could collaborate with technologists, nurses, and patients to develop scripts to let patients know how they can cooperate for neuroimaging studies. Communication and establishing rapport with patients are fundamental for managing patient distress, discomfort, or anxiety.<sup>29</sup> Patients may experience various discomforts, such as having to undress, needle sticks, and contrast effects, as well as uncomfortable positioning during image acquisitions. For neuroradiology, discomfort is mostly related to MR imaging, less so to CT imaging on modern scanners.<sup>30</sup> Simple interventions to decrease discomfort in MR imaging include shorter scanning protocols and audiovisual distraction with goggles and/or headphones.<sup>31</sup>

Before discharging the patient after the images have been acquired, there is an opportunity to give patients a preliminary report, or there may be a necessity to manage patients with critical findings immediately. While discussing preliminary results with patients is still not common practice in radiology, it was shown to be feasible in academic settings, such as head and neck cancer imaging, and is appreciated by patients.<sup>32,33</sup> Interestingly, patients may only appreciate the service after they have experienced it.<sup>33</sup> Decades of negative stereotypes about radiologists, such as radiologists avoiding patient contact, being antisocial, and focused on lifestyle or money rather than patient care<sup>34</sup> have slowed the adoption of direct communications with patients. In a European practice model, results communication directly to patients resulted in highly relevant changes to the radiology report in one-third of cases.<sup>35</sup> Interestingly, radiologists who did not offer direct communication with patients were viewed by patients as being less competent.<sup>35</sup> In the United States, there is currently no established reimbursement model for diagnostic radiology consultations with patients that could drive broader adoption of this service.

On occasion, critical findings may be uncovered on an outpatient imaging examination and may necessitate immediate action. For example, a brain tumor may be found on outpatient imaging for headaches or seizures. The technologist may alert the radiologist to such a finding to facilitate modifying the imaging protocol, such as adding IV contrast and/or potentially adding spine imaging. The changes in the imaging protocol may alert the patient that something unusual has occurred which can cause increased anxiety and questions. Radiologists may be

asked to explain the situation to the patient and should be prepared to do so.

Radiologists should be trained in explaining imaging findings.<sup>36,37</sup> The American College of Radiology provides a free Communication Curriculum for patient communications that can be used by any radiologist, practicing or in training.<sup>38</sup> Key concepts in communicating with patients include a supportive environment, ability to establish rapport, ability to open a discussion, ability to elicit more information, ability to understand the patient's and family's preferences, ability to share information at the patient's literacy level, providing accurate information, being empathetic, and providing closure.<sup>36,39</sup>

When all is said and done, it may not be clear to patients what will happen next. At the time of discharging patients from the imaging facility additional information can be provided, such as instructions on how to access results, which is of immediate interest to most patients.<sup>40</sup> In addition, discharge information to engage patients may include options for contacting a radiologist, a reminder to follow-up with the referring provider, an invitation to provide feedback regarding the services in a survey, or instructions on how to exit the facility. Patients who had a contrast reaction may be given documentation of the contrast that was administered, the type of reaction that was observed, and how it was treated, so they can make future decisions regarding the risks of repeat IV contrast administrations. Similarly, there may be follow-up instructions for patients with contrast extravasations.

Three case studies have been added for this section: *Reading Room in Brain Tumor Clinic* (Online Supplemental Data), *A Companion Case of Embedded Reading Rooms: One Stop Shop* (Online Supplemental Data), and *Bad News Bear Program* (Online Supplemental Data).

#### Stage 5: Ongoing Care

**Definition.** Dealing with imaging results (eg, deciding next steps in care, dealing with a diagnosis and with unexpected actionable findings, dealing with diagnostic uncertainty).<sup>4</sup>

**Narrative Review.** The radiology results can play an important role in the patient's ongoing care, such as anxiety relief when a severe diagnosis is excluded, informing further management when a diagnosis is established, indicating and coordinating the use of additional resources to arrive at a diagnosis, and providing information regarding prognosis for an established diagnosis.

Normal imaging results are valuable for diagnoses that lack specific diagnostic criteria and require exclusion of other entities, such as hypertensive encephalopathy.<sup>41</sup> Additionally, in adult headache patients, normal imaging results can decrease patient anxiety and lower cost by reducing downstream utilization of health care services.<sup>42</sup> Radiologists have an opportunity to use the word "normal" rather than more obscure verbiage ("negative") to make it easy for patients to understand this type of result.<sup>43</sup>

When a diagnosis is established through radiology findings, it is important that patients can understand what this finding means to make decisions regarding next steps. The Joint Commission's National Patient Safety Goals state that patients make better health care decisions when they understand their personal health data.<sup>44</sup> Radiology results are always documented



and communicated in writing. The key tenets for patient engagement entail making radiology written reports both accessible and understandable to patients.<sup>30</sup> To improve patients' ability to comprehend radiology reports, a variety of interventions can be used, such as lay summaries,<sup>45</sup> Generative Pretrained Transformer translations,<sup>46</sup> or multimedia reports that link to lexica and explanatory images.<sup>47</sup> Interestingly, 82% of patients preferred receiving the detailed report rather than a lay summary, particularly for abnormal results.<sup>48</sup> In addition, radiologists could make themselves available to patients if there are questions, for example, by adding their phone number to the report or offering virtual consultations.<sup>49,50</sup>

There remain concerns regarding patients' reactions to reports when there is a finding, such as increased anxiety. While a few cases of suicide in response to devastating radiology results have been reported, patients prefer getting access to results even when it increases their anxiety.<sup>51</sup>

Patients are increasingly viewing radiology reports via patient portals, but portals are far from being used by all patients, which likely reflects a variety of disparities based on race, primary language, insurance status, and other factors.<sup>52</sup> A set of "Universal Precautions" has been proposed to improve communication and participation for all patients regardless of health literacy.<sup>52</sup> These precautions contain 18 actions that promote the development of effective patient-centered communications.<sup>52</sup> Besides forming a team and working with patients on the development of communications, additional advice includes offering actionable content, by using intuitive design, tailoring messages to specific patient needs, and much more.<sup>52</sup>

An evolving area for patient engagement in radiology pertains to follow-up recommendations for actionable incidental findings. Radiologists are using direct patient notifications to increase adherence to follow-up recommendations, which could be as low as 52%.<sup>53,54</sup> The impact of direct notification of the patient on follow-up adherence may be low in systems with an existing reliable process for notifying providers of recommended follow-up.<sup>55,56</sup> There is currently not enough scientific evidence exploring other patient engagement benefits from direct notifications, such as building trust and loyalty, which represents a research opportunity for neuroradiologists.

Two case studies have been added for this section: *Video Reporting* (Online Supplemental Data) and *Actionable Incidental Findings Notifications to Patients* (Online Supplemental Data).

## CONCLUSIONS

The vision for neuroradiology is to cultivate patient engagement and transform the traditional practice model into a collaborative effort that creates an empowered patient journey. Neuroradiologists can demonstrate commitment to this vision through initiatives that promote transparent communication, accessible information, and shared decision-making for patients. This vision is grounded in collaboration between patients, neuroradiologists, and health care providers to align products and services with patients' needs and preferences. By valuing patient perspectives, neuroradiologists can inspire a new era of collaboration in health care.

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