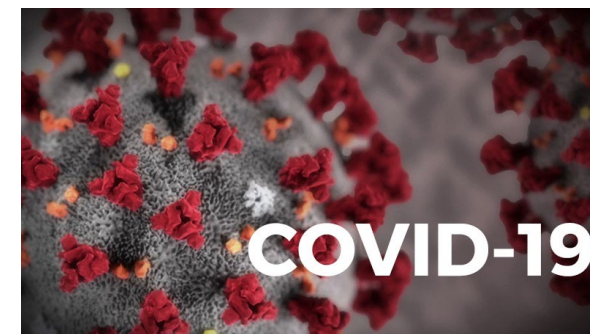


ADRC Response to COVID crisis...

**GREG JICHA ON BEHALF OF
THE CLINICAL CORE
STEERING COMMITTEE**

COVID crisis: ADRC response



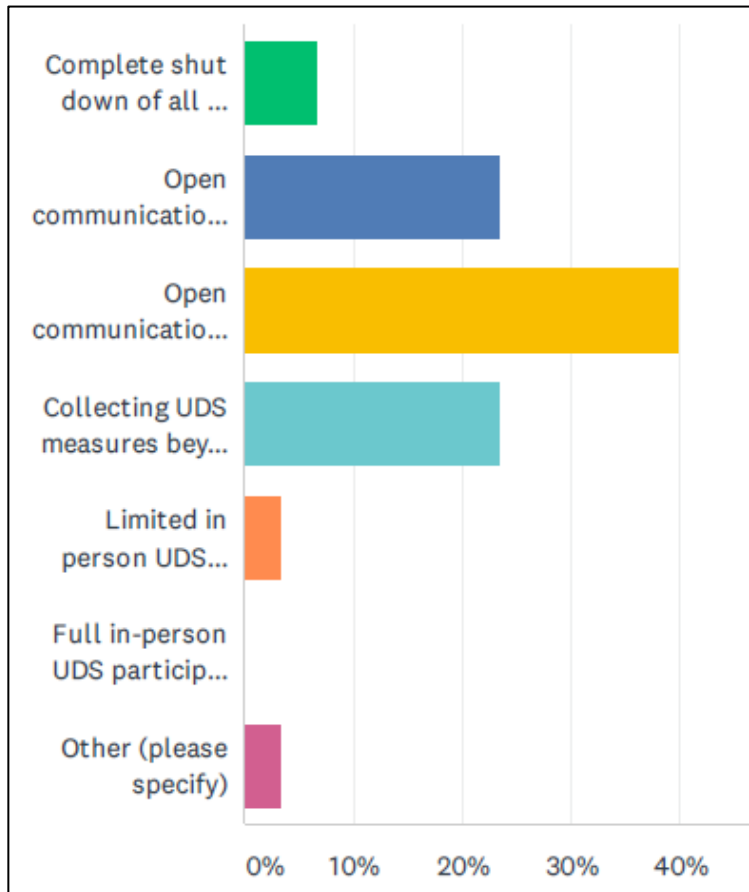
SURVEY RESPONSES	ADRC MEETING	SHORT-TERM SOLUTIONS	BACK TO WORK?
Where are we now?	And now?	Work to create interim solutions	How we use this to create the future of UDS 4.0
Individual site reactions and responses	Exploring flexible yet uniform processes	Creating a flexible uniform process focused on remote assessment	Possible creating a flexible uniform assessment that can embrace both remote and traditional visits

Survey Results from ADRCs 4/7/20

- 30/31 centers responded
- Wide range of responses with some centers completely shut down and others engaging at some levels
- Debate on whether we should have a uniform or site-specific approach?
- Debate on what modalities of remote monitoring of subjects are ready or not-ready for prime time?



Current status of ADRCs...

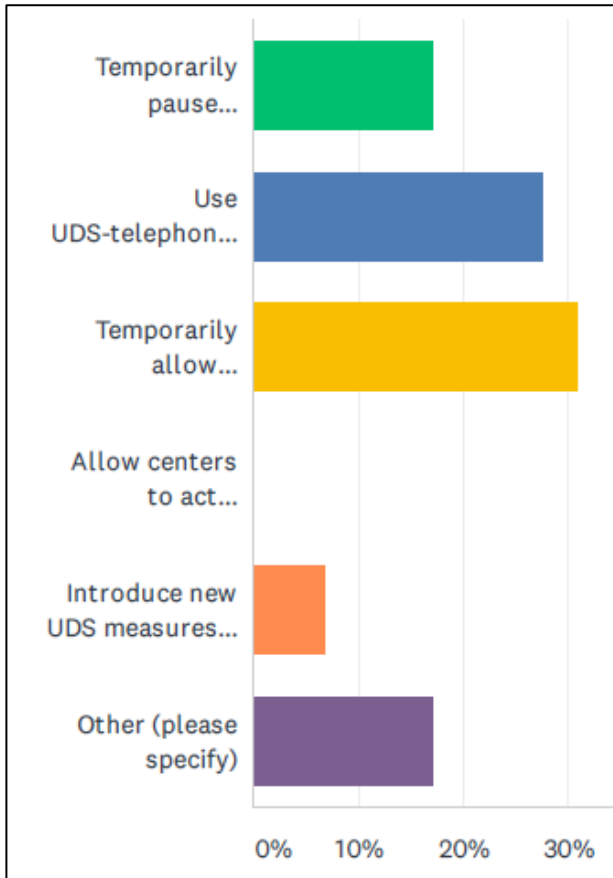


- **0% of sites continue to collect full UDS data through traditional face to face methods**
 - This is common ground
- **30% of sites completely shut down for UDS data collection**
 - 1/3 ADRCs cannot conduct research operations at all
- **40% of sites using UDS 3.0 Telephone packet**
 - Allows maintenance of standard data collection procedures
- **23% of sites collecting UDS 3.0 data using non-traditional modality approaches**
 - May call into question the validity of such approaches
- **Limited UDS engagement with face to face evaluations in only 3.3% sites**
 - This is the exception rather than the case, and while we applaud the effort we need to find a better way to function together

There is a general consensus that...

- This crisis and our ability to conduct traditional UDS in person visits will be delayed by more than 3 months and possibly 6 months or more
- Biomarker collections are almost completely shut down, with the exception of 24% sites that are collecting only if safety measures require such collection
- 83% of sites allow visit windows up to the NACC limit of +/- 6 months with only 10% of sites allowing less than 3-month windows
- 62% of sites are going to have trouble meeting NACC visit windows within the next 3 months
- 100% ADRC staff are working from home, but 14% have been redeployed preventing work on ADRC initiatives

Areas where there is less than consensus? What approach to use?



17% of ADRCs recommend pausing until we can restart with traditional evaluations

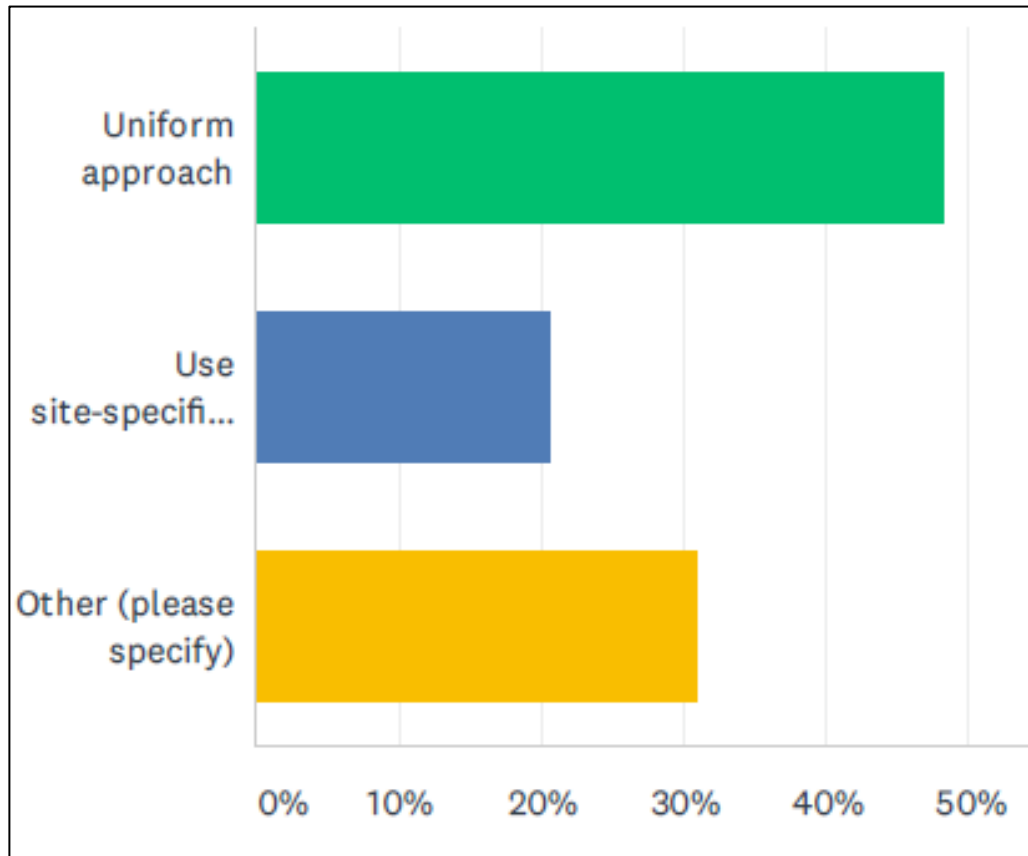
28% of ADRCs favor using the NACC-approved current telephone visit follow-up packet

31% favor ADRCs using site flexibility in gathering standard UDS 3.0 measures

0% favor allowing sites to independently do whatever they want to do

7% favor introducing new remote UDS measures that allow remote assessment

Should we do this together, or do our specific situations require a non-uniform approach?

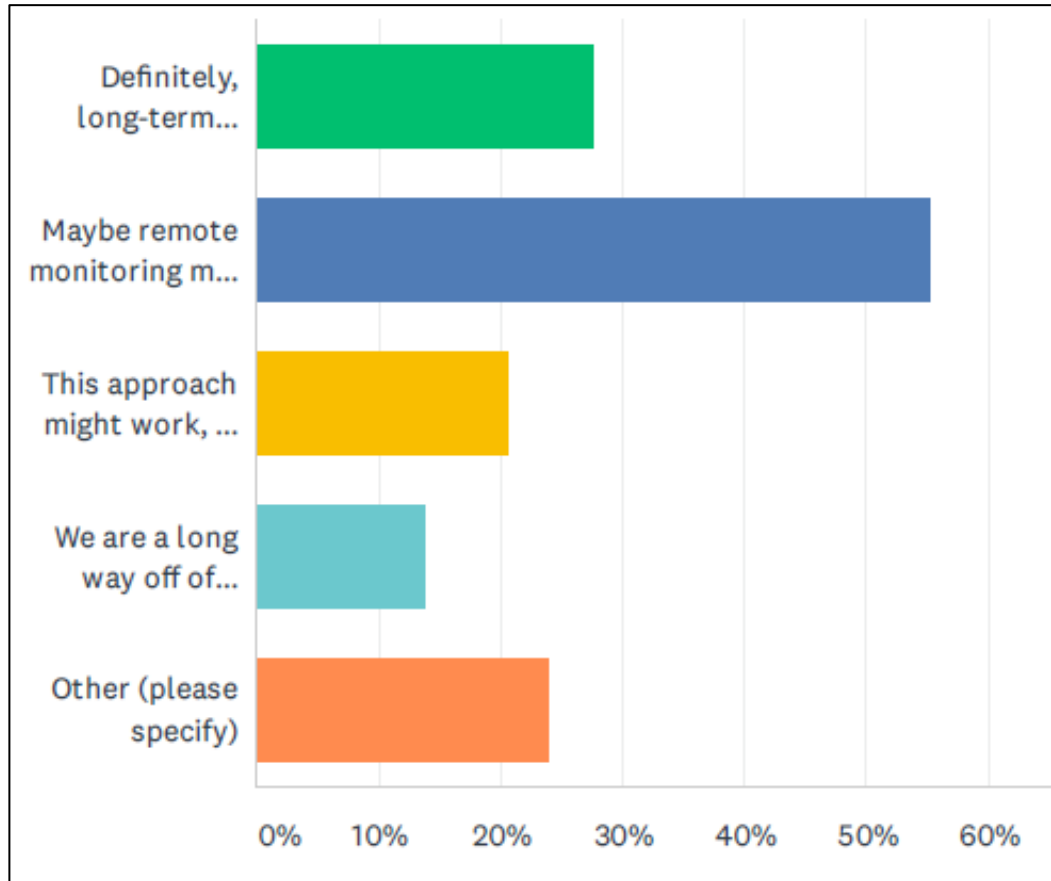


Only 48% of centers favor adopting a uniform approach to UDS data collection during the COVID crisis

21% of sites favor site specific approaches

A large number of sites (31%) deferred to the answer “other”, primarily suggesting a mixed approach

Consideration of remote monitoring of our research participants?



28% recommend remote monitoring be a long-term solution now

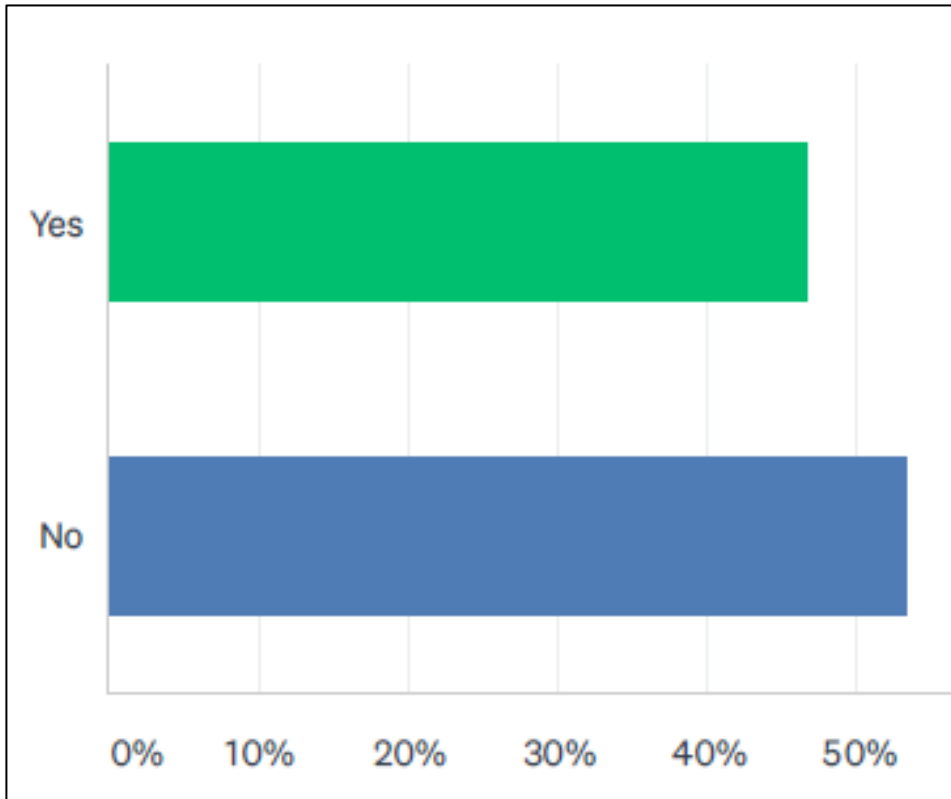
55% think we need more data

21% think it may work, but will detract from the work we are doing

14% think we are a long way off and would avoid contamination of NACC data with such approaches at present

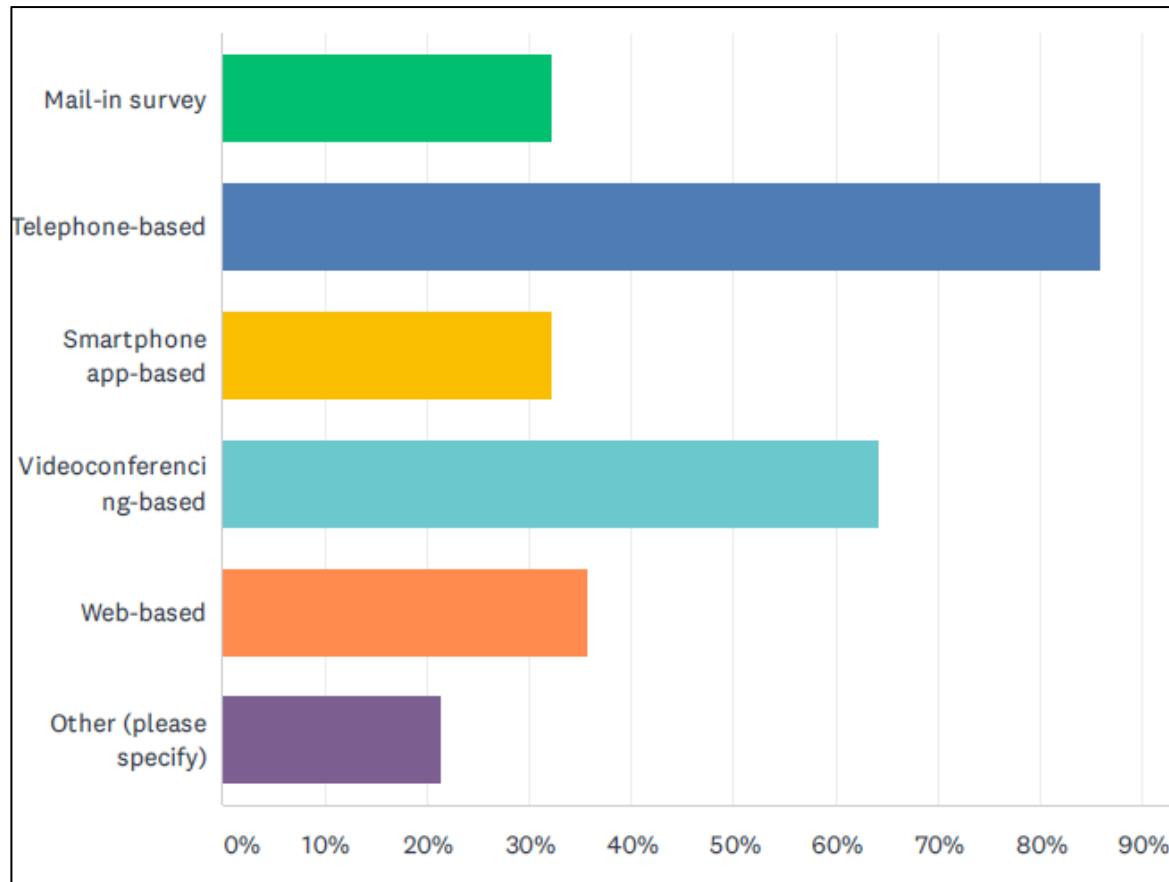
**And yet we have a
wealth of experience
to bare...**

Sites collecting data remotely for non-UDS NACC projects



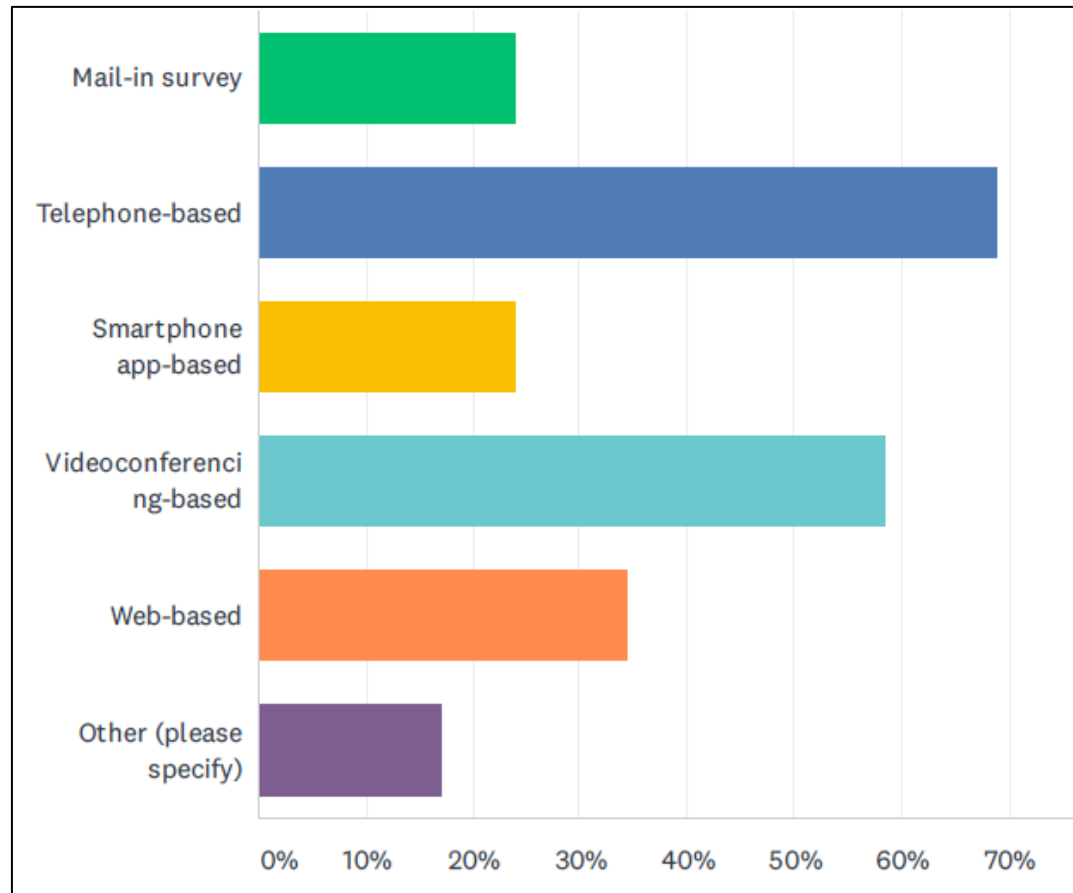
- Nearly ½ of ADRCs are already using remote data collection for affiliated studies
- This brings a wealth of experience and active engagement to bear!

What modalities (current/past) have ADRCs use for remote data collection?



- 32% have used mail in surveys
- 86% ADRCS have used telephone assessments
- 32% have used smartphone apps
- 64 % have used telemedicine/video methods
- 36% have used web-based methods

What modalities do you favor for future use by ADRCs for remote data collection?



➤ 24% favor mail in surveys

➤ 69% favor telephone assessments

➤ 24% favor smartphone apps

➤ 59 % favor telemedicine/video methods

➤ 34% favor web-based methods

Comments on challenges?

- ✓ This a difficult time and we should proceed with caution- there are many opportunities in this time of crisis and we need to consider all the contingencies, including accessibility, inclusivity, feasibility and the impact on legacy data as we embrace the technological advances available to us.
- ✓ Let's take advantage of this difficult time to develop some tools that may be helpful in the future, while doing our best to preserve the integrity of the data we have worked so hard to collect over the years.
- ✓ The implications for remote assessment in terms of reaching out to new populations (e.g. states without ADCs, underserved populations (e.g. rural), are profound.
- ✓ Consider this the "wave of the future" and a unique opportunity to innovate.

Comments reflecting ADRC “spirit”

- ✓ A shared plan across Centers will be important.
- ✓ Happy to pilot anything the team needs!
- ✓ This survey is especially thoughtful and well done!
- ✓ Everyone, please stay safe and healthy!

What is the take-home message and where should we focus our conversation?

12:30 CTF Cognitive Working Group update: Andrew Saykin, PsyD & Lisa Barnes, PhD

- Recommendation for a remote telephone-based cognitive assessment using UDS 3.0 and similar methods

12:50 CTF Clinical Measures & Diagnosis Working group update: Cindy Carlsson, MD

- Recommendations for potential modification of non-cognitive components of the UDS 3.0

1:00 Telephonebased data collection: Suzanne Craft, PhD

- Stanford, Wake, Unknown, UCDavis, Rush

1:10 Telemedicine/ video-based data collection: Mary Sano, PhD

- UK, OHSU, Emory,

1:20 App-based data collection: Rhoda Au

- Unknown, WashU, Northwestern,

1:30 Web-based data collection: Jeff Kaye, MD

- Northwestern, OHSU

1:40 Open discussion

Understand current recommendations
Understand our expertise across a wide range of possibilities