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The Voice of Experience -Patient Engagement: The Experience of the RSNA Image Share Patient Help Desk

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The challenge of Image Sharing

Traditionally, sharing of diagnostic quality medical imaging across healthcare institutions has posed significant challenges and limitations [1-6]. Typically, images are copied onto a Compact Disk (CD) which is given to the patient for subsequent sharing with a healthcare provider or institution [7]. However, these CDs have been associated with numerous issues

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such as difficulties installing software due to hospital or clinic administrative access limitations, lack of associated reports, and non-adherence to standards such as the Integrating the Healthcare Enterprise (IHE) portable media profile, making them difficult to access. The CD's almost never contain the imaging reports and these issues often resulted in delayed diagnosis and treatment and are often a source of frustration for patients and healthcare providers.

Intervention

As a remedy to these problems, the Radiological Society of North America (RSNA) piloted a program that enables exchange of medical images, under the control of patients through their image enabled Personal Health Record (PHR) accounts. Funded by the National Institute for Biomedical Imaging and Bioengineering, this initiative has allowed efficient sharing of images for the past three years and gives patients control over the distribution and viewing of images and radiology reports through secure online, vendor provided image enabled PHRs.

Patients have a considerable role in this paradigm of image sharing. Specifically, patients must have Internet access, sign up for a PHR account, and use it to review and share their images and reports. Given these requirements for patient involvement, an RSNA Help Desk was set up to field any questions and concerns patients had regarding the process. One of the major functions of the Help Desk was to gain understanding of the most important issues and barriers associated with the initiative.

The RSNA Help Desk is staffed at one of the seven participating University Hospitals. A toll free number was provided to all participants for any potential issues encountered for the project. The Help Desk is staffed by two individuals Monday-Friday 8 am to 6 pm Eastern Standard Time. When issues arose (via telephone or email), a "virtual ticket" was created automatically using Mantis, a free web based issue tracking system; and appropriate action was taken to resolve issues.

A total of 1,128 issues were recorded in the three year interval from 2011- 2014. All issues tracked by Mantis were stratified into various categories, such as patient specific, PHR Vendor # 1, PHR Vendor # 2, PHR Vendor # 3, Edge Server, Image Clearinghouse, Downtime, Mixed, and General issues. Issues related to PHR vendors were logged when patients had questions about what a PHR vendor was or questions regarding the actual use of PHR accounts. Issues related to the Edge Server (an "appliance" at each participating site that collects images and reports from the PACS and Radiology Information System (RIS) and enables site personnel to send them to the Clearinghouse through the Internet) pertained to questions about a patient's initial images and reports at the specific site where the images were obtained; as well as storage problems. Another issue that required Help Desk assistance was associated with problems with the interface and communication between the Clearinghouse and PHR. The Image Clearinghouse receives images from all sites, caches them transiently, and allows the patient's PHR or medical centers to retrieve them. Downtime issues were related to unexpected inactivity of the various components of the network software; such as Edge Server software, Image Clearinghouse, or PHR vendors;

and these issues were also tracked. Issues related to a combination of any of the above categories were categorized as “Mixed”. Problems that did not fall into any of these other groups were classified as General issues.

Patient specific problems were further stratified into seven categories: inability to access images, request to upload new exams, request for program information, password/token issue, 72 hour timing issue, new account request, and general issues.

1. Inability to access images -logged if a patient could not access their images despite having their password/token ID,
2. Request to upload new exams -logged if a patient requested more than one examination to be pushed to the Image Clearinghouse from the Edge Server after the initial upload,
3. Request for program information -related to when patients had questions about their enrollment in the RSNA Image Share Network program.
4. Password/token issues-logged as issues if a patient could not recall their password or token ID,
5. 72 hour timing issue -related to when patients called to view images within 72 hours of their diagnostic examination, as the Edge Server did not send images to the Image Clearinghouse until 72 hours after the examination per protocol,
6. New account requests- logged as separate issues when patients demanded new accounts after failing to log into the accounts initially created for them,
7. General issues- related to patient specific issues that could not be stratified into any of the above categories.

Outcomes

Over a three year period from August 2011- July 2014, seven health care institutions participated in the RSNA Image Share Project. Patients were allowed to voluntarily participate in the program, and to date; a total 13,458 patients have participated by enrolling at the seven health care institutions. 4,100 patients have closed the loop and actually established a PHR account by retrieving their imaging exams and reports. Patients chose one of three possible PHR vendors: Dell Passport (Dell Corp, Round Rock, TX), LifeImage , or DICOM Grid (DICOM Grid Corporation, Phoenix, AZ).

As demonstrated from Figure 1, the total number of issues reported increased from 2011 to 2014 (75 issues reported from 2011-2012, and 803 reported from 2013-2014. As Figure 2 demonstrates, increased number of issues reported was a direct result of increased participation in the project with time as only 935 patients had participated in the Image Share Project from 2011-2012, compared to 5,745 patients from 2013-2014.

Site 3 had the most patients enrolled in the program (2,950 patients, 180 issues reported), but had significantly fewer issues requiring Help Desk support when compared to several other sites such as Site 1 (2600 patients, 460 issues reported) that had fewer patients enrolled (Fig. 3 and 4). We hypothesize that this is a result of the fact that the RSNA Help Desk was

staffed from Site 3 and the personnel educating patients regarding the RSNA Image Share Project were the same as those supporting the Help Desk. They had a higher level of experience regarding the patient challenges associated with the project and PHR accounts as opposed to personnel at other sites, such as Site 1. The personnel at other sites were often clerks with numerous other responsibilities.

As Figure 5 illustrates, the vast majority of issues logged revolved around patient centric issues. In fact, over 75% of the issues tracked were patient specific issues. Many of the most important issues tracked involved new account requests, inability to access images due to forgotten passwords, requests to upload new images, as well as initial growing pains with the PHR vendors. In addition, a large percentage of issues tracked involved educating patients regarding their PHR accounts and how to use them effectively.

Only a small percentage of issues centered on downtime or the Edge Server software functionality. In fact, only 1% of the total issues tracked corresponded to downtime issues, while 2% corresponded to Edge Server software functionality (Fig. 5). This data reflects positively on the overall reliability of the RSNA Image Share technology over the three years studied. Patients have been competent to engage with the technical aspects of the network. The large number of patient specific issues surrounding inability to access images or request for new accounts exposes the challenges patients encounter when they are directly involved with the transfer of their images on the Internet and associated requirements. The Image Share Project requires that patients have Internet access, get passwords, set up PHR accounts, and use these accounts to view images. The vast majority of issues tracked through the Help Desk reflected these challenges with patient use of the network.

Within a three-year period, only 1,128 issues were tracked; which suggests that patients overwhelmingly were able to access images without the need for help. With regards to improving the patient experience and decreasing dependence on the Help Desk, we have learned that more in depth education and instruction at the time of enrollment is necessary to make patients more informed regarding how to access their images. Instructions regarding password maintenance, access to images, and the 72 hour timing issue should be clearly explained when patients decide to participate in the project. Patients are provided detailed brochures but may require a greater degree of personal instruction.

Another limitation with the Help Desk was the hours available for staff to take calls and track issues; from 8 am to 6 pm Eastern Standard Time Monday-Friday. No analytical data were collected regarding patient satisfaction or dissatisfaction regarding Help Desk hours, but our two Help Desk Staff do recall at least five instances where callers, particularly from the West Coast, expressed disappointment in not being able to contact Help Desk staff during normal business hours. This was in large part due to time zone differences as calls were not taken past 6 pm Eastern Standard Time, which translated to 3 pm Pacific Standard Time on the West Coast. Thus, the Help Desk was only accessible by phone to Pacific time zone callers from the hours of 5 am to 3 pm Monday to Friday. These hours may not be optimal for individuals on the West Coast, and data should be collected in the future to gauge patient satisfaction with Help Desk hours of operation.

Despite the limitations noted above, the experience of the Help Desk has been important in several ways. First and foremost has been the ability to provide guidance to patients encountering a problem that might discourage them from using the RSNA Image Sharing system. Generally, the Help Desk has enabled the patient encountering a challenge to successfully gain access to their images in a PHR account. Importantly, the RSNA Image Share is a pilot project, which by its design can modify its approach and technical solution to reflect lessons learned. The RSNA Image Share Steering Committee has used the data shared in this report to modify the system to address concerns. For example, the 72 hour moratorium on sharing the images with the patients has at times been considered an undesirable constraint. Some sites are now allowed to set their own time frame between when images are obtained and sent from the Edge Server to the Clearinghouse. Furthermore, the overarching emphasis of patient engagement with more active involvement in accessing imaging reports and sharing those images with clinicians has allowed for value-based healthcare whereby the patient is at the center of his/her healthcare with regards to their imaging studies.

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Fig. 1.

Bar graph demonstrating the number of total issues reported to the RSNA Help Desk for the three years since its inception for the RSNA Image Share Project. The total number of issues reported has increased significantly since its inception in 2011. Each year is represented from August to July of the following year. Thus, 2011-2012 represents the timeframe from August 2011 to July 2012.

Fig. 2.

Bar graph showing the total number of patients participating in the RSNA Image Share Project as a function of year. Each year is represented from August to July of the following year.

Fig. 3.

Bar graph illustrating the number of total issues reported to the RSNA Help Desk at the seven various participating sites for three years. Each year is represented from August to July of the following year.

Fig. 4.
Bar graph depicting the total number of patients participating in the RSNA Image Share Project at the seven different sites.

General Category of Issues

Figure 5

Fig. 5.

Pie chart showing the general category of issues reported to the RSNA Help Desk. The vast majority of issues were classified as patient specific issues, while the remaining were mostly technical issues.