

## 2020-2025 Federal Health IT Strategic Plan: Comments from the Patient & Carepartner Perspective

**Page 3:** *Thanks to provisions enacted by Congress, the U.S. Government is working to bring more robust health information into patients' hands and ensure that technology and smartphone applications (apps) will help them better manage their health and enable them to shop for care.*

**Comment:** From a patient and carepartner perspective, it's important to clarify that having access to robust health information via technology and smartphone applications doesn't **only** help us better manage our health and shop for care. This access is critical to make informed, empowered decisions about our care in real-time when dealing with an unexpected emergency or when faced with a life-altering, or life-limiting diagnosis, such as cancer. This strategic plan must recognize that patients do not always have the luxury of consumers in other industries. We often do not have the luxury of "shopping" for ideal care of preference, but rather are frequently forced to make crucial decisions under high-stress circumstances, with limited resources, transparency, and access to information for the sake of survival, not convenience or consumerism. References to "shopping for care" trivializes many of the life and death healthcare situations millions of individuals face across the nation each day. This Federal Health IT Strategic Plan must recognize the spectrum of consumer and patient experiences, ranging from "shopping for care" to literal acts of acts of survival in order to be properly framed and implemented. We do not want to underestimate and trivialize the significant role patients and their carepartners must play in their healthcare in 2020 and beyond.

**Page 3:** *These efforts include coordinated investments, standards and policies for secure, standards-based application programming interfaces (APIs), and user-focused technologies.*

**Comment:** From a patient and carepartner perspective, there are currently no user-focused technologies available to hold the healthcare ecosystem accountable and change its behavior when it is the barrier and problem hampering an individual's healthcare trajectory and goals. We mustn't fall victim to the assumption that it is only the patient that must change their behavior in order to improve their health, quality of care, outcomes, and associated costs.

**Page 4:** *With this 2020-2025 Federal Health IT Strategic Plan (Plan), federal partners will continue to play a role in ensuring that patients get access to their electronic health information and have the full transparency that they need to shop for care.*

**Comment:** From a patient and carepartner perspective, in addition to the aforementioned comment on "shopping for care", we want access to our health information to be master curators of our data, to correct errors in documentation, fill in gaps, and clarify omissions, so as to have a comprehensive narrative of our life in order to be confident that our caregiver(s) and care team(s) have all the information they need to help us with shared-decision making and treatment planning. Access also empowers patients and their carepartners to not only participate in, but also genuinely drive innovative research that traditional private or academic sectors do not prioritize or fund.

Also, it is important to point out that access the EHR alone is not enough to shop for care or make an empowered healthcare decision. In cases of chronic illnesses, multiple comorbidities, disability, rare disease, cancer, and life-limiting conditions, in order to truly make an educated decision about the best doctor, care provider, hospital or healthcare organization, we need transparency and access to data that demonstrate volumes of patients a doctor has seen with a particular diagnosis or for a specific procedure. Take for example a parent with a disabled child that need a spinal surgery. Upon searching provider directories or organizational websites on the internet, one cannot see how many spinal surgeries a pediatric neurosurgeon may have performed annually or what the outcomes and safety data are reported as; all one can see, at best, is a brief bio, a list of academic accomplishments, perhaps publications and professional memberships. This does **not** provide factual evidence of safe expertise in a particular diagnosis or procedure. Patients are forced to “shop for care”, even in critical situations, with limited transparency and useful information to make an educated decision about their care.

**Page 4:** *Yet, much work remains to make sure patients and caregivers have access to information they value and can use.*

**Comment:** From a patient and carepartner perspective, we need a digitized way of communicating our needs, in real-time, from our local communities to both our local healthcare providers as well as to federal policy thought leaders. We need to be given the tools to be empowered to push back from the bottom-up in order to report local acts of HIPAA non-compliance, information blocking, and lack of transparency. The barriers we face locally need to be carefully tracked so as to help both local healthcare organizations improve their workflows and met our data access and transparency needs quickly as well as to escalate HIPAA and information blocking violations seamlessly and actionably to the offices of OCR and ONC.

**Page 5:** *Improve the health and well-being of individuals and communities using technology and health information that is accessible when and where it matters most.*

**Comment:** From a patient and carepartner perspective, one of the most critical times we need access to technology and health information is when we are faced with a life threatening emergency, a life-altering, or life-limiting diagnosis. We don't have time for faxing, making endless phone calls begging for someone to listen and grant us access to our medical records and images on CDs. We don't have time to call medical device manufacturers begging for access to our loved one's remote patient monitoring data while they lay in the emergency after a stroke. The information blocking we face during these crucial moments can mean life or death as precious minutes and hours tick by on the clock while we wait. We need access to tools that will help us hold the healthcare ecosystem accountable when we desperately need interoperability and transparency the most.

**Page 5:** *Through this federal health IT strategy, the government strives to: Put individuals first.*

**Comment:** Appendix A states *ONC collaborated with over 25 federal organizations involved in health IT* to develop this Plan for public comment. What percentage of actual patients and carepartners make up the representation from these 25 federal organizations? The health IT

advisory committee is reported to be comprised of “[No fewer than 2 members are advocates for patients or consumers of health information technology](#),” assumingly, in theory, this makes for at least 2 patient/carepartner voices. In order to authentically put individuals first, there must be equal, if not greater, representation that is diverse and inclusive of many voices in order to truly capture and prioritize the foundations of patient and carepartner unmet needs. Patients and carepartners do not need other stakeholders representing their best interests. They need to be brought to the table and relied on to lead the discussions, not referred to as an afterthought or in a gesture of tokenism.

**Page 5:** *Through this federal health IT strategy, [the government strives to: Put research into action.](#)*

**Comment:** From a patient and carepartner perspective, there needs to be greater patient education initiatives to proactively educate members of the US healthcare system about the importance of one’s health information, access, basics of HIPAA, human data science, population health, as well fostering opportunities for patients and carepartners to partner in more research initiatives.

**Page 5:** *Through this federal health IT strategy, [the government strives to: Be a responsible steward.](#)*

**Comment:** From a patient and carepartner perspective, we must prioritize protecting all patients’ digital dignity. A large portion of EHR data is generated when we enter hospitals and healthcare facilities in our darkest moments of despair and in the depths of our vulnerability where the vow is “[Do No Harm](#)”. We come through these doors in survival mode trusting our doctors and care providers with our lives. We consent to care from the care givers who have dedicated their lives to healing, who recognize that the doctor-patient relationship is a sacred space, who are humbled by the privilege to practice medicine and care for patients.

We share our symptoms, family histories, and PHI with you. We share choices we regret. We share painful realities, heartbreaks, and the messiness of our lives in hopes these details will somehow help our doctors help us get better. These intimate conversations that take place at the point of care are documented. The data generation begins. We trust our caregivers and our hospitals to keep our confidentiality safe. Most patients have no idea what happens with their health information. To be responsible stewards, we must develop health IT policies that proactively educate patients about their health information, provide opportunities for choice, as well as the ability to opt-in/opt-out of certain data use cases.

**Page 6:** *Goal 1 Promote Health and [Wellness](#)*

**Comment:** From a patient and carepartner perspective, wellness is not always possible. The words we use matter and wellness can leave many patients feeling not prioritized or excluded. Many individuals are born with various conditions, diagnoses, and disabilities or develop them throughout their lifetime. Wellness is not the best way to frame this goal. Instead, life-focused care is a better, more inclusive choice. Life-focused care means supporting all individuals to live

their best possible life and quality of life, no matter what their diagnosis(es) may be, connecting them with the information, technology, tools, public resources, and care they need to thrive where they are in their local community. This will require: 1) addressing social determinants of health, 2) incorporating digital technology to better connect and monitor patients where they reside, 3) earlier introduction of palliative care as an extension of the core care team in cases of chronic illness and life-altering, life-limiting conditions for whole-person care.

**Page 7:** *With the use of health IT rapidly advancing, it is essential for the federal government to continue to ensure health IT and electronic health information are accessible to patients and are used appropriately to improve healthcare decision making and health outcomes.*

**Comment:** From a patient and carepartner perspective, there isn't enough being done to locally enforce HIPAA and hold care providers and health organizations accountable for rampant information blocking. We need and want to help enforce clear instances of violations as well as work towards improved work flow solutions in our local communities. Patients and carepartners want to be empowered with tools that build patient autonomy and help people to take charge of their health information.

**Page 9:** *Even when patients and caregivers can access health information electronically, they may have low levels of health literacy and may not understand what the information means.*

**Comment:** Patients and their carepartners need to be proactively supported at the point of care with education and guidance on the importance of accessing and reviewing one's medical records to coordinate one's care as well as their rights according to HIPAA. When a patient is hospitalized, there is a revolving door of people who enter the room: doctors, attendings, residents, fellows, interns, nurses, nurse practitioners, nursing students, TV and phone service staff, physical therapists, social workers, case managers, housekeeping staff, spiritual chaplains, food and beverage staff, transport staff and discharge planners. All of these hospital employees play an essential role in a patient's care at the hospital. There is one person missing: someone from the medical records department. It's time to change the lens we are using to view the importance of medical records to patient success and health. We must remember that there is no course, curriculum, or degree in being a professional patient!

No one currently visits the patient and their carepartner to discuss the importance of having a copy of their medical records post-discharge and maintaining a personal medical history file. No one verifies authorization for the release of medical records. No one asks what medical records the patient needs upon discharge. No one confirms what doctors need a copy of the patient's medical records: like a primary care doctor, or cardiologist or neurologist that the patient will need a follow-up within the next week or so (even though it's documented as part of the discharge plan!). Patient education must be part of this Plan if we are to level the playing field for ALL patients, especially those with low health literacy, language barriers, or from marginalized communities that would benefit from additional support and efforts to build trusting relationships with their local healthcare providers and organizations. More here:

<https://www.theberylinstitute.org/blogpost/947424/283339/Changing-the-Lens-Bringing-Medical-Records-to-the-Patient-Bedside>

**Page 10:** *As a result of health IT, individuals now have greater opportunity to review quality and cost information to make more informed decisions on where to seek care for themselves and their families.*

**Comment:** From a patient and carepartner perspective, what resources have been generated as a result of health IT that may be directly utilized by patients and carepartners to assess quality and costs associated with care? Providing examples of resources linked within the plan would be very helpful. Examples from a patient advocacy standpoint that may be helpful include are [GoodRx](#) and [Healthcare Bluebook](#).

**Page 11:** *These shifting incentives place greater importance on addressing social determinants of health and patient health behaviors, and engaging in preventive care, population health management, and disease management.*

**Comment:** From a patient and carepartner perspective, we need to expand our definition of patient health behaviors. Healthy patient behavior shouldn't only be viewed from the narrow lens as the ability of an individual to modify their life-style and ability for self-management, such as eating healthier, quitting smoking, reducing alcohol consumption, exercising more, and taking medications as prescribed by one's doctor. Healthy behaviors that also need to be recognized, encouraged, and supported with health IT include patient activation, participatory medicine, patient advocacy, and lived experience amplification. It is critical to have patients and carepartners engaged in healthcare ecosystem improvement, refinement, and remodeling through trusting partnerships and multi-directional feedback loops. Our current model of addressing patient behaviors is limited in that it only explores the potential of improving a patient's behavior from a clinical standpoint. Patients and carepartners have significantly more power and potential than that! We have yet to explore the possibilities of partnering routinely with activated, super engaged patients and carepartners, advocates, and citizen scientists to improve the behaviors of our healthcare ecosystem. This is patient empowerment of the future. This is how we collectively move towards value-based care.

**Page 11:** *In addition, as required in the 21st Century Cures Act, ONC proposed regulations that address information blocking, which is generally described as the practice of interfering, preventing, or discouraging the access, exchange, and use of electronic health information for competitive or other reasons.*

**Comment:** From a patient and carepartner perspective, there is no way for us to report and manage the numerous types of information blocking we experience while coordinating our care in our local communities. From struggling to access all of our medical records, the burden of being unable to get images on CDs, dealing with patient portals that have little to no useful information, being unable to file a medical record addendum to correct errors found within records, having no manner to request data from remote monitoring technologies, and having zero access to transparency as to who has accessed to our health information and where it may have been shared or sold, patients recognize no one is coming to save us. All of these are examples of real-world information blocking.

**Page 12:** *In the 21st Century Cures Act, Congress emphasized the importance of easing regulatory and administrative burden associated with the use of health IT and directed ONC and CMS to develop a strategy for reducing this burden.*

**Comment:** Patients and carepartners need to have access to strategically designed tools which reduce the organizational and healthcare providers' administrative burden associated with medical records requests, addendum requests, requests for transparency, as well as streamlining digital health information requests. Patients and carepartners do not want to fax in 2020, drop off hand written requests at the front desks' of their provider's office, or repeatedly call the office with requests for information or records.

**Page 12:** *Even with the implementation and use of robust privacy practices in response to federal and state regulations, health information can still be misused or inappropriately disclosed in ways that harm consumers. Individuals and their caregivers need education on data practices, their associated risks, and opportunities to provide consent to these uses.*

**Comment:** This is a call to action to have every healthcare organization, facility, and company that participates in the sale of anonymized PHI to be fully transparent to every customer, patient, and person they engage with. Patients and carepartners demand universal human data science transparency.

Hospitals, doctors, pharmacies, direct-to-consumer (DTC) genomic testing companies, labs, insurance companies, payers, *etc.* should be required to clearly post a sign at their front desk reception, in their product insert, on their website, *etc.* emphasizing that one's PHI is de-identified and sold by them for commercial profit. Tangible items such as products, reports, forms, websites, *etc.* should be stamped with an easy to identify pictogram that can be universally understood to mean: Warning: de-identified data may be sold for commercial purposes at your expense.

Patient education materials must be created and made available in waiting rooms, exam rooms, and in the hospital to educate the lay person about what these processes are and if they are happening at the location they frequent for their care. Practices and organizations should be required to report end of year profits from the sale of anonymized patient health records. User friendly national registry that patients can search to see if their health care facility, pharmacy, doctor, payer, *etc.* participates in the sale of de-identified PHI. This is how we begin to level the playing field on business as usual, raise awareness, educate about common data science and business practices, and engage more people in robust discusses on data science and privacy of the future.

**Page 12:** *Despite the risk of cybersecurity attacks, breaches, and other threats, healthcare organizations still have poor understandings of cybersecurity risks and best practices.*

**Comment:** In the wake of the report detailing the Ascension-Google, Project Nightingale, patients were left wondering what the consequences of this, and other similar tech giant partnerships, would be for their near and long-term future. Patients fear being discriminated against, suffering a reputation loss, the risk of losing employment opportunities, and being classified in a manner that makes insurance unaffordable or potentially inaccessible. There are legitimate concerns about the commercialization of biased AI predictive decision-making algorithms that may negatively impact their care as has been recently [reported](#). Many patients are frustrated and angry, feeling repeatedly taken advantage of and powerless in the midst of digital tech transformation. We must make transparency a priority and give patients the choice to opt-out of certain data science practices and data uses in order to begin building trust. Trust is essential for digital transformation and this Plan. What should patients fear more: potential cybersecurity risks or how their data is used legally and HIPAA compliantly under business associate agreements (BAAs) that have more legal loopholes than actual protections in place.

**Page 13:** *Enable individuals to [access their health information by ensuring that they are able to view and interact with their data via secure mobile apps, patient portals, and other tools](#).*

**Comment:** It is critical to also empower patients and carepartners to be able to address when their health information is NOT accessible. Patients and carepartners need tools to directly report instances of information blocking to their healthcare organizations and care providers, systemically tracking all interactions and steps taken to resolve the barriers. Similarly, if barriers are not resolved and information blocking continues, patients and carepartners should be armed with a streamlined way to escalate matters efficiently to regulatory bodies and the public domain.

**Page 15:** *Moreover, [data entry and reporting requirements for healthcare providers mean that the experience of care for patients is not always optimal](#).*

**Comment:** From a patient and carepartner perspective, there are significant errors often found within individual medical records, such mistakes in documenting diagnoses, gaps in medical histories, outdated medication lists, copy and paste errors, and even incorrect patient records appearing in one's chart. In order to enhance the delivery and experience of care, patients need to be able to curate their records, need to be supported in reviewing and contributing to their information, as well as supported in correcting errors that may have been found by way of record addendums. Our human data science, ML, and AI algorithms would also benefit from quality, curated data.

**Page 15:** *Promote interoperability and data sharing through widely-accepted standards to [ensure health information is freely available across care settings for patient care, public health, research, and emergency and disaster preparedness, response, and recovery](#).*

**Comment:** The hospital patient Bill of Rights needs to be universally updated to explicitly define human data science practices, use of data for commercial purposes, and the associated risks and benefits so as to adequately and transparently inform the general public of business-as-usual data practices.

**Page 16:** Educate consumers on the availability of quality and price information and how to use this information to shop for care based on value.

**Comment:** As previously discussed, it would be helpful to provide links to resources on quality and price information. It must be clarified that “shopping for care based on value” does not apply for emergency situations or life-altering diagnoses. Patients and carepartners in emergency situations or living with social determinants of health (SDoH) that evoke survival mode need to be best supported through the use of health IT to prevent surprise billing that may cause catastrophic financial burden or complete financial toxicity. In addition to “shopping for care”, individuals should also be connected to publicly available resources and all forms assistance that may be available.

**Page 16:** To help reduce health IT expenditures, federal agencies, researchers, payers, and healthcare provider organizations should use innovative approaches to automate care processes through health IT so healthcare providers can spend more time on patient care.

**Comment:** Patients and carepartners also should be empowered with tools to use and innovative approaches to automate unnecessary administrative processes on their end. Patients don't have time to manually request their medical records, hunt for images on CD, request pathology slides for second opinions, call payers to appeal insurance denials, call pharmacies to see if prescriptions are covered by their plan, or call to negotiate surprise bills that for emergency procedures that were deemed out-of-network. Patients and carepartners need health IT to also have an efficient workflow when managing their care.

**Page 18:** Vast amounts of health data are generated every day at the individual and population levels that can be ethically leveraged for disease prevention, quality improvement, and outcomes research.

**Comment:** Ethically as defined by who? In order for the apex of ethics to be defined and upheld, patients and carepartners must comprise at least half of the defining body as it is our data, our digital dignity that is at stake.

**Page 19:** Promote trustworthiness of health IT through rigorous enforcement of information blocking and privacy and security laws when applicable, and by encouraging consumer reviews and reports on health IT products.

**Comment:** Patients and carepartners must be empowered and encouraged to play a role in the rigorous enforcement of information blocking and HIPAA laws in their local communities, reporting any barriers to their care providers and health systems as well as escalating practices that unnecessarily restrict data sharing to regulatory bodies. Enforcement of regulations needs to be from the top-down and the bottom-up.

**Page 20:** As capabilities for health information access, exchange, and use continue to expand, federal partners must prioritize protecting individuals' health data from misuse and threats like cybersecurity attacks, fraud, and other harms. Additionally, patients and caregivers must be



*informed to understand how health data may be used and to provide their privacy preferences where appropriate.*

**Comment:** Point of care is no longer where the doctor is; it's where patients are. Patients and carepartners are online and often participate in peer health discussions on a variety of social media platforms, including "closed" Facebook groups, Twitter, and Instagram. Patients and carepartners need their privacy and health information kept safe when they seek peer health support.