

All of Us Research Program

Update on *All of Us*'s Tribal Engagement Activities



National Institutes
of Health

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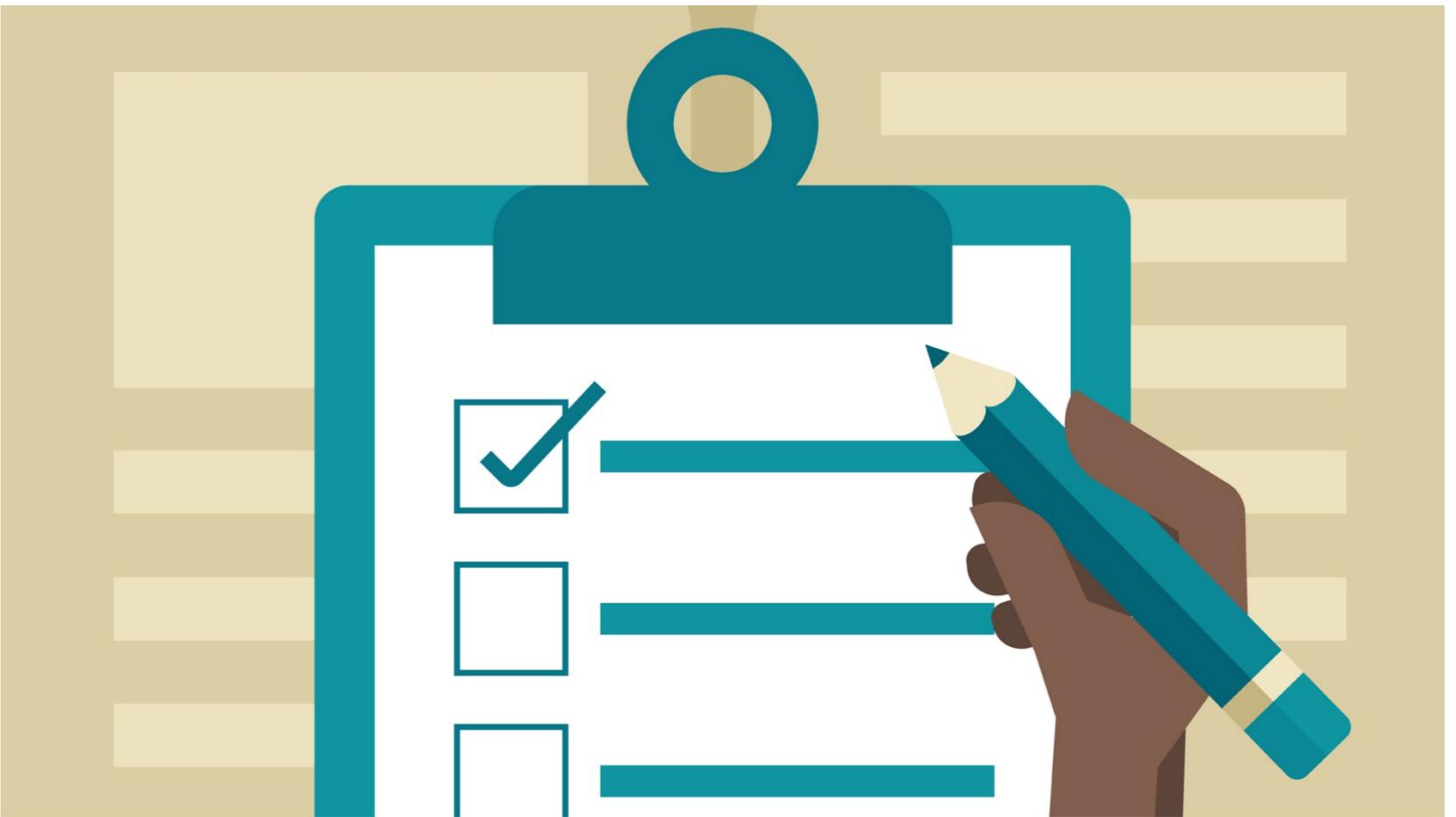
#JoinAllofUs

Goals for today's session

- Provide an update on *All of Us*'s tribal engagement activities

- Respond to questions received from TAC

- Request your help to plan an impactful consultation
 - Ask for advice with agenda, questions, and logistics
 - Ask for help with disseminating to your communities



Updates

A recap of where we are...

- Finalized the **Tribal Collaboration Working Group (TCWG) Report** –*April*
- Requested **listening sessions** with tribal organizations – *March to June*
- **Posted the TCWG Report** on the *All of Us* website – *August*
- **Plan Consultation** – *ongoing*



Follow-up on August TAC call

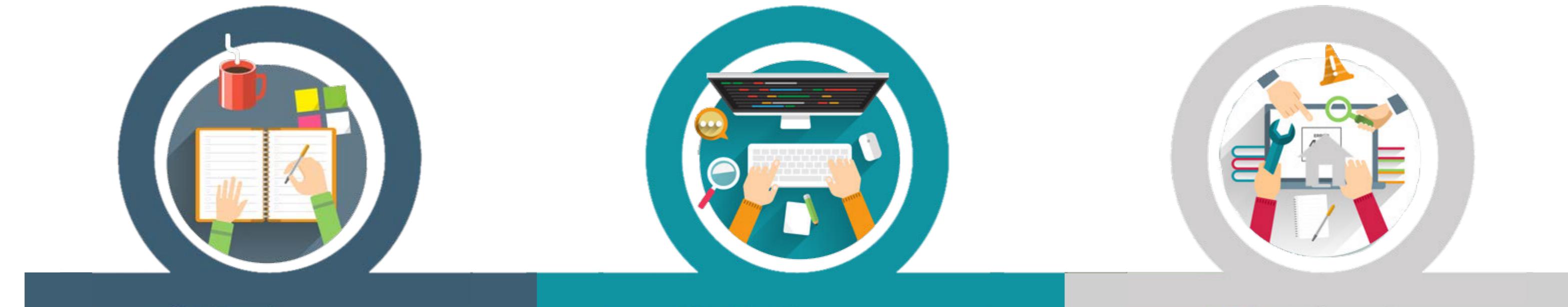
- After Chief Malerba presented to TAC in August, we were asked about our plans regarding the TCWG input.
- We are planning to:
 - Add one **tribal representative to the *All of Us***
 - On all other input, the *All of Us* senior leadership will **evaluate and prioritize after consultation**, when we will have had a chance to get a totality of recommendations from tribal leaders.



Our engagement plan has always been to allow the TCWG report to inform consultation.

Next Steps

Consultation plans



PARTNERSHIP & PLANNING

- Ask NIH Tribal Advisory Committee for support.
- In partnership with TAC and David Wilson's office (THRO), identify appropriate timing and venue.
- Plan consultation, including agenda and questions in collaboration with TAC & THRO.

DISSEMINATION

- Draft and send Dear Tribal Leader Letter & Framing Letter.
- Publish Consultation information in the Federal Register.
- Promote the opportunity via tribal organizations & TAC contacts.

CONSULTATION

- Hold one-day in-person Consultation with tribal leaders.
- Following the Consultation, host a multi-hour webinar with tribal leaders for further input.
- Following the webinar, release an RFI – to be open for 30 days – for additional input from tribal communities.

This plan was developed based on guidance from Dr. Wilson and we welcome your advice & feedback.

Potential agenda for consultation

Time	Topic	Presenter/Facilitator
9:00 - 9:15 am	Opening Blessing	Tribal Leader
9:15 - 9:30 am	Welcome and Introductions <ul style="list-style-type: none">• Opening Remarks• Introductions• Consultation Procedures	NIH or <i>All of Us</i>
9:30 - 10:30 am	Overview of the All of Us Research Program <ul style="list-style-type: none">• Mission and objectives, protocol• Status of the program• <i>All of Us's</i> tribal engagement activities	<i>All of Us</i> Senior Leader
10:30 – 10:45 am	Break	
10:45 – 11:30 am	Tribal Collaboration Working Group Report <ul style="list-style-type: none">• Purpose of the report• Composition of the WG & Process• Highlights from the report	TCWG Co-chairs and Members
11:30 am - 12:30 pm	Panel Discussion with All of Us and TCWG Representatives <ul style="list-style-type: none">• Q&A about <i>All of Us</i> and the TCWG Report	<i>All of Us</i> Senior Leadership and PIs TCWG Co-chairs and Members Tribal Leaders and Participants
12:30 – 1:30 pm	Lunch	
1:30 – 4:30 pm	Perspectives and Recommendations from Participating Tribal Members about the All of Us Research Program	Tribal Leaders and Participants
4:30 – 4:45 pm	Wrap Up and Next Steps	<i>All of Us</i> Senior Leader
4:45 – 5:00 pm	Closing Prayer	Tribal Leader

Potential questions for consultation

- The *All of Us* Research Program recognizes there are many unique considerations when partnering with tribal nations, including tribal sovereignty, cultural beliefs and traditions, and historical trauma. What are the associated challenges and **best practices for biomedical research initiatives?**
- The Tribal Collaboration Working Group report outlines many points for the *All of Us* Research Program to consider around collaboration with tribal nations and communities. Are there specific **points in the report that you strongly support** or that you disagree with?
- How should *All of Us* **collaborate with tribal nations, clinics, and organizations** to enable AI/AN participation in this program? What **initial pilot partnerships** should the program consider?
- What are the **major research questions** that are of most interest to your nation or community?

We welcome your input and feedback on these or additional questions.

Additional areas for your input

- What is the right **timing** for this consultation?

- How can we **make it as inclusive** as possible?
 - Co-locate with a conference (pro: tribal leaders may already be traveling to the event; con: time options more limited)
 - Host a separate event (pro: flexibility in time/place; con: logistical challenges for attendees and organizers)

- If you advise us to partner with a conference, do you have recommendations of the most **appropriate conference**? We've considered...
 - NIHB National Tribal Public Health Summit – Apr 2018
 - NCAI Mid-Year Conference – June 2019
 - AAIP Annual Conference – July 2019



All of Us's plans following consultation



Thank you!
