

# *All of Us* Research Program

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



National Institutes  
of Health

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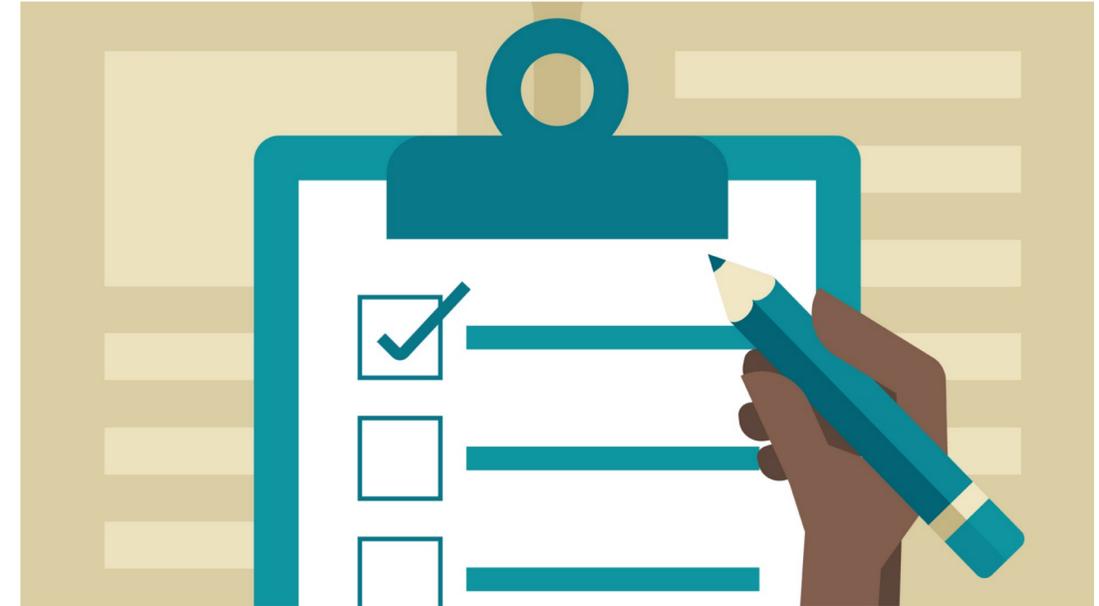


#JoinAllOfUs

# Goals for today's session

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- 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

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## A recap of where we are...

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- ⦿ 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

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- 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* Advisory Panel.**
  - 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.

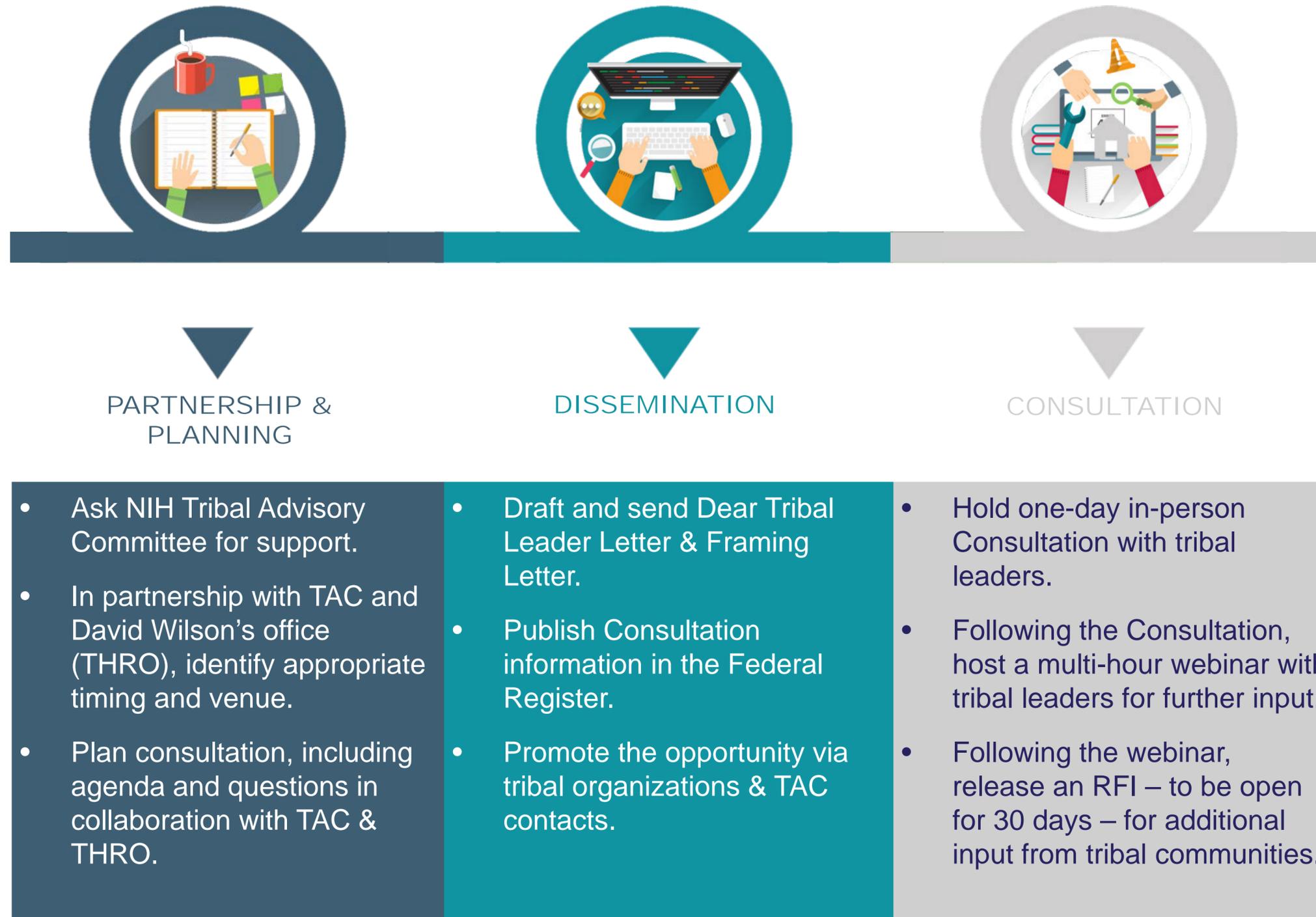


**Our engagement plan has always been to allow the TCWG report to inform consultation.**

# Next Steps

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# Consultation plans



**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	<b>Welcome and Introductions</b> <ul style="list-style-type: none"> <li>• Opening Remarks</li> <li>• Introductions</li> <li>• Consultation Procedures</li> </ul>	NIH or <i>All of Us</i>
9:30 - 10:30 am	<b>Overview of the All of Us Research Program</b> <ul style="list-style-type: none"> <li>• Mission and objectives, protocol</li> <li>• Status of the program</li> <li>• <i>All of Us's</i> tribal engagement activities</li> </ul>	<i>All of Us</i> Senior Leader
10:30 – 10:45 am	Break	
10:45 – 11:30 am	<b>Tribal Collaboration Working Group Report</b> <ul style="list-style-type: none"> <li>• Purpose of the report</li> <li>• Composition of the WG &amp; Process</li> <li>• Highlights from the report</li> </ul>	TCWG Co-chairs and Members
11:30 am - 12:30 pm	<b>Panel Discussion with All of Us and TCWG Representatives</b> <ul style="list-style-type: none"> <li>• Q&amp;A about <i>All of Us</i> and the TCWG Report</li> </ul>	<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	<b>Perspectives and Recommendations from Participating Tribal Members about the <i>All of Us</i> Research Program</b>	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

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- ① 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**?
- ① 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?
- ① 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?
- ① 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

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- ⦿ 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!

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