

Does the United States Need to Strengthen the System of Care for Infectious Diseases?

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MITRE

A project sponsored by the

CMS Alliance to Modernize Healthcare (CAMH)

A Federally Funded Research and Development Center (FFRDC)
sponsored by the Centers for Medicare & Medicaid Services (CMS)

For more information on this publication, visit www.rand.org/t/rr2046.

Published by the RAND Corporation, Santa Monica, Calif., and the MITRE Corporation, McLean, Va.

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Preface

The Assistant Secretary for Preparedness and Response asked the Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare Federally Funded Research and Development Center to conduct an exploratory analysis of whether the nation’s current system for caring for patients with rare but serious infectious diseases might benefit from additional strengthening. Based on a literature review of prior responses to infectious disease outbreaks, interviews with selected stakeholders, and discussions with two working groups, we identified opportunities to strengthen the current system of care for infectious diseases in the United States. Such opportunities include, but are not limited to, the three tiers of acute care facilities that were established during the Ebola outbreak of 2014–2016. Other potential opportunities for further exploration include such options as the development of a “brain trust,” using mobile teams, and enhancing air and ground systems for safely transferring infected (or potentially infected) patients. We also laid the groundwork for future discussions around key financial considerations to ensure the sustainability of an enhanced approach to rare but serious infectious diseases.

To build on this preliminary work, additional analyses and broader stakeholder engagement are necessary, given that the key assets and capabilities required to care for patients with rare but serious infectious diseases lie outside of direct federal control. Accordingly, we intend to advance the discussion of how the current system of care for rare but serious infectious disease might be strengthened or more formalized.

This research was funded by the Assistant Secretary for Preparedness and Response through the Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare Federally Funded Research and Development Center and carried out within the Access and Delivery Program in RAND Health Care.

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Summary

The Assistant Secretary for Preparedness and Response asked the Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare Federally Funded Research and Development Center (CAMH FFRDC) to conduct an exploratory analysis of whether the nation’s current system of care for patients with rare but serious infectious diseases might benefit from additional strengthening. This analysis reviewed challenges with responses to prior infectious disease outbreaks and identified options that might, given further exploration, strengthen the current system of care. The current system of care was developed in response to the 2014–2016 Ebola outbreak and divides acute care facilities into frontline health care facilities, Ebola assessment hospitals, and ten regional Ebola treatment centers. While the current system provides an important foundation for the care of Ebola, a number of additional issues may require further exploration. In particular, a system of care must be able to sustain capacity, capabilities (including expertise in special populations, such as pediatrics and geriatrics), the geographic distribution of resources needed to manage infectious disease scenarios involving other novel pathogens, and/or meet a high demand for services resulting from social risk amplification (also known as the creation of an “epidemic of fear”). In this report, we consider the need to strengthen the current system of care, discuss potential opportunities for strengthening the system, and identify topics for further exploration with a focus on three primary questions: (1) What does experience with past outbreaks suggest about the strengths and gaps of the current system, and is a strengthened or more formalized system of care for infectious diseases needed? (2) How might the current system be strengthened or more formalized to address existing gaps? and (3) How could a more formalized system be financed, both in terms of initial investments *and* long-term sustainability?

Based on a literature review of prior responses to infectious disease outbreaks, interviews with selected stakeholders, and discussions with two working groups, we identified options for improving the current system of care for rare but serious infectious diseases in the United States. These options included enhancing or building on the three-tiered system of care developed during the Ebola outbreak of 2014–2016, a “brain trust” composed of experts from a variety of clinical specialties and disciplines, mobile teams with specialized expertise, and enhanced air and ground systems for safely transferring infected or potentially infected patients.

One of the most important challenges we identified was how a system of care for rare but serious infectious diseases might be financed, as this system is needed only intermittently and requires highly specialized expertise and resources to be rapidly activated in the event of an emergency. Our discussions with key stakeholders and working groups identified a number of financial challenges and potential considerations for such a system, including, but not limited to, high start-up costs; ongoing costs of being on “stand-by” to keep both staff and infrastructure

prepared; high costs of direct patient care that often go unreimbursed; and opportunity costs (e.g., taking revenue-generating patient beds “off-line” to create a specialized isolation unit at a hospital).

Because many of the key assets, capabilities, and financing involved in caring for patients with rare but serious infectious diseases lie outside of direct federal control, engagement of a broad array of stakeholders and an iterative learning process would be needed to strengthen the current system and to ensure integration with other systems and preparedness efforts (i.e., taking an “all-hazards” approach). In this report, we provide a summary of expert discussions that identified topics and considerations that might inform such a process, and it is intended as a starting point for future work.

Acknowledgments

We thank our working group members for sharing their time, valuable insights, and feedback:

- Amesh Adalja, M.D. (University of Pittsburgh Medical Center)
- James Augustine, M.D. (U.S. Acute Care Solutions)
- Kevin Bowman, M.D., MPH (Anthem, Inc.)
- Patrick Brennan, M.D. (University of Pennsylvania Health System)
- Stewart Wright Caughman, M.D. (Emory University)
- Cara Christ, M.D., M.S. (Arizona Department of Health Services)
- Wendy Chung, M.D. (Dallas County Health and Human Services)
- William Daniel, M.D., M.B.A. (University of Texas Southwestern Medical Center)
- Stan Deresinki, M.D. (Stanford Medical Center)
- Jane Englebright, Ph.D., RN (Hospital Corporation of America)
- Laura Evans, M.D., M.Sc. (Bellevue Hospital Center)
- Rebecca Fischer, M.P.A. (Bellevue Hospital Center)
- Bryce Gartland, M.D. (Emory University Hospital)
- Angela Hewlett, M.D. (Nebraska Medical Center)
- Matthew Icenroad (The Joint Commission)
- Robert Kimball, M.D. (Piedmont Healthcare)
- Colleen Kraft, M.D., M.Sc. (Emory University Hospital)
- Chris Kratochvil, M.D. (University of Nebraska Medical Center)
- Kevin Lanciotti, M.B.A. (Geisinger Medical Center)
- Elaine Larson, Ph.D., RN (Columbia University)
- Grace Lee, M.D., M.P.H. (Boston Children's Hospital)
- John Lowe, Ph.D. (University of Nebraska Medical Center)
- Ruth Lynfield, M.D. (Minnesota Department of Health)
- Joseph Masci, M.D. (Elmhurst Hospital Center)
- Gregg Pane, M.D., M.P.A. (Association of American Medical Colleges)
- Andrew Pavia, M.D. (University of Utah)
- Connie Savor Price, M.D. (Denver Health)
- Thomas Priselac, M.D., M.P.H. (Cedars-Sinai Hospital)
- Bruce Ribner, M.D., M.P.H. (Emory University Hospital)
- Jonathan Sevransky, M.D. (Emory University)
- Skip Skivington, M.B.A. (Kaiser Foundation Health Plan and Hospitals, Inc.)

- Keith Wages (Georgia Department of Health).

Our acknowledgment of their contributions does not imply that these individuals endorse the contents of this report.

About the CMS Alliance to Modernize Healthcare

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Abbreviations

AAMC	American Association of Medical Colleges
AAR	After Action Report
AHIP	America’s Health Insurance Plans
ASPR	Assistant Secretary for Preparedness and Response
CAMH	Centers for Medicare & Medicaid Services Alliance to Modernize Healthcare
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
DoD	U.S. Department of Defense
DRF	Disaster Relief Fund
DRG	Diagnosis-Related Group
DSH	Disproportionate Share Hospital
EMS	emergency medical services
FEMA	Federal Emergency Management Agency
FFRDC	federally funded research and development center
GME	Graduate Medical Education
HHS	U.S. Department of Health and Human Services
HPP	Hospital Preparedness Program
IDSA	Infectious Disease Society of America
IME	Indirect Medical Education
MERS	Middle East Respiratory Syndrome
MRSA	methicillin-resistant <i>Staphylococcus aureus</i>
NASEMSO	National Association of State EMS Officials
NDMS	National Disaster Medical System
NETEC	National Ebola Training and Education Center
PPE	personal protective equipment
SARS	Severe Acute Respiratory Syndrome

SHEA Society for Healthcare Epidemiology of America
SNS Strategic National Stockpile
XDR TB extensively drug-resistant tuberculosis

Chapter One

Background and Purpose

All health care facilities treat routine infectious diseases, while complicated and high-risk cases are referred to academic medical centers and other tertiary care facilities, which have considerable capabilities and expertise. Typically, the capacity of health care facilities to treat infectious diseases is based on daily and seasonal demand, rather than on the need to treat less-frequent but serious diseases, such as Ebola virus disease (hereafter, “Ebola”), Severe Acute Respiratory Syndrome (SARS), and other diseases.

During the Ebola outbreak of 2014–2016, a three-tiered system of care was developed in the United States that divides acute care facilities into (1) frontline facilities that are expected to promptly identify, isolate, and triage patients with suspected Ebola infection; (2) assessment hospitals that are expected to safely manage patients being evaluated for Ebola infection for up to five days; and (3) treatment centers, including ten regional Ebola treatment centers that can manage a patient with confirmed disease for the duration of the illness. This system of inpatient care interacts with preexisting systems and processes in public health, emergency management, and transportation.

However, funding for the three-tiered system—which supports planning, exercising, training, and purchasing of personal protective equipment (PPE)—will expire soon, and the financial sustainability of this approach to care for infectious diseases may be a challenge. In particular, the approach to care must be able to sustain capacity, capabilities (including expertise in such special populations as pediatrics and geriatrics), the geographic distribution of resources needed to manage infectious disease scenarios involving other novel pathogens, and/or meet a high demand for services resulting from social risk amplification (also known as the creation of an “epidemic of fear”). It is also unclear whether transport capabilities are sufficient to manage the inter-facility transfer of these patients. Meanwhile, approaches to the delivery of and reimbursements for health care—including care related to infectious diseases—have been rapidly changing and remain in flux, resulting in uncertainty. Globally, trends in travel, commerce, and urbanization increase the likelihood that serious infectious diseases will continue to emerge and could spread quickly.

Purpose

The Assistant Secretary for Preparedness and Response (ASPR) asked the Center for Medicare & Medicaid Services (CMS) Alliance to Modernize Healthcare (CAMH) Federally Funded Research and Development Center (FFRDC) to conduct an analysis to inform potential

future discussions about the nation's system of care for patients with rare but serious infectious diseases. Specifically, the report addresses the following questions:

- What does experience with past outbreaks suggest about the strengths and gaps of the current system of inpatient care for rare but serious infectious diseases, and is a strengthened or more formalized system of care for infectious diseases needed?
- What are some potential options to address the gaps in the current system?
- How could a strengthened or more formalized system be financed, both in terms of initial investments and long-term sustainability?

The remainder of this chapter describes the focus of this work, and Chapter Two discusses our methods. Chapters Three, Four, and Five present responses to the three questions just listed. Specifically, Chapter Three reviews the strengths and weaknesses of the current system's response to recent outbreaks to address whether a strengthened or more formalized system of care for rare but serious infectious diseases in the United States would be beneficial. Chapter Four presents options that might be considered to address the gaps identified in Chapter Three. Chapter Five introduces a range of financial considerations for the long-term sustainability of a more formalized system of care. Lastly, Chapter Six proposes next steps for how a strengthened or more formalized system of care might be designed, financed, and operated.

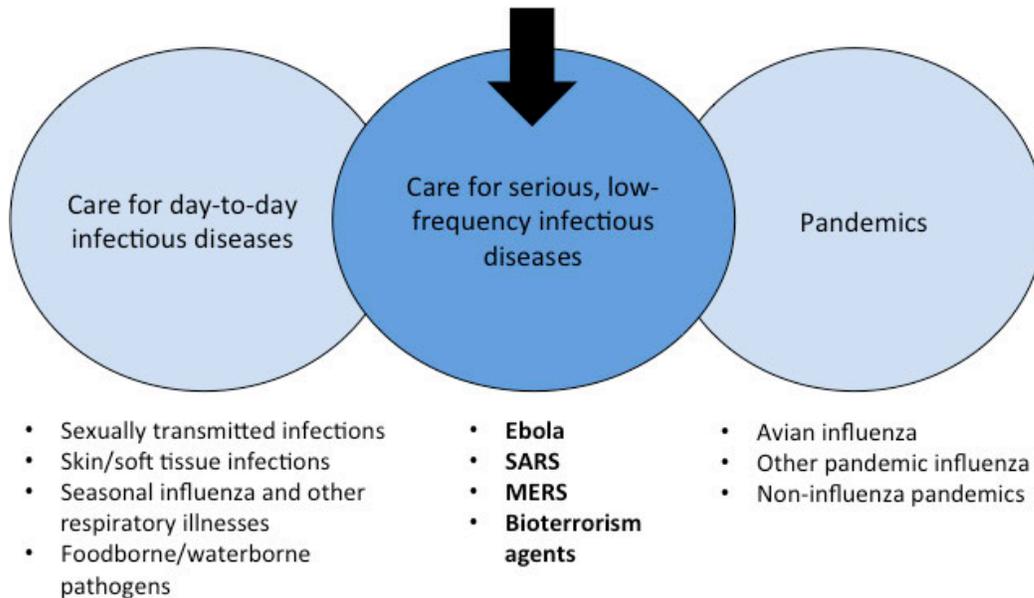
Primary Focus

Before proceeding to the remainder of the report, it is important to clarify the infectious diseases and the health care settings that are the focus of this analysis.

Focus on Rare but Serious Infectious Diseases

We focused on infectious diseases that are serious but occur with low frequency. Specifically, we consider those infectious diseases that cause widespread alarm or an “epidemic of fear” because they are novel, highly transmissible, affect a certain population, and require high degrees of specialty care and enhanced biocontainment practices. Examples include Ebola, Middle East Respiratory Syndrome (MERS), SARS, such emerging antimicrobial-resistant infections as multidrug-resistant *Pseudomonas aeruginosa*, extensively drug-resistant tuberculosis (XDR TB), and others. We do not include routine, day-to-day infectious diseases, such as sexually transmitted infections, seasonal influenza, and other respiratory conditions. Nor do we focus on pandemic influenza, which has been the focus of extensive strategic planning for many years (Figure 1.1). Indeed, one purpose of a system of care for infectious diseases is to collaborate with public health and other systems to contain rare but serious diseases before they spread to the point at which implementing pandemic plans becomes necessary.

Figure 1.1. Project Focus, with Illustrative Examples



Focus on Inpatient Settings

Furthermore, the scope of this work is limited to acute inpatient care of patients with the diseases of interest listed in Figure 1.1. Inpatient settings could include community hospitals, tertiary care centers, and specialized biocontainment units. We recognize that inpatient care does not happen in isolation and that critical interactions occur with outpatient settings, long-term care facilities, emergency departments, and systems outside the health care delivery system, such as public health and emergency management. Thus, we considered how the inpatient setting *interfaces* with these other settings and systems.

Chapter Two

Analytic Approach

In this chapter, we discuss the analytic approach used to answer the three questions posed in Chapter One.

Literature Review

We began by performing a targeted literature review of three of the most-recent rare but serious infectious disease outbreaks—Ebola, SARS, and MERS—to understand the strengths and challenges of the current system of care for rare but serious infectious diseases in the United States. We also included two additional infectious diseases in our review—Zika and H1N1—even though they do not meet our definition of rare but serious events. We reasoned that since these diseases have spread in recent years, lessons learned might be salient to a system of care for rare but serious infectious diseases.

We conducted literature searches for each disease, with a focus on health care system factors that were critical in responding to the infectious disease outbreak. We searched multiple databases, including PubMed, Web of Science, and SCOPUS, and limited the search to articles published from 2006 to 2016 (except for SARS, for which our literature review went back to 2001). In addition, we used an ad hoc Internet search to identify publicly available, national-level After Action Reports (AARs) for the U.S. response to each of the five outbreaks. We compiled information from the articles using an abstraction form to capture the characteristics of the health care system that were relevant to the response (including a general description of the response, the setting in which it took place, and the strengths and weaknesses of the response) and the lessons learned.

We synthesized the results of the literature searches, along with findings from stakeholder interviews to serve as a springboard for discussion at the first of two working group meetings, which we describe in more detail in the next section.

Stakeholder Engagement

Much of the critical infrastructure involved in caring for patients with rare but serious infectious diseases resides in hospitals and other health care facilities that are largely outside of the direct control of the federal government. Thus, we engaged a select group of health care system stakeholders through two working groups, which each met once, and through individual interviews.

Working Group 1 to Assess the Need for a New System of Care for Infectious Diseases

Together with ASPR, we iteratively developed and refined a list of stakeholder groups for Working Group 1, whose purpose was to assess the need for a new system of care for infectious diseases. We first created a list of potential stakeholder groups and a set of criteria for inclusion in the working group. The main criterion was whether the stakeholder groups were essential system actors. We tried to maximize the range of viewpoints represented, and we focused on groups that had less-direct involvement with past federal responses to infectious disease outbreaks and similar public health emergencies. Based on these criteria, and in discussion with ASPR, we created the final list of stakeholder groups and corresponding organizations to include in the working group. Any stakeholder groups that were not invited to the working group meeting were considered for inclusion in a set of interviews that supplemented knowledge gathered in the working group meeting. Table 2.1 shows groups selected for inclusion in the meeting.

Table 2.1. Stakeholder Groups Represented in Working Group 1

Stakeholder Group	Specific Expertise	Stakeholder Organization
Clinical	Infectious diseases	Infectious Diseases Society of America (IDSA)
	Infection prevention	Society for Healthcare Epidemiology of America (SHEA)
	Emergency medicine	American College of Emergency Physicians (ACEP)
	Critical care	Society of Critical Care Medicine (SCCM)
	Nursing	American Nurses Association (ANA)
	Primary care	American College of Physicians (ACP)
	Pediatrics	American Academy of Pediatrics (AAP)
Health care settings	Urgent care/retail clinics	Urgent Care Association of America (UCAOA)
	Hospitals	American Hospital Association (AHA)
	Academic hospitals	American Association of Medical Colleges (AAMC)
	Urban/inner-city hospitals	America's Essential Hospitals (AEH)
Transportation	Emergency Medical Services (EMS)	National Association of State EMS Officials (NASEMSO)
Insurers	Payers	America's Health Insurance Plans (AHIP)
Public health organizations	Local	National Association of County and City Health Officials (NACCHO)
	States/territories	Association of State and Territorial Health Officials (ASTHO)

The project team asked each relevant stakeholder organization to nominate two or three individuals to participate in the working group. We chose the final working group, which met on November 28th and 29th, 2016, in McLean, Virginia, to maximize unique viewpoints on infectious diseases outbreaks and achieve geographic diversity.

We conducted an informal poll at the beginning of the meeting to obtain a general sense of the baseline opinions of the working group members on whether a strengthened or more formalized system of care would be beneficial for the care of infectious diseases. We divided the remainder of the meeting into sessions, each addressing a different aspect of the need for a more formalized system of care. By the end of the first day, there was strong consensus that the current system of care for infectious diseases in the United States should be strengthened. After the working group came to this consensus, we used the second day of the meeting to elicit input on how this might be accomplished. We also presented characteristics of potentially analogous systems of care (trauma, stroke, and cancer) as a starting point for discussion, while keeping in mind the unique considerations for infectious diseases, including their transmissibility, associated stigma, and infrequent, unpredictable nature. Appendix A summarizes key themes from the high-level review and working group discussion of the trauma, stroke, and cancer systems of care. After the meeting, we offered working group members the opportunity to comment on a draft of this report to ensure that the reported findings accurately reflected the discussion at the meeting.

Working Group 2 to Assess the Financial Sustainability of a System of Care for Infectious Diseases

Challenges related to long-term sustainability were a strong theme in the discussions of Working Group 1. To further explore these challenges, we convened Working Group 2 on June 30, 2017, by telephone and webinar.

Whereas the first working group was composed of members with primarily clinical backgrounds, the second working group was assembled to provide additional insights on business and operational issues. Members included payers, hospital and health system leadership, and an accreditation body. We also included representatives from the National Ebola Training and Education Center (NETEC) (Table 2.2). Prior to the webinar, we asked Working Group 2 members to review a brief memo summarizing our findings to date, including those from the meeting of Working Group 1. During the four-hour telephone and webinar meeting, we guided participants in a discussion of challenges to financing a system of care for infectious diseases and explored potential financial mechanisms that might benefit from further review. At the end of the meeting, we asked members to prioritize solutions for future consideration by ranking the three most-feasible and the three least-feasible options discussed.

Table 2.2. Stakeholder Groups Represented in Working Group 2

Stakeholder Group	Specific Expertise	Stakeholder Organization
Insurers	Health insurers	AHIP
	Commercial insurers	Commercial insurer
	Integrated health systems	Integrated health system (Pennsylvania)
Hospital/health system leadership	Hospitals/health systems	Hospitals/health systems (California, Colorado, Georgia, Massachusetts, Texas)
	Safety net hospitals	America's Essential Hospitals
Incentives/accreditation	Accreditation	The Joint Commission
	Incentives	AAMC
Others	Ebola response	NETEC
	Infectious diseases	IDSA, SHEA

Supplemental Stakeholder Interviews

In addition to the perspectives included in the working groups, we interviewed 13 additional stakeholders with the following perspectives:

- public health
- health care facility and system executive leadership
- payers
- accreditation/verification
- telehealth.

These stakeholders were chosen purposely to supply viewpoints not represented in the working groups and to fill in gaps in our findings. Some were selected using a “snowball sampling” approach, i.e., based on recommendations from working group members and other interviewees. These semistructured interviews lasted 45–60 minutes and were conducted before and after the two working group meetings, depending on the information being sought and the availability of the stakeholder.

We prepared an interview guide that provided consistent discussion points, key topics to be covered (tailored to the stakeholder), and a set of probes that could be used, depending on the direction of the discussion. The interviewer used such standard techniques as treating interviewees with respect, avoiding leading questions and judgmental comments, active listening, restating key points to ensure understanding, probing for additional information on key topics, and ensuring that all major topics were addressed during the discussion.

Analysis

After completion of the interviews and each of the working group meetings, we reviewed our detailed notes and the audio recordings to extract key themes that emerged on whether the current system of care for the treatment of infectious diseases might benefit from further

strengthening or formalization and, if so, what ideas might be promising to explore. Thematic analysis was performed independently by two researchers and combined to create a final list of themes and recommendations.

Limitations of Our Analytic Approach

Much of the peer-reviewed literature we reviewed focused on the public health system, preparedness that was not specific to the health care system, and risk communication with the public. It provided fewer insights on the health care system, which is the focus of this project. This made our elicitation of stakeholder input through interviews and the two working groups all the more critical to understanding the “on-the-ground” perspective that was not reflected in the peer-reviewed literature.

In addition, the literature review was not systematic; instead, it was a targeted review of literature. We examined publicly available AARs and selected white papers to supplement the review. The results of the literature search were constrained by what was available in the peer-reviewed literature and was less complete for more-recent outbreaks.

Finally, for Working Group 1, we focused on consulting with “on-the-ground” stakeholders, although the majority of those nominated by the stakeholder organizations were physicians. In Working Group 2, we also sought out those who could provide a perspective on business and operational issues. We did not attempt to consult all potentially relevant stakeholders given the scope of this work, but we recognize that a diverse set of perspectives from other allied health professionals, infection control specialists, laboratorians, and others would be important moving forward. In Chapter Six, we identify additional stakeholder perspectives that should be considered in the future.

Chapter Three

Examining the Current System of Care for Rare but Serious Infectious Diseases

This chapter focuses on the answer to the first of the key questions posed in Chapter One: **What does experience with past outbreaks suggest about the strengths and gaps of the current system, and is a strengthened or more formalized system of care for infectious diseases needed?** In answering that question, we note that the current three-tiered system was put in place in response to Ebola; thus, responses prior to the Ebola outbreak were not conducted under the current, more formal system. Nevertheless, to the extent that the three-tiered system builds on preexisting capabilities, examining these earlier cases can provide useful lessons about the current system.

We found that, overall, *there was strong consensus among working group members and other experts interviewed for this work that a more formalized system of care for serious infectious diseases would be beneficial.* In applying a set of criteria, the working group identified specific challenges to providing optimal care in the inpatient setting to patients with rare but serious infectious diseases during recent outbreaks, as well as key strengths on which to build. *In addition, there was consensus that a strengthened or more formalized system should neither start from scratch nor be superimposed on the existing approach to care. Rather, it should build on existing systems and resources, while more deliberately organizing these components to optimize how they interact.* The members of Working Group 1 and other experts also noted that there is wide variability in the performance of local health care systems and settings; something that works well in one local setting may be very challenging in another. Furthermore, federal agencies' responses to infectious diseases have been variable, and challenges exist with collaboration among different jurisdictions (federal, state, and local).¹ Stakeholders emphasized that the consideration of financial stability is a critical piece of formalizing a system of care. In short, a formalized and better-organized approach to care could more effectively integrate existing systems and resources, with the goals of harmonizing the response across various federal agencies and, importantly, reducing unnecessary variation in care. We elaborate on these findings in the following sections.

¹ Jonathan Fielding, Thad Allen, Benjamin Chu, Julia Galdo, and Helene Gayle, *Report of the Independent Panel on the U.S. Department of Health and Human Services (HHS) Ebola Response*, Washington, D.C.: U.S. Department of Health and Human Services, June 2016.

Criteria Used

We presented the working group with a set of suggested criteria, based on the Institute of Medicine’s dimensions of quality, to assess the performance of the current system of care for infectious diseases and decide whether a strengthened or more formalized system would be beneficial.² The working group debated and revised the criteria; specifically, they agreed that safety should be a top priority, suggested an expanded definition of equity, and elaborated on our definition of efficiency to include deliberate collaboration. Given those changes, we arrived at the refined criteria presented in Table 3.1.

Table 3.1. Criteria to Assess the Quality of Care for Rare but Serious Infectious Diseases

Criterion	Description
Safety	Ability to contain and prevent the further spread of disease to other patients, providers, first responders, and the public
Timely escalation	Ability to move quickly from conventional to contingency to crisis modes
Effective triage	Ability to match patients with treatments, across all parts of the patient care process
Surge capacity ^a	Ability to provide care for more than the usual number of patients with the rare infectious disease of interest
Continuity of operations	Ability to maintain continuity of critical day-to-day operations (i.e., the delivery of health care)
Equity	Ability to provide care regardless of urban/rural location, race, age, gender, etc.

^a As used in these criteria, *surge* may be only a small number of patients in the case of a serious infectious disease. For example, even one or two patients with Ebola in the United States would require a response from a system of care.

The working group then used these criteria to judge the performance of the current system during recent outbreaks—that is, to identify the key strengths on which to build and the important gaps that could be addressed with a more formalized system of care.

Strengths Identified from Recent Outbreaks: What Worked Well?

The expert stakeholders identified several existing strengths of the current system of care for rare but serious infectious diseases that built on past investments.

First, they highlighted the *tiered system of care* developed during the Ebola outbreak of 2014–2016 as a successful model for triaging patients and transporting them to the most appropriate site of care. This system is the most formalized component of our current system of care for rare but serious infectious diseases, although it was developed specifically for Ebola and has not been activated for other threats. The three tiers of acute health care facilities include (1) frontline health care facilities, including hospital-based emergency departments and other

² Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century*, Washington, D.C.: National Academies Press, 2001.

settings, such as urgent care clinics and critical access hospitals; (2) Ebola assessment hospitals; and (3) Ebola treatment centers. Frontline facilities are expected to promptly identify, isolate, and triage patients with suspected Ebola infection. They are not expected to provide prolonged care (defined as more than 24 hours) for a patient with severe illness. Assessment hospitals are expected to safely manage a patient who is being evaluated for Ebola infection for up to five days while Ebola is being confirmed or ruled out, and/or until the patient can be discharged or transferred. Ebola treatment centers can manage a patient with confirmed disease for the duration of the illness. As of 2017, there were 63 hospitals with Ebola treatment centers (ten of which were designated as regional Ebola treatment centers). This tiered system works in concert with public health departments, emergency management agencies, and other components that are critical to a coordinated response.³ A unique feature of the Ebola response was the expertise provided by NETEC, comprising three institutions with direct experience treating patients with Ebola.

The working group cited this three-tiered network of care facilities, along with a national training and education center developed to support and sustain this network, as valuable investments. They recognized that it would be infeasible to equip every hospital with the necessary resources to care for a patient with Ebola or other rare but serious infectious diseases for an extended period of time, but that it was necessary to prepare hospitals to recognize a potential case, isolate the patient, inform the necessary clinical and public health staff, and make rapid decisions about where to send the patient. The three-tiered system has implications for the criteria in Table 3.1, supporting *effective triage* by matching patients to the appropriate level of care, and improving *safety* by making NETEC’s expertise available to all facilities. The system also promotes *equity*, at least in part by avoiding the concentration of expertise in a particular geographic area.

In several jurisdictions, a strong *relationship between the local public health and health care systems* was critical to a high-quality response to a serious infectious disease outbreak. For example, some experts noted that the long-standing respect and collaboration between the New York City Department of Health and Mental Hygiene and health care facilities—such as the one to which an Ebola patient was admitted upon developing symptoms after a high-risk exposure—highlighted the importance of well-defined roles, open communication, formalized protocols, and a strong interface between these systems.⁴ Additionally, during H1N1, community

³ Office of the Assistant Secretary for Preparedness and Response, U.S. Department of Health and Human Services, “National Health Security Strategy,” webpage, updated December 26, 2017.

⁴ Isaac Benowitz, Joel Ackelsberg, Sharon E. Balter, Jennifer C. Baumgartner, Catherine Dentinger, Anne D. Fine, Scott A. Harper, Lucretia E. Jones, Fabienne Laraque, Ellen H. Lee, Giselle Merizalde, Celia Quinn, Sally Slavinski, Ann I. Winters, Don Weiss, Kari A. Yacisin, Jay K. Varma, and Marcelle C. Layton, “Surveillance and Preparedness for Ebola Virus Disease—New York City, 2014,” *American Journal of Transplantation*, Vol. 15, No. 1, 2015, pp. 278–280.

pharmacies were faced with shortages of antiviral medications. They worked with departments of health to address this issue, thereby preventing more-severe infections that might have resulted in inpatient admissions.⁵ These relationships improved *safety* during outbreaks, as outlined in Table 3.1, by preventing infections and improving the outcomes for infected patients. As discussed later, however, there is wide variation in the strength of the linkage between public health and the health care system in various parts of the country.

Another strength of recent responses to serious infectious diseases was the *leveraging, in certain parts of the country, of such existing statewide systems as the trauma system*. In the state of Georgia, the existing infrastructure for trauma care, consisting of strong relationships between EMS and the health care system, formed the foundation for adapting existing protocols for the triage, transport, and care of patients with trauma to meet the unique needs of patients with Ebola, thus addressing the *effective triage* and *surge capacity* criteria in Table 3.1.⁶ This “systems approach” and way of thinking about trauma was a beneficial starting point when developing a statewide approach to Ebola. Existing infrastructure, relationships, protocols, and policies could be built upon, rather than designed from scratch.

Similarly, in the current era of increasing value-based purchasing and the development of quality metrics that impact hospital reimbursement rates, health care facilities have developed *systems to prevent health care–associated infections as part of routine care*. Existing practices (and quality improvement initiatives across hospitals or health care systems) to prevent person-to-person transmission of such common pathogens as methicillin-resistant *Staphylococcus aureus* (MRSA) and *Clostridium difficile* were built upon by infection prevention experts and regulatory bodies as hospitals prepared for the possibility of a patient with a rare and serious pathogen. Furthermore, the emerging interest in creating and strengthening “cultures of safety,” wherein everyone in a health care facility feels safe to alert the rest of the team when an infection prevention practice is violated, was identified as a strength of the current system that could be enhanced and standardized in a more formalized system of care, thus improving performance on the *safety* criterion in Table 3.1.

Another identified strength of the current system was that *data systems increasingly are being integrated at the federal level so that data can be collected in a standardized fashion*, aggregated, and used for clinical and policy decisions as well as to provide situational awareness. Although there were challenges with consistent data collection during H1N1, one working group

⁵ Lisa A. Rosenfeld, Paul Etkind, Alfred Grasso, Alex J. Adams, and Mitchel C. Rothholz, “Extending the Reach: Local Health Department Collaboration with Community Pharmacies in Palm Beach County, Florida for H1N1 Influenza Pandemic Response,” *Journal of Public Health Management and Practice*, Vol. 17, No. 5, 2011, pp. 439–448.

⁶ C. Harris, T. Waltz, J. P. O’Neal, K. Nadeau, M. Crumpton, and S. Ervin, “Conceptualization of a Health Care Coalition Framework in Georgia Based on the Existing Regional Coordinating Hospital Infrastructure,” *Disaster Medicine and Public Health Preparedness*, Vol. 10, No. 1, 2015, pp. 174–179.

member noted that the collaborative aspect of the weekly conference calls by jurisdictions around the country to provide data on H1N1 morbidity and mortality to the federal government in a coordinated way were helpful to the response. During the Zika response, the Centers for Disease Control and Prevention (CDC)—with the collaboration of state, tribal, local, and territorial health departments—established the U.S. Zika Pregnancy Registry to collect information about pregnancy and infant outcomes following laboratory evidence of Zika virus infection during pregnancy.⁷ Data from this federal registry are being analyzed and findings disseminated to update recommendations for clinical care, plan for services for affected women and families, and inform prevention efforts, contributing to the improved *safety* criterion in Table 3.1.

Finally, the working group members praised the *use of technology to communicate rapidly changing clinical guidelines, especially in the case of Zika*. This technology includes web-based dissemination tools and social media outlets. Working group members suggested that the CDC’s efforts to quickly disseminate evolving clinical guidelines for managing patients at risk for Zika, especially in the face of rapidly changing knowledge, has been a success. The communication strategies used in response to Zika represent significant progress when compared with the difficulties delivering harmonized recommendations during SARS and H1N1. Making such clinical guidance widespread and available electronically might improve performance on the *equity* and *safety* criteria in Table 3.1.

What Are the Gaps? Challenges Identified from Recent Outbreaks

Working group members also noted some gaps in the current system that present challenges. Among these challenges is the fact that the effectiveness of responses during past events varied widely at the local and regional levels.⁸ Indeed, for almost every aspect of the response that was identified as a challenge in one area, another expert cited it as a strength in their jurisdiction. For instance, we previously discussed close collaboration between the New York City public health department and the health care facility where an Ebola patient was cared for as an exemplar that facilitated the rapid containment of the patient and the prevention of secondary transmission in the community. However, in other parts of the country, working group members noted limitations in these relationships (e.g., a lack of coordinated planning). Members also expressed

⁷ Centers for Disease Control and Prevention, “U.S. Zika Pregnancy Registry,” webpage, last updated December 28, 2017.

⁸ Carina Storrs, “As Zika Reaches U.S. Shores, States and Cities Struggle to Respond,” *Health Affairs*, Vol. 35, No. 7, 2016, pp. 1156–1159; Christopher T. Lee, Neil M. Vora, Waheed Bajwa, Lorraine Boyd, Scott Harper, Daniel Kass, Aileen Langston, Emily McGibbon, Mario Merlino, Jennifer L. Rakeman, Marisa Raphael, Sally Slavinski, Anthony Tran, Ricky Wong, and Jay K. Varma, “Zika Virus Surveillance and Preparedness—New York City, 2015–2016,” *Morbidity and Mortality Weekly Report*, Vol. 65, No. 24, 2016, pp. 629–635; Rossana Rosa, Lilian M. Abbo, Girish Kapur, Peter Paige, Reynald Jean, Edhelene Rico, and Abdul M. Memon, “Development and Implementation of a Zika Virus Disease Response Protocol at a Large Academic Medical Center,” *Disaster Medicine and Public Health Preparedness*, Vol. 11, No. 2, April 2017, pp. 256–258.

concerns about guidance not being standardized, insufficient coordination, the geographic distribution of resources, and the economic and other incentives faced by health care providers. To paraphrase one working group member, “The raw materials are in place, but they aren’t working well together.” There was also a recognition that recent outbreaks (e.g., SARS, MERS, Ebola) produced relatively few cases in the United States, and that the current system may not be resilient enough to withstand a more serious stress than the country has faced to date. Next, we discuss these themes in greater detail, bearing in mind the criteria from Table 3.1.

Guidance Is Not Sufficiently Standardized

Although working group members highlighted the use of technology to communicate rapidly changing clinical guidelines around Zika as a strength, there was concern that guidance was not sufficiently *standardized*, particularly in earlier outbreaks. Hospitals around the country reported receiving conflicting information and, at times, confusing guidance from all levels (federal, state, and local), particularly around triage protocols, PPE guidelines, and testing and monitoring procedures.⁹ For instance, during SARS, there was confusion around PPE guidelines, which was compounded by the general concern that the best available evidence was not informing recommendations.¹⁰ Additionally, local infection prevention plans for SARS were highly variable in their stringency and led to uncertainty among providers about which protocols to use.¹¹ Therefore, the equipment available and the guidance around how to use it varied by health care facility.

This challenge has undesirable implications for many of the criteria in Table 3.1. Clear guidelines are critical to ensure the protection and *safety* of the patient, other patients, health care workers, and support staff. *Untimely* (or slow) *escalation* hinders the health care system’s ability to ramp up during the initial phase of a response. Triage decisions must be made objectively, and *effective triage* decisions regarding when, where, and how to transfer patients rely on timely, clear, and consistent protocols. Confusing and conflicting guidelines hamper an *efficient* response and ultimately have *safety* implications.

⁹ For triage protocols, see Rosa et al., 2017. For PPE guidelines, see Peter Katona, “Bioterrorism Preparedness: Practical Considerations for the Hospital and the Physician,” *Drug Benefit Trends*, Vol. 16, No. 11, 2004, pp. 559–563, and Marie-Helen Maras and Michelle D. Miranda, “The Weaponization of Ebola: A New Risk in the Wake of an Outbreak?” *Comparative Strategy*, Vol. 35, No. 1, 2016, pp. 72–79. For testing and monitoring procedures, see Rosa et al., 2017, and Ivan J. Gotham, Linh H. Le, Debra L. Sottolano, and Kathryn J. Schmit, “An Informatics Framework for Public Health Information Systems: A Case Study on How an Informatics Structure for Integrated Information Systems Provides Benefit in Supporting a Statewide Response to a Public Health Emergency,” *Information Systems and E-Business Management*, Vol. 13, No. 4, 2015, pp. 713–749.

¹⁰ Allison McGeer, “Let Him Who Desires Peace Prepare for War: United States Hospitals and Severe Acute Respiratory Syndrome Preparedness,” *Clinical Infectious Diseases*, Vol. 39, No. 2, 2004, pp. 275–277.

¹¹ Arjun Srinivasan, Daniel B. Jernign, Laura Liedtke, and Larry Strausbaugh, “Hospital Preparedness for Severe Acute Respiratory Syndrome in the United States: Views from a National Survey of Infectious Diseases Consultants,” *Clinical Infectious Diseases*, Vol. 39, No. 2, 2004, pp. 272–274.

Mechanisms Are Insufficient for Coordinating Information and Resources

Another common theme identified in discussions with expert stakeholders and in the literature review was insufficient coordination mechanisms.

The first example of this theme relates to the challenge of collecting, sharing, and using real-time clinical data for situational awareness and allocation of resources. In a public health emergency, the focus is on a timely and effective response, and efforts to collect data for real-time or future analyses are often a much lower priority. The example of H1N1 highlights an exceptional situation in which a network of intensive care units successfully collaborated to collect and share clinical data. This led to the evidence-based finding that many patients with H1N1 were dying from bacterial superinfections due to MRSA. While this finding eventually led to beneficial changes in patient management, it was not discovered until many months into the event. Thus, there were gaps in hospitals' ability to provide a timely and effective response to this source of excess mortality. A related gap during the H1N1 response was that emergency department data were difficult to integrate with public health department data for decisionmaking because existing relationships and data-sharing agreements were lacking.¹²

The expert stakeholders noted that one of the key challenges during an infectious disease response is making difficult decisions about triaging and transferring patients among different levels of inpatient care in a timely, safe, and efficient fashion. Decisionmaking is hindered by working in silos without adequate coordination. In general, facilities and EMS appeared to lack a shared understanding about the level of care each facility could and should provide, the thresholds for transfer, and where best to transport patients. A related challenge was transporting patient waste across state borders when several patients with Ebola were hospitalized. The transfer of patient waste proved to be very expensive and logistically complex because of varying regulations from state to state. Triage networks and policies, such as those for waste disposal, function less effectively when there are weak or nonexistent relationships between facilities and state entities.

The lack of coordination among key assets in the current system (which led to challenges with data-sharing and patient transfers) has implications for each of the criteria listed in Table 3.1. In particular, it limits *timely escalation* of responses, *effective triage* of patients among levels of care, and *surge capacity* if situational awareness is compromised by a lack of data-sharing and if processes to transfer patients are not operating smoothly. Furthermore, lack of coordination impacts both *equity* in terms of access to different levels of inpatient care and *efficiency* of operations.

¹² Lee et al., 2016; AHC Media, "Hospitals Prepare Plans, Drill Staff to Ensure That Potential Ebola Patients Are Identified, Isolated, and Managed Safely," *ED Management*, Vol. 26, No. 12, 2014, pp. 138–141.

Expertise Is Geographically Concentrated

The tiered system of care developed during the Ebola outbreak assumes that facilities lacking the expertise to treat patients with rare but serious infectious diseases will transfer them to facilities that have that expertise. Nonetheless, there was concern about whether there are enough facilities and skilled personnel in the system, and whether they are distributed in a way that affords equitable access to individuals across the country. Working group members noted that most infectious disease specialists have little or no direct experience with such rare but serious infectious diseases as MERS and Ebola. Because of the rarity of the infectious diseases, transferred patients either had to be directly admitted to a specialized biocontainment unit where expertise was concentrated (particularly in the case of Ebola), or facilities had to enlist in an ad hoc manner the clinical expertise of a small group of infectious disease physicians with experience in treating the particular pathogen. To illustrate the level of subspecialty expertise required in these situations, one director of infection control at a large health system described being frustrated when federal public health officials were unable to provide guidance on the laboratory tests that should be obtained in a hypothetical patient with Ebola. Thus, the working group emphasized the importance of a sustainable mechanism to connect (remotely or physically) the limited number of people with the necessary knowledge to those on the front lines providing care.

An “Epidemic of Fear” May Reduce Incentives for Hospitals to Self-Identify as Biocontainment Units

Rare but serious infectious diseases often cause alarm in the general population—the so-called “epidemic of fear.” This has several potential consequences for the nation’s ability to sustain a viable system of patient care for these diseases. Potential patients (e.g., those who are deciding where to deliver their baby or have an elective surgery) may avoid hospitals that potentially manage these rare pathogens. As a result, hospitals may be reluctant to accept the transfer of patients with rare but serious infectious diseases who are perceived to be a safety risk to staff or other patients. Indeed, health care workers voiced significant concerns about lacking the necessary PPE, personnel, and facilities to safely care for patients with Ebola, especially after two nurses in Dallas were infected.¹³ As a result, hospitals may perceive a strong financial disincentive to participate in a formal system of care, accept the transfer of patients who may have rare but serious infectious diseases, and make the costly investments necessary to care for

¹³ Maras and Miranda, 2016; M. D. de Jong, C. Reusken, P. Horby, M. Koopmans, M. Bonten, J. D. Chiche, C. Giaquinto, T. Welte, F. Leus, J. Schotsman, and H. Goossens, “Preparedness for Admission of Patients with Suspected Ebola Virus Disease in European Hospitals: A Survey, August–September 2014,” *European Communicable Disease Bulletin*, Vol. 19, No. 48, 2014, p. 20980.

such patients.¹⁴ For instance, one leader of a health care system that cared for a patient with Ebola believed that if the infection had spread to any health care workers or other patients, the hospital's financial situation and reputation would have been profoundly damaged, potentially beyond repair. Concerns about hospital exposure to financial risk might affect the system's ability to satisfy most of the criteria in Table 3.1 (e.g., creating surge capacity in a timely manner, ensuring safety of patients and responders). These concerns are addressed in greater detail in Chapter Five, which focuses on the financial sustainability for a system of care for infectious diseases.

¹⁴ Jocelyn J. Herstein, Paul D. Biddinger, Colleen S. Kraft, Lisa Saiman, Shawn G. Gibbs, Philip W. Smith, Angela L. Hewlett, and John J. Lowe, "Initial Costs of Ebola Treatment Centers in the United States," *Emerging Infectious Disease Journal*, Vol. 22, No. 2, 2016, p. 350.

Chapter Four

Identifying Potential Approaches to Strengthening the Current System of Care

This chapter addresses the question, **What are some potential components of a more formalized system that might address existing gaps?** While this work was not intended to present a detailed description of a strengthened or more formalized system of care for infectious diseases, several specific ideas emerged from Working Group 1 that may prove fruitful in efforts to design such a system. These design elements include (1) enhancing the tiered system of facilities developed during Ebola; (2) developing a “brain trust”; (3) creating mobile teams; and (4) strengthening the ability to safely transport infected or potentially infected patients to specialized centers. It should be emphasized that any of the elements described, if implemented in isolation, might make only incremental improvements to the way we care for patients with rare but serious infectious diseases. In the remainder of this chapter, we provide more detail on options for enhancing, or adding elements to, a more formalized system of care and present an overview of each of the four design elements.

Element 1: Enhancing the Tiered System of Facilities Developed During Ebola

Expert stakeholders supported enhancing and building upon the three-tiered system that was created during the Ebola event in the United States. Working group members expressed concern about how to distinguish among the tiers so that each had a well-defined role in the care of patients with rare but serious infectious diseases. Some members suggested that top-tier facilities could specialize in diseases with specific syndromic characteristics or modes of transmission (e.g., infections transmitted by droplet versus fecal-oral transmission) to promote further specialization. The members of Working Group 1 also indicated the need for well-articulated triage protocols to specify where and when patients are transferred. They discussed potential mechanisms for identifying tiered hospitals, including a verification process (as is used by the American College of Surgeons for trauma hospitals) or a certification process (as is used by the Joint Commission for clinical programs in diabetes or cardiac care, or acute stroke-ready hospitals).

Several experts felt that a body similar to NETEC would be the most appropriate entity to provide subject-matter expertise in assigning the tiers for such facilities. The rationale was that doing so required highly subspecialized knowledge about these emerging pathogens, above and beyond broader expertise in public health. For this reason, the experts also did not feel that the Joint Commission was the most appropriate body to determine the criteria for different tiers or verify that facilities met those criteria. In summary, the experts suggested a central coordinating

body with both subspecialized infectious disease expertise and a “bird’s-eye view” of the situation across the country.

In addition, the expert stakeholders emphasized the need to develop clear plans for using specialized biocontainment facilities and all levels of a potentially tiered system during intra-emergency periods. These plans would ensure that the facilities and equipment, the people that operate them, and the processes through which they work would be on stand-by, primed and ready for activation with a moment’s notice. Several experts observed that these specialized units could play important roles in education within institutions and be the sites of frequent trainings and drills. Furthermore, rather than lying dormant between outbreaks, these units could care for patients infected with emerging and increasingly frequent antimicrobial-resistant pathogens (e.g., XDR TB).

This suggestion relates to another core issue, which is the tension between primarily focusing on infectious diseases versus deliberately organizing the system so that it would have the capability to respond to a range of events in an “all-hazards” model. An “all-hazards” model takes into account the intersections between the preparedness and response requirements of infectious diseases and those of radiologic or nuclear disasters, bioterrorism, or other serious threats. For instance, the convened experts strongly supported exploring whether using biocontainment units to respond to a broad set of diseases (based on mode of transmission, such as bloodborne or airborne, or perhaps based on the syndromes that they cause) could be a more efficient use of resources than focusing solely on infectious diseases.

Element 2: Developing a “Brain Trust”

Expert stakeholders suggested that a brain trust—a virtual network of expert clinicians available to consult on cases anywhere in the country—could help address concerns about the fact that the clinical expertise needed to treat rare infectious diseases is not evenly distributed across the country. Such a brain trust could be modeled after programs like the Arizona Perinatal Trust, a “private-public partnership among hospitals, health care professionals, and state agencies throughout Arizona.”¹⁵ The Trust’s mission is to ensure that every mother and baby in Arizona receives the right perinatal care at the right time and in the right place, regardless of where they live. It has a voluntary certification program (a quality improvement process that matches hospital capabilities and capacity to established guidelines); a perinatal education component; and an ongoing data-collection and review process. In short, it works to implement an effective regionalized perinatal care system in Arizona and helps to make real-time, critical decisions about how best to triage high-risk pregnancies throughout the state.

Along with providing assistance on clinical decisions, an infectious disease brain trust could provide evidence-based, objective, highly subspecialized subject-matter expertise to inform

¹⁵ “Arizona Perinatal Trust,” homepage, undated.

ethical allocation of scarce resources, patient transfers, and logistics, drawing on the principles of crisis standards of care. Moreover, having a network of specialists established in advance of an outbreak who could consult on cases across the country could help promote coherence and consistency even where it is not possible or desirable to rely on highly standardized protocols. Advances in technology (e.g., telemedicine) mean that remote consults are more feasible and can be of higher quality, with the potential addition of both audio and video input. An infectious disease brain trust could operate at the national level as a network of experts from a variety of clinical specialties (infectious diseases, emergency medicine, critical care, pediatrics, obstetrics, etc.), clinical backgrounds (nurses, physicians, respiratory therapists, infection preventionists, laboratorians, etc.), and fields, including ethics, public health, emergency responders, health information technology, hospital administrators, insurers, and others. This entity would have the relevant subspecialized expertise, infrastructure, and mechanisms for collecting and using real-time data to give credible guidance to frontline facilities.

A suggestion was made to include a brain trust in current efforts to expand on the NETEC model, which has been evolving in recent years to include a larger scope of emerging diseases. A brain trust supported by a body such as NETEC could be rapidly mobilized when needed. A brain trust could also help sustain expertise and training efforts during interemergency periods by (1) fostering collaboration among facilities; (2) providing training on clinical care and the use of PPE; (3) providing peer review and support to facilities, including on-site assessments and measurement of their performance against certain metrics; and (4) developing common approaches to readiness testing and other activities needed to sustain a viable standing capability to respond to these rare but serious events. It was also suggested that participation in such a system might provide reputational benefits that could help induce facilities to participate in the system.

Element 3: Creating Mobile Teams

Another suggestion from the expert stakeholders is the use of a small number of mobile teams of clinicians (building on the strengths of the existing National Disaster Medical System, or NDMS) deployable around the country as needed, with subspecialized expertise in rare but serious infectious diseases. Such units could work in coordination with a brain trust (e.g., using the brain trust's advice and passing it along to local decisionmakers) and could address gaps in the existing tiered system of clinical facilities. Mobile teams have been used in the global health and humanitarian response fields for decades and can assist smaller, less-resourced facilities by expanding their capacity and enhancing their on-the-ground capabilities when remote guidance is not sufficient.

However, the disadvantage of mobile teams is that they are entering an unfamiliar setting and may not have a grasp of the local culture, the chain of command, the day-to-day operations, and the key people with whom to work. The team may not even be able to access the local electronic

health record or enter restricted units of the hospital or operating rooms upon their arrival. They may not be able to bring all the necessary equipment, and they would require an expedited credentialing process to be able to legally work in different states. Other barriers include transit time and the cost of transporting personnel and equipment for these mobile teams. Thus, it would be important to access lessons learned from other examples of the use of mobile teams (e.g., organ procurement organizations, Strategic National Stockpile [SNS]) and to build on the strengths of the NDMS in any future discussions about this idea. For example, although SNS teams are logistical in nature and largely move resources rather than personnel, there may be important lessons to learn about infrastructure and resource management.

Element 4: Strengthening the Ability to Safely Transport Patients to Specialized Centers

A tiered system of care requires that patients can be safely and rapidly transported to designated treatment units regardless of where they first seek medical attention. For certain clusters of rare but serious diseases, using resources to transport the patient(s) to a higher level of care rather than deploying clinicians to the patient's location may be more efficient. This approach mitigates the challenges of sending a mobile team to an unfamiliar environment, but it does introduce complexities of cost and infection prevention en route. Existing models, such as Phoenix Air Group's ambulance service, could be strengthened and expanded as one design element that would support the tiered system.¹⁶ However, there is also a need to strengthen the ground transport of patients, as there is currently a lack of both expertise and funding for the purchase of equipment to safely transport patients with rare but serious infectious diseases. Furthermore, this ground transport system should collaborate closely with the potential tiered system of facilities to develop clear protocols for patient transfer. Organizations such as the National Association of State EMS Officials (NASEMSO) could help to inform exploration of this capacity.

¹⁶ Phoenix Air Group, "Phoenix Air Ambulance," webpage, undated.

Chapter Five

Exploring Financial Mechanisms to Sustain a System of Care for Infectious Diseases

This chapter focuses on the third of our three guiding questions: **How could a strengthened or more formalized system be financed, in terms of both initial investments and long-term sustainability?**

As noted in Chapter Three, one of the most important challenges identified by Working Group 1 was how a system of care for infectious diseases could or should be financed. Serious infectious diseases will inevitably emerge or reemerge with some regularity, but when and where these diseases will appear, or which pathogen will be responsible, is unknown. This uncertainty means that the business case for individual facilities to invest in maintaining a standing capability to respond to these diseases is unclear. In the remainder of this chapter, we lay out the challenges to financing a strengthened or more formalized system of care for infectious diseases, as identified by both working groups. We also describe a wide range of potential options identified by Working Group 2, review the key strengths and weaknesses of each, and highlight those that appear most worthy of more in-depth analysis and exploration. The material presented in this chapter is meant to serve as a starting point for discussions of financial mechanisms that might be considered to provide care for patients during future outbreaks and to maintain standing capacity to do so over time.

Given the scope of the project, however, our analysis focused primarily on strategies that do *not* rely heavily on annual federal appropriations, which in recent years have been variable and may depend on unpredictable external factors. We also did not delve into the role of assets and funding mechanisms associated with the U.S. Department of Defense (DoD), the Veterans Health Administration, CMS, and other federal agencies. Such funding sources may be important elements of a comprehensive strategy for financing a system of care, but our purpose here was to focus on nonfederal approaches.

Challenges to Financing a System of Care for Infectious Diseases

Working group members described various cost-related challenges with creating and sustaining a system of care, which can be categorized as follows:

1. *Start-up costs* related to capital investment in specialized units and equipment. During the 2014 Ebola outbreak, for instance, 45 Ebola treatment centers reported average costs to construct their units at \$1.2 million, which did not include the ongoing costs of maintaining these sites.¹⁷

¹⁷ Herstein et al., 2016.

2. *Costs of being on “stand-by”* to keep both staff and infrastructure prepared between infectious disease threats. One stakeholder noted that in the prehospital setting (e.g., EMS), there is continuous preparation for high-risk, low-frequency events. This kind of preparation is immensely challenging in the inpatient setting due to competing priorities.
3. *High costs of patient care.* When hospitals have cared for patients with rare but serious infectious diseases, the costs have often been significantly under-reimbursed. Our literature review and expert input revealed that it cost up to \$30,000 per day to care for a patient with Ebola. For patients whose health care was to be covered by workers’ compensation insurance, the maximum limit was quickly exceeded. Patients with commercial insurance also reached and then exceeded lifetime caps. In addition, one hospital that cared for an individual with Ebola estimated that the cost of waste disposal alone was \$1 million. Another separate but related problem is the cost of unreimbursed care for uninfected patients who must be tested and treated to rule out the possibility that they have highly contagious diseases. The cost of keeping patients in the strict isolation required while ruling out Ebola resulted in a high level of care, and there were no corresponding billing codes that physicians could use. When patients ultimately turned out to have more routine diagnoses, such as influenza or malaria, the physicians and hospitals could bill only for these diseases, not for ruling out Ebola, which was much more resource-intensive.
4. *Opportunity costs.* Working group participants repeatedly noted how costly it was for hospitals to prepare for patients with Ebola who never came; taking as few as six to eight patient beds “off-line” to create a specialized isolation unit comes at a great cost to hospitals already operating at full capacity. It was also costly for those facilities that did care for patients to sustain high levels of patient care required for extended hospitalizations. Similarly, during the SARS response, maintaining a supply of PPE and biocontainment equipment was costly for health systems.¹⁸ Finally, there is the potential loss of revenue (which may be difficult to quantify) from patients avoiding facilities out of fear. Such avoidance not only could cause damage to a hospital’s brand (which was noted as increasingly important in the competition to gain market share), but it could also cause financial losses if patients avoid elective procedures that are a critical funding source for sustaining hospitals. While a hospital’s reputation may benefit from performing well in caring for patients with rare but serious diseases, there is also the risk that if care goes poorly, it could lead to even more damage to a hospital’s bottom line.

The U.S. government provides additional funding to prepare for and respond to public health emergencies, including cooperative agreement programs and special funding for specific incidents. However, these sources have declined over time and are often unpredictable. For instance, the current Ebola treatment centers and NETEC are supported at least in part by various federal funding sources. These funding sources are set to end in 2020 (depending on the specific source), and it is unclear whether funding will continue and, if so, in what amount.¹⁹

¹⁸ Katona, 2004; Srinivasan et al., 2004.

¹⁹ U.S. Congress, 113th Cong., Consolidated and Further Continuing Appropriations Act of 2015, Washington, D.C., H.R. 83, 2015.

Stakeholders report that, currently, the decision to participate in caring for rare but serious diseases largely hinges on a sense of moral obligation, often driven by a single person or a small group of people at an institution. As one member of Working Group 2 said, “We want to help, but we don’t have an unlimited treasury in our hospital.” Thus, financial sustainability concerns can limit some stakeholders’ willingness to contribute to a more formalized system of care.

Potential Options to Ensure Financial Sustainability

Despite the critical role of health care facilities and systems in the response to infectious disease threats, reimbursement for the delivery of care during these responses constitutes only a small percentage of their finances. Consequently, preparing for infectious threats is not prioritized in health care facility and system budgets, which tend to favor high-margin and high-frequency services (e.g., chronic care and elective operations). Existing incentives may not motivate health care facilities and systems to invest in increasing their capacity to respond to rare infectious threats when there is no clear or immediate return on investment.

In this section, we identify and assess a range of funding options that (1) leverage existing assets and resources, (2) create new funding streams, and (3) create incentives that encourage hospitals to invest in providing care or that remove barriers to investment.

Options That Leverage Existing Assets and Resources

Table 5.1 summarizes three funding options that leverage assets and resources from other activities.

Table 5.1. Funding Options That Leverage Assets and Resources from Other Activities

Option	Description
Aligning with the trauma system	The trauma system may provide a promising model for a broader, more sustainable system of care for infectious diseases and act as a leverageable asset to be used in a more formalized system to care for infectious disease patients (e.g., transportation networks).
Aligning with routine infection prevention and patient safety	Resources invested in hospital infection control practices could be adapted to support the infection control requirements of a system of care.
Pooling resources among groups of hospitals	Networks of hospitals could pool their resources in one facility to serve as a regional treatment center. Non-treatment centers would agree to perform key related functions (e.g., identification of patients, transport).

Aligning with the Existing Trauma System

Level 1 trauma centers already maintain specialized and expensive capabilities. The trauma center certification process could be used as a model for certifying a hospital for infectious disease care, could be leveraged for certification (i.e., certification for trauma would include infectious diseases), or could be leveraged as an asset to a new system (e.g., use of existing

transportation networks). As such, trauma centers may provide a solution to the longitudinal challenge of maintaining equipment and staff readiness during interemergency periods. During an actual outbreak, working group members suggested that the trauma system could be leveraged for patient transportation, given its well-established networks. However, they noted that the trauma system is not designed for rare but serious infectious diseases and thus would provide only a partial infrastructure.

Trauma centers are currently financed through a combination of state and federal funds and receive some of their resources through their participation in safety net systems. As a result, they depend somewhat on state funding, with some states investing more than others. The working group had serious concerns about relying on state funding if there are potentially significant cuts to state budgets and believed that there was a measure of increased sustainability from federal funding. There was also concern about a fractured system if funding levels vary by state.

Aligning with Routine Infection Prevention and Patient Safety

Resources invested in hospital infection prevention and, more broadly, patient safety practices could help inform and potentially support a system of care. The idea of aligning with infection prevention is particularly appealing in theory, as many of the patient safety issues in infectious outbreaks relate to preventing infection in staff and other patients in the hospital. The idea of aligning a system of care for infectious diseases with infection prevention and patient safety was discussed during the second working group. However, infection prevention and patient safety were reported to already be overburdened and thus is not the best avenue for dissemination and leadership of a system of care for infectious diseases.

Pooling Resources Among Groups of Hospitals

One idea presented to the working group was that networks of hospitals could pool their resources in one facility to serve as a regional treatment center. Non-treatment centers would agree to perform key related functions (e.g., identification of patients, transport). This concept appealed to some working group members, who noted that the health care coalitions funded by the Hospital Preparedness Program (HPP) could be expanded to serve this resource-sharing function. However, other members expressed concern about the variability and long-term sustainability of HPP funding. In addition, while some health care coalitions have been successful, these coalitions are widely variable in function and maturity.²⁰

Options That Create New Funding Streams

Table 5.2 summarizes three options that would create new streams of funding.

²⁰ Joie Acosta, Stefanie Howard, Anita Chandra, Danielle Varda, Sara Sprong, and Lori Uscher-Pines, “Contributions of Health Care Coalitions to Preparedness and Resilience: Perspectives From Hospital Preparedness Program and Health Care Preparedness Coalitions,” *Disaster Medicine and Public Health Preparedness*, Vol. 9, No. 6, 2015, pp. 690–697.

Table 5.2. Options That Create New Funding Streams

Option	Description
Disaster fund model	A fund analogous to the Federal Emergency Management Agency (FEMA)'s Disaster Relief Fund (DRF) could be created. The DRF has no-year funding (i.e., appropriations remain available for an indefinite period) and is used for individual assistance (e.g., temporary assistance to individuals who are not covered by insurance or loans), public assistance (e.g., debris removal), and hazard mitigation (e.g., funds to help states prepare for future hazards).
Vaccine Injury Compensation Trust Fund model	The Vaccine Injury Compensation Trust Fund—a pool of funding to which manufacturers contribute via an excise tax on vaccines—could serve as a potential model for establishing a similar fund for rare but serious infectious diseases.
SNS model	The SNS, which acquires, stores, and deploys critical medical countermeasures and equipment during public health emergencies, has been called on to support responses to past outbreaks. A similar model might be used specifically for rare but serious infectious diseases.

Disaster Fund Model

FEMA’s DRF provides funding for disaster response and recovery after disaster declarations under the Robert T. Stafford Disaster Relief and Emergency Assistance Act.²¹ The fund relies on congressional appropriations but attempts to deal with year-to-year funding variations by functioning as a reserve fund, with unspent money carrying forward into future years. Designers of a system of care could investigate the feasibility of either creating a separate fund for infectious disease outbreaks and other public health emergencies, or expanding the scope and funding of the DRF to include these types of incidents. The existence of such a reserve fund could be used to help providers care for clusters of patients and free up resources to bear the costs of maintaining longitudinal preparedness. We note that such a fund would need to be in addition to or part of public health emergency funds, not in place of them.

Vaccine Injury Compensation Trust Fund Model

Some working group members brought up the Vaccine Injury Compensation Trust Fund as a potential model for establishing a similar fund for rare but serious infectious diseases. Manufacturers pay a \$0.75 excise tax on each dose of childhood vaccines. These funds are then used for the National Vaccine Injury Compensation Program, which is a no-fault alternative to the legal system for resolving lawsuits related to vaccine injury.²² This approach was created in the 1980s as a means of ensuring the sustainability of vaccine manufacturing, when the lawsuits against vaccine manufacturers and health care providers resulted in threats of vaccine shortages. This idea was appealing to working group members, but feasibility was a concern. Also, working

²¹ Public Law 93-288, Robert T. Stafford Disaster Relief and Emergency Assistance Act, as amended August 2016; Bruce R. Lindsay, *FEMA’s Disaster Relief Fund: Overview and Selected Issues*, Washington, D.C.: Congressional Research Service, R43537, May 7, 2014.

²² Health Resources and Services Administration, “National Vaccine Injury Compensation Program,” webpage, March 2017.

group members had questions and concerns about who or what would be taxed, how funds would be allocated, and how the fund would be governed; all of these details would need to be considered if this solution were to be pursued. Working group members suggested that if it were to be pursued, it should function at a hospital-based level (in contrast to preparedness funding, which primarily flows through public health departments).

Strategic National Stockpile Model

The SNS, which acquires, stores, and deploys critical medical countermeasures and equipment during public health emergencies, has been called on to support responses to past outbreaks. For instance, the SNS distributed antivirals during the 2009 H1N1 outbreak. It also plays a coordinating role, as it did during the Ebola outbreak when it supported state and local governments in acquiring, managing, and sharing PPE.²³ The SNS also provides technical assistance to state and local governments in planning, exercising, and response and provides grants to repository facilities that must agree (as a condition) to participate in responses to infectious diseases. Several working group members suggested that the SNS could play an even larger role in maintaining a standing national capacity to treat patients with rare but serious infectious diseases by aiding in the purchase, stockpiling, maintenance, or distribution of equipment. It was also suggested that the SNS could provide on-the-ground logistical support and coordinate among state and local government, hospitals, and others. However, the SNS does not currently play such a role, and additional discussion would be required to elaborate on this idea and assess its feasibility. Moreover, an additional long-term appropriation might be needed to ensure the sustainability of such an approach.

Options That Create Incentives to Encourage Hospitals to Invest in Providing Care or That Remove Barriers to Investment

Table 5.3 summarizes six funding options that create incentives to encourage hospitals to invest in providing care or that remove barriers to investment.

²³ Centers for Disease Control and Prevention, “The Strategic National Stockpile: Key to Protecting the Nation’s Health,” Public Health Matters Blog, April 29, 2016.

Table 5.3. Funding Options That Create Incentives to Encourage Hospitals to Invest in Providing Care or That Remove Barriers to Investment

Option	Description
Accreditation by The Joint Commission or other body	Making participation in a system of care a condition of accreditation may incentivize hospitals to participate in a system of care for infectious diseases.
New quality measures tied to payment	Creating relevant quality measures (ideally endorsed by the National Quality Forum) may encourage participation in a system of care, but likely only if these measures were tied to financial incentives or public reporting.
Business continuity insurance models to protect health care facilities from financial risk	Such a model would insure against the financial risk that hospitals assume by treating patients for rare but serious infectious diseases (e.g., unreimbursed treatment costs, reputational costs, liability).
Tax incentives and other payments for serving underserved populations	To maintain nonprofit tax exemption status, hospitals must prove that they provide a certain quantity of services that provide “community benefit.” The care of infectious diseases could potentially be incorporated into this type of required service. In addition, federal law requires that state Medicaid programs make Disproportionate Share Hospital (DSH) payments to qualifying hospitals that serve a certain proportion of Medicaid–insured or uninsured individuals and therefore incur uncompensated costs.
Graduate Medical Education (GME) funding	GME funding is financed through the Medicare Trust Fund and might be another stream of funding to incentivize preparation for the care of infectious diseases. The Medicare program also includes an Indirect Medical Education (IME) adjustment in its prospective payment system, which accounts for indirect medical education costs and other factors that increase costs in teaching hospitals.
Increasing reimbursement for participating hospitals	Increasing reimbursement for hospitals that agree to participate in a system of care for infectious diseases may act as an incentive (e.g., by reimbursing selected Diagnosis-Related Groups [DRGs] at a higher rate). Another way to increase reimbursement would be to offset federal penalties (such as those for hospital readmissions from CMS) if hospitals participate in a system of care for infectious diseases.

Accreditation by The Joint Commission or Other Body

The working group discussed the possibility of making participation in a system of care for infectious diseases a condition of accreditation to incentivize hospitals to participate. Accreditation includes standard-setting, quality measurement, and patient safety. However, some working group members noted that because the accreditation for preparedness currently takes a risk-stratification approach (i.e., a focus on those threats deemed more likely and therefore of higher risk), preparedness for rare infectious diseases would likely not be prioritized over other, more likely hazards. For this reason, one member speculated that their institution would be unlikely to invest in preparing for rare but serious infectious diseases, even with accreditation as an incentive to do so. There were also concerns that hospitals, despite being accredited to take care of patients with the diseases of interest, may hesitate to “step up” during an infectious threat, leading to inequities if only some of the accredited hospitals actually participate. Of note, members representing NETEC highlighted that it leverages the unique expertise, resources, and experience of the three civilian institutions that successfully cared for patients with Ebola. Activities of NETEC include (1) assisting health care facilities by assessing readiness with

metrics; (2) educating and training providers, both on-site and online; (3) providing real-time technical assistance; and (4) building research infrastructure in the United States. This model can potentially inform and facilitate future comprehensive accreditation models for facilities.

New Quality Measures Tied to Payment

During interviews with stakeholders, one suggestion was to create relevant quality measures (ideally endorsed by the National Quality Forum) to encourage participation in a system of care. However, these measures would likely only work as an incentive if they were tied to either reimbursement (as with value-based purchasing or in the setting of an accountable care organization) or public reporting. The working group members generally did not agree that this was a useful idea to pursue. Specifically, some members felt strongly that a sustainable system should use “carrots” (i.e., rewards) as opposed to “sticks” (i.e., consequences, such as loss of reimbursement). Moreover, hospitals are already asked to report on a large number of quality measures, so there was concern about excessive measurement and overly complex incentives.²⁴

Business Continuity Insurance Models to Protect Health Care Facilities from Financial Risk

Insurance is often used to address situations in which entities underinvest in an important public good. One example presented for discussion to the working group was creating a model that insures against the financial risk that hospitals assume by treating patients for serious infectious diseases (e.g., unreimbursed treatment costs, reputational costs, liability). One working group member reported that their hospital had purchased reinsurance against financial risks during pandemics. However, the insurance policy was extremely expensive and, if exercised, would not have provided enough coverage to offset the costs of a pandemic. Ultimately, following modeling of various scenarios, this working group member’s organization chose not to retain the insurance policy because it was not deemed a good investment. There was skepticism about the viability of any insurance model, from both payer and provider perspectives.

Tax Incentives and Other Payments for Serving Underserved Populations

To maintain nonprofit tax exemption or status, hospitals must prove that they provide certain services that provide “community benefit.” Similar incentives to offset the costs of serving underserved populations include DSH payments to qualifying hospitals from state Medicaid programs required by federal law. These payments are intended for hospitals that serve a certain proportion of Medicaid-insured or uninsured individuals and, therefore, incur uncompensated costs. Working group members posited that because DSH payments are intended for services that hospitals could not otherwise provide, such payments could serve as a mechanism to fund the care of infectious diseases. However, other members were concerned that DSH payments were already endangered in terms of long-term funding and might not be a sustainable option.

²⁴ Marty Stempniak, “Don Berwick Offers Health Care 9 Steps to End Era of ‘Complex Incentives’ and ‘Excessive Measurement,’” *Hospitals and Health Networks*, December 11, 2015.

Graduate Medical Education Funding

GME funding is currently financed through the Medicare Trust Fund and is another stream of funding that could be leveraged to incentivize preparation for the care of infectious diseases. In addition, the Medicare program includes an IME adjustment in its prospective payment system that accounts for indirect medical education costs and a variety of other factors that increase costs in teaching hospitals. Working group members were largely unenthusiastic about leveraging this funding. They noted that trainees would likely not play a large role in a system of care for infectious diseases (in fact, during Ebola there was an effort to spare trainees from involvement with actively or potentially infected patients); thus, it would be hard to justify using this stream of funding for such a system.

Increasing Reimbursement for Participating Hospitals

One idea that was met with enthusiasm by the working group was increasing reimbursement for hospitals that agree to participate in a system of care for infectious diseases. One specific mechanism discussed was reimbursing selected DRGs at a higher rate. DRGs would include those that overlap well with the types of activities related to the care of rare but serious infectious diseases. This increased reimbursement would offset the ongoing costs of preparedness and potentially allow hospitals to set aside funds for actual outbreaks.

Working group members were also enthusiastic about the idea of offsetting federal penalties (such as for hospital readmissions from CMS) if hospitals participate in a system of care for infectious diseases or meet accreditation or other standards. One working group member noted that the penalties for readmissions were increasing and were particularly burdensome for public hospitals. Offsetting federal penalties would be another way to increase reimbursement for hospitals, allowing them to fund preparedness activities for infectious diseases that are not otherwise reimbursed. However, we note that this option may be philosophically less appealing to both federal policymakers and patients, given that the goal of these federal penalties is to improve the quality of hospital-based care.

Prioritizing Potential Options

At the end of the Working Group 2 meeting on financial sustainability, members were asked to use an online voting system to select the three potential options they considered the most feasible and the three they viewed as least feasible. Table 5.4 summarizes these results.

Table 5.4. Most- and Least-Feasible Options to Finance a System of Care for Infectious Diseases

Most Feasible	Least Feasible
1. Building on and/or leveraging the trauma system model	1. Pooling resources among hospitals
2. Using the SNS model	2. Using insurance models to insure against the financial risk that hospitals assume by treating patients for serious infectious diseases
3. Increasing reimbursement for participating hospitals ^a	3. Increasing routine infection prevention and patient safety efforts

^a Working group members were asked to vote separately on increasing reimbursement directly via DRGs and indirectly via offsetting federal penalties. Both solutions were tied at third place and are listed together.

Overall, the working group gave higher priority to solutions that involved federal funding. This finding may not be surprising given that the group was composed of nonfederal stakeholders. However, working group members did emphasize that hospitals are operating at the margin and feeling overburdened at the best of times. One exception was safety-net hospitals, which are accustomed to being “in the red” (i.e., not making profit and possibly net negative for revenue) and thus are more able to take on risk (although this is likely because they receive federal DSH payments). However, members felt that there are some viable options to incentivize hospitals to participate in a strengthened or more formalized system of care for infectious diseases, albeit with some substantial federal investment over time.

Summary and Future Considerations

This analysis serves as a foundation for discussions about the current system of care for patients in the United States with rare but serious infectious diseases. Based on a literature review, interviews with key stakeholders, and discussions with two working groups, our findings suggest that the United States would indeed benefit from a strengthened or more formalized system of care. Moreover, any strengthened or more formalized system should build on the current system, including, but not limited to, the three tiers of acute care facilities developed during the response to Ebola. Proposing a fully formed design for a system of care was beyond the scope of this project. However, we did identify a number of options (a brain trust, mobile teams, and enhanced air and ground transport systems) and possible financing mechanisms that could inform future discussions.

Given that many of the key assets and capabilities involved in caring for patients with rare but serious infectious diseases lie outside direct federal control, any effort to design and implement an improved system should actively engage a broad array of stakeholders. In addition, the complex interactions among the many “moving parts” require a design process that features continuous experimentation and learning. Such a design process should also take into consideration the integration of a strengthened or more formalized system of care for infectious diseases with other systems and preparedness efforts (i.e., an “all-hazards” approach). While we provide a sample roadmap to inform future discussions, the contents of this report are intended to advance the debate and outline key issues related to strengthening or formalizing the current system of care for patients with rare but serious infectious diseases.

Estimate the Necessary Capacity of the System

As noted earlier, a strengthened or more formalized system of care for infectious diseases could be considered to address highly infectious threats of uncertain origin, timing, and size. Planning for and including key considerations for every scenario would be difficult, likely would require significant analyses based on how many patients may need simultaneous treatment, and would include additional considerations contingent upon the specific types of infectious agents. Given this, facilities might instead identify a range of *plausible scenarios* (e.g., based on past experience, expert opinion) and identify the likely *amount of capacity and capability* needed. The most efficient way to accomplish this might be to review existing literature, government planning documents (e.g., National Planning Scenarios), and existing modeling scenarios, and to seek out subject-matter expertise to identify potential ranges of capacity and capability. These estimates would then inform estimates of the costs of developing and maintaining readiness for various outbreak scenarios. The estimates could also inform decisions about how to structure networks of providers, including the size of provider networks. For instance, larger and more-

diffuse networks might increase requirements for transport capabilities and introduce delays in care (e.g., because of distance). In addition, networks with more participants may make it more difficult to arrive at collective decisions.²⁵

Engage with Additional Stakeholders to Identify Other Strategies and Investigate Proposed Funding Sources

Many types of stakeholders were engaged in the analysis, including both on-the-ground providers (for Working Group 1) and health care executives and others involved with the financing of health care (for Working Group 2). However, additional relevant stakeholder groups emerged that should be engaged in the detailed conceptualization, design, and implementation of a strengthened or more formalized system of care if it is to move forward. Table 6.1 provides a list of suggested additional stakeholders and the rationale for including them in future discussions alongside the stakeholders engaged to date.

Table 6.1. Suggested Additional Stakeholders to Engage in a Design Process

Stakeholder Group	Rationale
Allied health professionals experienced with the care of patients with rare but serious infectious diseases	<p>This would include infection preventionists, nurses, laboratorians, respiratory therapists, occupational health, social work/chaplaincy professionals, EMS, public health, etc.</p> <p>Hospitals (and other health care settings) involve teams of professionals who have different views of health care systems than physicians and who often gain insights into broader factors influencing patients and their care. Thus, it would be beneficial to reach out to broader stakeholders both to generate additional strategies to strengthen the U.S. system of care for rare but serious infectious diseases and to obtain input and ideas about the brain trust concept (e.g., how it can best include practice-based expertise in these and other areas that impact both quality of care and safety).</p>
DoD	<p>Engaging with DoD was out of scope for this project, but several stakeholders suggested that we consider investigating possible civilian-military partnerships as part of a system of care for infectious diseases. Such a partnership could benefit civilians by increasing equipment and operational capability (trained, exercised staff) while giving DoD staff more chances to practice between deployments. One drawback is that deploying the military would take precedence over assisting with a more formalized system of care for infectious diseases. One way to overcome this would be to establish an integrated core of staff from both DoD and the civilian sector who would remain available in the event of an infectious disease emergency.</p>
Veterans Health Administration	<p>The Veterans Health Administration may have assets useful to a system of care for infectious diseases (e.g., staff credentialed across the Veterans Health Administration system). One key question is whether there are opportunities for increased efficiency through the “dual use” of common assets. One limitation to relying on assets from the Veterans Health Administration is that they provide neither pediatric nor obstetric care, and thus could not include key vulnerable</p>

²⁵ James M. Buchanan and Gordon Tullock, *The Calculus of Consent: Logical Foundations of Constitutional Democracy*, Indianapolis, Ind.: Liberty Fund, 1962.

Stakeholder Group	Rationale
ASPR	<p>populations.</p> <p>ASPR would play a key role in such a system, given ASPR's responsibilities in preparing the nation for a number of threats, including rare but serious infectious diseases.</p>
CMS	<p>The second working group highlighted a number of solutions that would involve either increased reimbursement for certain DRGs or forgiveness of some financial penalties if a hospital were to participate in a system of care for infectious diseases. Directly involving CMS to discuss the feasibility of increased reimbursement or decreased penalties would be an important next step.</p>
CDC	<p>CDC is likely to have a role in a future system of care for infectious diseases in a number of capacities. One is as the possible "first call" for a brain trust (given that setting up and disseminating a brand-new call system would be a challenge). In addition, CDC's role in the SNS might provide valuable experience, expertise, and lessons learned.</p>
State departments of public health	<p>Although public health departments were not a central part of this more hospital-oriented analysis, the interaction between public health and hospitals was considered. Given their role in planning and coordinating responses among hospitals, public health departments may be a key stakeholder to include in designing a system of care for infectious diseases. Their role in the trauma system—if it were to be used as a model for a strengthened or more formalized system of care for infectious disease—would also be relevant.</p>
State workers' compensation commissions	<p>The inability of state workers' compensation programs to adequately pay for the risks of acquiring rare but serious infectious diseases was a major barrier to reimbursement. Engaging this payer in designing and financing care for infectious diseases may help to identify ways to overcome this barrier when exposures are work-related.</p>

Convene a Standing Working Group to Oversee an Iterative Design and Development Process

The two working groups convened during the project were invaluable in providing insights and input that could not have been gleaned solely from reviewing the literature. Additional insights and strategies will likely be gained by engaging additional stakeholder groups. For example, what is the role of strengthening the capacity for and visibility of infection prevention and safety structures in health care facilities—a topic which arose tangentially but has not been fully addressed to date? Given the wide range of institutions and entities involved in patient care, ensuring broad input on potential strategies for strengthening the current system of care and ensuring ongoing and meaningful stakeholder engagement will be critical. Regularly convening a mix of clinical, operations, and financing stakeholders would help to ensure that the various components of a strengthened or more formalized system are designed to function effectively as a whole. One important charge for such a group would be to consider both financial sustainability challenges and broader challenges to sustainability, such as maintaining expertise, training, and operational readiness. Next, we provide specific suggestions for constructing and managing such a group.

Select and Recruit Stakeholders to Represent Professional Societies and Other Organizations

When recruiting stakeholders for the working groups conducted during this project, we asked organizations representing a variety of viewpoints to nominate individuals. We made clear to both the organizations and the individuals that they were not representing the viewpoints of their nominating organizations. Given that buy-in to a system is key to a successful conceptualization, design, and implementation process, we suggest that in the future participants explicitly represent their stakeholder organizations when asked to participate in this proposed working group. As noted earlier in the report, Working Group 1 primarily consisted of physicians ably representing many areas of expertise critical to addressing this issue. Following additional input from an array of health care professionals, a standing working group to design this system should reflect the broader scope of health care teams (e.g., infection preventionists, nursing, respiratory, occupational health, and others, as outlined in Table 6.1), which are critical for the effective care of these patients, in addition to identified medical and operations expertise.

The current work focused on the acute inpatient care of patients with rare but serious infectious diseases. However, as noted earlier, we acknowledge that inpatient care does not happen in isolation, and that critical interactions occur with other settings and systems, such as emergency departments, urgent care facilities, primary care, and public health and emergency management systems. Thus, future stakeholder engagement should take into account how the inpatient setting *interfaces* with other settings and systems.

Frame the Process Around Explicit Performance Requirements

Framing a process in terms of clear performance requirements is important in ensuring that the resulting system design meets the needs of key stakeholders. Such requirements can be drawn from the performance criteria gaps described in Chapter Three and additional analysis and input and should be updated as needed to reflect new knowledge.

Use a Subgroup Structure to Continuously Integrate Specific Components and Overall System Architecture

In considering the design of a strengthened or more formalized system for the care of infectious diseases, two levels of design should be considered. The first is the overall system architecture, along with cross-cutting financing and other incentive mechanisms. The second is component-specific design and financing, (e.g., a brain trust, transportation network). We recommend that the process begin with a general sketch of the overall architecture and how specific components (e.g., brain trust, mobile teams) fit together. However, moving quickly—and even in parallel—to prototype and develop specific components can yield key insights about the overall architecture. One way to accomplish this is to task subgroups with designing specific components that would report back to the overall working group. The overall working group

would have responsibility for tasking the subgroups, specifying design criteria, and considering how to integrate the outputs from each subgroup into a coherent full-system design.²⁶

Regularly Seek and Use Feedback to Refine Prototypes

Regularly obtaining on-the-ground feedback (and evidence, when possible) from relevant stakeholders on prototypes will be important throughout this process. In some cases, the feedback may simply be verbal descriptions and diagrams of processes (e.g., a flow diagram showing how a clinic would interact with a brain trust) or perhaps simple tabletop exercises that ask participants to “play through” a proposed process using a written scenario. This approach would provide high-level, early input on system components to avoid further investment in ideas that are not feasible.²⁷ This approach is likely to be familiar to hospitals and other institutions engaging in quality improvement, particularly if framed as a Plan-Do-Study-Act (PDSA) cycle.

Conclusion

Based on a literature review of prior responses to infectious disease outbreaks, interviews with selected stakeholders, and discussions with two working groups, we found that the United States may benefit from a strengthened or more formalized system of care for rare but serious infectious diseases. This preliminary work identified options for improving the current system of care as well as key challenges, particularly in the area of financial sustainability, that could be further explored with a broad array of stakeholders and an iterative learning process. There was broad consensus that modifications to the current system should build on existing assets and be integrated with other systems and preparedness efforts. This report is intended as a starting point for future work.

²⁶A similar approach was used in developing performance indicators for CDC’s Cooperative Agreement on Public Health Emergency Preparedness. See Shoshana R. Shelton, Christopher Nelson, Anita W. McLees, Karen Mumford, and Craig Thomas, “Building Performance-Based Accountability with Limited Empirical Evidence: Performance Measurement for Public Health Preparedness,” *Disaster Medicine and Public Health Preparedness*, Vol. 7, No. 4, 2013, pp. 373–379.

²⁷Eric Ries, *The Lean Startup: How Today’s Entrepreneurs Use Continuous Innovation to Create Radically Successful Businesses*, New York: Crown Publishing Group, 2011; R. Moen, *A Guide to Idealized Design*, Cambridge, Mass.: Institute for Healthcare Improvement, 2002; William Shrank, “The Center for Medicare and Medicaid Innovation’s Blueprint for Rapid-Cycle Evaluation of New Care and Payment Models,” *Health Affairs*, Vol. 32, No. 4, 2013, pp. 807–812; Michael Quinn Patton, *Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use*, New York: Guilford Press, 2011.

Appendix A

Building on Other Systems of Care

The working group members and other expert stakeholders were asked to consider how lessons from other systems of care (trauma, stroke, and cancer systems) could inform our discussions about how to structure a strengthened or more formalized system for infectious diseases. Key themes are summarized in Table A.1.

Table A.1. Characteristics of Other Systems to Consider for the Care of Infectious Diseases

Characteristics of the Other Systems	Considerations for the Care of Infectious Diseases
The trauma and stroke systems are organized at the state level, with regional cooperation. Cancer care is more diffuse and not as structured.	Infectious diseases easily cross geographic boundaries, so state-level organization may not be effective.
All three systems have a tiered system of facilities that meet certain criteria.	The tiered system developed during Ebola might serve as a foundation for a more formalized, less disease-specific system that ensures that patients who need specialized care for particular infectious diseases of interest have a place to go.
The trauma and stroke systems emphasize inclusiveness, meaning that every facility in the system has a clearly defined role in providing appropriate care in accordance with its capacity and facilitating transfer to a higher level of care when indicated.	Inclusiveness is critically important for infectious diseases because of how they first appear in patients and because patients may seek care in any facility anywhere in the country.
All three systems emphasize the need for seamless transitions of care among phases of care (diagnosis, treatment, rehabilitation or palliative care, as applicable) and among locations (inpatient, outpatient).	Transitioning patients with infectious diseases between locations has the added complexity of aiming to prevent transmission to health care workers, first responders, and those performing the transport.
Communication among providers is paramount, and all three systems emphasize the importance of clear, written protocols.	Clear communication and written protocols are needed to safely and effectively care for patients with novel infectious diseases. Protocols for clinical care, triage, waste management, and other aspects of care for patients with rare infectious diseases will likely be developed rapidly and may evolve frequently throughout the response as more is learned, unlike protocols for trauma and stroke, which are more established and less likely to undergo rapid modifications.
Rapid triage can be lifesaving in the trauma and stroke systems.	Rapid triage of the individual patient is important for preventing transmission to other patients and health care workers, which is unique to infectious diseases; at a macro-level, rapid activation of a health facility or system to respond to an infectious disease event is unusual as well.
Trauma systems are financed by a combination of state and federal funds. Cancer care and stroke systems are implementing alternative payment models to move away from an episode-based, reimbursement-focused model of payment.	Historically, sustainable funding mechanisms have been a challenge; as novel infectious diseases come and go, the public's and policymakers' attention is rapidly diverted elsewhere when the acute threat has ended.
Data collection is important in all three systems to facilitate evidence-based management.	Data collection in the setting of emerging infectious diseases is central to understanding these novel pathogens and building the much-needed evidence base to address them.

Characteristics of the Other Systems	Considerations for the Care of Infectious Diseases
All three systems note the key role public health plays in surveillance, prevention, education, and communication with the public.	For infectious diseases, the public health system plays a central role in surveillance, prevention, education, and communication with the public; stakeholders noted that the single most important factor in determining the success of a health care system's response to an emerging infectious disease was its integration and collaboration with the local public health system.

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