



April 2, 2015

Honorable Karen DeSalvo, MD  
National Coordinator for Health Information Technology  
200 Independence Avenue, SW  
Washington, D.C. 20201

Dear Dr. DeSalvo,

Nemours Children's Health System (Nemours) is pleased to submit comments on *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap, Version 1.0*. We commend the Office of the National Coordinator for Health Information Technology (ONC) for working closely with stakeholders to develop this iteration of the Roadmap. In general, we found the Roadmap provides a thoughtful analysis of existing opportunities and barriers to robust information exchange. Nemours is grateful for the opportunity to share feedback, based on our unique experience.

As you are aware, Nemours has long embraced health IT as a key driver in improving access to health care, quality and safety, lowering costs and enhancing the patient/family experience. Through NemoursOne, our fully integrated, system-wide EHR platform, we have connected and coordinated all phases of care for our patients: in our hospitals, primary or specialty care settings, and at the referring physician's office. In addition, we are leveraging our EHR to achieve national patient safety goals, improving clinical decision support, and facilitating better patient outcomes in obesity prevention, reducing asthma-related ED visits and increased immunization rates. Finally, MyNemours, our secure, online patient/family portal, enables parents and guardians 24/7 access to the most current health information - including downloading a Health Summary from past visits - and the ability to conveniently request an appointment, renew prescriptions, send photos of their child and communicate directly with the care team.

We have made these investments because we believe interoperable technology and information exchange are vital underpinnings of payment reform and health care delivery transformation in the United States. Achieving a health care system that improves health outcomes by paying for value and promoting accountability is not possible without the support of reliable and accessible data. Yet, significant barriers to information exchange remain. We offer the following comments to illustrate our experience and bolster and improve upon the foundational work ONC has prepared in developing this Roadmap.

### ***Our Experience***

#### **A. Successes**

Nemours began electronically exchanging clinical records with other Epic organizations in 2011. Utilization of this functionality has increased tremendously since then. In 2014 alone, Nemours exchanged over 40,000 documents (incoming and outgoing), more than 2011-2013 combined. The number of documents exchanged reflects not only those obtained through a query/response model of exchange, but also Continuity of Care Documents (CCDs) received through inbound transitions of care workflows we implemented in August 2014. Additionally, after going live

with the Surescripts HISP in February 2015, we have begun receiving clinical documents from non-Epic organizations. These include clinical summaries, discharge notices, and immunization records.

Nemours credits the Meaningful Use program for pushing the industry forward by spurring positive developments in health information exchange. Many of our providers have come to rely on their ability to obtain patients' outside records through the EHR and use this information to assist in the care of their patients. In the last year, we have also been fielding many inquiries from referring providers regarding our electronic exchange capabilities as they embark on implementing Direct exchange capabilities.

Our experience has shown that the greatest success is achieved when there is standardization. In addition to using the Epic platform, Nemours participates in the Delaware state-wide Health Information Exchange (HIE), Delaware Health Information Network (DHIN). Both require a standardized data structure for information to be exchanged, and a large percentage of the documents we have exchanged are within those two platforms.

As we pursue *meaningful* use of our systems, it is always encouraging to learn of concrete examples where technology has a positive impact on the care of our patients. With regard to information exchange and interoperability, our providers have been able to quickly and securely access a patient's health records outside of our system. In one case, one of our Nemours pulmonologists recently saw a medically-complex two-year-old boy who had previously received care at University of Florida Health and at Children's Hospital in San Diego. The patient arrived without any records. Our physician was able to retrieve records from both sites electronically through our EHR. This enabled our physician to provide the care the child needed at the first visit, rather than having to wait for medical records to be sent to Nemours. In another example, a Philadelphia-area patient arrived for specialized care in our Gastroenterology department at our Jacksonville, FL location. Upon the patient's mother disclosing that the child had a history of care in Philadelphia, our GI provider was able to quickly obtain the Philadelphia hospital records during the patient visit, allowing him to have access to a rich patient history.

As more health care systems are implementing functionality to support the "Summary of Care" Meaningful Use Stage 2 objective, Nemours is receiving more electronic clinical summaries as providers at community hospitals are referring their patients to us. It is certainly beneficial to have clinical documentation for a patient in advance of their first visit.

Currently, institutions like Nemours measure the value of information exchange one patient at a time rather than on a population basis. We believe that macro and micro analyses can go a long way to demonstrating the impact, yet we acknowledge that the industry is still very early in the evolution of information exchange to see a measurable impact on patient health and population health. We encourage ONC to provide an avenue for collecting success stories and other, larger studies to demonstrate the impact of robust health information exchange on individuals and populations.

## **B. Challenges and Barriers**

As a pediatric health system, we find that, at times, health IT policy does not consider the unique needs of children, their families and their care teams. In an era of patient-centered care (which we elevate to a level of family-centered care), we believe it is imperative to address the specific health IT needs of our youngest and often most vulnerable patients. Prevention and early intervention are keys to achieving the Triple Aim and addressing population health. Given the prevalence of many adult chronic conditions such as asthma, obesity, diabetes and others, effective care for patients begins in childhood and adolescence.

Health IT addressing the unique needs of children requires a few factors to consider:

The pediatric continuum of care is different than the adult continuum and should be reflected in the overall life-cycle of health information, especially in information exchange. It includes:

- a. Prenatal and perinatal care – It is unclear when data travels with mom versus baby and how to retain a record of perinatal interventions that follow a child.
- b. School nurses – Though children receive a considerable amount of care at school, there is very little information sharing between school nurses, health clinics and community providers. A barrier to this is the FERPA law that considers a child's school health records (including immunization records) as "education records" rather than clinical records. FERPA law is more restrictive than HIPAA and makes it a requirement that consent be obtained prior to the sharing of records. Obtaining a consent is a challenge particularly in school districts where there is a large population of underprivileged, non-English speaking families. Nemours has a model in Delaware demonstrating information sharing between our providers and schools that recognizes the important role that school nurses play in the daily management of children's health, and grants these nurses access to medical records. Through this work, and communication with other pediatric health systems, we have recognized the need for better alignment between HIPAA and FERPA to promote exchange between these settings of care. This would benefit from common data sharing requirements and privacy standards between the two regulatory frameworks.
- c. Transition to adult care through adolescence – Pediatric care involves complex interaction with proxies in child and adolescent care that is not well addressed in current policy. Further, it is unclear when ownership of data transfers from parent/guardian to the adolescent. This makes exchange challenging, particularly when considering privacy issues regarding reproductive health and other sensitive information that the individual does not want shared with his/her parent/guardian.

In addition, we believe the greatest barrier to interoperability and seamless information exchange is a misalignment of incentives. We address this in more detail in the section of this letter entitled *Supportive Business, Clinical, Cultural and Regulatory Environment*, but would highlight the following:

- 1) A fee-for-service payment model counters the value of information exchange by disincentivizing information sharing between providers. As long as providers are paid according to volume, sharing patients and reducing duplication will result in a reduction in revenue.

- 2) Interoperability is often the path of most resistance. The level of effort, resources and fear of liability surrounding information exchange – especially considering that much of the information is not valuable – is not justifiable in many cases. Interoperability is very expensive, yet the value proposition is not clear.
- 3) The system is biased toward large systems with resources, such as Nemours. Primary care providers in small practices are often among those in most need of exchanged patient data, but they often cannot afford robust systems or the IT support to use them. Additionally, this shifts the cost burden to larger health systems like ours to fund HIEs and other exchange models.
- 4) While we do not posit that the majority of interoperability barriers are due to a lack of existing technology solutions, we do note that vendor-to-vendor interoperability is extremely important. There needs to be more standardization among health records so that information can be easily translated from one system to the other. Without this underlying compatibility, the remainder of the goals outlined in this roadmap will be very difficult to achieve.

### ***Value proposition***

As mentioned above, the current level of effort and resources required to support information exchange is very high. Considering this reality, it is imperative that providers see a clear value proposition. As it currently stands, the system provides no such clear and predictable value for providers because much of the information that is required by Meaningful Use to be exchanged is not useful, missing, or difficult to sift through.

Nemours does not believe the value of CCDs have been demonstrated in a use case. This needs to be developed in order to gain provider buy-in, particularly if this is a requirement of Meaningful Use. Currently, providers struggle to extract useful information from the CCD because usability is poor; formatting is not standard, there is too much “noise” in the document and content can be missing as a result of system-to-system compatibility issues.

Additionally, we are concerned about the current state of centralized HIEs, which we believe may be unsustainable. Nemours belongs to one statewide exchange and is assessing the value of joining another state exchange, as well as a nationwide exchange. However, participation is very costly and we have concerns about long-term ROI, as the future of these exchanges remains quite uncertain. We note that this subject was noticeably absent from the Roadmap and request that ONC address this issue for the many organizations in the industry that have made considerable investments in HIE participation.

Nemours also has concerns that market forces and consumerization may render the provider-to-provider model of exchange that we are collectively pursuing obsolete before it fully yields its potential. While we are a family-centric institution and believe that patients and families should be actively engaged in their care, we note that the advancements and rapid proliferation of consumer health technology (devices, applications, personal health records, etc) raises the possibility that the patient will become the hub of clinical data exchange and interoperability rather than (or faster than) an HIE, or health institution owned EHRs. We believe that ONC and other federal policy makers need to be proactive in providing standards that acknowledge this

technology trend and allow it to work alongside and in a complimentary fashion to cross-institution data sharing.

### ***Rules of Engagement and Governance***

We agree with ONC's timetable to achieve benchmarks in this area. However, we believe ONC should be more aggressive in pushing the industry toward these benchmarks. Though the various "calls to action" are appropriate, we are concerned that they lack a carrot or stick to incent action.

The majority of Nemours' concerns related to rules of engagement and governance reference government regulation, which we address in the following section. We would highlight the tension between industry-developed governance and the alignment of incentives, often as a result of state or federal law. Nemours is committed to facilitating information exchange through transparent, appropriate and supportive policies and practices, but we recognize the current regulatory environment is not aligned with this notion. Once information exchange and interoperability are not only the "right way" but also the "easy way," we can truly realize the promise of technology to help achieve the Triple Aim and facilitate a population health model.

One specific area where Nemours would like to see additional guidance and governance is patient-generate health data (PGHD). We would like to see policies that stimulate innovation and development (for vendors) to create a medium for PGHD that abides by the same standards as clinical EHRs so that data is easily exchanged between EHRs and personal health records. The absence of such a standard interface could result in multiple, proprietary structures that further exacerbate interoperability challenges. Finally, strong privacy, ownership, liability and use polices need to be developed for PGHD, just as with other clinical information.

### ***Supportive Business, Clinical, Cultural and Regulatory Environment***

As mentioned previously, Nemours believes the biggest obstacle to information exchange and widespread interoperability is a misalignment of incentives in all arenas. In most cases, business, clinical and cultural practices are shaped by the regulatory environment. As a result, it is critical that the right regulatory incentives are in place at the state and federal level.

As long as the fee-for-service model persists, the healthcare system will struggle to achieve robust and free-flowing information exchange. It is currently more profitable to "hoard" clinical information and resist efforts to reduce duplication of services. As the healthcare system moves to value-based payment models, information exchange and care coordination will become increasingly attractive from a business perspective. We commend ONC for their recognition of this challenge in the Roadmap and remain hopeful that ONC and its partners can shape federal policy to improve incentive alignment.

In the meantime, much should be done to adjust existing laws and regulations in favor of information exchange. At the federal level, Nemours believes the Meaningful Use program measures should be altered to promote the centrality of the patient centered medical home (PCMH) or primary care provider (PCP). It is not reasonable to treat every provider as the same, particularly specialty providers. For example, if specialty or urgent care providers were required to provide information back to a patient's PCMH or PCP rather than providing yet another

patient portal, we believe care coordination and information exchange would improve. Having the same exchange measures for every eligible provider (EP) on the continuum is effective or beneficial.

However, as noted earlier, significant challenges plague smaller providers, often primary care practices or practices serving the underprivileged. At a time of decreasing reimbursement, the overhead cost of technology, IT support and continuous updates is prohibitive for the providers who most need it. This is a natural barrier to information exchange and interoperability.

On a related note, the openness and design necessary for cross-platform integration is not part of the traditional business model for long-standing health technology vendors. Given the positive revenue impact that federal support (MU, etc) has had on EHR vendors, ONC could set more prescriptive expectations for technology to support “plug-and-play” interoperability.

Nemours also believes guidance from ONC on cultural transformation could help alleviate internal, cultural barriers to information exchange. As ONC mentioned in the Roadmap, establishing trust at all levels of exchange is among the first and most important steps in building a robust infrastructure. Hesitation by care providers to adopt discrete data reconciliation suggests the mistrust institutions might have for information that originated elsewhere. We believe this is true at the institution level as well. Shifting toward trust, data sharing and standardization of care are all very disruptive to the workforce, workflow and culture of an institution, and can potentially create barriers of their own. Specifically, recommendations on developing a plan of action designed to account for current culture and workflow, as well anticipating future industry-wide changes, would be very helpful to the field.

At the state level, Nemours has found that navigating multiple regulatory landscapes, on top of federal regulations, is a barrier as well. Our health system, like many others, operates across state lines, making it difficult to abide by privacy, consent, and other compliance requirements. This is particularly relevant for pediatric systems, facing more specific questions of consent, when we consider state laws governing adolescent privacy.

Nemours commends ONC for acknowledging many of the challenges providers face with HIPAA and information exchange. We have found that state laws which are more stringent than HIPAA create confusion and fear of liability, especially for health systems that operate in multiple states like Nemours. We strongly urge ONC to account for the unfeasibility in an interoperable ecosystem for an EHR to know which state borders its data is crossing and how to obey each state’s unique set of laws.

To help address these barriers, Nemours suggests that ONC and its federal partners explore the option of federal law governing interstate health information exchange, particularly as we consider ways to take action against “bad actors” as suggested by ONC. In the meantime, we urge ONC and HHS to provide guidance to both states and providers on how to overcome these barriers. Guidance to states should provide guidelines and/or examples of adjusting HIPAA laws at the state level in a way that supports information exchange and interoperability goals.

Further, while we generally agree with the timetable set forth in Table 2 of the Roadmap, we believe ONC could go further to drive change at the state level. Specifically, we would like to see #10 in section B2 of Table 2 (“Call to action: All states should use initiatives around value-based arrangements under Medicaid to provide electronic tools to improve care coordination and deliver quality improvement data to providers”) be moved up in the timeline, as we believe this is a key driver. Additionally, providing a clear description of the desired outcomes might help states develop policies that accomplish them; this could be included in the guidance to states referenced above. We understand and appreciate the challenges presented by a federal system of government, but again encourage ONC, in collaboration with other federal policy makers, to align incentives for states to partner in achieving national interoperability goals. Continuing the work HHS is already doing to promote shifts to alternative payment methods is an excellent intermediate step, as suggested in B3 of Table 2 in the Roadmap. Much progress is being made with Medicare; we hope to see similar progress in the Medicaid and private markets, as those are major payers for pediatric health systems.

In order to track progress on these vital benchmarks in Table 2, we believe ONC should define realistic and coherent measures. Nemours recommends that one measure include the percentage of states that have adopted value-based payment systems in their Medicaid policies, and that the information be provided in regular reporting updates.

Finally, with regard to technology, we urge ONC and other partners to keep pace with trends in the consumer technology space as consumer-driven healthcare becomes a growing reality. We would also recommend that ONC consider ways to encourage developers of future ancillary systems to consider interoperability when developing the next generation(s) of their products.

### ***Privacy and Security Protections for Health Information***

Nemours agrees with ONC’s comments and analysis HIPAA requirements on authorization and consent issues. We have found two major barriers to information exchange in the privacy policy arena:

- 1) Fear of liability is a limiting factor. Providers are fearful of being held liable for a breach when exchanging information under certain circumstances.
- 2) The absence of consistent state opt-out policies limits the flow of information, particularly as institutions like Nemours span multiple state borders.

To achieve a high rate of participation in nationwide interoperability, Nemours recommends that HHS provide further guidance on information exchange in the context of HIPAA compliance. In particular, liability concerns persist regarding breaches of privacy in cases where patient data is shared with other providers. For example, our providers often receive referrals or refer a patient to another provider, triggering an exchange of patient information. Sometimes patients do not present to us when referred or to the external provider when we refer them, but in each case their information has been shared. Additionally, it is possible for providers to make mistakes when choosing a provider to send a transition of care document to, meaning the patient’s information could be unintentionally shared with individuals who have no need for it. These grey areas create a significant amount of fear, sometimes resulting in an unwillingness to exchange information in order to avoid liability for breaches.

On the subject of consent, we appreciate ONC's careful and thoughtful consideration of this topic in the Roadmap. Nemours recommends a national opt-out policy in order to support interoperability and alleviate the barriers presented by inconsistent state opt-in/opt-out laws. Such a policy should preserve exceptions for certain sensitive information such as behavioral health data. Further, we agree with ONC's treatment of "basic choice v. granular choice" in developing governance for privacy and security of patient data. We echo previous comments regarding adolescent consent and the transition of ownership as a child reaches adolescence. This should be addressed explicitly, as it is an important transition in the continuum of care. We find this is particularly important in cases where children are wards of the state and have pieces of their health record in multiple places as they age.

An additional concern we have is related to central data repositories like those hosted by some health information exchanges. In central data repositories, ONC should establish assurances that the data collected and held is being shared on an as-needed basis. Further, it is unclear who has access to those records. In theory, users would be limited to providers with a relationship to that patient, or in an emergency situation, but we believe a greater number of people have access than is necessary. Additionally, HIEs often end up hosting production level data in their test environments as a result of hospital systems sending real patient data during testing, yet a stringent audit trail does not exist for that information. In general Nemours supports and recommends query based exchange models in order to preserve privacy and security of patient data.

### ***Core Technical Standards and Functions***

#### **Patient Matching**

Nemours believes that a major priority should be the development of a consistent patient matching strategy. Without patient matching, the industry cannot have a meaningful conversation on interoperability. Though we have developed a workable, internal patient matching strategy, we would note institution to institution patient matching is a challenge, even when both use the same EHR platform.

Pediatric-specific scenarios make patient matching even more difficult. For example when attempting to match newborn baby names, the birthing hospital may have a child's record identified with the mother's maiden name and "babyboy" as the first name while the other facility may have the father's last name and the baby's given name. Under this scenario, social security numbers are not available as a matching criterion because they have not yet been assigned, parents don't know them, or parents refuse to provide them upon registration. The use of "dummy values" at registration does not help. Further, demographic data elements collected (and sent) vary by organization, and there are variances in data entry. For example, commercial labs do not collect as much patient demographic data as hospitals do, creating a non-match or duplicate chart issue as a result of minimal information being sent in interface messages.

Currently, Nemours uses an algorithmic patient matching system that is supplemented by human review. In the absence of a single, nationwide patient matching strategy, we ask ONC to provide guidance or regulation to standardize algorithmic models. For example, such algorithmic systems should be required to reach a specified level of confidence. It's worthwhile to note that, in our



system, once two records are matched and reviewed by human eyes, those records are then linked, not integrated. This happens for two primary reasons: 1) it allows for “undoing” if a mistake is made; 2) data provenance is clearer and it alleviates fears of liability when acting on potentially faulty information received from outside our institution.

More could be done at the regulatory level to address data provenance specifically, and patient matching in general. The steps outlined in Table 13 of the Roadmap move the industry in the right direction. However, we recommend that ONC:

- 1) Define additional data elements to assist in patient data matching, especially for pediatric patients. These should include mother’s maiden Name, Birth City, last 4 digits of SSN, aliases (in addition to roadmap suggestions of cell phones and emails)
- 2) Agree on a required minimum set of demographic elements that need to be collected and passed through in query requests
- 3) Make these data elements required fields for all healthcare organizations (both at time of patient data collection as well as when query requests are sent)
- 4) Require EHR technology to have the ability to make certain fields required and put strict field formatting in place in order to reduce missing data and data entry errors

#### Provider Directories

Nemours agrees with ONC’s analysis of reliable resource location, particularly as it relates to provider directories. We have found the lack of robust provider directories to be a barrier to accurate and appropriate exchange. The inability to identify a provider’s electronic exchange capability and other necessary details causes organizations to inefficiently expend resources. We support the Roadmap’s call to provide open access to exchange services, such as access to an organization’s provider directory. We agree with ONC’s suggestion that, through Medicaid funding, states should work on designing and developing a provider directory. We would suggest as an alternative to a state-level directory, a national level database which could be queried to find providers who have electronic exchange capabilities, details including which EHR technology they use and identify their Direct addresses. We further recommend using the National Provider Identifier (NPI) registry model where, through a CMS maintained website, anyone can obtain a provider’s “national provider identifier” in addition to other information about the provider.

#### Miscellaneous

Nemours’ other concerns include the lack of interoperability with medical devices and the cycle of continuous technology upgrades. We have found that the lack of seamless interoperability between medical devices and EHRs places a significant burden on our clinicians to constantly correct mistakes when medical devices incorrectly record information in the EHR. Further this presents a very real patient safety issue if inaccurate data is recorded. Additionally, with regard to standards development, we believe an accidental burden of the various incentive programs is ‘continuous upgrade mode’. The pursuit of functionality and enhancement often exceeds the capacity of organizations to fully and successfully implement and adopt technology and standards. To address this, we believe ONC should set a timetable of intervals for updates and changes to standards, and commend ONC for addressing this issue in Table 1 of the Roadmap.

### ***Tracking Progress and Measuring Success***

We commend ONC for committing to tracking and measuring success, a critical piece of an effective strategy for change. The approach outlined in Figure 11 is a sound and robust strategy for measuring the quality of interoperability. The measures are short-term, quantifiable and measurable, and tie directly to the Triple Aim. This construct is based on sound scientific measurement.

However, we are concerned about the approach to measuring progress on long-term goals. In the “Impacts” column of Figure 12, we find that the items are no longer measures but rather seem to be objectives that are not easily translated into measures. While we agree that these objectives are critical, we recommend that ONC clearly delineate that they are objectives, and note that measures are not being proposed in Figure 12.

### ***Conclusion***

Once again, Nemours commends ONC for producing a thoughtful document that very clearly incorporates stakeholder feedback and addresses major challenges facing interoperability and information exchange. We appreciate the opportunity to provide additional feedback and stand ready to help inform and implement an interoperable health care system for the nation, particularly as it relates to pediatric care. Please continue to keep us in mind as this work moves forward and feel free to contact me at [christopher.revere@nemours.org](mailto:christopher.revere@nemours.org) or Katie Boyer, Manager of Advocacy, [katie.boyer@nemours.org](mailto:katie.boyer@nemours.org) at any time.

Sincerely,

A handwritten signature in black ink that reads "Christopher J. Revere". The signature is fluid and cursive, with a long horizontal flourish extending to the right.

Christopher Revere  
Director, Office of Child Health Policy  
Nemours Children’s Health System