

# Biomeasure Gaining Cooperation and Informed Consent

---

## The Complexity of Informed Consent

Katie O'Doherty



# Biomeasures collected on various projects

Senses	Body	Activity	BioSamples
<ul style="list-style-type: none"> <li>• Smell</li> <li>• Taste</li> <li>• Touch</li> <li>• Vision</li> <li>• Hearing</li> </ul>	<ul style="list-style-type: none"> <li>• Weight</li> <li>• Waist circumference</li> <li>• Hip circumference</li> <li>• Height</li> <li>• Blood pressure</li> </ul>	<ul style="list-style-type: none"> <li>• Chair stand</li> <li>• 10 foot walk</li> <li>• 6 minute walk</li> <li>• Accelerometer</li> </ul>	<ul style="list-style-type: none"> <li>• Saliva</li> <li>• Blood</li> <li>• Vaginal sample</li> <li>• Urine</li> </ul>

# Outline

01 Interviewer Administered Biomeasures

---

02 Self-Administered Biomeasures

---

03 Health Visit with Phlebotomist

---

04 Refusal Conversion

---



---

# Interviewer Administered Biomeasures

## In-Person Gaining Cooperation & Consent Process

- **Advance materials provide high-level information** about biomeasure collection but do not provide extensive detail.
- **Field interviewer provides additional information at doorstep** to gain cooperation for interview
- **Obtain written informed consent for interview** -- includes overview of biomeasures, risks, benefits, results, confidentiality
- **Place biomeasure collection in middle of interview** to allow interviewer to establish rapport and trust with respondent
- **Verbal consent for individual measures is obtained throughout interview** as part of ongoing consent process - interviewer provides detailed explanation of individual measures at time of collection

## Other considerations



- Provide single incentive for interview
- Individual results to respondents
- Consider respondent burden (overall + measure specific)
- Pretest

## NSHAP in-person biomeasure cooperation rates

Biomeasure	Round 1	Round 2	Round 3
Weight	98%	98%	98%
Waist	97%	98%	97%
Height	99%	98%	99%
BP and Pulse	98%	98%	98%
Balance	--	--	99%
Timed Walk	--	96%	98%
Chair Stands	--	94%	98%
Smell	98%	96%	96%
Saliva	89%	95%	91%
Vaginal Swabs	68%	73%	--
Blood Spots	85%	92%	92%
Accelerometry	--	78%	84%

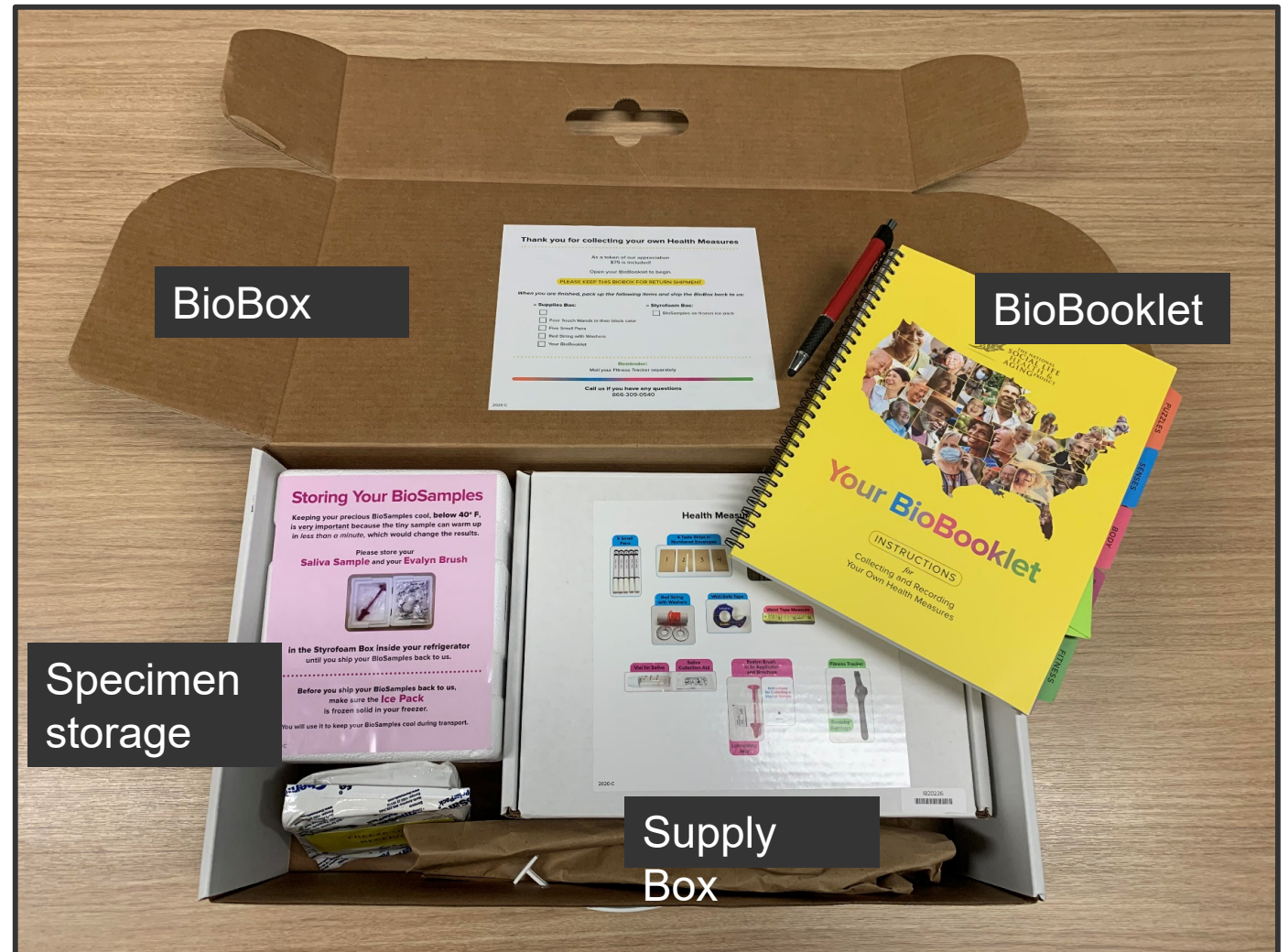
\*Percent agreed of number asked in interview

---

# Self Administered Biomeasures

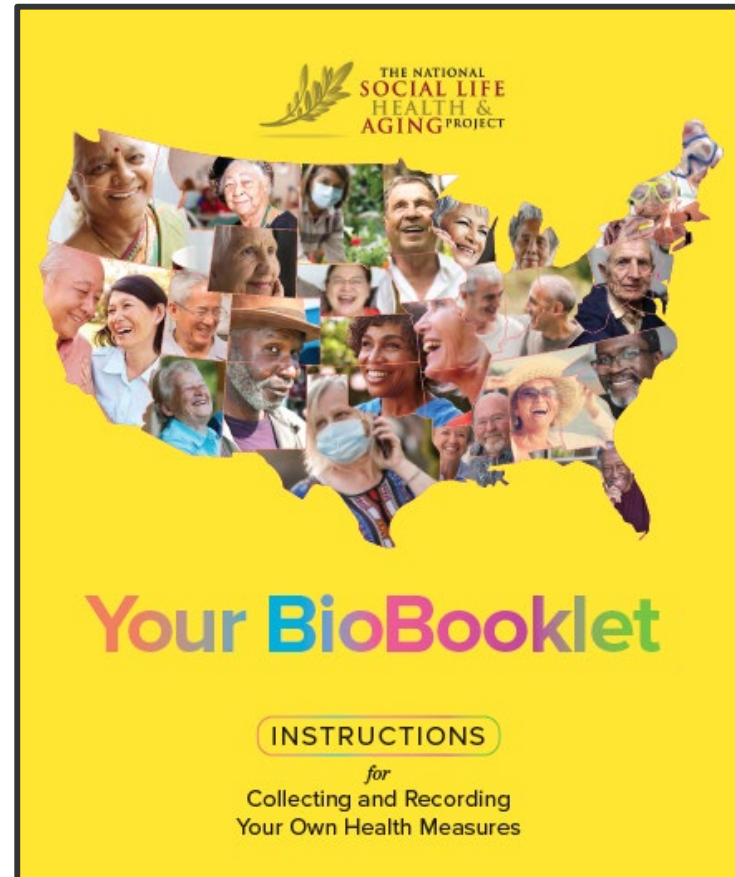







# NSHAP BioBox: Developed self administered measures for remote data collection in Round 4



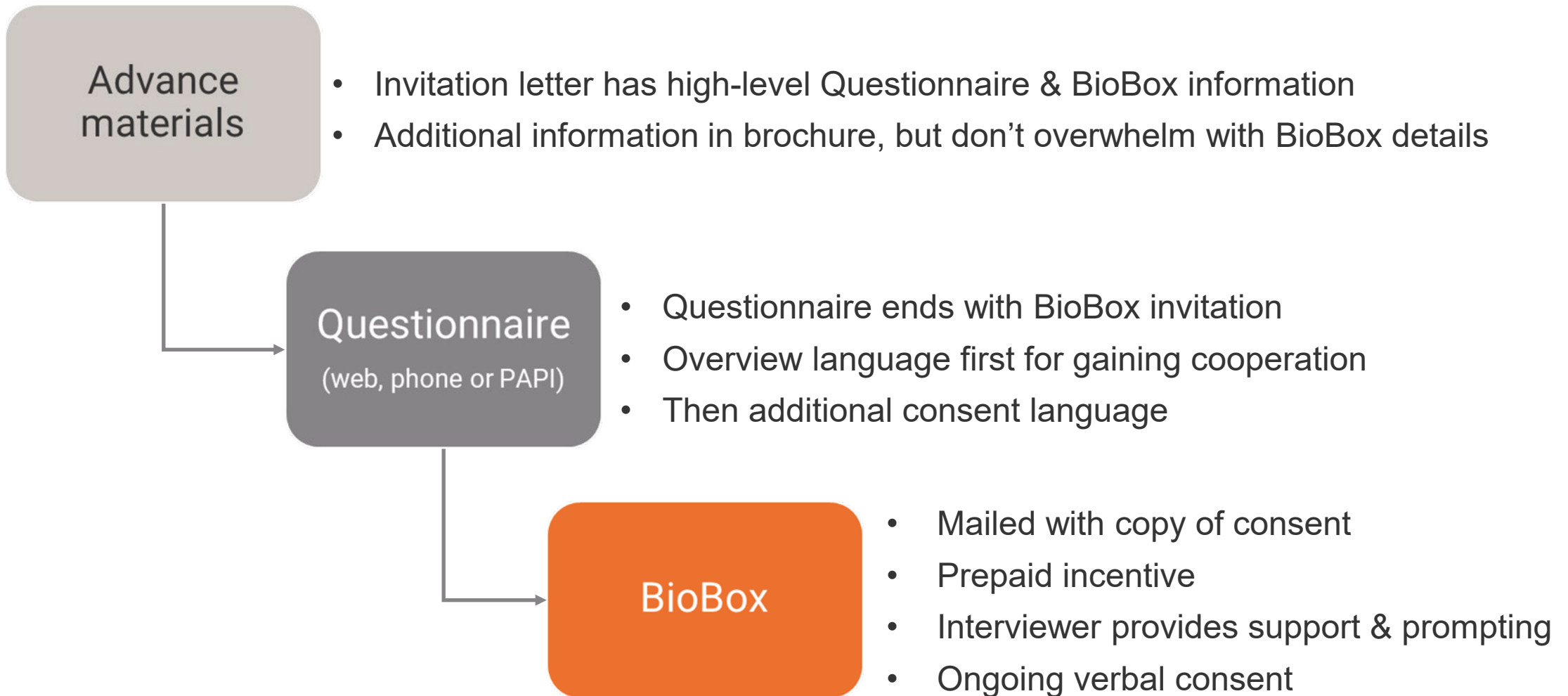
## Design considerations

- Simplify collection instructions
- Organization of supplies and presentation of instruction
- Not all measures were transitioned from in-person to self administered
- Lab pilot and two pretests

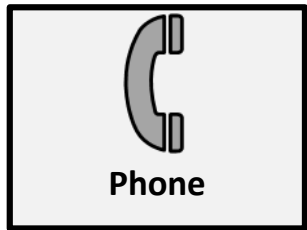


Pen	Smells like...
 1	<input type="checkbox"/> Chamomile <input type="checkbox"/> Raspberry <input type="checkbox"/> Rose <input type="checkbox"/> Cherry
	   

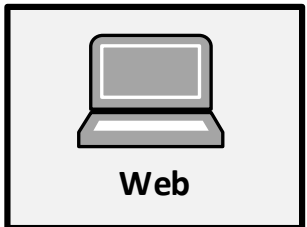
## NSHAP BioBox: Gaining Cooperation & Consent Process



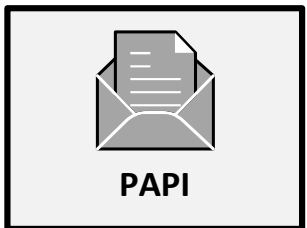
## Tailoring biomeasure consent by remote mode



- Allow interviewers to gain cooperation using talking points in own words and then read consent script verbatim



- Present overview of biomeasure collection on initial screen and then display full consent language



- Formatted brochure with overview of biomeasure collection and then additional consent information



## Example of formatted information in PAPI brochure

**The next part of our interview is the collection of your health measures!**

If you agree to receive a BloBox in the mail, you will get:

- » **\$50 Gift Card**  
in your BloBox
- » **Your health measure results**



So you can learn more about yourself and other U.S. adults over 50!

## NSHAP Pretest Results: BioBox Yield by Box Type (percent returned of number asked)

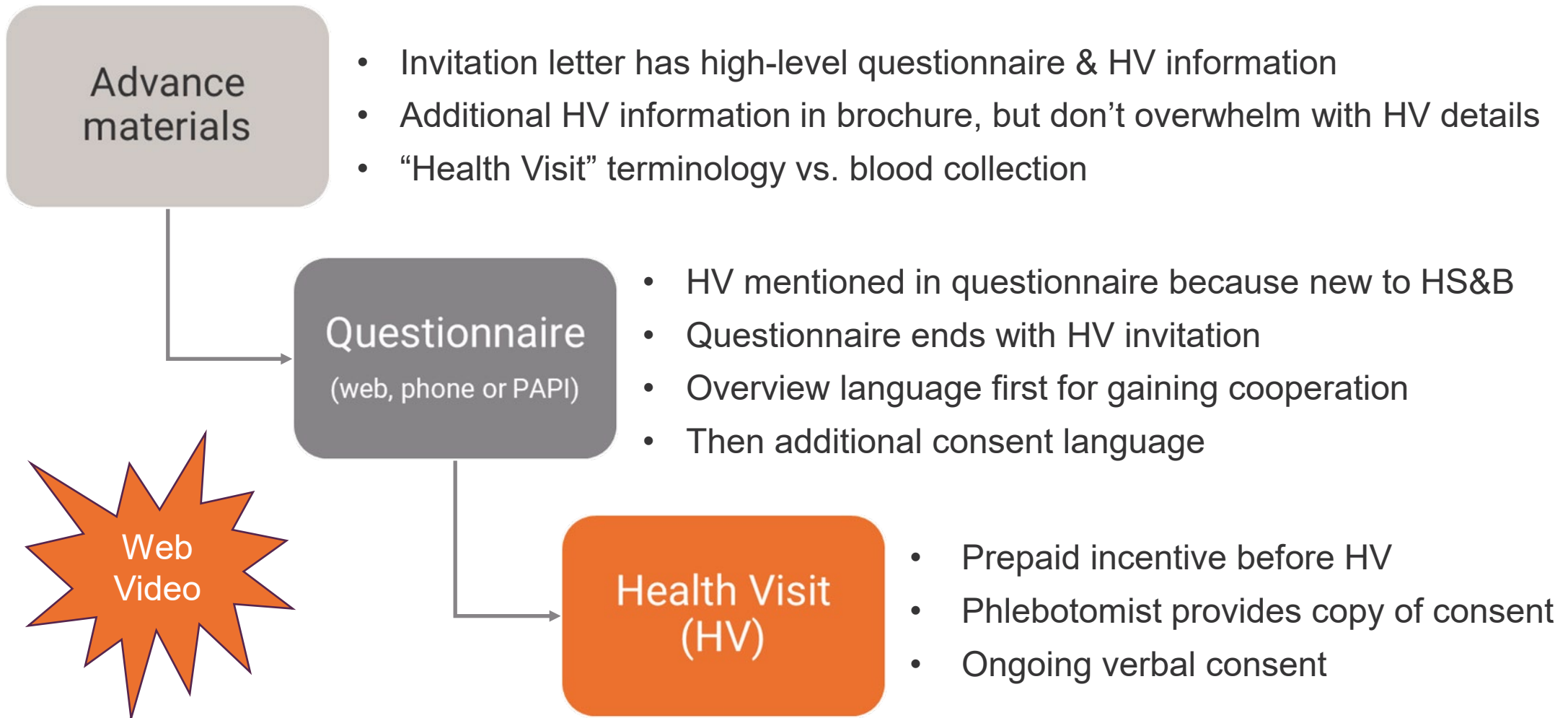
	Blood		No Blood	
	Returned	Asked	Returned	Asked
Short (1 hr) Activity	60%	102	64%	105
Short (1 hr) Biosample	52%	110	57%	94
Long (1 ½ hr) Complete	36%	111	53%	104
Total	49%	323	58%	303

- Based on pretest results, we selected 1 hour version for Round 4
- Data collection for Round 4 is currently in progress

---

# Health Visit with Phlebotomist

## HS&B Health Visit (HV): Gaining Cooperation & Consent Process





---

# Refusal Conversion

## Biomeasure Refusal Conversion for Remote Interviews

- Respondents that initially refused NSHAP BioBox or HS&B Health Visit, are being recontacted about 1 month after remote interview
- Using experienced interviewers to call respondents to revisit biomeasure collection and answer questions
- Offering higher incentive amount
- Both data collection efforts in progress, but preliminary results show we are converting some respondents


- The National Social Life, Health and Aging Project is supported by the National Institute on Aging and the National Institutes of Health (R01AG021487; R37AG030481; R01AG033903; R01AG043538, R01AG048511). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.
- NSHAP is directed by Linda J. Waite, Principal Investigator
- NSHAP Co-Investigators: Kathleen A. Cagney, Benjamin Cornwell, William Dale, Louise Hawkey, Elbert Huang, Megan Huisingh-Sheetz, Diane Lauderdale, Edward Laumann, Martha McClintock, Colm O'Muircheartaigh, Jayant Pinto, and L. Philip Schumm.
- McClintock Survey Biomeasure Laboratory (University of Chicago), Sera Burke (SBDWorks Inc.), and Terri Coughlin (Classic Color Inc.) responsible for BioBooklet design and PAPI Consent Brochure design
- High School & Beyond (HS&B) is supported by the National Institute on Aging and the National Institutes of Health (R01AG058719-01A1). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.
- HS&B is directed by Rob Warren, Principal Investigator
- HS&B Co-Investigators: Eric Grodsky, Jennifer Manly, and Chandra Muller.
- NORC is responsible for data collection design, data collection, and delivery

A top-down view of a meeting around a wooden table. A woman on the left points at a document with a pie chart. A man on the right holds a pen. Another person at the bottom has their hands clasped. Papers with bar and line charts are on the table. A circular logo with a star is on the table.

# Thank you.

**Katie O'Doherty**  
Senior Research Director  
[odoherty-katie@norc.org](mailto:odoherty-katie@norc.org)

---

 Research You Can Trust™

---

 **NORC** at the  
University of  
Chicago