```
WEBVTT

01:00:11.626 --> 01:00:13.667
Thank you for coming
to learn about

01:00:13.667 --> 01:00:15.375
the National Library
of Medicine's

01:00:15.375 --> 01:00:17.000
contributions to COVID response

01:00:17.000 --> 01:00:19.292
both within the
library and across

01:00:19.292 --> 01:00:21.334
the National
Institutes of Health.

01:00:21.334 --> 01:00:22.417
Since January 2020,

01:00:22.417 --> 01:00:25.125
NLM has been actively
contributing to the

01:00:25.125 --> 01:00:27.709
process that help make
vaccines available.

01:00:27.709 --> 01:00:30.000
This includes efforts
such as making

01:00:30.000 --> 01:00:32.834
sure the genomic
basis for vaccines

01:00:32.834 --> 01:00:35.000
and therapeutics were
freely available

01:00:35.000 --> 01:00:38.083
to the public by our
GenBank database.

01:00:38.083 --> 01:00:40.751
Also providing the
severe acute respiratory

01:00:40.751 --> 01:00:43.292
syndrome coronavirus-two
data hub which

01:00:43.292 --> 01:00:45.667
```

is a website for
researchers to search,

01:00:45.667 --> 01:00:47.792
retrieve, and analyze data for

01:00:47.792 --> 01:00:50.000
more than 150,000
digital genomic

01:00:50.000 --> 01:00:51.584
sequences of the virus.

01:00:51.584 --> 01:00:54.709
Or through making
COVID information

01:00:54.709 --> 01:00:57.209
and studies findable through

01:00:57.209 --> 01:00:59.167
ClinicalTrials.gov
and MedlinePlus.

01:00:59.167 --> 01:01:01.667
Our goal for this
session is to provide

01:01:01.667 --> 01:01:04.292
you with an overview
of the range

01:01:04.292 --> 01:01:06.292
of activities and
contributions the

01:01:06.292 --> 01:01:08.584
library continues
to make as part of

01:01:08.584 --> 01:01:11.042
the effort to respond
to an advance

01:01:11.042 --> 01:01:13.334
our understanding
of COVID as well

01:01:13.334 --> 01:01:15.417
as as its impacts on our bodies,

01:01:15.417 --> 01:01:16.459
families and communities,

01:01:16.459 --> 01:01:18.999
both now and over the long term.

01:01:21.292 --> 01:01:23.459
To date, approximately
$2.5 billion

01:01:23.459 --> 01:01:26.125
in funding has been provided to

01:01:26.125 --> 01:01:28.167
the NIH for
coronavirus response.

01:01:28.167 --> 01:01:30.709
This funding has resulted in new

01:01:30.709 --> 01:01:32.999
an expanded
activities within the

01:01:32.999 --> 01:01:35.501
library and also
opportunities to

01:01:35.501 --> 01:01:37.626
work on interdisciplinary
initiatives

01:01:37.626 --> 01:01:40.209
across NIH. By the
end of this session,

01:01:40.209 --> 01:01:43.667
after covering the five
areas you see listed,

01:01:43.667 --> 01:01:46.542
we aim to leave you
with highlights of

01:01:46.542 --> 01:01:49.250
NLM's recent and
ongoing contributions,

01:01:49.250 --> 01:01:52.792
including NLM and NIH
tools and resources,

01:01:52.792 --> 01:01:55.417
overviews of some
of the major trans-

01:01:55.417 --> 01:01:57.459
NIH COVID response
initiatives, and

01:01:57.459 --> 01:02:00.000
examples of how LIS
professionals have

01:02:00.000 --> 01:02:03.000
and can contribute
to these activities.

01:02:05.667 --> 01:02:07.999
Hello, I'm Gina Demner-Fushman.

01:02:07.999 --> 01:02:11.292
I am an investigator
with the intramural

01:02:11.292 --> 01:02:13.667
research program at the National

01:02:13.667 --> 01:02:16.292
Library of Medicine
and today I'm

01:02:16.292 --> 01:02:19.999
going to talk about
our research at the

01:02:19.999 --> 01:02:22.125
library and the
research community

01:02:22.125 --> 01:02:24.834
overall response and
contribution to

01:02:24.834 --> 01:02:28.042
fighting of the pandemic.

01:02:31.167 --> 01:02:34.167
As you all know, the
pandemic brought

01:02:34.167 --> 01:02:37.250
about lots and lots of questions

01:02:37.250 --> 01:02:40.083
from various
stakeholders from the

01:02:40.083 --> 01:02:42.834
researchers, from
the administrators,

01:02:42.834 --> 01:02:46.083
from a consumers, us.
So it's impossible

01:02:46.083 --> 01:02:49.417
to cover all the
information needs

01:02:49.417 --> 01:02:52.417
in this very short presentation,

01:02:52.417 --> 01:02:55.584
so I will focus on three

01:02:55.584 --> 01:02:57.209
very specific examples.

01:02:57.209 --> 01:03:00.501
The first example being
finding relevant

01:03:00.501 --> 01:03:03.667
literature to support
decisions to advance

01:03:03.667 --> 01:03:06.292
research in

01:03:06.292 --> 01:03:08.834
virus understanding and vaccine

01:03:08.834 --> 01:03:12.501
development and this
was of course we

01:03:12.501 --> 01:03:15.584
are working on information
retrieval for

01:03:15.584 --> 01:03:19.042
biomedical purposes
for many years now.

01:03:19.042 --> 01:03:22.209
So what was different
and unprecedented

01:03:22.209 --> 01:03:25.417
for this pandemic
is the explosion

01:03:25.417 --> 01:03:28.999
of the literature
and also that the

01:03:28.999 --> 01:03:31.459
process of creating
a publication

01:03:31.459 --> 01:03:34.834
with sort of exposed
to the public,

01:03:34.834 --> 01:03:37.417
because the things

were published

01:03:37.417 --> 01:03:40.751
immediatelyas the findings
were coming in and

01:03:40.751 --> 01:03:43.375
then after the peer
review process,

01:03:43.375 --> 01:03:46.751
some of the publications were

01:03:46.751 --> 01:03:48.125
changing significantly.

01:03:48.125 --> 01:03:50.459
These needs were addressed in

01:03:50.459 --> 01:03:52.999
the TREC-COVID evaluation that

01:03:52.999 --> 01:03:54.542
I will describe first,

01:03:54.542 --> 01:03:57.083
then I will talk about what we

01:03:57.083 --> 01:03:59.999
found out in the TREC-COVID

01:03:59.999 --> 01:04:02.792
evaluation that the amount of

01:04:02.792 --> 01:04:04.667
relevant literature is huge,

01:04:04.667 --> 01:04:07.834
so we really need to
answer the questions

01:04:07.834 --> 01:04:10.501
that people have and we focused

01:04:10.501 --> 01:04:12.667
on researching the
best approaches

01:04:12.667 --> 01:04:15.417
for answering
questions that arise

01:04:15.417 --> 01:04:18.167
during a pandemic.
And specifically,

01:04:18.167 --> 01:04:19.542

various stakeholders focusing

01:04:19.542 --> 01:04:21.834
on the experts and consumers.

01:04:21.834 --> 01:04:24.083
And finally when we were

01:04:24.083 --> 01:04:26.375
discussing what is an answer,

01:04:26.375 --> 01:04:29.167
our judges were
hesitant to say what

01:04:29.167 --> 01:04:32.709
is a good answer and
we just decided

01:04:32.709 --> 01:04:36.000
to split this into
first finding the

01:04:36.000 --> 01:04:39.042
answer and then
determining what if

01:04:39.042 --> 01:04:43.250
the answer is good and
the facts are true.

01:04:43.250 --> 01:04:48.501
So and that was
explored in the TREC

01:04:48.501 --> 01:04:50.000
Misinformation track evaluation.

01:04:51.000 --> 01:04:53.375
The text retrieval conference

01:04:53.375 --> 01:04:57.334
was started in 1992
by DoD and NIST

01:04:57.334 --> 01:05:00.292
for the purposes of
finding relevant

01:05:00.292 --> 01:05:02.417
information for
information analysts

01:05:02.417 --> 01:05:06.000
and the very first
search engines were

01:05:06.000 --> 01:05:09.834
developed within
these initiatives.

01:05:09.834 --> 01:05:13.167
Relatively soon
after TREC started,

01:05:13.167 --> 01:05:15.334
specific interest to biomedical

01:05:15.334 --> 01:05:18.000
literature searches
and support of

01:05:18.000 --> 01:05:20.209
clinical decisions brought about

01:05:20.209 --> 01:05:22.999
many specific TREC and text

01:05:22.999 --> 01:05:24.999
analysis conference evaluations,

01:05:24.999 --> 01:05:28.501
such as our joint
initiative with FDA

01:05:28.501 --> 01:05:31.999
on finding drug-drug
interactions and

01:05:31.999 --> 01:05:35.626
adverse drug reactions
in drug labels.

01:05:35.626 --> 01:05:39.751
And NLM was an
active participant,

01:05:39.751 --> 01:05:41.626
organizer and data provider

01:05:41.626 --> 01:05:43.999
for all of these challenges.

01:05:48.417 --> 01:05:51.542
So I already
mentioned these very

01:05:51.542 --> 01:05:54.542
specific needs of
the information

01:05:54.542 --> 01:05:57.626
retrieval during a pandemic.

01:05:57.626 --> 01:06:00.292
And on TREC involvement with

01:06:00.292 --> 01:06:01.999
information retrieval overall,

01:06:01.999 --> 01:06:06.125
so it's not surprising
that the White House,

01:06:06.125 --> 01:06:09.042
when they urged the community to

01:06:09.042 --> 01:06:11.999
speed up research of COVID-19,

01:06:11.999 --> 01:06:14.834
turned to NIST to organize these

01:06:14.834 --> 01:06:18.042
evaluations of how
well the information

01:06:18.042 --> 01:06:21.083
sciences are
supporting the basic

01:06:21.083 --> 01:06:24.125
and clinical research in COVID.

01:06:24.125 --> 01:06:27.751
And NIST turned to the usual

01:06:27.751 --> 01:06:29.584
medical TREC organizers.

01:06:29.584 --> 01:06:32.250
Oregon Health Sciences,
UTHealth, us

01:06:32.250 --> 01:06:36.334
and Ai2. And then we
started addressing

01:06:36.334 --> 01:06:39.709
these very specific
pandemic needs that

01:06:39.709 --> 01:06:43.083
you know we need to
find literature fast.

01:06:43.083 --> 01:06:45.501
We might have some feedback

01:06:45.501 --> 01:06:46.999
in these judgments,

01:06:46.999 --> 01:06:50.709
so we decided to have
five very rapid rounds

01:06:50.709 --> 01:06:54.626
of turn around of
finding the literature,

01:06:54.626 --> 01:06:58.125
giving the judgments
back to the teams

01:06:58.125 --> 01:07:01.125
that are participating
in the evaluation.

01:07:01.125 --> 01:07:02.999
And finding and addressing

01:07:02.999 --> 01:07:04.667
the new questions again.

01:07:04.667 --> 01:07:07.542
And we also decided to add new

01:07:07.542 --> 01:07:09.792
questions as they were arising

01:07:09.792 --> 01:07:12.209
taking out of NLM blogs,

01:07:12.209 --> 01:07:15.501
NLM role in that also was that

01:07:15.501 --> 01:07:18.584
the index section
provided a large

01:07:18.584 --> 01:07:21.751
number of judges for
the literature.

01:07:24.792 --> 01:07:29.209
So here's an example
of a typical TREC

01:07:29.209 --> 01:07:32.459
information need
expressed as a topic.

01:07:32.459 --> 01:07:34.751
And on the right you see the

01:07:34.751 --> 01:07:37.334
interface that was
used by the judges

01:07:37.334 --> 01:07:39.209
to evaluate whether the document

01:07:39.209 --> 01:07:41.709
is relevant to the topic or not.

01:07:41.709 --> 01:07:44.626
And we also see
that although the

01:07:44.626 --> 01:07:47.375
topics seemed sort
of long standing,

01:07:47.375 --> 01:07:50.834
but the aspects of the
topic were changing.

01:07:50.834 --> 01:07:52.250
So, for example,

01:07:52.250 --> 01:07:55.042
if early on people were asking

01:07:55.042 --> 01:07:58.209
where can they find
a mask, later on

01:07:58.209 --> 01:08:00.834
They started asking
how protective those

01:08:00.834 --> 01:08:03.459
masks actually are.

01:08:08.999 --> 01:08:11.999
The lessons we learned in the

01:08:11.999 --> 01:08:14.375
TREC-COVID evaluation are mostly

01:08:14.375 --> 01:08:17.209
along the lines
that the community

01:08:17.209 --> 01:08:19.999
was very eager to participate.

01:08:19.999 --> 01:08:22.999
We had in all five rounds

01:08:22.999 --> 01:08:25.999
we had an excellent
community participation,

01:08:25.999 --> 01:08:27.999

including the major search

01:08:27.999 --> 01:08:31.751
engines such as
Google, Microsoft.

01:08:31.751 --> 01:08:36.459
We also had

01:08:38.584 --> 01:08:41.042
an incredible
number of judgments

01:08:41.042 --> 01:08:44.125
close to 70,000
documents were judged.

01:08:44.125 --> 01:08:48.459
We've also seen that
many of those documents

01:08:48.459 --> 01:08:51.709
were actually relevant
to the topics.

01:08:51.709 --> 01:08:54.292
And although we were not

01:08:54.292 --> 01:08:57.375
able to judge more than, say,

01:08:57.375 --> 01:09:01.501
1% of the documents
retrieved for each topic,

01:09:01.501 --> 01:09:04.083
Ellen, who was the

01:09:04.083 --> 01:09:06.125
lead on that evaluation,

01:09:06.125 --> 01:09:08.751
found that the collection that

01:09:08.751 --> 01:09:12.542
was created as a result of these

01:09:12.542 --> 01:09:14.626
TREC-COVID evaluation is

01:09:14.626 --> 01:09:18.667
stable and can be
used to advance

01:09:18.667 --> 01:09:21.792
literature retrieval
in the future.

01:09:25.083 --> 01:09:28.125
As I mentioned, we
have these huge

01:09:28.125 --> 01:09:30.334
numbers of relevant documents,

01:09:30.334 --> 01:09:33.667
so it is clear that
the researchers,

01:09:33.667 --> 01:09:36.709
the administrators and
the consumers just

01:09:36.709 --> 01:09:40.167
don't have the ability
to process all

01:09:40.167 --> 01:09:42.834
that information and
what they really

01:09:42.834 --> 01:09:46.083
need is the answers
to their questions.

01:09:46.083 --> 01:09:47.999
Therefore, we organize

01:09:47.999 --> 01:09:50.459
these text analysis task,

01:09:50.459 --> 01:09:52.584
answering questions that are

01:09:52.584 --> 01:09:55.834
arising during a
pandemic asked by

01:09:55.834 --> 01:09:58.792
experts and asked
by the consumers.

01:09:58.792 --> 01:10:01.042
Our index section
provided judgments,

01:10:01.042 --> 01:10:04.626
and the judgments were
provided in two steps.

01:10:04.626 --> 01:10:07.709
First, they looked at
the answers provided

01:10:07.709 --> 01:10:10.999
by the systems and
created answer keys.

01:10:10.999 --> 01:10:12.250
So, for example,

01:10:12.250 --> 01:10:15.834
if the question is
about what kinds of

01:10:15.834 --> 01:10:19.083
masks are protective
the judge might list,

01:10:19.083 --> 01:10:21.792
the types of masks that exist,

01:10:21.792 --> 01:10:24.501
and then take that answer key,

01:10:24.501 --> 01:10:27.000
that they created and in the

01:10:27.000 --> 01:10:29.751
second step of the evaluation,

01:10:29.751 --> 01:10:32.751
go back to the
answers and assign

01:10:32.751 --> 01:10:36.083
which all the items
of the answer

01:10:36.083 --> 01:10:39.042
key are answered
by that question.

01:10:39.042 --> 01:10:41.584
And we had two rounds
of this evaluation.

01:10:41.584 --> 01:10:44.167
In the first round we built the

01:10:44.167 --> 01:10:46.584
document collection
so that we can

01:10:46.584 --> 01:10:49.083
train AI and deep
learning approaches

01:10:49.083 --> 01:10:50.375
in the second round.

01:10:50.375 --> 01:10:53.542
And the second round was
the main evaluation.

01:10:56.792 --> 01:10:58.626
Our assumption that although

01:10:58.626 --> 01:11:00.999
the questions might be similar,

01:11:00.999 --> 01:11:03.000
the answer should be different

01:11:03.000 --> 01:11:05.626
for the experts and for the

01:11:05.626 --> 01:11:07.999
consumers were confirmed by the

01:11:07.999 --> 01:11:10.501
nuggets and the
relevant answers.

01:11:10.501 --> 01:11:12.792
As you can see here,

01:11:12.792 --> 01:11:15.501
the answer to the
consumers question

01:11:15.501 --> 01:11:18.667
what is the origin
of COVID-19 and

01:11:18.667 --> 01:11:21.375
the answer to the
experts question

01:11:21.375 --> 01:11:24.209
look quite different
and the experts

01:11:24.209 --> 01:11:27.000
get many more details that

01:11:27.000 --> 01:11:30.250
might not interest
the consumers.

01:11:32.584 --> 01:11:35.125
We had a fairly
good participation

01:11:35.125 --> 01:11:37.375
as well in this task,

01:11:37.375 --> 01:11:39.792

although the task is of course

01:11:39.792 --> 01:11:41.999
much more complex
than information

01:11:41.999 --> 01:11:44.792
retrieval task and
we had industry

01:11:44.792 --> 01:11:47.250
and academia and government well

01:11:47.250 --> 01:11:50.167
represented in these
tasks as well.

01:11:52.751 --> 01:11:55.667
So we've learned
that we can develop

01:11:55.667 --> 01:11:58.834
systems that are
answering the questions,

01:11:58.834 --> 01:12:01.250
but there is still lots and

01:12:01.250 --> 01:12:04.042
lots of room for improvement,

01:12:04.042 --> 01:12:07.125
and that we indeed
need different

01:12:07.125 --> 01:12:09.751
approaches to answer
consumers' and

01:12:09.751 --> 01:12:12.042
experts' questions
and the aspects

01:12:12.042 --> 01:12:15.042
of the answers that should be

01:12:15.042 --> 01:12:17.626
provided to these
different groups.

01:12:21.999 --> 01:12:24.375
Very briefly, now that we

01:12:24.375 --> 01:12:27.167
have the answer, how good is it?

01:12:27.167 --> 01:12:29.125

And particularly
for the consumers

01:12:29.125 --> 01:12:31.999
who are turning to
the web more and

01:12:31.999 --> 01:12:34.834
more often in search
of the answers.

01:12:34.834 --> 01:12:37.125
And the TREC Health
Misinformation

01:12:37.125 --> 01:12:38.792
track approached that question

01:12:38.792 --> 01:12:40.417
specifically from 2 viewpoints.

01:12:40.417 --> 01:12:43.083
One, they had a task where they

01:12:43.083 --> 01:12:45.167
were saying rank the documents

01:12:45.167 --> 01:12:47.751
so that the most trustworthy

01:12:47.751 --> 01:12:50.834
are at the top and
the second one,

01:12:50.834 --> 01:12:52.999
from the other end,

01:12:52.999 --> 01:12:56.250
find all the documents
that are not

01:12:56.250 --> 01:12:59.834
reliable that do not
provide true facts.

01:12:59.834 --> 01:13:03.000
Our team participated in that

01:13:03.000 --> 01:13:06.334
evaluation with
fairly good results.

01:13:06.334 --> 01:13:10.042
And it was also
the community was

01:13:10.042 --> 01:13:13.334

very much interested
in these tasks

01:13:13.334 --> 01:13:16.542
and overall that
area of research,

01:13:16.542 --> 01:13:17.792
detecting misinformation,

01:13:17.792 --> 01:13:20.292
fact checking specifically for

01:13:20.292 --> 01:13:23.459
health is developing
very quickly.

01:13:27.292 --> 01:13:29.834
I would like to
thank our wonderful

01:13:29.834 --> 01:13:32.334
judges from the index
section listed

01:13:32.334 --> 01:13:35.459
here and also my group
that contributed

01:13:35.459 --> 01:13:38.000
to the development
of the approaches

01:13:38.000 --> 01:13:40.542
that I was discussing.
Thank you.

01:13:43.584 --> 01:13:45.083
Hello I'm Valerie Florence.

01:13:45.083 --> 01:13:48.417
Some of you may know
me from the past.

01:13:48.417 --> 01:13:50.292
I'm a librarian like you,

01:13:50.292 --> 01:13:52.375
but I'm also acting
scientific director

01:13:52.375 --> 01:13:54.792
for the NLM's Intramural
Research program.

01:13:54.792 --> 01:13:56.667
And if you know me,

01:13:56.667 --> 01:13:59.334
then you know that
having librarians

01:13:59.334 --> 01:14:01.792
involved in research,
embedded in research

01:14:01.792 --> 01:14:04.999
is always been a goal
of mine and still is.

01:14:04.999 --> 01:14:07.501
So I'm happy to give this talk.

01:14:10.459 --> 01:14:13.999
So I'm going to talk
a bit about RADx.

01:14:13.999 --> 01:14:16.083
You know we're
government, we always

01:14:16.083 --> 01:14:18.125
call things by their acronym,

01:14:18.125 --> 01:14:20.501
Rapid Acceleration of
Diagnostics is what

01:14:20.501 --> 01:14:23.667
this is. And you've
already heard

01:14:23.667 --> 01:14:26.542
about how much money
has come to NIH.

01:14:26.542 --> 01:14:29.584
But the the staff of
NIH program grant

01:14:29.584 --> 01:14:31.999
management, that
type of people, in

01:14:31.999 --> 01:14:34.209
particular, staff
at all levels have

01:14:34.209 --> 01:14:36.501
formed four committees to

01:14:36.501 --> 01:14:38.792
work on these four
different areas.

01:14:38.792 --> 01:14:42.334
I'm only going to talk
about two of them.

01:14:42.334 --> 01:14:44.626
But the fundamental point is

01:14:44.626 --> 01:14:46.501
speeding innovation to develop,

01:14:46.501 --> 01:14:47.999
commercialize and implement

01:14:47.999 --> 01:14:49.292
technologies for testing.

01:14:49.292 --> 01:14:52.042
That's what the RADx is for.

01:14:55.250 --> 01:14:58.834
So I want to talk
about two of those

01:14:58.834 --> 01:15:01.250
four that I've
participated in for

01:15:01.250 --> 01:15:02.459
RADx underserved populations.

01:15:02.459 --> 01:15:04.999
You can tell by its name

01:15:04.999 --> 01:15:06.501
that the concern was,

01:15:06.501 --> 01:15:09.667
we know there are

01:15:09.667 --> 01:15:12.042
disparities in the
delivery of health

01:15:12.042 --> 01:15:14.999
care and other things
in our country,

01:15:14.999 --> 01:15:17.209
and we want to
particularly reach

01:15:17.209 --> 01:15:20.125
out and make sure
that underserved

01:15:20.125 --> 01:15:22.125

and vulnerable populations

01:15:22.125 --> 01:15:24.626
have access to the

01:15:24.626 --> 01:15:26.999
information and tools that will

01:15:26.999 --> 01:15:29.000
help them protect themselves.

01:15:32.083 --> 01:15:34.709
So in this initiative we put out

01:15:34.709 --> 01:15:36.334
four different grant
announcements

01:15:36.334 --> 01:15:38.999
and I just listed them there.

01:15:38.999 --> 01:15:40.501
They sound boring, right?

01:15:40.501 --> 01:15:43.459
But one of them is on social,

01:15:43.459 --> 01:15:45.250
ethical and behavioral
implications

01:15:45.250 --> 01:15:47.501
to try and understand what

01:15:47.501 --> 01:15:49.542
makes people do what they do.

01:15:49.542 --> 01:15:52.334
And there are also additional

01:15:52.334 --> 01:15:54.667
projects for Community
engaged research

01:15:54.667 --> 01:15:57.417
to involve people
out in the field.

01:15:57.417 --> 01:15:57.999
And

01:15:57.999 --> 01:16:00.999
there were in all they were

01:16:00.999 --> 01:16:03.417
about 80 grants awarded,

01:16:03.417 --> 01:16:05.584
including a consortium
data coordination

01:16:05.584 --> 01:16:08.334
center that will sort of oversee

01:16:08.334 --> 01:16:10.417
those community based projects.

01:16:10.417 --> 01:16:12.751
Things like that.

01:16:15.334 --> 01:16:17.709
One of NLM's existing

01:16:17.709 --> 01:16:20.584
grantees received
a RADx-UP award

01:16:20.584 --> 01:16:22.999
Doctor Ogunyemi at Charles Drew

01:16:22.999 --> 01:16:25.834
University already
had a grant from

01:16:25.834 --> 01:16:28.459
us on predicting
diabetic retinopathy.

01:16:28.459 --> 01:16:30.999
Working with safety net health

01:16:30.999 --> 01:16:33.292
care providers in her community,

01:16:33.292 --> 01:16:36.334
and so she proposed to go ahead

01:16:36.334 --> 01:16:39.209
and continue working
with the Los

01:16:39.209 --> 01:16:41.751
Angeles County
Department of Health

01:16:41.751 --> 01:16:44.501
Services and safety net

01:16:44.501 --> 01:16:47.292
patients who require
COVID testing.

01:16:47.292 --> 01:16:49.626
To try and understand

and improve

01:16:49.626 --> 01:16:51.834
the chances of their getting,

01:16:51.834 --> 01:16:54.292
testing and so

01:16:54.292 --> 01:16:57.542
she's planning to
implement a community

01:16:57.542 --> 01:16:59.751
health worker based intervention

01:16:59.751 --> 01:17:02.042
which reminded me of back in I

01:17:02.042 --> 01:17:04.584
want to say the 80s or so right.

01:17:04.584 --> 01:17:07.125
There were promotoras
being sent out by

01:17:07.125 --> 01:17:10.125
in our national network
to help people

01:17:10.125 --> 01:17:12.459
in Spanish speaking communities

01:17:12.459 --> 01:17:15.250
have access to public
health information.

01:17:15.250 --> 01:17:18.792
So this is an idea
I'm excited about.

01:17:21.626 --> 01:17:25.167
So RADx-RAD ate the
last year of my

01:17:25.167 --> 01:17:28.834
life and I spent a
lot of time in this

01:17:28.834 --> 01:17:32.709
group because this one
is my kind of thing.

01:17:32.709 --> 01:17:33.999
It's it's new,

01:17:33.999 --> 01:17:34.834
nontraditional approaches.

01:17:34.834 --> 01:17:36.834
Still thinking
about and so rapid

01:17:36.834 --> 01:17:39.250
detection could be home
based technologies

01:17:39.250 --> 01:17:41.834
for testing. New
or non traditional

01:17:41.834 --> 01:17:43.542
applications of
existing approaches

01:17:43.542 --> 01:17:46.209
and also it's a different space

01:17:46.209 --> 01:17:49.000
from the other ones
we're talking about

01:17:49.000 --> 01:17:51.417
where they're using
the known. We're

01:17:51.417 --> 01:17:54.501
trying to deal with the unknown.

01:17:56.834 --> 01:18:00.167
We put out 11 grant
announcements and

01:18:00.167 --> 01:18:04.417
I love the topic so
I just you can read

01:18:04.417 --> 01:18:08.667
them but I have to
read some of them

01:18:08.667 --> 01:18:11.584
too, waste water detection
and surveillance.

01:18:11.584 --> 01:18:13.459
The electronic nose chemosensory

01:18:13.459 --> 01:18:15.292
testing, private
contract tracing,

01:18:15.292 --> 01:18:18.501
the surveillance of high

```
01:18:18.501 --> 01:18:21.083
risk clustered populations like

01:18:21.083 --> 01:18:23.792
nursing homes in college dorms.

01:18:23.792 --> 01:18:25.334
Pretty important really.

01:18:25.334 --> 01:18:29.083
And so 50 awards
were made including

01:18:29.083 --> 01:18:31.375
a data coordinating center.

01:18:34.792 --> 01:18:35.999
So for NLM,

01:18:35.999 --> 01:18:39.292
two of those awards are
owned/managed by us.

01:18:39.292 --> 01:18:40.042
The first,

01:18:40.042 --> 01:18:43.042
the one on the left on my slide.

01:18:43.042 --> 01:18:45.125
The bioinformatics framework for

01:18:45.125 --> 01:18:47.167
wastewater based
surveillance was

01:18:47.167 --> 01:18:49.667
already an NLM grant
and you might

01:18:49.667 --> 01:18:51.792
ask why on Earth is the library

01:18:51.792 --> 01:18:53.584
in this area? We're in it

01:18:53.584 --> 01:18:55.834
'cause we love data
science right?

01:18:55.834 --> 01:18:57.709
And we have scientists who

01:18:57.709 --> 01:18:59.626
want to understand the data,

01:18:59.626 --> 01:19:01.000
```

how to analyze it,

01:19:01.000 --> 01:19:04.125
how to capture it in
their communities.

01:19:04.125 --> 01:19:06.584
And so this
particular project is

01:19:06.584 --> 01:19:09.459
going to look at what water

01:19:09.459 --> 01:19:12.250
is the best water to use

01:19:12.250 --> 01:19:14.751
to identify whether there are,

01:19:14.751 --> 01:19:17.125
whether the virus rates going up

01:19:17.125 --> 01:19:19.999
or new viruses are coming in and

01:19:19.999 --> 01:19:22.626
try and predict it
before the body

01:19:22.626 --> 01:19:25.584
starts showing up
in the morbidity

01:19:25.584 --> 01:19:27.667
and mortality reports, right?

01:19:27.667 --> 01:19:32.125
This is really important
to public health.

01:19:32.125 --> 01:19:33.834
And this particular project is a

01:19:33.834 --> 01:19:35.417
collaboration between one of our

01:19:35.417 --> 01:19:37.125
intramural researchers
and our grantees,

01:19:37.125 --> 01:19:39.999
so that's a new kind
of thing for us,

01:19:39.999 --> 01:19:41.834
and we're quite
excited about that.

01:19:41.834 --> 01:19:44.042
I won't say much
of anything about

01:19:44.042 --> 01:19:45.000
this other one,

01:19:45.000 --> 01:19:47.042
because you're going to hear my

01:19:47.042 --> 01:19:48.751
colleague Yanli Wang tell you

01:19:48.751 --> 01:19:50.000
about it in a minute.

01:19:50.000 --> 01:19:50.626
But first,

01:19:50.626 --> 01:19:52.667
I do want to say I love this

01:19:52.667 --> 01:19:54.999
idea that there will be centers

01:19:54.999 --> 01:19:57.042
that will pull together the data

01:19:57.042 --> 01:19:59.125
from all of those
50 projects that

01:19:59.125 --> 01:20:01.334
I told you about
will be available

01:20:01.334 --> 01:20:02.999
through a single center. So

01:20:02.999 --> 01:20:04.667
if you're interested in pursuing

01:20:04.667 --> 01:20:06.083
more using their data,

01:20:06.083 --> 01:20:08.375
it will be much easier for you

01:20:08.375 --> 01:20:10.626
to have access to and you will

01:20:10.626 --> 01:20:12.999
notice that Dina is also a part

01:20:12.999 --> 01:20:14.584
of this.

01:20:16.999 --> 01:20:19.250
And because I can't resist,

01:20:19.250 --> 01:20:23.209
I have to remind
everybody of what a

01:20:23.209 --> 01:20:24.501
great resource the
reporter.nih.gov is.

01:20:24.501 --> 01:20:27.834
So for you in your
own organizations,

01:20:27.834 --> 01:20:30.667
you can do what I did.

01:20:30.667 --> 01:20:33.501
You could search COVID-19, your

01:20:33.501 --> 01:20:36.792
organization and I
search COVID-19 and

01:20:36.792 --> 01:20:40.167
NLM and got a list
of 23 projects,

01:20:40.167 --> 01:20:42.999
$14.8 million that
we've invested

01:20:42.999 --> 01:20:45.167
in COVID-related projects

01:20:45.167 --> 01:20:47.999
in 2019 and 2020 and 2021.

01:20:51.167 --> 01:20:53.667
And an important thing
about this list for

01:20:53.667 --> 01:20:55.999
me because of my current
responsibilities

01:20:55.999 --> 01:20:58.709
in addition to showing
the grantees, some

01:20:58.709 --> 01:21:01.626
of them you've already
heard me mention, it

01:21:01.626 --> 01:21:05.209

also, if you look at the
bottom of the slide,

01:21:05.209 --> 01:21:08.292
you see one with a weird
grant number that

01:21:08.292 --> 01:21:11.626
starts with a Z that is
a intramural research

01:21:11.626 --> 01:21:14.584
project being done by
one of our scientists,

01:21:14.584 --> 01:21:17.834
in our intramural
program. And so.

01:21:17.834 --> 01:21:21.999
of course I have to brag

01:21:21.999 --> 01:21:24.375
about a couple of
those intramural

01:21:24.375 --> 01:21:26.751
people because that's my job.

01:21:26.751 --> 01:21:29.626
So I just wanted to
say NLM, like your

01:21:29.626 --> 01:21:32.292
universities and
other organizations,

01:21:32.292 --> 01:21:34.709
has scientists at
work doing research

01:21:34.709 --> 01:21:37.792
every day on topics
that we care about.

01:21:37.792 --> 01:21:40.834
So these two, one of
them is looking at

01:21:40.834 --> 01:21:43.667
rapidly evolving
proteins in SARS CoV-2

01:21:43.667 --> 01:21:46.501
that could have roles
in pathogenesis.

01:21:46.501 --> 01:21:48.999
Another one is
looking at genomic

01:21:48.999 --> 01:21:50.125
features that differentiate.

01:21:50.125 --> 01:21:54.999
SARS CoV-2 from other
SARS virus or COV viruses

01:21:54.999 --> 01:21:57.626
that you remember

01:21:57.626 --> 01:22:01.999
from the past.

01:22:01.999 --> 01:22:04.334
And of course you will never

01:22:04.334 --> 01:22:07.209
forget to look at NLM's website,

01:22:07.209 --> 01:22:10.709
which is where we have
the best complete,

01:22:10.709 --> 01:22:13.834
and amazing set of resources and

01:22:13.834 --> 01:22:17.792
information about COVID.

01:22:17.792 --> 01:22:20.000
And that's all I have to say.

01:22:20.000 --> 01:22:21.999
And if you want to know more

01:22:21.999 --> 01:22:23.417
about our intramural research,

01:22:23.417 --> 01:22:25.375
you can go to that URL and

01:22:25.375 --> 01:22:27.083
find out who are investigators

01:22:27.083 --> 01:22:29.000
are and what they're doing.

01:22:29.000 --> 01:22:31.167
Otherwise you know how
to find everything.

01:22:31.167 --> 01:22:32.417
So back to you.

01:22:36.292 --> 01:22:38.626
My name is Yanli Wang.

01:22:38.626 --> 01:22:41.999
I am a program officer
in the extramural

01:22:41.999 --> 01:22:45.626
program at the National
Library of Medicine.

01:22:45.626 --> 01:22:48.999
So today I'm going
to provide the

01:22:48.999 --> 01:22:52.334
introduction for
the RADx-rad Data

01:22:52.334 --> 01:22:55.250
Coordination Center
project and to tell

01:22:55.250 --> 01:22:58.709
you a bit about what
kind of functions,

01:22:58.709 --> 01:23:02.000
what controls it plays for

01:23:02.000 --> 01:23:05.334
the RAdx-rad initiative.

01:23:05.334 --> 01:23:08.459
Doctor Valerie Florence
has introduced

01:23:08.459 --> 01:23:13.834
the RADx Radical or
RADx-rad initiative,

01:23:13.834 --> 01:23:17.584
which is the first
initiative in the age

01:23:17.584 --> 01:23:21.999
RADx program and its
overall goal is

01:23:21.999 --> 01:23:25.792
to support novel and
non traditional

01:23:25.792 --> 01:23:28.999
approaches or new applications

01:23:28.999 --> 01:23:32.709
of existing approaches that help

01:23:32.709 --> 01:23:37.083
to address gaps
in COVID-19 test.

01:23:37.083 --> 01:23:41.375
And the other goal is to develop

01:23:41.375 --> 01:23:44.375
platforms for future pandemic

01:23:44.375 --> 01:23:48.999
outbreaks. So under
RADx-rad 49 awards,

01:23:48.999 --> 01:23:51.501
are made through the extramural

01:23:51.501 --> 01:23:53.501
program and then,

01:23:53.501 --> 01:23:56.542
when intramural project
is also founded.

01:23:56.542 --> 01:23:59.999
So from the map you can see

01:23:59.999 --> 01:24:02.792
the distribution of the funded

01:24:02.792 --> 01:24:06.042
organizations across
the country and

01:24:06.042 --> 01:24:09.584
the URL provided on this slide

01:24:09.584 --> 01:24:11.709
provides more information for

01:24:11.709 --> 01:24:13.834
each of the project.

01:24:17.125 --> 01:24:20.167
So the RADx-rad supports a very

01:24:20.167 --> 01:24:22.584
broad range of research areas,

01:24:22.584 --> 01:24:25.334
so this slide and
following one will

01:24:25.334 --> 01:24:28.292

give you an idea
about the research

01:24:28.292 --> 01:24:31.375
areas. And then the
under each area,

01:24:31.375 --> 01:24:33.834
how many awards
are made and what

01:24:33.834 --> 01:24:36.000
are the funded organizations.

01:24:38.667 --> 01:24:42.501
Like all other RADx initiatives,

01:24:42.501 --> 01:24:45.751
RADx-rad is coordinated by

01:24:45.751 --> 01:24:47.999
discovery and data Coordination,

01:24:47.999 --> 01:24:49.709
Center recalled DCC,

01:24:49.709 --> 01:24:53.292
so this is a single cooperative

01:24:53.292 --> 01:24:56.417
Agreement award
under the program

01:24:56.417 --> 01:24:59.459
developed by Doctor
Valerie Florence

01:24:59.459 --> 01:25:03.042
and RADx-rad Leadership
at the RFA-OD-20-019

01:25:03.042 --> 01:25:09.209
it is U 24 and so this

01:25:09.209 --> 01:25:12.375
award is managed
by the NLM team of

01:25:12.375 --> 01:25:15.542
the leadership and

01:25:15.542 --> 01:25:17.834
Grant Management Program

01:25:17.834 --> 01:25:20.626
Officer and Project scientist,

01:25:20.626 --> 01:25:21.834
including D-NUP

01:25:21.834 --> 01:25:26.000
So, DCC provides overarching

01:25:26.000 --> 01:25:29.751
support and guidance
for all RADx-rad

01:25:29.751 --> 01:25:32.250
awardees through
its administrative

01:25:32.250 --> 01:25:36.167
call and data call
and diagnostic call.

01:25:36.167 --> 01:25:40.792
So the award went to a team of

01:25:40.792 --> 01:25:43.292
Researchers at University
of California,

01:25:43.292 --> 01:25:46.999
San Diego on and
also the researchers

01:25:46.999 --> 01:25:49.375
at the University of Texas,

01:25:49.375 --> 01:25:52.501
UTHealth Science
Center at Houston.

01:25:53.626 --> 01:25:55.167
You see this website.

01:25:55.167 --> 01:25:57.542
So this is the information web

01:25:57.542 --> 01:26:00.125
portal that DCC set up for.

01:26:00.125 --> 01:26:02.042
The RADx-rad program.

01:26:02.042 --> 01:26:05.334
So there is a lot
of information here

01:26:05.334 --> 01:26:08.709
if you would like to explore.

01:26:08.709 --> 01:26:12.501
The idea for the DCC

is to serve as a

01:26:12.501 --> 01:26:14.834
communication Center
for RADx-rad awardees

01:26:14.834 --> 01:26:18.459
and serves as a spoke in the

01:26:18.459 --> 01:26:21.209
larger NIH initiatives
by providing

01:26:21.209 --> 01:26:25.542
deidentified data to
an NIH RADx data hub.

01:26:25.542 --> 01:26:28.292
It also serves as
a liaison between

01:26:28.292 --> 01:26:32.125
the RADx awardees and all other

01:26:32.125 --> 01:26:34.125
NIH supported RADx initiatives,

01:26:34.125 --> 01:26:36.459
and it coordinates
collaborations between

01:26:36.459 --> 01:26:39.999
RADx-rad and other
organizations.

01:26:39.999 --> 01:26:42.584
You will see some
more information

01:26:42.584 --> 01:26:44.334
in the following slide.

01:26:44.334 --> 01:26:46.751
So to be more specific,

01:26:46.751 --> 01:26:50.334
so DCC supports the the IRB

01:26:50.334 --> 01:26:54.375
design and helps
awardees to manage data

01:26:54.375 --> 01:26:57.209
use agreement about
language for example,

01:26:57.209 --> 01:27:00.334

and help awardees to
organize and share

01:27:00.334 --> 01:27:03.292
data to support
the compliance to

01:27:03.292 --> 01:27:06.375
the NIH data sharing policy and

01:27:06.375 --> 01:27:09.250
communicate and guide the use of

01:27:09.250 --> 01:27:11.542
minimum common data elements and

01:27:11.542 --> 01:27:13.083
develop additional Datasheet

01:27:13.083 --> 01:27:15.125
dictionaries,
standards and models

01:27:15.125 --> 01:27:18.626
that are specific to each

01:27:18.626 --> 01:27:21.292
technology area and
provide advice

01:27:21.292 --> 01:27:24.501
on statistics and AI methods and

01:27:24.501 --> 01:27:27.626
to help to prepare the data set

01:27:27.626 --> 01:27:31.584
to be AI ready and so DCC

01:27:31.584 --> 01:27:34.709
will also assist
the summation of

01:27:34.709 --> 01:27:38.167
the data set to
the NIH Data Hub.

01:27:38.167 --> 01:27:41.999
So it also provides
a preconfigured

01:27:41.999 --> 01:27:43.792
laboratory information
management

01:27:43.792 --> 01:27:46.334
system to help awardees

01:27:46.334 --> 01:27:49.250
for data collection sharing and

01:27:49.250 --> 01:27:51.626
their diagnostic call provides

01:27:51.626 --> 01:27:54.751
protocol support
and viral quality

01:27:54.751 --> 01:27:57.792
assurance panels
with known viral

01:27:57.792 --> 01:27:59.792
concentrations and sequencing

01:27:59.792 --> 01:28:03.000
information through
all viral variants.

01:28:03.000 --> 01:28:06.459
It provides general
information on the

01:28:06.459 --> 01:28:10.834
the vendors and resources and

01:28:10.834 --> 01:28:14.083
helps to answer
regulatory questions.

01:28:14.083 --> 01:28:17.167
In preparing for FDA submission.

01:28:19.250 --> 01:28:23.209
And so the RADx-rad holds a lot

01:28:23.209 --> 01:28:26.709
of coordination responsibility.

01:28:26.709 --> 01:28:29.501
So, it actively works on

01:28:29.501 --> 01:28:32.459
with RADx-rad data hub,

01:28:32.459 --> 01:28:35.834
so the data hub is
the place where

01:28:35.834 --> 01:28:39.417
all RADx data will be deposited

01:28:39.417 --> 01:28:42.042
and will be made accessible,

01:28:42.042 --> 01:28:44.459
available to the
public community.

01:28:44.459 --> 01:28:49.584
So the DCC also collaborates

01:28:49.584 --> 01:28:52.250
with other RADx initiatives,

01:28:52.250 --> 01:28:56.626
so one important work is to work

01:28:56.626 --> 01:29:00.709
with the RADx pack and to

01:29:00.709 --> 01:29:04.459
test technology an
evaluation to help

01:29:04.459 --> 01:29:06.999
with testing
technology evaluation

01:29:06.999 --> 01:29:08.209
and acceleration.

01:29:08.209 --> 01:29:12.751
so this is to
evaluate the progress

01:29:12.751 --> 01:29:17.334
and the stage of the
RADx-rad project

01:29:17.334 --> 01:29:21.250
and to identify
the project which

01:29:21.250 --> 01:29:25.542
are getting close
for the emergency

01:29:25.542 --> 01:29:27.459
use authorization application

01:29:27.459 --> 01:29:31.250
at FDA or identify a project

01:29:31.250 --> 01:29:34.417
that is highly potential

01:29:34.417 --> 01:29:36.000
for commercialization.

01:29:36.000 --> 01:29:39.334

So this is equal coordinates
interactions with

01:29:39.334 --> 01:29:42.250
FDA get FDA are

01:29:42.250 --> 01:29:44.584
consolidations and
update the awardees

01:29:44.584 --> 01:29:47.709
with most recent

01:29:47.709 --> 01:29:50.999
regulatory information
at FDA and a

01:29:50.999 --> 01:29:55.375
lot of outreach to CDC and NIST.

01:29:55.375 --> 01:29:58.375
For example this is to work with

01:29:58.375 --> 01:30:01.834
the community to
learn and integrate

01:30:01.834 --> 01:30:04.584
Community established
data standard

01:30:04.584 --> 01:30:06.667
all technology standard.

01:30:06.667 --> 01:30:10.375
So the slides just
show you some of

01:30:10.375 --> 01:30:14.125
the examples from the
ongoing activities.

01:30:14.125 --> 01:30:17.834
There are a lot
of meating calls,

01:30:17.834 --> 01:30:21.584
monthly meeting
call with RADx-rad

01:30:21.584 --> 01:30:24.751
Leadership, PO program
officers and PI,

01:30:24.751 --> 01:30:27.209
and then the weekly technical

01:30:27.209 --> 01:30:30.334
office hours for IRB support and

01:30:30.334 --> 01:30:33.125
data related questions and or

01:30:33.125 --> 01:30:35.417
diagnostic test
related questions.

01:30:35.417 --> 01:30:37.375
And so the DCC.

01:30:37.375 --> 01:30:40.334
Has helped to form RFA specific

01:30:40.334 --> 01:30:43.626
Data Dictionary working group.

01:30:43.626 --> 01:30:47.417
This is to develop
the the common data

01:30:47.417 --> 01:30:50.709
element or terminology
regarding to

01:30:50.709 --> 01:30:54.417
each specific
technologies that are

01:30:54.417 --> 01:30:57.667
being developed by the RADx-rad.

01:30:57.667 --> 01:31:00.834
And meet with RADx data hub

01:31:00.834 --> 01:31:03.167
every other week
and specifically

01:31:03.167 --> 01:31:06.667
to discuss the RADx-rad related

01:31:06.667 --> 01:31:09.042
questions and monthly by joining

01:31:09.042 --> 01:31:11.834
all other RADx date according

01:31:11.834 --> 01:31:14.167
to the centers to discuss

01:31:14.167 --> 01:31:17.292
common issues and so the

01:31:17.292 --> 01:31:21.417

DCC and together
with the RADx-rad

01:31:21.417 --> 01:31:24.792
leadership and to meet with FDA

01:31:24.792 --> 01:31:28.209
on a monthly basis
to bring up the.

01:31:28.209 --> 01:31:33.626
The questions raised by
the RADx-rad awardees

01:31:33.626 --> 01:31:36.209
And so there are
active development

01:31:36.209 --> 01:31:39.209
on going for the various tools

01:31:39.209 --> 01:31:41.542
to support these activities,

01:31:41.542 --> 01:31:44.042
so the data management
goals across

01:31:44.042 --> 01:31:48.209
the RADx-rad programs
is to promote

01:31:48.209 --> 01:31:50.667
research integrity and better

01:31:50.667 --> 01:31:53.709
characterized the studies
and the RADx-rad

01:31:53.709 --> 01:31:56.999
and the new technologies and

01:31:56.999 --> 01:31:59.999
to ensure the
participant privacy

01:31:59.999 --> 01:32:02.999
is well protected and to

01:32:02.999 --> 01:32:06.000
promote data sharing and provide

01:32:06.000 --> 01:32:09.751
tools to enable reuse of data.

01:32:09.751 --> 01:32:14.042
So as an NIH data

harmonization effort,

01:32:14.042 --> 01:32:16.542
minimum common data element data

01:32:16.542 --> 01:32:20.375
set is developed by the NIH CDE

01:32:20.375 --> 01:32:21.584
Executive Committee.

01:32:21.584 --> 01:32:25.250
So this is the latest
version of the

01:32:25.250 --> 01:32:29.125
final version which
includes twelve elements,

01:32:29.125 --> 01:32:32.834
and so this data set this CDE

01:32:32.834 --> 01:32:35.042
data set is

01:32:37.375 --> 01:32:42.167
Applicable to all
RADx-rad projects

01:32:42.167 --> 01:32:46.667
so to support the compliance of

01:32:46.667 --> 01:32:50.542
the minimum common data element

01:32:50.542 --> 01:32:55.042
so the DCC conducted survey for

01:32:55.042 --> 01:32:59.999
the minimum RADx CDE data set.

01:32:59.999 --> 01:33:04.459
And so following the survey

01:33:04.459 --> 01:33:07.751
DCC met with the NIH

01:33:07.751 --> 01:33:10.459
CDE Executive committee
and leadership

01:33:10.459 --> 01:33:13.501
to review the service statistics

01:33:13.501 --> 01:33:16.834
and discuss about
the concerns that

01:33:16.834 --> 01:33:19.999
were heard from the
survey responses

01:33:19.999 --> 01:33:25.209
and so which led to develop the.

01:33:25.209 --> 01:33:29.501
code book as
responses to each of

01:33:29.501 --> 01:33:33.834
the CDE element and so right now

01:33:33.834 --> 01:33:37.834
DCC and NIH are working together

01:33:37.834 --> 01:33:41.209
to establish a procedure
for reviewing

01:33:41.209 --> 01:33:44.584
the request that a PI may raise,

01:33:44.584 --> 01:33:49.083
for example to modify
a CDE based on

01:33:49.083 --> 01:33:53.999
the needs of the
project and situation.

01:33:53.999 --> 01:33:58.751
The DCC and NIH are also

01:33:58.751 --> 01:34:03.000
providing translations
of the CDE for

01:34:03.000 --> 01:34:06.375
multiple languages
because we are

01:34:06.375 --> 01:34:10.626
working with a very
broad community.

01:34:10.626 --> 01:34:13.375
So just a brief
description about

01:34:13.375 --> 01:34:18.751
the survey statistics. So the.

01:34:18.751 --> 01:34:21.999
43 Project after

the 49 Extra mural

01:34:21.999 --> 01:34:24.709
project responded
to this CDE survey

01:34:24.709 --> 01:34:27.999
and so that include
both human subject

01:34:27.999 --> 01:34:31.042
project and and non-human
subject project.

01:34:31.042 --> 01:34:34.250
Even though the CDE is only a

01:34:34.250 --> 01:34:37.167
requirement is
only applicable to

01:34:37.167 --> 01:34:39.584
the human subject project.

01:34:39.584 --> 01:34:43.417
So for each CDE element
there are seven

01:34:43.417 --> 01:34:46.209
questions being asked
in the survey.

01:34:46.209 --> 01:34:49.792
So basically to get an idea of

01:34:49.792 --> 01:34:52.999
Understanding to see
how straightforward

01:34:52.999 --> 01:34:56.834
that compliance is
or how challenging

01:34:56.834 --> 01:35:01.125
it is to collect the
CDE information.

01:35:01.125 --> 01:35:05.125
The survey was done on
the larger CDE site

01:35:05.125 --> 01:35:07.626
which contains 60 elements,

01:35:07.626 --> 01:35:11.125
and so this. So from
this screenshot.

01:35:11.125 --> 01:35:14.125
So basically we
can identify the,

01:35:14.125 --> 01:35:18.125
you know the few CDE on the top,

01:35:18.125 --> 01:35:20.751
the first row for
which basically

01:35:20.751 --> 01:35:22.584
the information collecting is

01:35:22.584 --> 01:35:24.167
pretty straightforward,

01:35:24.167 --> 01:35:28.000
but we also see
there are a number

01:35:28.000 --> 01:35:31.334
of those CDE element that the.

01:35:31.334 --> 01:35:34.209
People think the Pi think so.

01:35:34.209 --> 01:35:36.125
The project change maybe

01:35:36.125 --> 01:35:38.083
changes may be needed.

01:35:38.083 --> 01:35:40.459
For example, to amend IRB.

01:35:40.459 --> 01:35:42.250
Just as an example.

01:35:42.250 --> 01:35:46.501
And so the feedback we
heard from the survey

01:35:46.501 --> 01:35:50.083
can be something like
OK for education.

01:35:50.083 --> 01:35:52.459
It's OK to collect, however,

01:35:52.459 --> 01:35:54.417
the original response,

01:35:54.417 --> 01:35:57.459
at least as showing on the

01:35:57.459 --> 01:35:59.667
right hand of the slide.

01:35:59.667 --> 01:36:01.250
As you know, overwhelming.

01:36:01.250 --> 01:36:05.459
So as hard. It is very
difficult to collect,

01:36:05.459 --> 01:36:09.250
so at the end of
discussion with NIH.

01:36:09.250 --> 01:36:13.000
So this I mean comes
down to a years

01:36:13.000 --> 01:36:16.626
of education becomes acceptable.

01:36:16.626 --> 01:36:21.167
And as another example
for the domicile

01:36:21.167 --> 01:36:26.334
address and so some
PIs see it is as very

01:36:26.334 --> 01:36:30.292
intrusive an that
will discourage the

01:36:30.292 --> 01:36:35.375
participant to join the
research project so.

01:36:35.375 --> 01:36:37.584
As a result of the discussion,

01:36:37.584 --> 01:36:41.167
so this is chance to like zip

01:36:41.167 --> 01:36:42.709
code is acceptable.

01:36:42.709 --> 01:36:47.751
So just as a summary
on the of the

01:36:47.751 --> 01:36:52.501
CDE effort of the
NIH RADx project,

01:36:52.501 --> 01:36:57.626
the the minimum CDE
our data set and

01:36:57.626 --> 01:37:01.167
requirement has been
thoroughly communicated

01:37:01.167 --> 01:37:06.167
and discussed with the RADx-rad.

01:37:06.167 --> 01:37:06.667
awardees

01:37:06.667 --> 01:37:10.792
through the effort
of DCC and then a

01:37:10.792 --> 01:37:14.792
procedure is being developed
now for the PIs and

01:37:14.792 --> 01:37:17.292
awardees to submit a petition.

01:37:17.292 --> 01:37:21.083
If there is a need
for waiver for

01:37:21.083 --> 01:37:24.417
certain CD elements and DCC is,

01:37:24.417 --> 01:37:27.083
see now is actively

01:37:27.083 --> 01:37:29.709
actively working with the

01:37:29.709 --> 01:37:32.792
awardees on lapse
of technology or

01:37:32.792 --> 01:37:35.250
other data elements
for each FOA.

01:37:35.250 --> 01:37:37.709
I think I'm going to stop

01:37:37.709 --> 01:37:40.375
here and thank you very much.

01:37:42.751 --> 01:37:45.250
Hello my name is Amanda Wilson

01:37:45.250 --> 01:37:47.751
and I'm NLM's, designee for the

01:37:47.751 --> 01:37:49.834
NIH Research Initiative on post.

01:37:49.834 --> 01:37:51.999
Acute sequelae of SARS-CoV2

01:37:51.999 --> 01:37:54.834
infection or PASC.
In December 2020

01:37:54.834 --> 01:37:57.125
This initiative was funded for

01:37:57.125 --> 01:38:00.375
four years in the
amount of $1.15

01:38:00.375 --> 01:38:03.125
billion as part of
the coronavirus

01:38:03.125 --> 01:38:05.042
response and Relief Act.

01:38:05.042 --> 01:38:07.125
As PASC is just now ramping up,

01:38:07.125 --> 01:38:09.751
my goal is to
provide you with an

01:38:09.751 --> 01:38:11.125
understanding of the initiative

01:38:11.125 --> 01:38:13.417
and give a window into how NLM

01:38:13.417 --> 01:38:15.792
is contributing to the effort.

01:38:15.792 --> 01:38:17.501
As PASC-related activities come

01:38:17.501 --> 01:38:19.209
on line across the country,

01:38:19.209 --> 01:38:21.501
it's also my hope that with this

01:38:21.501 --> 01:38:23.167
information you have enough to

01:38:23.167 --> 01:38:25.334
know how you can get involved or

01:38:25.334 --> 01:38:27.417
support others in
their involvement.

01:38:31.667 --> 01:38:34.083
While PASC is not
well understood yet,

01:38:34.083 --> 01:38:36.125
the magnitude of
the public health

01:38:36.125 --> 01:38:38.334
impact of these
post acute sequelae

01:38:38.334 --> 01:38:40.667
is potentially large
given the number

01:38:40.667 --> 01:38:43.209
of people of all
ages who have been

01:38:43.209 --> 01:38:45.834
or will be infected
with SARS-CoV-2.

01:38:45.834 --> 01:38:48.250
People are reporting
a constellation of

01:38:48.250 --> 01:38:50.459
symptoms well after
they've recovered

01:38:50.459 --> 01:38:53.292
from the initial stages
of infection that

01:38:53.292 --> 01:38:56.209
can be after 8 to
12 weeks or longer.

01:38:56.209 --> 01:38:59.501
Some persistent
symptoms you may have

01:38:59.501 --> 01:39:03.042
heard about our
shortness of breath,

01:39:03.042 --> 01:39:05.626
brain fog, sleep
disorders, fever,

01:39:05.626 --> 01:39:08.626
anxiety, and depression.

01:39:08.626 --> 01:39:10.042
From what we know,

01:39:10.042 --> 01:39:12.999
PASC may not be a
singular syndrome

01:39:12.999 --> 01:39:15.626
but constitute
multiple syndromes.

01:39:15.626 --> 01:39:17.042
Quickly characterizing PASC

01:39:17.042 --> 01:39:20.501
Will allow us to move
toward effective

01:39:20.501 --> 01:39:23.125
treatment and over 18 of NIH is

01:39:23.125 --> 01:39:24.792
Institute centers and programs

01:39:24.792 --> 01:39:27.334
have come together to guide and

01:39:27.334 --> 01:39:29.375
develop this trans NIH effort.

01:39:33.209 --> 01:39:35.334
The PASC initiative
brings together

01:39:35.334 --> 01:39:37.042
research and
scientific communities

01:39:37.042 --> 01:39:38.999
across disease and other focus

01:39:38.999 --> 01:39:40.626
areas and partnership
with people

01:39:40.626 --> 01:39:44.250
who've been infected
by SARS-CoV-2.

01:39:44.250 --> 01:39:46.167
The three scientific
questions you

01:39:46.167 --> 01:39:49.250
see on this slide
are what will be

01:39:49.250 --> 01:39:51.083
investigated to

identify the causes

01:39:51.083 --> 01:39:53.999
of PASC to develop
ways of treating

01:39:53.999 --> 01:39:56.000
individuals who
don't fully recover

01:39:56.000 --> 01:39:59.626
and ultimately to
prevent the disorder.

01:39:59.626 --> 01:40:01.501
Initially, the program focuses

01:40:01.501 --> 01:40:02.999
on four things,

01:40:02.999 --> 01:40:06.584
which I'll cover in a
little more detail.

01:40:06.584 --> 01:40:08.417
A meta cohort, an investigator

01:40:08.417 --> 01:40:09.334
consortium, studies,

01:40:09.334 --> 01:40:11.083
and data repository.

01:40:11.083 --> 01:40:11.751
Eventually,

01:40:11.751 --> 01:40:14.626
exploratory clinical
trials will be

01:40:14.626 --> 01:40:18.459
funded as we move
toward designing PASC

01:40:18.459 --> 01:40:20.542
treatment and
prevention strategy.

01:40:20.542 --> 01:40:23.167
Pictured here are the
research questions

01:40:23.167 --> 01:40:25.999
aligned with the cohort and the

01:40:25.999 --> 01:40:28.083
studies components

of the initiative.

01:40:28.083 --> 01:40:29.542
As a starting point,

01:40:29.542 --> 01:40:32.125
the recovery cohort
is a meta cohort.

01:40:32.125 --> 01:40:33.999
The initiative will track at

01:40:33.999 --> 01:40:35.792
least 40,000 adults
and children.

01:40:35.792 --> 01:40:37.999
To learn more about who develops

01:40:37.999 --> 01:40:39.834
long term effects of SARS-CoV-2

01:40:39.834 --> 01:40:43.334
infection and who does not.

01:40:43.334 --> 01:40:45.250
Participants in the cohort are

01:40:45.250 --> 01:40:47.667
not limited to the
United States.

01:40:47.667 --> 01:40:50.167
Along with people
experiencing PASC

01:40:50.167 --> 01:40:52.667
the cohort will
include comparator,

01:40:52.667 --> 01:40:54.542
an control case it.

01:40:54.542 --> 01:40:56.999
The comparators are
COVID positive

01:40:56.999 --> 01:40:59.542
PASC-negative cases, and the

01:40:59.542 --> 01:41:02.083
controls are COVID
negative cases.

01:41:09.626 --> 01:41:11.667
The recovery cohort
is this central

01:41:11.667 --> 01:41:14.375
source to begin to
address the key

01:41:14.375 --> 01:41:16.042
scientific questions for PASC.

01:41:16.042 --> 01:41:17.834
Initially, three
types of studies are

01:41:17.834 --> 01:41:20.042
being funded to advance
our understanding,

01:41:20.042 --> 01:41:21.834
starting with clinical studies,

01:41:21.834 --> 01:41:25.667
these are listed on the
left of this slide.

01:41:25.667 --> 01:41:28.167
To understand the pathology

01:41:28.167 --> 01:41:30.000
autopsy cohort studies

01:41:30.000 --> 01:41:32.334
will identify tissue
injury due to SARS-CoV-2,

01:41:32.334 --> 01:41:35.792
infection, or its sequelae.

01:41:35.792 --> 01:41:38.792
The EHR, and real-world
data studies,

01:41:38.792 --> 01:41:41.292
aim to inform the case

01:41:41.292 --> 01:41:43.292
definition of PASC, describe

01:41:43.292 --> 01:41:44.292
patient demographics,

01:41:44.292 --> 01:41:45.292
identify comorbidities,

01:41:45.292 --> 01:41:47.792
define health care
utilization patterns,

01:41:47.792 --> 01:41:51.083

and provide data for comparative

01:41:51.083 --> 01:41:52.375
effectiveness studies.

01:41:52.375 --> 01:41:53.751
On the right,

01:41:53.751 --> 01:41:55.999
the Investigator
Consortium requires all

01:41:55.999 --> 01:41:58.083
investigators to
collaborate and agree

01:41:58.083 --> 01:42:00.417
to share data and
biospecimens with

01:42:00.417 --> 01:42:03.042
each other and across
the PASC program.

01:42:03.042 --> 01:42:05.125
The Investigator
Consortium will also

01:42:05.125 --> 01:42:07.292
develop Common
Core protocols and

01:42:07.292 --> 01:42:08.999
gain consent from participants

01:42:08.999 --> 01:42:11.167
for all of the sharing of data,

01:42:11.167 --> 01:42:12.999
health information and
biospecimens required

01:42:12.999 --> 01:42:15.209
for this initiative
to be successful.

01:42:19.542 --> 01:42:21.584
These are the three
pillars supporting

01:42:21.584 --> 01:42:23.501
the cohort, and
investigator consortium.

01:42:23.501 --> 01:42:25.999
The clinical science
core will coordinate

01:42:25.999 --> 01:42:28.292
and support research
program development

01:42:28.292 --> 01:42:30.709
and implementation
across the consortium,

01:42:30.709 --> 01:42:33.542
as well as provide
expertise on clinical

01:42:33.542 --> 01:42:36.209
study, design and
implementation.

01:42:36.209 --> 01:42:38.459
The Biorepository
core will establish

01:42:38.459 --> 01:42:41.167
and maintain a secure
central repository

01:42:41.167 --> 01:42:43.626
for biospecimens and
it will function

01:42:43.626 --> 01:42:46.167
as a virtual
repository, tracking,

01:42:46.167 --> 01:42:49.417
availability and
location of bio samples

01:42:49.417 --> 01:42:52.334
maintained at other
initiative sites.

01:42:52.334 --> 01:42:54.334
The data resource core will

01:42:54.334 --> 01:42:56.292
coordinate data across
the consortium.

01:42:56.292 --> 01:42:59.292
The DRC will also
provide analytical

01:42:59.292 --> 01:43:01.417
tools and statistical support

01:43:01.417 --> 01:43:03.626
to the clinical science core.

01:43:03.626 --> 01:43:07.000
These cores work
closely along with the

01:43:07.000 --> 01:43:09.334
Administrative Coordinating
Center to form

01:43:09.334 --> 01:43:11.417
the infrastructure
of the initiative.

01:43:11.417 --> 01:43:12.250
For example,

01:43:12.250 --> 01:43:13.999
coordination areas
between clinical

01:43:13.999 --> 01:43:16.042
science and data resource cores

01:43:16.042 --> 01:43:17.709
include things
like commonalities

01:43:17.709 --> 01:43:20.834
and shared use of
clinical protocols.

01:43:20.834 --> 01:43:23.501
Data protection integration and

01:43:23.501 --> 01:43:24.792
interoperability standards.

01:43:24.792 --> 01:43:26.584
Analysis tools, consents,

01:43:26.584 --> 01:43:29.542
and identity management
and training.

01:43:33.125 --> 01:43:35.584
I'd like to spend the
next few moments

01:43:35.584 --> 01:43:37.999
on the overall
PASC data strategy

01:43:37.999 --> 01:43:40.542
which the data resource core or

01:43:40.542 --> 01:43:42.792
the DRC overseas and coordinates

01:43:42.792 --> 01:43:45.083
for the programs diverse data.

01:43:45.083 --> 01:43:47.250
You can envision the
overall strategy

01:43:47.250 --> 01:43:51.125
as a hub and spoke
model where the DRC

01:43:51.125 --> 01:43:53.459
is the hub coordinating
harmonization,

01:43:53.459 --> 01:43:55.999
access and standardization
across the

01:43:55.999 --> 01:43:59.292
spokes of the different
data repositories.

01:43:59.292 --> 01:44:02.709
At the top left, access
to recovery cohort

01:44:02.709 --> 01:44:05.501
participant data will
be restricted to

01:44:05.501 --> 01:44:07.834
PASC investigators
and time limited.

01:44:07.834 --> 01:44:10.501
Moving down the content of the

01:44:10.501 --> 01:44:11.375
digital pathology,

01:44:11.375 --> 01:44:13.459
an imaging repositories provides

01:44:13.459 --> 01:44:16.042
integrations between
the observed and

01:44:16.042 --> 01:44:18.584
measured clinical
phenotypes for PASC

01:44:18.584 --> 01:44:21.000
and the opportunity
to investigate

01:44:21.000 --> 01:44:23.125
tissue specimens for evidence.

01:44:23.125 --> 01:44:25.999
On the top right for the EHR

01:44:25.999 --> 01:44:27.792
and real-world data studies,

01:44:27.792 --> 01:44:30.584
content in the repository
includes clinical,

01:44:30.584 --> 01:44:31.292
laboratory,

01:44:31.292 --> 01:44:34.834
and diagnostic data
from hospitals.

01:44:34.834 --> 01:44:36.751
And finally, the bottom right,

01:44:36.751 --> 01:44:38.709
a new component
being funded within

01:44:38.709 --> 01:44:41.292
the next few months
is the mobile

01:44:41.292 --> 01:44:42.999
health platform and accompanying

01:44:42.999 --> 01:44:44.792
digital health data repository.

01:44:44.792 --> 01:44:46.709
They will handle many tasks,

01:44:46.709 --> 01:44:47.834
including recruitment and

01:44:47.834 --> 01:44:49.000
engagement of participants,

01:44:49.000 --> 01:44:52.000
as well as obtaining
their electronic consent

01:44:52.000 --> 01:44:54.042
and collecting
standardized information.

01:44:54.042 --> 01:44:56.834
Importantlthe mobile health platform will

01:44:56.834 --> 01:45:00.209
be a pathway for PASC to collect

01:45:00.209 --> 01:45:02.083
data from non hospitalized,

01:45:02.083 --> 01:45:02.751
underserved,

01:45:02.751 --> 01:45:05.375
rural and
underrepresented groups.

01:45:05.375 --> 01:45:07.167
The digital health
data Repository

01:45:07.167 --> 01:45:09.334
will also facilitate
data task for

01:45:09.334 --> 01:45:11.125
information collected
via mobile apps

01:45:11.125 --> 01:45:13.375
and sensors used by
PASC investigators.

01:45:18.999 --> 01:45:21.751
The intent for PASC
is to have a secure,

01:45:21.751 --> 01:45:23.834
rapid sharing of as much data as

01:45:23.834 --> 01:45:26.167
possible to as wide a group of

01:45:26.167 --> 01:45:28.042
authenticated researchers
as possible.

01:45:28.042 --> 01:45:30.417
The program will
make available a

01:45:30.417 --> 01:45:32.542
cloud based analytic
workbench for

01:45:32.542 --> 01:45:34.250
the broader research community.

01:45:34.250 --> 01:45:37.459
Illustrated in the
center you see examples

```
01:45:37.459 --> 01:45:40.292
of Workbench features
as its envisioned now.

01:45:40.292 --> 01:45:42.584
As the program continues
to come online,

01:45:42.584 --> 01:45:45.125
these will adapt and expand

01:45:45.125 --> 01:45:47.209
to meet emerging needs.

01:45:47.209 --> 01:45:48.999
I talked through
several repositories

01:45:48.999 --> 01:45:50.250
on the last slide,

01:45:50.250 --> 01:45:52.626
which are listed
here on the right,

01:45:52.626 --> 01:45:54.250
they'll be funded separately in

01:45:54.250 --> 01:45:56.334
the June to July time frame,

01:45:56.334 --> 01:45:58.667
and all of these
repositories will work

01:45:58.667 --> 01:46:00.042
collaboratively to
develop, operate,

01:46:00.042 --> 01:46:01.792
and maintain a digital
infrastructure

01:46:01.792 --> 01:46:04.417
that can meet the
needs of the program.

01:46:04.417 --> 01:46:06.751
Now an also over the long term.

01:46:11.083 --> 01:46:13.626
In summary, the key
important features

01:46:13.626 --> 01:46:16.792
of the research
```

initiative for PASC are

01:46:16.792 --> 01:46:18.667
a collaborative
governance structure.

01:46:18.667 --> 01:46:21.083
Community and patient
engagement in

01:46:21.083 --> 01:46:23.459
every component of
the initiative.

01:46:23.459 --> 01:46:25.999
Tight integration and close

01:46:25.999 --> 01:46:28.292
coordination of
initiative component.

01:46:28.292 --> 01:46:29.999
Flexibility and nimbleness to

01:46:29.999 --> 01:46:32.999
adapt as we learn
more about PASC.

01:46:32.999 --> 01:46:36.334
This is enabled
through NIH's other

01:46:36.334 --> 01:46:38.626
transaction authority
funding mechanism.

01:46:38.626 --> 01:46:40.834
Data sharing and
harmonization using

01:46:40.834 --> 01:46:43.999
standards such as common
data elements and

01:46:43.999 --> 01:46:46.375
informed consents for
current and future

01:46:46.375 --> 01:46:49.209
use of information
and biospecimens.

01:46:49.209 --> 01:46:50.375
But this initiative,

01:46:50.375 --> 01:46:53.083
over 25 NLM staff

have contributed to

01:46:53.083 --> 01:46:55.626
the range of features
I just discussed,

01:46:55.626 --> 01:46:57.375
including recruiting
over 100 other

01:46:57.375 --> 01:46:58.792
internal and external experts

01:46:58.792 --> 01:47:00.542
and volunteers to participate.

01:47:03.667 --> 01:47:06.125
The types of activities NLM

01:47:06.125 --> 01:47:08.250
staff have participated in so

01:47:08.250 --> 01:47:10.000
far include drafting funding

01:47:10.000 --> 01:47:13.334
announcements, recruiting, volunteering for or
service as reviewers

01:47:13.334 --> 01:47:15.459
participating in working
group activities,

01:47:15.459 --> 01:47:17.542
or advancing our scientific

01:47:17.542 --> 01:47:20.083
understanding of
aspects of PASC.

01:47:20.083 --> 01:47:23.125
One example of that
is reflected here.

01:47:23.125 --> 01:47:26.167
In addition, NLM
researchers are also

01:47:26.167 --> 01:47:29.042
completing a review
of published post

01:47:29.042 --> 01:47:31.542
mortem reports of
COVID-19 patients,

01:47:31.542 --> 01:47:34.501

so that's over 111 studies

01:47:34.501 --> 01:47:36.834
representing over 1000 patients.

01:47:36.834 --> 01:47:39.375
As a program evolves,
new opportunities

01:47:39.375 --> 01:47:41.042
for contributions will arise.

01:47:41.042 --> 01:47:43.501
I mentioned earlier
that clinical

01:47:43.501 --> 01:47:46.000
trials are a planned
component. Researcher

01:47:46.000 --> 01:47:48.125
engagement for the data resource

01:47:48.125 --> 01:47:50.751
core and patient
registries are the

01:47:50.751 --> 01:47:53.083
next two initiatives
also ramping up.

01:47:53.083 --> 01:47:54.250
To learn more,

01:47:54.250 --> 01:47:56.999
there will be a
PASC website soon.

01:47:56.999 --> 01:47:57.626
Until then,

01:47:57.626 --> 01:48:01.125
the URL on this slide
has links to research

01:48:01.125 --> 01:48:01.751
opportunity

01:48:01.751 --> 01:48:03.667
announcements and FAQs for the

01:48:03.667 --> 01:48:05.334
initial PASC program component,

01:48:05.334 --> 01:48:08.083
which I discussed today.

01:48:08.083 --> 01:48:10.834
And you can listen to the April

01:48:10.834 --> 01:48:12.999
28th congressional
hearing on PASC

01:48:12.999 --> 01:48:14.834
at which Doctor Francis Collins

01:48:14.834 --> 01:48:16.999
gave testimony by
searching these

01:48:16.999 --> 01:48:18.375
terms on the web.

01:48:18.375 --> 01:48:19.999
You can also feel free to reach

01:48:19.999 --> 01:48:21.834
out to me directly if you prefer

01:48:21.834 --> 01:48:23.792
and my email is
there. Thank you.

01:48:27.167 --> 01:48:28.626
Hello, I'm Robin Taylor and I'm

01:48:28.626 --> 01:48:30.292
the product lead for the NIH

01:48:30.292 --> 01:48:31.584
common data elements repository,

01:48:31.584 --> 01:48:32.999
which is hosted by NLM.

01:48:35.083 --> 01:48:37.250
Today I'm going to
tell you a little bit

01:48:37.250 --> 01:48:39.417
about common data
elements which you've

01:48:39.417 --> 01:48:41.292
heard mentioned several
times already.

01:48:41.292 --> 01:48:43.417
This hour, the important
role that NLM

01:48:43.417 --> 01:48:45.999
plays with CDE adoption

at NIH and will

01:48:45.999 --> 01:48:47.792
have focused on
COVID related CDEs.

01:48:47.792 --> 01:48:50.667
What are common data
elements? You've

01:48:50.667 --> 01:48:52.292
heard that mentioned
several times today.

01:48:52.292 --> 01:48:53.999
I'm going to give
some background so

01:48:53.999 --> 01:48:56.083
that we all have a
common understanding.

01:48:56.083 --> 01:48:58.167
First, will look at a typical

01:48:58.167 --> 01:49:00.501
scenario at NIH
that involves data

01:49:00.501 --> 01:49:02.626
elements that are not common.

01:49:02.626 --> 01:49:03.459
In this scenario,

01:49:03.459 --> 01:49:05.417
Alex gets a grant
to study gender

01:49:05.417 --> 01:49:07.000
differences in alcohol abuse,

01:49:07.000 --> 01:49:09.375
and Blake gets a grant
to study the effect

01:49:09.375 --> 01:49:11.709
of alcohol usage on
cancer treatment.

01:49:11.709 --> 01:49:13.250
The researchers
designed their studies,

01:49:13.250 --> 01:49:16.000
which will include
many data elements.

01:49:16.000 --> 01:49:18.042
Alex's study asks
how many drinks

01:49:18.042 --> 01:49:20.209
do you consume in a
typical week and

01:49:20.209 --> 01:49:22.292
the answer can be
any whole number.

01:49:22.292 --> 01:49:24.334
While Blake's study
asks how often do

01:49:24.334 --> 01:49:26.375
you consume alcohol
and there are

01:49:26.375 --> 01:49:27.834
three possible
responses allowed.

01:49:27.834 --> 01:49:29.459
The researchers
complete their studies,

01:49:29.459 --> 01:49:30.459
analyze their data,

01:49:30.459 --> 01:49:31.792
and published their findings.

01:49:34.083 --> 01:49:35.999
What happens to those
researchers data

01:49:35.999 --> 01:49:37.751
after their studies
are complete?

01:49:37.751 --> 01:49:39.042
Let's extend our example.

01:49:39.042 --> 01:49:40.709
Let's imagine the
third researcher

01:49:40.709 --> 01:49:42.751
Quinn wants to study
alcohol usage

01:49:42.751 --> 01:49:44.417
patterns during the
COVID-19 pandemic,

01:49:44.417 --> 01:49:46.417
comparing them with
pre pandemic studies.

01:49:46.417 --> 01:49:48.292
Now, if Quinn could combine data

01:49:48.292 --> 01:49:50.125
from Alex and Blake studies,

01:49:50.125 --> 01:49:52.125
the cohort would be much bigger.

01:49:52.125 --> 01:49:54.834
Unfortun that's not possible
without a lot of

01:49:54.834 --> 01:49:57.125
work or maybe not
possible at all.

01:49:57.125 --> 01:49:59.125
Why? Because Alex
and Blake collected

01:49:59.125 --> 01:50:00.792
their data in different ways.

01:50:00.792 --> 01:50:01.792
In other words,

01:50:01.792 --> 01:50:03.459
they use different
data elements.

01:50:05.999 --> 01:50:07.584
What if Alex and
Blake both used the

01:50:07.584 --> 01:50:09.584
same data element
to collect collect

01:50:09.584 --> 01:50:11.083
information about
alcohol consumption?

01:50:11.083 --> 01:50:12.250
What if they collected

01:50:12.250 --> 01:50:13.709
that data the same way?

01:50:13.709 --> 01:50:16.125
For example by asking
for the number

01:50:16.125 --> 01:50:18.334
of drinks consumed
in a typical week?

01:50:18.334 --> 01:50:20.334
That would be a
common data element,

01:50:20.334 --> 01:50:22.000
common to both their studies.

01:50:22.000 --> 01:50:22.792
In other words,

01:50:22.792 --> 01:50:24.417
common data elements or CDEs are

01:50:24.417 --> 01:50:26.125
data elements that are reused

01:50:26.125 --> 01:50:27.501
in multiple research projects.

01:50:29.751 --> 01:50:31.125
Here's the definition of CDEs

01:50:31.125 --> 01:50:32.584
from a recent request for

01:50:32.584 --> 01:50:34.250
information issued
by NLM & NINDS.

01:50:34.250 --> 01:50:36.501
Won't read the whole
thing out loud,

01:50:36.501 --> 01:50:38.834
but I do want to highlight that

01:50:38.834 --> 01:50:41.459
CDEs must be precisely defined.

01:50:41.459 --> 01:50:43.000
They must be used systematically

01:50:43.000 --> 01:50:44.542
in multiple studies or otherwise

01:50:44.542 --> 01:50:47.042
they're just data elements.

01:50:47.042 --> 01:50:48.999
And the goal here is consistent

01:50:48.999 --> 01:50:50.167

data collection to ensure

01:50:50.167 --> 01:50:52.000
interoperability
of research data.

01:50:54.626 --> 01:50:56.501
Now I'm going to
talk a bit about

01:50:56.501 --> 01:50:57.999
CDE adoption at NIH and NLM.

01:51:00.501 --> 01:51:02.501
So Doctor Florence
already showed us

01:51:02.501 --> 01:51:04.792
this great resource
NIH Reporter.

01:51:04.792 --> 01:51:06.626
This is a sample
funding announcement

01:51:06.626 --> 01:51:08.250
from Reporter that
mentions common

01:51:08.250 --> 01:51:10.167
data elements. NIH funded

01:51:10.167 --> 01:51:11.709
researchers are
sometimes encouraged,

01:51:11.709 --> 01:51:14.042
recommended or
required to use common

01:51:14.042 --> 01:51:16.709
data elements in their
in their studies.

01:51:16.709 --> 01:51:19.000
Now as we saw in the example,

01:51:19.000 --> 01:51:21.125
using common data
elements doesn't have to

01:51:21.125 --> 01:51:22.999
significantly change
an individual study,

01:51:22.999 --> 01:51:25.417
but it does expand the research

01:51:25.417 --> 01:51:26.250
possibilities downstream.

01:51:26.250 --> 01:51:28.501
What I mean by
that is that other

01:51:28.501 --> 01:51:29.999
researchers can more easily

01:51:29.999 --> 01:51:31.834
combine data from
previous studies.

01:51:31.834 --> 01:51:34.250
Aggregating data
in this way allows

01:51:34.250 --> 01:51:36.834
for comparison and
analysis of a larger

01:51:36.834 --> 01:51:38.834
set of data from
a larger cohort,

01:51:38.834 --> 01:51:40.000
increasing statistical power.

01:51:40.000 --> 01:51:42.250
Meta analyses and
systematic reviews would

01:51:42.250 --> 01:51:44.834
be simplified if the
studies being compared.

01:51:44.834 --> 01:51:46.209
Used common data elements.

01:51:48.999 --> 01:51:50.334
NIH recognizes the importance of

01:51:50.334 --> 01:51:52.083
common data elements
and, has written

01:51:52.083 --> 01:51:54.292
CDEs into the strategic plan for

01:51:54.292 --> 01:51:56.501
data science is shown
in this quote.

01:51:56.501 --> 01:51:57.999
And this little graph here

01:51:57.999 --> 01:51:59.292
shows the increase in mentions

01:51:59.292 --> 01:52:00.792
of common data
elements in PubMed

01:52:00.792 --> 01:52:02.417
It's still a low overall number

01:52:02.417 --> 01:52:03.999
relative to the full collection,

01:52:03.999 --> 01:52:06.626
but the trend is obvious.

01:52:06.626 --> 01:52:08.083
And looking beyond
clinical research

01:52:08.083 --> 01:52:10.000
if CDEs are aligned with patient

01:52:10.000 --> 01:52:11.999
registries and electronic
health records.

01:52:11.999 --> 01:52:13.292
There's potential to leverage

01:52:13.292 --> 01:52:15.292
large amounts of
real world data.

01:52:17.751 --> 01:52:19.999
So what is NLM's role with CDE?

01:52:19.999 --> 01:52:20.834
NLM supports research,

01:52:20.834 --> 01:52:22.751
data sharing and
health data standards,

01:52:22.751 --> 01:52:25.209
so it's natural
for it to support

01:52:25.209 --> 01:52:27.709
CDE's which are a
type of standard.

01:52:27.709 --> 01:52:29.542
The NLM strategic
plan, a quote from

01:52:29.542 --> 01:52:31.459
which is here on this slide,

01:52:31.459 --> 01:52:33.375
includes an objective to

01:52:33.375 --> 01:52:35.292
connect our digital resources.

01:52:35.292 --> 01:52:37.375
The strategic plan
also emphasizes

01:52:37.375 --> 01:52:39.834
that data should
be fair, findable,

01:52:39.834 --> 01:52:40.667
accessible, interoperable,

01:52:40.667 --> 01:52:41.459
and reusable.

01:52:41.459 --> 01:52:44.375
Use of CDEs supports
the fair principles,

01:52:44.375 --> 01:52:46.417
allowing seamless
exchange and reuse.

01:52:49.999 --> 01:52:52.250
Over the last 10 or more years,

01:52:52.250 --> 01:52:53.542
there's been growing interest

01:52:53.542 --> 01:52:55.834
in and adoption of CDEs at NIH.

01:52:55.834 --> 01:52:57.999
Several trans NIH CDE efforts

01:52:57.999 --> 01:52:59.626
are centered at NLM.

01:52:59.626 --> 01:53:03.083
NLM hosts and maintains
the CDE repository.

01:53:03.083 --> 01:53:06.167
NLM hosts the NIH
CDC task force.

01:53:06.167 --> 01:53:07.667
And NLM recently convened

01:53:07.667 --> 01:53:09.125
the new NIH CDE Governance

01:53:09.125 --> 01:53:10.999
Committee and I'm going to talk

01:53:10.999 --> 01:53:12.501
about each of those briefly.

01:53:15.209 --> 01:53:18.167
So in alignment with
our role as a library,

01:53:18.167 --> 01:53:20.999
NLM aims to make
CDEs accessible to

01:53:20.999 --> 01:53:23.667
NIH researchers in the
NIH CDE repository.

01:53:23.667 --> 01:53:25.042
The mission is on the screen.

01:53:25.042 --> 01:53:26.626
I won't read it out loud,

01:53:26.626 --> 01:53:28.501
but I will highlight
some key points.

01:53:28.501 --> 01:53:30.542
We provide access to CDEs.

01:53:30.542 --> 01:53:32.709
The CDEs should
be recommended or

01:53:32.709 --> 01:53:35.292
required by an NIH
body and our target

01:53:35.292 --> 01:53:37.667
audience or end users
are researchers.

01:53:37.667 --> 01:53:39.751
NIH funded researchers
to be specific.

01:53:44.459 --> 01:53:47.125
For about the last
five years or so,

01:53:47.125 --> 01:53:48.751
NLM has hosted the

01:53:48.751 --> 01:53:50.417
trans NIH CDE task Force,

01:53:50.417 --> 01:53:52.417
which has at least
one representative

01:53:52.417 --> 01:53:54.417
from every NIH IC.
Until recently,

01:53:54.417 --> 01:53:56.417
it's been basically
a community of

01:53:56.417 --> 01:53:58.417
practice with topics
like COVID CDEs,

01:53:58.417 --> 01:54:00.542
CDs for sex and
gender, behavioral,

01:54:00.542 --> 01:54:03.125
and social science
research data standards.

01:54:03.125 --> 01:54:04.083
But more recently,

01:54:04.083 --> 01:54:06.334
the Task Force has
begun taking steps

01:54:06.334 --> 01:54:08.083
to actively promote CDEs at NIH.

01:54:10.292 --> 01:54:12.125
For instance, Doctor
Brennan recently

01:54:12.125 --> 01:54:13.999
convened NIH CDE
Governance Committee,

01:54:13.999 --> 01:54:17.626
which is a subgroup of
the NIH CDE Task Force.

01:54:17.626 --> 01:54:19.501
The committee, which has about

01:54:19.501 --> 01:54:21.334
10 members from across NIH,

01:54:21.334 --> 01:54:22.792
is charged with deciding

01:54:22.792 --> 01:54:25.000
whether CDEs submitted to them

01:54:25.000 --> 01:54:26.459
meet criteria that merit

01:54:26.459 --> 01:54:27.999
their designation as NIH

01:54:27.999 --> 01:54:30.042
endorsed. The NIH
endorsed CDEs will

01:54:30.042 --> 01:54:32.375
be published in the
CDE repository.

01:54:36.417 --> 01:54:38.584
And now to talk about

01:54:38.584 --> 01:54:39.999
COVID-19 CDEs specifically.

01:54:42.375 --> 01:54:44.000
Alright, as the
previous presenters

01:54:44.000 --> 01:54:45.626
have described in great detail,

01:54:45.626 --> 01:54:47.292
there's multiple covid
initiatives that

01:54:47.292 --> 01:54:49.542
have sprung up over
the past year.

01:54:49.542 --> 01:54:51.167
We've heard about RADx and PASC.

01:54:51.167 --> 01:54:52.501
There's also Project 5,

01:54:52.501 --> 01:54:53.792
the Phoenix Covid collection,

01:54:53.792 --> 01:54:56.626
Pediatrics, maternal
health, and more.

01:54:56.626 --> 01:54:59.292
As SARS-CoV-2 and
COVID-19 emerged

01:54:59.292 --> 01:55:01.083

in late 2019, researchers around

01:55:01.083 --> 01:55:02.792
the world began planning study.

01:55:02.792 --> 01:55:05.000
Now, in 2021, new
research questions

01:55:05.000 --> 01:55:07.292
continue to emerge
as vaccines become

01:55:07.292 --> 01:55:09.501
available and as we learn about

01:55:09.501 --> 01:55:11.792
long term effects
of the disease.

01:55:11.792 --> 01:55:12.792
So, as we've shown,

01:55:12.792 --> 01:55:14.375
if researchers use CDEs in

01:55:14.375 --> 01:55:15.501
their investigation,

01:55:15.501 --> 01:55:17.375
if they ask questions
and collect

01:55:17.375 --> 01:55:18.999
responses in a standardized way,

01:55:18.999 --> 01:55:21.000
the data they collect can be

01:55:21.000 --> 01:55:22.834
combined and compared with data

01:55:22.834 --> 01:55:24.334
from other COVID-19 studies.

01:55:24.334 --> 01:55:26.334
Reuse of CDEs and
interoperability

01:55:26.334 --> 01:55:27.999
of data accelerates our

01:55:27.999 --> 01:55:29.250
understanding of this disease.

01:55:33.125 --> 01:55:35.000
So each of these

covid working groups

01:55:35.000 --> 01:55:36.999
at NIH has made
significant efforts

01:55:36.999 --> 01:55:39.125
to identify CDEs for
these grantees.

01:55:39.125 --> 01:55:41.999
Earlier, we saw the
RADx tier one CDEs

01:55:41.999 --> 01:55:45.083
which are required
for their grantees.

01:55:45.083 --> 01:55:46.667
To ensure that at least some

01:55:46.667 --> 01:55:48.250
of these common data elements

01:55:48.250 --> 01:55:49.999
are common across initiatives,

01:55:49.999 --> 01:55:52.584
NLM has taken a few action.

01:55:52.584 --> 01:55:55.501
So first NLM has
convened a covid

01:55:55.501 --> 01:55:57.209
CDE coordination Committee which

01:55:57.209 --> 01:55:59.792
meets BI Weekly to ensure that

01:55:59.792 --> 01:56:01.584
the different initiatives are

01:56:01.584 --> 01:56:03.709
informed of each
others progress.

01:56:03.709 --> 01:56:05.125
NLM is creating a so-called

01:56:05.125 --> 01:56:07.375
staging area and CDE repository

01:56:07.375 --> 01:56:09.167
where NIH staff will be able to

01:56:09.167 --> 01:56:11.042

view other CDEs in
development before

01:56:11.042 --> 01:56:13.125
they're published
so they can align

01:56:13.125 --> 01:56:15.999
their own efforts with those.

01:56:15.999 --> 01:56:16.999
And then Lastly,

01:56:16.999 --> 01:56:18.709
there's an expectation
that these

01:56:18.709 --> 01:56:20.459
covid working groups will submit

01:56:20.459 --> 01:56:22.083
their CDEs to the Governance

01:56:22.083 --> 01:56:23.999
Committee to earn
NIH endorsement,

01:56:23.999 --> 01:56:27.626
and publication in the
NIH CDE repository.

01:56:27.626 --> 01:56:29.125
So as you can see,

01:56:29.125 --> 01:56:31.125
the challenges that
we face are not

01:56:31.125 --> 01:56:33.083
just technical but
also policy related.

01:56:33.083 --> 01:56:35.417
There's a huge amount
of coordination

01:56:35.417 --> 01:56:36.999
and communications
required for success.

01:56:36.999 --> 01:56:38.834
But the reward for
this coordination

01:56:38.834 --> 01:56:40.626
effort is not only accelerated

01:56:40.626 --> 01:56:42.542
understanding of covid because

01:56:42.542 --> 01:56:44.459
lessons learned and
infrastructure

01:56:44.459 --> 01:56:46.501
created now for
Covid will support

01:56:46.501 --> 01:56:48.375
future trans NIH
efforts to combat

01:56:48.375 --> 01:56:50.209
other diseases and explore new

01:56:50.209 --> 01:56:51.667
areas of biomedical research.

01:56:51.667 --> 01:56:52.626
So thank you.

01:56:52.626 --> 01:56:54.250
Here is my contact information

01:56:54.250 --> 01:56:56.542
and please feel
free to reach out

01:56:56.542 --> 01:56:57.792
at anytime with questions.

01:57:00.459 --> 01:57:02.584
Thank you again for joining

01:57:02.584 --> 01:57:04.250
us for this session,

01:57:04.250 --> 01:57:06.083
providing some
insight, and frankly,

01:57:06.083 --> 01:57:08.999
points of pride for
NLM's contributions

01:57:08.999 --> 01:57:10.999
to advancing the
fight against the

01:57:10.999 --> 01:57:13.083
COVID-19 pandemic.
At last year's

01:57:13.083 --> 01:57:16.000

MLA the NLM update
theme was resilience,

01:57:16.000 --> 01:57:18.125
relevance, and
reinvention. This year,

01:57:18.125 --> 01:57:20.542
NLM is highlighting and

01:57:20.542 --> 01:57:23.167
exploring how over a year later,

01:57:23.167 --> 01:57:26.501
we're turning to
a new set of Rs,

01:57:26.501 --> 01:57:28.626
reflect, reimagine,
and re energize.

01:57:28.626 --> 01:57:31.167
We're certainly
doing that at NLM.

01:57:31.167 --> 01:57:33.626
On Covid response and
across our collections,

01:57:33.626 --> 01:57:35.042
programs, products and services,

01:57:35.042 --> 01:57:38.417
We hope that you join
us in doing the same.