Best Practices for Treating Long COVID Summit

Summary Report

February 27, 2023

Prepared for
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services

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Introduction

Purpose

The Best Practices for Treating Long COVID Summit was held on January 27, 2023, in Richmond, Virginia. Sponsored by the Agency for Healthcare Research and Quality (AHRQ) in partnership with the Office of Senator Tim Kaine, the Summit's goal was to hear directly from patients and clinicians about their experiences with Long COVID.

The discussions were designed to drive Senator Kaine's work in the Senate and to further AHRQ's efforts to support healthcare clinicians and health systems to better provide patient-centered, coordinated care for patients with Long COVID.

Beyond that, the conversation was intended to inform the whole of the U.S. Department of Health and Human Services' (HHS') efforts to address Long COVID, involving patients, caregivers, clinicians, and community organizations in shaping initiatives to address this complex condition.

Opening Remarks

Following a brief welcome from **Dr. Edmondo Robinson**, Summit facilitator, **Senator Tim Kaine** shared his experience of living with Long COVID. He noted that although he has a mild case, he believed that it was important to champion the cause of Long COVID given his seat on the U.S. Senate's Committee on Health, Education, Labor, and Pensions.

Senator Kaine shared statistics indicating that 14.4 percent of Americans and 13.9 percent of Virginians state that they have Long COVID, with 85 percent of those in Virginia who report Long COVID noting that it significantly limits their activities. He also mentioned a study from the Brookings Institution that found that 500,000 Americans are no longer working as a result of Long COVID, in addition to those who may be struggling at work as a result of the condition.

Subsequently, three HHS leaders shared opening remarks.

Admiral Rachel L. Levine, M.D., Assistant Secretary for Health, HHS, described the National Institutes of Health's (NIH's) Researching COVID to Enhance Recovery (RECOVER) initiative as a critical component of HHS's response to Long COVID, including treatment and prevention. She highlighted the participation of patients and families as foundational to this work and to framing the most important research questions to be addressed while promoting greater inclusion.

ADM Levine also discussed three high-level HHS publications:

- Services and Support for the Longer-Term Impacts of COVID-19, a report outlining federally funded activities for those experiencing Long COVID and related conditions (mental health, substance use, and bereavement).
- National Research Action Plan on Long COVID, outlining a comprehensive and equitable strategy informing the national response to Long COVID, including research programs under NIH's RECOVER initiative, the Centers for Disease Control and Prevention's INSPIRE study, and the U.S. Department of Veterans Affairs.

- Health+ Long Covid report, which complements the existing pool of statistics, scientific literature, and policymaking.

Alison Barkoff, J.D., Acting Administrator and Assistant Secretary for Aging, U.S. Administration for Community Living (ACL), highlighted the role that ACL plays in partnering with States and communities to provide supportive services through community organizations. As the entity within HHS with responsibility for disability research funding and advocacy at the Federal level, ACL has built a set of resources to support people with Long COVID. This includes a guide to available services and supports, a national hotline to connect people with Long COVID to local resources, and information on protections for people with Long COVID under Federal civil rights law.

Robert Otto Valdez, Ph.D., M.H.S.A., Director, AHRQ, emphasized the need to support rural and urban healthcare systems caring for patients with Long COVID by identifying what is working well and what is not, modifying as necessary, and building on AHRQ's core competencies in research and implementation. He acknowledged that the U.S. healthcare system is not designed for complex health issues involving multiple body systems and that clinicians and healthcare systems are struggling with workforce burnout, overcrowding, and the triple pandemic of influenza, respiratory syncytial virus, and COVID-19. He also highlighted the need to serve patients effectively through better partnerships between healthcare systems and clinicians.

Agenda

Following the opening remarks, **Sherri Wilson, D.N.P., M.P.A., R.N.**, President, Virginia Nurses Association, moderated a patient panel. The goal of hearing from the panel was to gain a better understanding of how policymakers and clinicians can best advocate for those living with Long COVID. This conversation provided crucial context for the entire Summit, with patients each describing their own journey with Long COVID and the challenges they have experienced in receiving the care and support that they need.

Subsequently, a series of breakout sessions enabled deeper conversation on three general topics:

1. **Identifying patients with Long COVID.** These discussions included an overview of strategies and tools that healthcare systems are using to identify and triage patients with Long COVID; barriers that healthcare organizations are facing in identifying these patients; attempts healthcare systems are making to reach communities disproportionately affected by COVID-19; and health services research needed to improve patient identification.
2. **Interacting with primary care.** These conversations focused on how primary care clinicians are working with specialists; education and consultation programs that healthcare systems are providing for primary care clinicians; how healthcare systems are addressing the social and mental health needs of Long COVID patients; and the top barriers healthcare systems confront in working with primary care clinicians to provide whole-person care and care coordination.
3. **Strategies and tools for treating Long COVID.** These breakout groups discussed strategies, tools, and staffing models that healthcare systems are using to care for Long COVID patients, including care coordination, navigation services, and social work support, as well as the barriers healthcare systems face in providing care to Long COVID patients.

Each breakout group was also asked to suggest ways that healthcare systems within Virginia could best coordinate and share learnings to improve whole-person care for patients with Long COVID.

The breakout sessions were followed by time for a member of each group to report out to all Summit attendees and by brief closing remarks from Summit moderator Dr. Edmondo Robinson.

Listening to Patients

The patient panel and subsequent conversations described four key challenges that Long COVID patients face: the impact of the condition itself, challenges in getting needed care and support, not being trusted or believed, and reliance on a single clinician "hero."

Debilitating Impact of Long COVID

Patients described the debilitating impact that Long COVID has had on their lives. Each patient experienced a transition from being a highly active, engaged person to having a far more limited range of activities within their reach. They described extreme fatigue, brain fog, and an inability to work, attend school, and/or participate in family activities in the ways they previously had. Patients experienced depression as a result of having Long COVID and described its symptoms to be as disabling as their physical symptoms.

Tremendous Challenges in Getting Needed Care and Support

Each patient described the tremendous challenges involved in getting needed care, including difficulty identifying knowledgeable clinicians and months-long waits to see needed specialists. In addition, patients have faced extensive travel times to reach some specialists, particularly if the patients were coming from rural areas; they noted that telehealth services are of no use for patients in rural areas where broadband service is not available.

Patients have had little to no support outside of their families for addressing their non-clinical needs, such as making appointments, arranging transportation, and obtaining their medical records. They also highlighted the enormous obstacles they face in filing disability claims.

Also, because clinicians from multiple practices and healthcare systems are involved in the care of each Long COVID patient, patients described serving as their own de facto cross-system medical record, often hand-carrying paper copies of medical records and test results to visits with clinicians from different healthcare systems.

Not Being Trusted or Believed by Clinicians

The patient panelists all described disturbing experiences of clinicians not believing or trusting them. These experiences included the following:

- Clinicians denying the existence of Long COVID.
- Clinicians denying the possibility that a patient has Long COVID because a symptom the clinician was expecting was not present.
- Patients having the existence of their symptoms denied by clinicians.
- Patients being accused of illicit drug use or drug-seeking behavior.
- Patients being diagnosed with behavioral health conditions because a clinician could not find evidence of a specific physical problem.

In response to the patient panel, one clinician from the audience noted how different this experience is from a disease such as cancer, where clinicians and non-clinical staff work together to ensure that patients' needs are met (reducing fragmentation of care), and clinicians do not question the clinical feasibility of patients' reported symptoms (increasing trust).

Reliance on a Clinician "Hero"

For each patient on the panel, better care and health improvements hinged upon finding a single clinician who was willing to champion their cause—a clinician "hero." These clinicians spend unusually large amounts of time with the patient (up to three hours in a single visit); routinely make themselves available to patients outside of appointments (phone calls, correspondence via patient portal); and provide extensive care coordination.

Each patient had a painfully long journey to find their clinician hero, with many months passing and many clinicians visited. Core to each relationship with a clinician hero is the experience patients report of that clinician believing and trusting them.

Patients' experiences with these clinician heroes are radically different from their Long COVID experiences with other clinicians. As a result, one patient stated that when their clinician hero went on maternity leave, they waited to seek care until the clinician returned, because they lacked confidence that other clinicians would understand or believe their experiences.

Listening to Clinicians and Patients: Opportunities for Action

Conversations with patients and clinicians throughout the Summit suggested opportunities for action in several key areas.

Convene

Convene Specialty Societies

Throughout the Summit, clinicians repeatedly noted that multiple specialty societies and other organizations have put forth definitions of Long COVID and guidelines for how to treat it. But according to Summit participants, few of these definitions and guidelines account for the full range of body systems involved in Long COVID, and therefore a multi-disciplinary treatment approach is needed.

Further, participants highlighted that the existence of conflicting definitions and the lack of broad consensus on what symptoms and body systems are involved in Long COVID undermine efforts to communicate about clinical care. Throughout the Summit, clinicians commented on the challenges that the lack of standardized definitions and language pose to triaging, diagnosing, and treating Long COVID patients.

Participants repeatedly called for **convening multiple specialty societies to agree on definitions of Long COVID; a common, Long COVID-specific vocabulary to facilitate communication between clinicians; a comprehensive list of symptoms and body systems involved based on what is known to date; and the roles different specialists, therapists, and support teams may play in caring for Long COVID patients.** Clinicians also noted the need to ensure that these conversations address Long COVID separately in children and in adults.

The National Academies of Sciences, Engineering, and Medicine is conducting public workshops to examine the current U.S. Government working definition of Long COVID. Although the National Academies will seek input from a range of stakeholder groups, their work does not address the need for promulgating cross-specialty definitions and vocabularies that will directly support communication about clinical care.

Convene Electronic Health Record Vendors

An additional opportunity exists to **convene electronic health record vendors to address concerns that both patients and clinicians expressed about lack of access to medical records and test results.** Other Federal partners, such as the Office of the National Coordinator for Health Information Technology, and non-Federal partners, such as the American Medical Informatics Association, would be important partners in this work.

Patients at the Summit described hand-carrying paper copies of medical records and test results to clinician appointments, because receiving care from different practices and healthcare systems means that none of their clinicians have access to their full health record.

Clinicians noted that when their patients are seen in other practices or healthcare systems, they typically lack access to patients' records and test results from those clinicians. One clinician noted that, as a result of a special arrangement, he has read-only access to medical records from one healthcare system with which he is not affiliated, but he is unable to obtain records for the same patient from other systems.

Consolidate

Consolidate Information

Clinicians at the Summit repeatedly described the need to **create a single, trusted source of up-to-date, vetted, turnkey information about Long COVID symptoms, treatments, and resources**.

In particular, primary care clinicians expressed frustration at having to search for information about the diagnosis and treatment of Long COVID, finding conflicting information from different sources, and not having information readily available when they need it to treat their patients.

Consolidate Care Provision

Several clinicians called for the consolidation of care, emphasizing the benefits of **creating Centers of Excellence for Long COVID care**. These benefits include:

- Having multi-disciplinary groups work collaboratively as patient care teams.
- Ensuring the existence of a group of specialists who "get it"—that is, a group of specialists who believe patients' reports of their Long COVID experiences and are willing to work with them.
- Building a group of clinicians who have deep experience and expertise in treating Long COVID, akin to the way in which a surgeon develops expertise by repeatedly performing specific surgical procedures.

Care Pathways

During the Summit, clinicians called for **identifying and clarifying care pathways** that would support them in caring for their patients, which would include the following:

- Intake forms and intake processes that can be completed by case managers.
- Approaches to patient assessment, including information about what tests should be run and which tests should be run before making referrals to specific types of specialists so that specialists have everything they need to complete the patient's diagnosis and treatment planning.
- Information on which specialists should be involved.
- Best practices for involving therapists in the care of Long COVID patients (occupational therapy, physical therapy, speech language pathology, and behavioral health).

Clinicians also highlighted the need for clinical practice guidelines, although some acknowledged that symptoms and patient experiences are so diverse that preparing clinical practice guidelines may currently be impractical. They also stated a desire to have a validated screening tool for Long COVID that addresses all body systems and symptoms known to date.

Create Communities of Practice

Clinicians at the Summit discussed the need for and opportunities to **create closer connections between primary care clinicians and specialists, including the ability for primary care clinicians to receive virtual "curbside consults" to support their care of Long COVID patients**.

Patients and clinicians also discussed the need to connect with patients via telehealth and the challenges of doing so in rural areas that lack broadband services.

Several clinicians suggested the need for registries of Long COVID patients that would connect clinical information from multiple sources and enable clinicians to benchmark their own care provision against others, learn about typical treatment pathways, and offer timelines based on data from many patients that indicate when a patient might expect to see improvement.

Many of the clinicians noted that being at the Summit helped them meet their colleagues, learn more about Long COVID, learn about local resources of which they were unaware, and identify clinicians to whom they could refer their patients for care. They also highlighted the benefits of conversations such as those held during the Summit to help reduce feelings of isolation among primary care clinicians in particular. Together, these remarks suggest that there is an opportunity to **create geographically based communities of practice** to better support clinicians and inform patient care.

Listening to Clinicians and Patients: Opportunities for Research

Learning from Existing Care Models

Throughout the Summit, clinicians noted the challenges they face in arranging and delivering complex, multi-disciplinary care for their Long COVID patients. In many conversations, they noted that the way that care for Long COVID patients is organized could benefit from being informed by how care is organized and delivered for other health conditions.

One example that frequently arose during the Summit is cancer care. Several clinicians highlighted the need that Long COVID patients have for the types of multi-disciplinary care that cancer centers provide, where oncologists and other physicians, physical therapists, behavioral health clinicians, nurses, case managers, and social workers all partner within the same center or clinic to provide care. Other clinicians noted the use of tumor boards, in which oncologists and other clinicians hold a standing meeting to review and discuss new and complex cancer cases and to provide guidance to the primary treating clinician. Other examples of multi-disciplinary care models provided during the Summit included sepsis care, sarcoidosis, and traumatic brain injury.

These conversations highlight an opportunity for AHRQ to sponsor **research on demonstrated ways to bring together expertise from multiple disciplines to plan and deliver care to Long COVID patients**. Key questions to be addressed include the following:

- What can be learned from existing models of multi-disciplinary care about how to best organize clinics and care centers to treat and support patients with complex conditions?
- How might such care teams be designed? What specialties should be included for Long COVID?
- What are proven ways to overcome communications challenges that such teams may experience?
- What administrative support is required for these models to be effective?
- Have any such teams been proven to work when clinicians are distributed among multiple healthcare organizations and systems? Have they reduced fragmentation of care from a patient perspective? What has helped them succeed?
- How might a model akin to a tumor board function for Long COVID? A tumor board involves supporting a primary treating clinician in decision making by convening a broad range of expertise to periodically discuss specific patients.

Identifying such models and what makes them successful could benefit Long COVID patients and support the clinicians who treat them. In addition, such research could be used to identify principles of multi-disciplinary collaborative care models that could support the diagnosis and treatment of other seemingly ill-defined health conditions that affect multiple body systems and require the expertise of multiple clinical specialties.

Identifying Feasible Payment Models

During the patient panel, each speaker noted the tremendous importance of a single clinician to their care. The clinicians they described spend significant amounts of time with patients beyond what is typically reimbursed, routinely make themselves available to patients outside of appointments, and handle extensive care coordination far beyond the usual.

Clinicians who spoke during the Summit also described spending far more time than would be typical searching for usable information to inform clinical decision making and investing significant time identifying specialists who are willing to work with Long COVID patients and who believe their patients. Clinicians also described the need for curbside consults to informally obtain information and guidance from their colleagues.

This extra time and effort are generally uncompensated. Relatedly, clinicians noted that many Long COVID clinics are staffed for limited hours each week and that additional staffing is not financially feasible for small clinics or clinics that receive limited financial support from larger healthcare systems.

These challenges suggest that there is an opportunity for AHRQ to sponsor **research on feasible financial models for Long COVID care**. Key questions to be addressed include the following:

- What is the work required for primary care clinicians to manage the complex care of a variety of Long COVID patients who may have multiple body systems involved, and what compensation is required to support this work?
- What financial models might support multi-disciplinary collaborative care for Long COVID patients?
- How might clinicians be compensated for the care of patients outside of office visits, such as through e-consults or other population-based models of consultation?

Identify Strategies for Shifting Clinician Beliefs About Long COVID Patients

Patient panelists at the Summit all described disturbing experiences of clinician disbelief, distrust, or stigmatization, as well as of having their descriptions of physical symptoms attributed solely to mental health problems when no structural or chemical problem could be identified. Multiple clinicians noted that the large majority of their Long COVID patients have few objective test results that signify a clear diagnosis, and yet they all live with a wide array of deeply challenging symptoms—a pattern that is inconsistent with the typical symptoms-diagnosis-treatment pattern that characterizes much of current clinical care.

These experiences suggest the opportunity for AHRQ to sponsor **research focused on shifting the culture of clinical practice to more positively support Long COVID patients** and others with complex conditions affecting multiple body systems. Drawing from the well-established field of doctor-patient communication, as well as fields outside the typical realm of health services research, such as communications research, industrial/organizational psychology, and the psychology of behavior change, this research could help to identify strategies that could improve the experiences of Long COVID patients and ways to effectively implement those strategies.

Additional Policy Considerations

Disability

Patients and clinicians both discussed the extensive challenges that Long COVID patients face in obtaining disability designation and benefits, including under the Social Security Disability Insurance (SSDI) program. Months-long waiting periods followed by denials of benefits were described as not uncommon, even after patients have lost their jobs because of their inability to work and have only two to three hours each day during which they feel well enough to function. Further, the range of criteria required for disability designation and benefits causes confusion, with patients being approved for State disability programs while being denied SSDI or vice versa.

Clinicians also described the challenges they experienced when interacting with various systems for disability designation. These challenges include the extensive amount of time required to complete the required forms; lack of reimbursement for completing the forms; and difficulties determining whether a patient has a temporary, episodic, or permanent disability.

Because so little is known about the likely progression of Long COVID and patients' symptoms and experiences vary widely, clinicians repeatedly noted their inability to answer the required questions associated with disability application forms. These include questions such as when a patient will be able to lift a 10-pound weight and how long the patient can sit—questions that clinicians described as more suited to patients who have clear, stable health problems than to patients with Long COVID.

Children

Care for children with Long COVID was discussed several times during the Summit. The presence of an 11-year-old child on the patient panel highlighted the added challenges that children and families experience when seeking care for Long COVID. Notably, Long COVID can affect a child's development, socialization, and schooling. Summit attendees emphasized the importance of school involvement in the care of children with Long COVID to ensure that their educational needs are met.

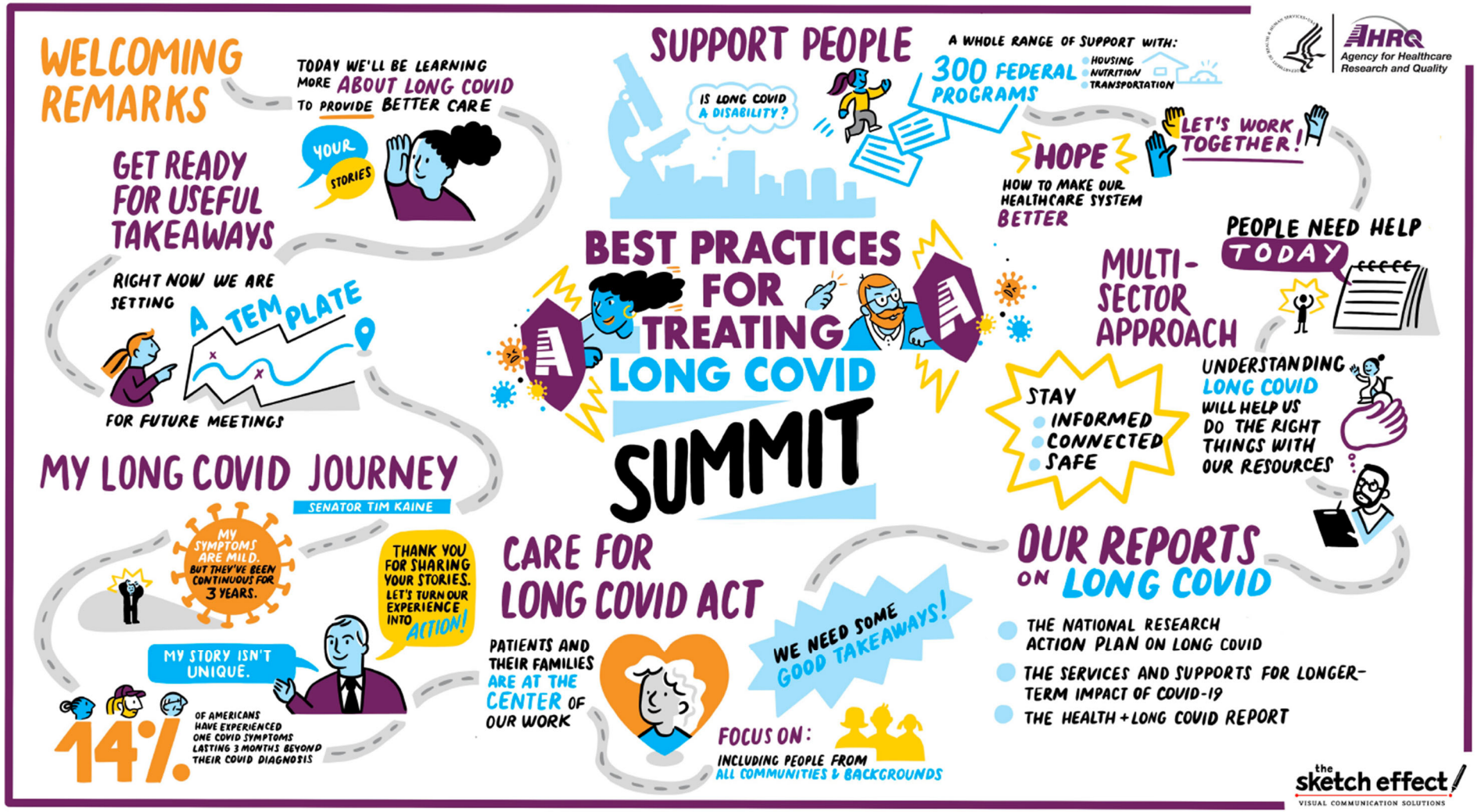
Appendices

Appendix 1: Graphic Recording

Appendix 2: Summit Agenda

Appendix 3: Summit Participants

Appendix 1: Graphic Recording


WELCOMING REMARKS
TODAY WE'LL BE LEARNING MORE ABOUT LONG COVID TO PROVIDE BETTER CARE
YOUR STORIES
GET READY FOR USEFUL TAKEAWAYS
RIGHT NOW WE ARE SETTING A TEMPLATE
FOR FUTURE MEETINGS
MY LONG COVID JOURNEY
SENATOR TIM KAINE
MY SYMPTOMS ARE MILD. BUT THEY'VE BEEN CONTINUOUS FOR 3 YEARS.
MY STORY ISN'T UNIQUE.
THANK YOU FOR SHARING YOUR STORIES. LET'S TURN OUR EXPERIENCE INTO ACTION!
14%
OF AMERICANS HAVE EXPERIENCED ONE COVID SYMPTOMS LASTING 3 MONTHS BEYOND THEIR COVID DIAGNOSIS
SUPPORT PEOPLE
IS LONG COVID A DISABILITY?
A WHOLE RANGE OF SUPPORT WITH:
300 FEDERAL PROGRAMS
HOUSING
NUTRITION
TRANSPORTATION
HOPE
HOW TO MAKE OUR HEALTHCARE SYSTEM BETTER
LET'S WORK TOGETHER!
BEST PRACTICES FOR TREATING LONG COVID
SUMMIT
PEOPLE NEED HELP TODAY
MULTI-SECTOR APPROACH
STAY
INFORMED
CONNECTED
SAFE
UNDERSTANDING LONG COVID WILL HELP US DO THE RIGHT THINGS WITH OUR RESOURCES
CARE FOR LONG COVID ACT
PATIENTS AND THEIR FAMILIES ARE AT THE CENTER OF OUR WORK
WE NEED SOME GOOD TAKEAWAYS!
FOCUS ON:
INCLUDING PEOPLE FROM ALL COMMUNITIES & BACKGROUNDS
OUR REPORTS ON LONG COVID
THE NATIONAL RESEARCH ACTION PLAN ON LONG COVID
THE SERVICES AND SUPPORTS FOR LONGER-TERM IMPACT OF COVID-19
THE HEALTH + LONG COVID REPORT
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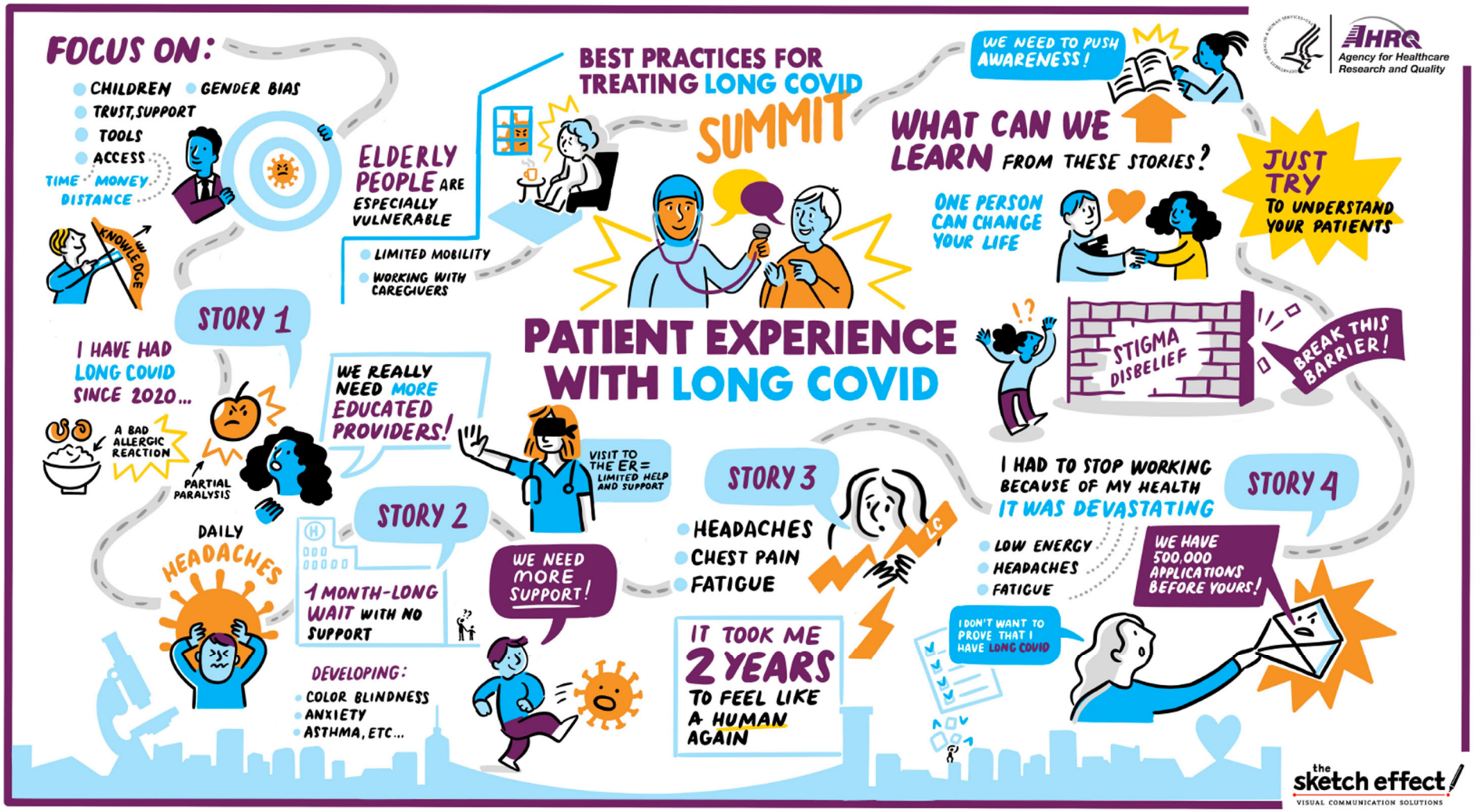
VISUAL COMMUNICATION SOLUTIONS


FOCUS ON:
CHILDREN
GENDER BIAS
TRUST, SUPPORT
TOOLS
ACCESS
TIME · MONEY · DISTANCE
KNOWLEDGE
BEST PRACTICES FOR TREATING LONG COVID SUMMIT
ELDERLY PEOPLE ARE ESPECIALLY VULNERABLE
LIMITED MOBILITY
WORKING WITH CAREGIVERS
WE NEED TO PUSH AWARENESS!
WHAT CAN WE LEARN FROM THESE STORIES?
ONE PERSON CAN CHANGE YOUR LIFE
JUST TRY TO UNDERSTAND YOUR PATIENTS
PATIENT EXPERIENCE WITH LONG COVID
STIGMA
DISBELIEF
BREAK THIS BARRIER!
STORY 1
I HAVE HAD LONG COVID SINCE 2020...
A BAD ALLERGIC REACTION
PARTIAL PARALYSIS
DAILY HEADACHES
WE REALLY NEED MORE EDUCATED PROVIDERS!
VISIT TO THE ER = LIMITED HELP AND SUPPORT
STORY 2
1 MONTH-LONG WAIT WITH NO SUPPORT
WE NEED MORE SUPPORT!
DEVELOPING:
COLOR BLINDNESS
ANXIETY
ASTHMA, ETC...
STORY 3
HEADACHES
CHEST PAIN
FATIGUE
LC
IT TOOK ME 2 YEARS TO FEEL LIKE A HUMAN AGAIN
I HAD TO STOP WORKING BECAUSE OF MY HEALTH
IT WAS DEVASTATING
LOW ENERGY
HEADACHES
FATIGUE
STORY 4
WE HAVE 500,000 APPLICATIONS BEFORE YOURS!
I DON'T WANT TO PROVE THAT I HAVE LONG COVID
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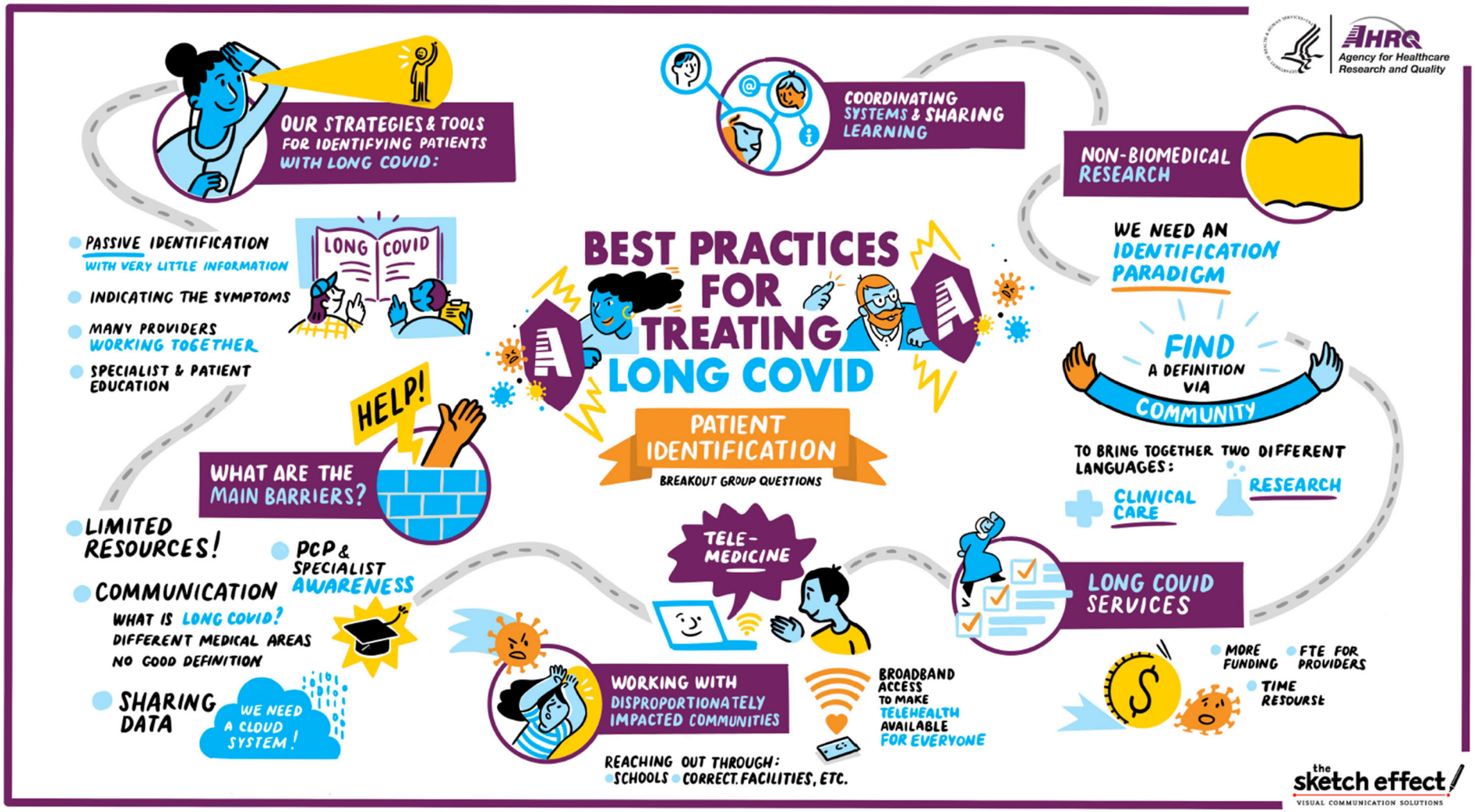
VISUAL COMMUNICATION SOLUTIONS


AHRQ
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BEST PRACTICES FOR TREATING LONG COVID
PATIENT IDENTIFICATION
BREAKOUT GROUP QUESTIONS
OUR STRATEGIES & TOOLS FOR IDENTIFYING PATIENTS WITH LONG COVID:
PASSIVE IDENTIFICATION
WITH VERY LITTLE INFORMATION
INDICATING THE SYMPTOMS
MANY PROVIDERS WORKING TOGETHER
SPECIALIST & PATIENT EDUCATION
LONG COVID
WHAT ARE THE MAIN BARRIERS?
HELP!
LIMITED RESOURCES!
COMMUNICATION
WHAT IS LONG COVID?
DIFFERENT MEDICAL AREAS
NO GOOD DEFINITION
PCP & SPECIALIST AWARENESS
SHARING DATA
WE NEED A CLOUD SYSTEM!
COORDINATING SYSTEMS & SHARING LEARNING
NON-BIOMEDICAL RESEARCH
WE NEED AN IDENTIFICATION PARADIGM
FIND A DEFINITION VIA COMMUNITY
TO BRING TOGETHER TWO DIFFERENT LANGUAGES:
CLINICAL CARE
RESEARCH
LONG COVID SERVICES
MORE FUNDING
FTE FOR PROVIDERS
TIME RESOURCES
TELE-MEDICINE
WORKING WITH DISPROPORTIONATELY IMPACTED COMMUNITIES
BROADBAND ACCESS TO MAKE TELEHEALTH AVAILABLE FOR EVERYONE
REACHING OUT THROUGH:
SCHOOLS
CORRECT. FACILITIES, ETC.
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VISUAL COMMUNICATION SOLUTIONS

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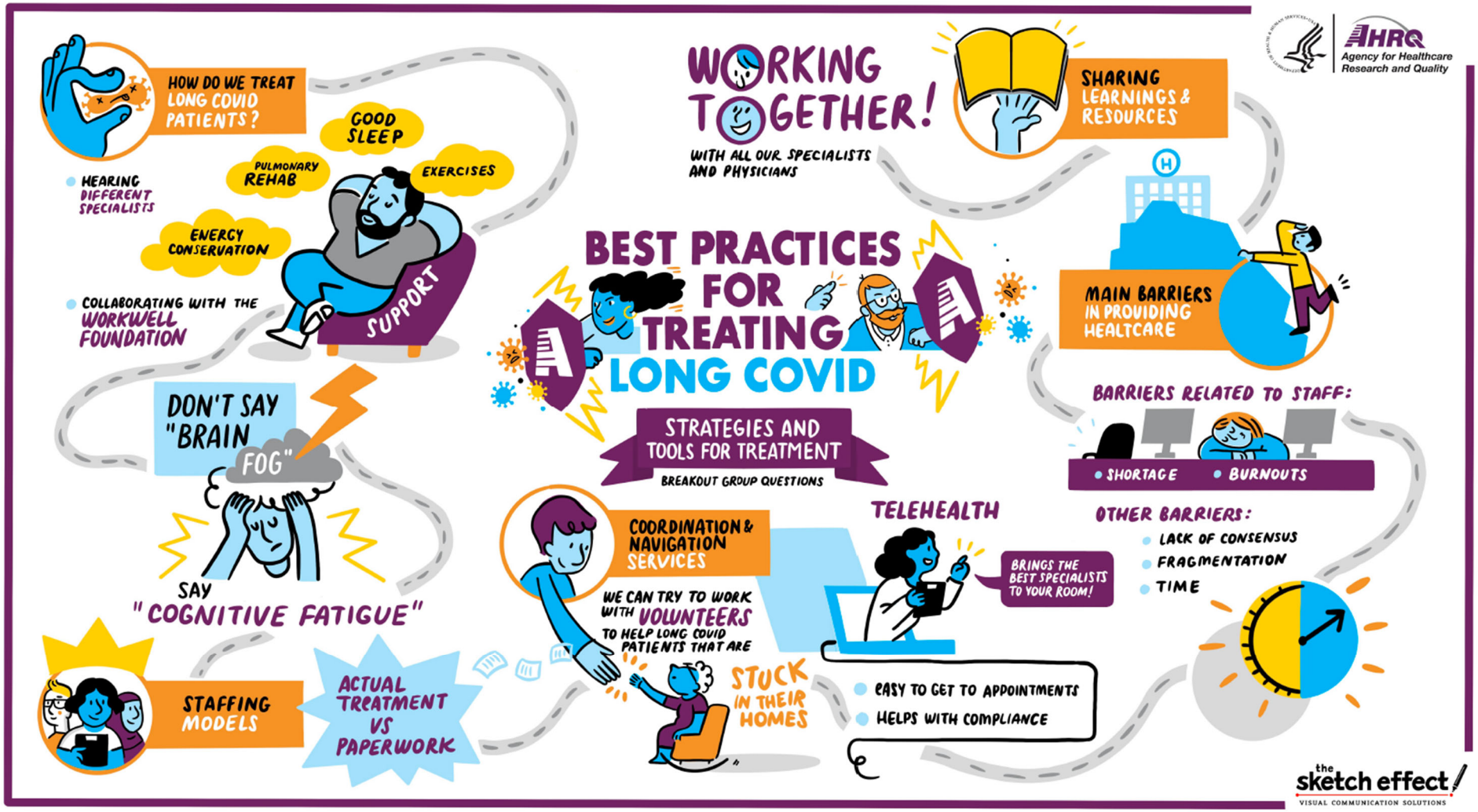
BEST PRACTICES FOR TREATING LONG COVID
INTERACTION WITH PRIMARY CARE
BREAKOUT GROUP QUESTIONS
WORKING WITH PRIMARY CARE CLINICIANS
EDUCATION
COMMUNICATION
24/7 SUPPORT FOR LONG COVID PATIENTS
WE CAN BE A SOURCE OF TRUTH
CONSULTATIONS FOR PRIMARY CARE CLINICIANS
PROVIDING EMOTIONAL SUPPORT
CARE COORDINATION
REIMBURSEMENT FOR PRIMARY CARE
SOCIAL & MENTAL CARE FOR LONG COVID PATIENTS
CREATING A HOTLINE OR A MENTAL HEALTH ACCESS PROGRAM FOR LONG COVID PATIENTS
MULTIDISCIPLINARY CLINICS FOR MULTIDISCIPLINARY PROBLEMS
THE GUIDANCE FOR TREATMENT
A
B
C
STANDARDIZED CASE DEFINITION FOR LONG COVID
SHARING LEARNINGS TO IMPROVE WHOLE-PERSON LONG COVID CARE
RESEARCH WILL MAKE A DIFFERENCE FOR ALL PEOPLE WITH CHRONIC ISSUES
RESEARCH NEEDS TO BE DONE COLLABORATIVELY
MAIN BARRIERS IN PRIMARY CARE
CAPACITY
ACCESS
TIME
MONEY
IMPROVING TELEHEALTH IS IMPORTANT!
the sketch effect
VISUAL COMMUNICATION SOLUTIONS


BEST PRACTICES FOR TREATING LONG COVID
HOW DO WE TREAT LONG COVID PATIENTS?
GOOD SLEEP
PULMONARY REHAB
EXERCISES
ENERGY CONSERVATION
SUPPORT
HEARING DIFFERENT SPECIALISTS
COLLABORATING WITH THE WORKWELL FOUNDATION
DON'T SAY "BRAIN FOG"
SAY "COGNITIVE FATIGUE"
STAFFING MODELS
ACTUAL TREATMENT VS PAPERWORK
WORKING TOGETHER!
WITH ALL OUR SPECIALISTS AND PHYSICIANS
SHARING LEARNINGS & RESOURCES
STRATEGIES AND TOOLS FOR TREATMENT
BREAKOUT GROUP QUESTIONS
COORDINATION & NAVIGATION SERVICES
WE CAN TRY TO WORK WITH VOLUNTEERS TO HELP LONG COVID PATIENTS THAT ARE STUCK IN THEIR HOMES
TELEHEALTH
BRINGS THE BEST SPECIALISTS TO YOUR ROOM!
EASY TO GET TO APPOINTMENTS
HELPS WITH COMPLIANCE
MAIN BARRIERS IN PROVIDING HEALTCARE
BARRIERS RELATED TO STAFF:
SHORTAGE
BURNOUTS
OTHER BARRIERS:
LACK OF CONSENSUS
FRAGMENTATION
TIME
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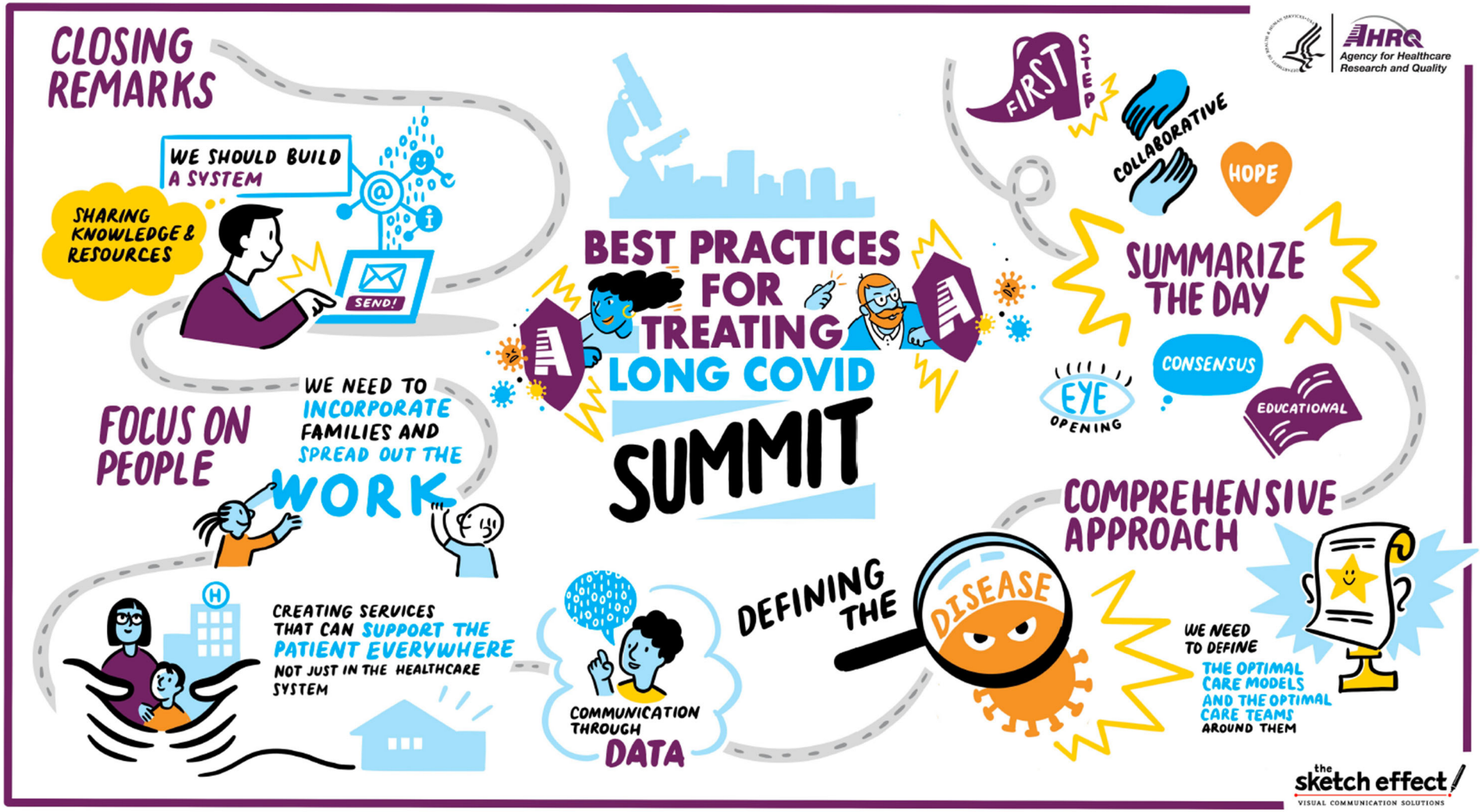
VISUAL COMMUNICATION SOLUTIONS


CLOSING REMARKS
WE SHOULD BUILD A SYSTEM
SHARING KNOWLEDGE & RESOURCES
SEND!
FOCUS ON PEOPLE
WE NEED TO INCORPORATE FAMILIES AND SPREAD OUT THE WORK
CREATING SERVICES THAT CAN SUPPORT THE PATIENT EVERYWHERE NOT JUST IN THE HEALTHCARE SYSTEM
COMMUNICATION THROUGH DATA
BEST PRACTICES FOR TREATING LONG COVID SUMMIT
DEFINING THE DISEASE
COMPREHENSIVE APPROACH
WE NEED TO DEFINE THE OPTIMAL CARE MODELS AND THE OPTIMAL CARE TEAMS AROUND THEM
FIRST STEP
COLLABORATIVE
HOPE
SUMMARIZE THE DAY
EYE OPENING
CONSENSUS
EDUCATIONAL
AHRQ
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VISUAL COMMUNICATION SOLUTIONS

Appendix 2: Summit Agenda

Best Practices for Treating Long COVID Summit

January 27, 2023
10:00 a.m. – 3:00 p.m. EST

AGENDA

10:00 a.m. – 10:25 a.m.	**Welcoming Remarks** *Summit Facilitator:* Edmondo J. Robinson, M.D., M.B.A., M.S. Senior Vice President and Chief Digital Officer Moffitt Cancer Center Senator Tim Kaine United States Congress Admiral Rachel L. Levine, M.D. Assistant Secretary for Health U.S. Department of Health and Human Services Alison Barkoff, J.D. Acting Administrator and Assistant Secretary for Aging U.S. Administration for Community Living Robert Otto Valdez, Ph.D., M.H.S.A. Director Agency for Healthcare Research and Quality
10:25 a.m. – 11:40 a.m.	**Panel Discussion: Patient Experience with Long COVID** *Moderator:* Sherri Wilson, D.N.P., M.P.A., R.N. President Virginia Nurses Association *Panelists:* Cynthia Adinig (Fairfax County) Mattie Smith, R.N., M.S.N. (Tazewell County) ZZ DeFonde and Katherine Tochtrop (Prince William County) Rachel Beale, M.B.A. (Southampton County) Senator Tim Kaine
11:40 a.m. – 12:30 p.m.	**Lunch Break**

12:30 p.m. – 1:30 p.m.	**Breakout Sessions: Best Practices, Collaborations, Treatment Strategies, and Barriers with Long COVID** **Breakout 1: Patient Identification** Breakout 1a Location: Boulevard Room Breakout 1b Location: Shockoe Room **Breakout 2: Interaction with Primary Care** Breakout 2a Location: Mayo Room Breakout 2b Location: Lee Room **Breakout 3: Strategies and Tools for Treatment** Breakout 3a Location: Tredegar Boardroom Breakout 3b Location: James River Ballroom (back of room)
1:30 p.m. – 1:45 p.m.	**Transition Back to General Session Room**
1:45 p.m. – 2:30 p.m.	**Breakout Session Reports** *Facilitator:* Edmondo J. Robinson, M.D., M.B.A., M.S.
2:30 p.m. – 2:50 p.m.	**Post Breakout Reconvening/Discussion** *Facilitator:* Edmondo J. Robinson, M.D., M.B.A., M.S.
2:50 p.m. – 3:00 p.m.	**Closing Remarks** *Facilitator:* Edmondo J. Robinson, M.D., M.B.A., M.S.
3:00 p.m.	**Adjournment**

Appendix 3: Summit Participants

Cynthia Adinig
Patient Panelist
Fairfax County, Virginia

Lauren Arrigoni
Children's National
Washington, District of Columbia

Rachel Beale
Patient Panelist
Southampton County, Virginia

Elizabeth Buchanan
Southern Dominion Health System, Inc.
Victoria, Virginia

Justin Burton
Children's National
Washington, District of Columbia

Peter Charvat
Bon Secours Richmond
Richmond, Virginia

Thomas Chelimsky
Virginia Commonwealth University
Richmond, Virginia

Paula Collins
The Health Wagon
Wise, Virginia

Rachael Cox
Johnson Health Center
Lynchburg, Virginia

Georgean deBlois
CrossOver Healthcare Ministry
Midlothian, Virginia

ZZ DeFonde and Katy Tochtrop
Patient Panelists
Prince William County, Virginia

Kyle Enfield
University of Virginia
Charlottesville, Virginia

Jeffrey Feit
Valley Health System
Winchester, Virginia

Adiba Geeti
Augusta Health
Fishersville, Virginia

Lynn Gerber
Inova Health System
Bethesda, Maryland

Harry Gewanter
Medical Society of Virginia
Richmond, Virginia

Raouf Gharbo
VCU Health
Williamsburg, Virginia

Ian Giles
Eastern Shore Rural Health System, Inc.
Eastville, Virginia

Jeanine Guidry
Virginia Commonwealth University
Richmond, Virginia

Rachel Helton
The Health Wagon
Wise, Virginia

Linda Herbert
Children's National Hospital
Silver Spring, Maryland

Savanah Howe
University of Virginia Health System
Charlottesville, Virginia

Haroon Hyder
Bon Secours Mercy Health Richmond
Henrico, Virginia

Anna Maria Izquierdo-Porrera
Virginia Community Healthcare Association
Richmond, Virginia

Paul Jett
Ballad Health
Whitesburg, Tennessee

Lerla Joseph
Central Virginia Coalition of Healthcare Providers, LLC
Richmond, Virginia

Christopher Lane
Virginia Hospital Center
Arlington, Virginia

Jeffrey Lessar
Valley Health
Winchester, Virginia

Jessica Lewis
Augusta Health
Fishersville, Virginia

Jonathan Lively
Sentara Pulmonary and Sleep Medicine
Norfolk, Virginia

Rajiv Malhotra
HCA Healthcare System
Midlothian, Virginia

Leslie Mento
Sheltering Arms Institute
Richmond, Virginia

Lori Nelson-Madison
Centra Lynchburg Family Med Residency
Lynchburg, Virginia

Jake O'Shea
HCA Healthcare Capital Division
Richmond, Virginia

Vikas Pathak
Bon Secours Mercy Health System
Mechanicsville, Virginia

Amie Pathmann
Poplar Springs Hospital
Petersburg, Virginia

Steven Pearman
Sentara Healthcare
Virginia Beach, Virginia

Rufus Phillips
Virginia Association of Free and Charitable Clinics
Richmond, Virginia

Vivienne Pierce McDaniel
Central Virginia Chapter National Black Nurses Association
Chesterfield, Virginia

Talia Pollok
Virginia Physical Therapy Association
Lynchburg, Virginia

Pammela Poore
Ballad Health Medical Associates Center for Post-COVID Care
Kingsport, Tennessee

Kristina Powell
Virginia Chapter of American Academy of Pediatrics
Williamsburg, Virginia

Xian Qiao
Sentara Pulmonary, Critical Care, and Sleep Specialists
Norfolk, Virginia

Sterling Ransone
Riverside Fishing Bay Family Practice
Deltaville, Virginia

Jill Richmond
Central Virginia Health Services
Louisa, Virginia

Edmondo Robinson
Moffitt Cancer Center
Tampa, Florida

Matthew Roby
Carilion Clinic
Roanoke, Virginia

Regan Royer
UVA-Encompass Rehabilitation Hospital
Charlottesville, Virginia

Abraham Segres
Virginia Hospital and Healthcare Association
Glen Allen, Virginia

Jason Seltzer
Sheltering Arms Institute
Midlothian, Virginia

Mattie Smith
Patient Panelist
Tazewell County, Virginia

Ina Stephens
University of Virginia Medical Center
Charlottesville, Virginia

Monika Stolze
Inova Health System
Leesburg, Virginia

Brian Stone
VHC Health
Arlington, Virginia

Lornel Tompkins
Old Dominion Medical Society
Midlothian, Virginia

Robert Trestman
Carilion Clinic and Virginia Tech School of Medicine
Roanoke, Virginia

Michael Triggs
Poplar Springs Hospital
Petersburg, Virginia

Teresa Tyson
The Health Wagon
Wise, Virginia

Vivian White
UVA Encompass Health Rehabilitation Hospital
Charlottesville, Virginia

Melissa Williams
BHMA Center for Post Covid Care
Kingsport, Tennessee

Sherri Wilson
Virginia Nurses Association
Fairfax Station, Virginia

Alexandra Yonts
Children's National Hospital
Washington, District of Columbia

Federal Participants

Acting Administrator Alison Barkoff
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Washington, District of Columbia

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Amber Channer
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U.S. Department of Health and Human Services
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Richmond, Virginia

Mia Fisher
Office of Senator Tim Kaine
Richmond, Virginia

Boyce Ginieczki
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Howard Holland
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Jaime Zimmerman
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