



# The “P” in HIPAA Stands for Portability

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This Special Issue of the Journal of Digital Imaging and the world of shared digital healthcare information are privileged to have the expertise and wisdom of our Guest Editor David S. Mendelson, MD, FACR, Co-Chair Integrating the Healthcare Enterprise (IHE)-International, from Mt. Sinai Healthcare/Icahn School of Medicine at Mount Sinai [1]. Dr. Mendelson is the leader of international efforts to implement functioning imaging study exchange for patient care. David graciously accepted this huge task, and with his unwavering enthusiasm and contacts recruited an impressive array of international experts to provide perspective on the status of internet-based, non-physical (no portable media, i.e., CD/DVD) image study exchange from multiple countries. It has been a true privilege to work with him on this project.

Historically, Dr. Ronald Arenson led the radiology organizational effort to work on solutions to this problem.

The “P” in HIPAA [2] stands for Portability (of health data and insurance), not Privacy. As any radiologist or specialty physician reading this knows, the sad reality is that this problem is not solved in the world of daily practice, either for emergency care and transport (REF Canada paper in this issue) or long-term oncologic care, although help is “on the horizon” as you will see in several of the articles. How did we get stuck in this difficult place, where institutions such as the Mayo Clinic and MD Anderson still import imaging studies from many hundreds of CDs every day?

What makes it particularly confounding, as my colleague Dr. Robert Wachter described in his book “The Digital Doctor,” [3] radiology is the leading specialty in implementing digital technology to improve healthcare, because of our relentless and successful effort to implement the DICOM standard. Every medical, dental, and veterinary imaging device manufactured in the world today produces images in the DICOM format and transfers them through DICOM commands.

At the beginning of the DICOM adoption effort, three decades ago, I had the serendipitous privilege of meeting and befriending Andrew Grove, CEO and President of Intel Corp, and the leading Silicon Valley guru of his era. He was fascinated by standards, and the challenges of standards, including particularly healthcare and radiology: “Standards only happen for one of three reasons: (1) The vendors agree (e.g., the microprocessor pins have to fit the motherboard socket, or more simply the 220-V plug has to fit a European socket); (2) The government mandates it for some higher purpose; or (3) the customer base demands it” [4]. Radiology and DICOM clearly fall into the third category, as multiple previous leaders of SIIM will attest to, particularly “Dr. DICOM” Steve Horii, MD (and a previous editor of JDI), and as acknowledged by Dr. Wachter.

So what went wrong with Imaging Study Exchange? Besides being three decades into DICOM, we are also half a century past the Apollo Moon Landing, which would not have occurred without digital protocols spanning a quarter-million miles. This should not be this hard; we should not be in this conundrum.

Worldwide acceptance and implementation of DICOM defines the payload format of the digital images with only the problem of Patient ID or Local MRN [5]. There are additional technical issues less important than getting the study associated with the correct patient, such as local Accession Numbers and Exam Dictionary. However, even though there are transport protocols/commands that work locally, there is a breakdown between institutions for a whole set of reasons, including a lack of government leadership in multiple countries. The reasons are (1) Security and Privacy concerns disproportionately weighing against Portability for quality of care; (2) in countries (such as the USA) that lack a universal health care ID or national MPI, associating the imaging studies with the correct patient (identification and authentication) is a software implementation and procedural challenge; and (3) lack of regulatory or government leadership encourages creative but proprietary software solutions, which may be fee-based, and often are “silo-ed” in that they will not exchange with other proprietary systems.

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Another major impediment, particularly in the USA, is a lack of a commercial incentive to share patient records in a mostly private, for-profit healthcare system. Patient records, to those concerned with the health system's bottom line, are assets to be protected (to urge patients to continue to get services at the same health system).

In complex medical care situations spanning multiple physicians and more than one hospital, in satisfying the need for sharing of information and imaging, it isn't clear whether the "customer" is the patient or the physician. Whichever it is, he or she has probably had the experience of presenting a banking card across town or across the world, at an unrelated bank or ATM, and seamlessly withdrawing cash, even in a foreign currency. With years of such customer financial experience, it leads us to wonder why, in this day and age, the problem of medical information and image exchange is still so incredibly difficult.

It was precisely this problem that the NIH-funded RSNA led ImageShare [6] demonstration project was designed by Dr. Arenson to address and rectify, by setting an acceptable universal transport process that could and would be adopted by companies and healthcare institutional networks. However, the NIH prioritized patient-centered care and patient involvement (including the transport process), rather than tackling and prioritizing the more important care problem of simple patient authorization of exchange between care institutions first. That created a barrier to widespread adoption and success. To their credit, the NIH did mandate that all participants use standards identified by the RSNA.

Finally, a couple of years later, during Meaningful Use Stage 1 (which specifically included healthcare data sharing) [7], there was a unique opportunity in the USA for the

government, through ONCHIT, to mandate standard-based imaging study exchange. Leadership at that time did not fully recognize the requirements and importance of both the emergent and oncologic use cases of imaging study exchange for quality of care. That opportunity was missed, leading us to wander in the wilderness for almost an entire decade.

It is our fervent hope that the collection of international papers in this Special Issue on Image Exchange will enable a rapid solution to this one big remaining problem in digital imaging for healthcare for all countries and patients.

I am personally grateful to Dr. Mendelson for his efforts as Guest Editor to make this Special Issue a reality, and to Dr. Arenson for his continuous leadership and support of the goal of seamless imaging study exchange for quality of patient care.

## References

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