Add Health Biology & Birth Records Projects

Add Health User Conference National Institutes of Health July 23-24, 2018

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Wave V Biology Project

- Types of measures
- Measures & classification
- Field operations
- Results
- Quality control
- Birth records
- Surveillance of chronic disease events





Add Health Choice of Biological Data

- Biological states prevalent in the general young adult population
- Biological states and processes linked to future health
- Measures that can characterize those processes
- Feasible for a large, national, longitudinal field study
- Valid and reliable





TYPES OF MEASURES





Add Health Biological Content Across Waves I–V

Domains	Waves I, II (ages 12–20)	Wave III (ages 18–26)	Wave IV (ages 24–32)	Wave V (ages 32–40)
Anthropometric	\checkmark	\checkmark	\checkmark	\checkmark
Omic	\checkmark	\checkmark	\checkmark	\checkmark
Infectious		\checkmark		
Cardiovascular			\checkmark	\checkmark
Inflammatory/Immune			\checkmark	\checkmark
Metabolic			\checkmark	\checkmark
Neurocognitive			\checkmark	\checkmark
Pharmacoepidemiologic			\checkmark	\checkmark
Renal				\checkmark





MEASURES & CLASSIFICATIONS





Wave V Biomarkers that Approximate Clinical Values

Domains	Measures
REPEAT MEASURES AC	CROSS WAVES
Cardiovascular	systolic BP, diastolic BP, pulse rate
Anthropometric	weight, height, arm & waist circumference
Metabolic	HbA _{1c} , glucose, lipid panel
Inflammatory	high-sensitivity C-reactive protein (hsCRP)
Pharmacologic	prescription medication use & classification
NEW MEASURES	
Kidney function	creatinine, cystatin C

Results returned to respondents: HbA_{1c}, glucose, lipid panel, creatinine





Cardiovascular

- Primary
 - systolic blood pressure (SBP)
 - diastolic blood pressure (DBP)
 - pulse rate (PR)



Heart and Lungs





Cardiovascular

SBP/DBP classified according to ACC/AHA guidelines*

< 120 / 80 mm Hg
 Normal
 120-129 / < 80 mm Hg
 Elevated
 130-139 / 80-89 mm Hg
 ≥ 140 / 90 mm Hg
 Stage 1 Hypertension
 Stage 2 Hypertension

UNC CAROLINA POPULATION CENTER *Whelton PK, et al. 2017 ACC/AHA/AAPA/ABC/ACPM/AGS/APhA/ASH/ASPC/NMA/PCNA Guideline for the Prevention, Detection, Evaluation, and Management of High Blood Pressure in Adults. *Hypertension* 2018;71:1269-1324.



Anthropometric

- Primary
 - weight
 - height
 - waist circumference
- Secondary
 - body mass index (BMI = weight in kg / height in m²)





Underweight

Overweight

Obesity, Stage I

Obesity, Stage II

Obesity, Stage III

Normal

Anthropometric (Classified according to NHLBI Evidence Report*)

- BMI
 - < 18.5 kg/m²
 - 18.5-24.9 kg/m²
 - 25.0-29.9 kg/m²
 - 30.0-34.9 kg/m²
 - 35.0-39.9 kg/m²
 - ≥ 40.0 kg/m²
- Waist
 - \leq 88 cm in \bigcirc , \leq 102 cm in \bigcirc Lower Risk
 - > 88 cm in \bigcirc , > 102 cm in \bigcirc High Risk



*Clinical guidelines on the identification, evaluation, and treatment of overweight and obesity in adults – the evidence report. *Obesity Res* 1998;6(S2);51S-210S.



Metabolic, lipids

- Primary
 - total cholesterol (TC)
 - high density lipoprotein cholesterol (HDL-C)
 - triglycerides (TG)





Metabolic, lipids (Classified according to NCEP ATP III guidelines*)

 TC (mg/dl) 	< 200 200-239 ≥ 240	desirable borderline high high
 HDL-C (mg/dl) 	< 40 ≥ 60	low high
 LDL-C (mg/dl) 	< 100 100-129 130-159 160-189 ≥ 190	optimal near optimal borderline high high very high
• TG† (mg/dl)	< 150 150-199 200-499 ≥ 500	normal borderline high high very high



*Third Report of the National Cholesterol Education Program (NCEP) on Detection, Evaluation and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III). †Spuriously high in the non-fasting state.



Metabolic, glucose homeostasis

- Primary
 - glycosylated hemoglobin (HbA_{1c})
 - glucose





Metabolic, glucose homeostasis

- Classified according to Am Diabetes Assn guidelines*
 - fasting glucose
 - ≤ 99 mg/dl normal 100-125 mg/dl impaired ≥ 126 mg/dl diabetes
 - random glucose
 ≥ 200 mg/dl

diabetes

Hb_{A1c} 5.7-6.4%
 ≥ 6.5%

increased risk for diabetes diabetes



*American Diabetes Association. Classification and Diagnosis of Diabetes: Standards of Medical Care in Diabetes—2018. *Diabetes Care* 2018;41(S1): S13-S27.



Immune / Inflammatory

- high sensitivity C-reactive protein (hsCRP)
 - classified according to CDC / AHA guidelines*
 - -low < 1 mg/L
 - -average 1-3 mg/L
 - -high > 3 mg/L
 - values > 10 mg/L trigger search for factors capable of confounding hsCRP-based CVD risk estimates



*Pearson et al. Markers of inflammation and cardiovascular disease. Application to clinical and public health practice. A statement for healthcare professionals from the CDC and AHA. *Circulation* 2003;107:499-511.



Pharmacologic

- prescription medications
- select over-the-counter medications (salicylates/NSAIDS)
- therapeutically classifications (Multum Lexicon Plus®)
- classification examples
 - antihypertensives
 - antihyperlipidemics
 - antidepressants
 - other classes





FIELD OPERATIONS





The Home Visit at a Glance

Most visits Monday – Friday mornings

Visit lasts 30 – 60 minutes

Staff use Add Health-provided equipment

Visit guided by Samsung tablet





Scheduling In-Home Visits

- Visits are scheduled by examiner
 - Monday Friday morning or early afternoon
 - Evening or Sundays (as a last resort)
 - No Thursday or Friday evening / Saturday visits

 — Lab is closed on Sundays

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Morning		* *	* *	*	*	* *	×
Afternoon		* *	*	*			×
Evening					×	×	X





Steps of the In-Home Visit







Tablet Data Collection for Wave V Bio-visit

- Standardized instrument
 - Guides the visit
 - Collects factors that affect measures
 - Built-in skips and sub-study evaluation
 - Medication inventory
 - Guides blood processing and shipping
 - Increased data quality
 - Rapid receipt of the data







Wave V Biomarkers Cardiovascular Data Collection Protocol

- Resting & seated respondents
- Measure arm circumference, match cuff
- Systolic BP, diastolic BP & pulse rate
- Measure 3 times @ 30-sec intervals
- Average last 2 measures





*Whelton PK, et al. 2017 ACC/AHA/AAPA/ABC/ACPM/AGS/APhA/ASH/ASPC/NMA/PCNA Guideline for the Prevention, Detection, Evaluation, and Management of High Blood Pressure in Adults. *Hypertension* 2018;71:1269-1324.

Wave V Biomarkers Anthropometric Data Collection Protocol

- Respondent dressed, no shoes
- Scale placed on uncarpeted floor
- Standardized study equipment
- Measure Height, Weight, Waist







Medication Inventory

Initial Screen

▲ 😤 59% 🖥 11	:13 AM
ODK Collect > Add Health Wave 5 Biomarkers	ľ
Section E: Medication Inventory > Search Medications	
Add Medications	

Med1:

Med1: Code (Info source and Database)

First digit is 1 or 2 (Label or Memory) Second digit is 1 or 2 (Found in DB or not)

Med2:

Med2: Code (Info source and Database)

First digit is 1 or 2 (Label or Memory) Second digit is 1 or 2 (Found in DB or not)

Med3:

Med3: Code (Info source and Database)

First digit is 1 or 2 (Label or Memory)





Entering Medication

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Help	Nar	ne CONT/	AINS:	V N	ame Si	TARTS	with:	Save	Meds				
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Entering Source

100		🕈 🔋 95% 🗖 11:10 AM
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FERRO	OUS SULFATE	
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Add M	Med To List Add A Med Not Found	Clear Search Box
* Gather		iners if possible.
2) Tap A 3) When	Add Medication:	e survey.
	FERROUS SULFATE	
	Source:	
	O Label/Container	
	O Respondent Memory	
	Name found in database	
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Sym	★ / EN(US)	



Exam Blood Kit Contents

















Venous Whole Blood Collection

- Phlebotomists
- Fasting respondents (ideally)
- 5 or 6 vacutainer tubes collected
- Centrifuge as appropriate
- Package & ship to lab
- Provide most assay results to respondents who want them







Paper Version of Questionnaire

- Used only if tablet unavailable
- All calculations performed by hand
- Data must be transferred to tablet and uploaded within 24 hours.
- Follow all skip patterns carefully



Wave V Biomarker Survey and Recording Form – Paper Version

This form is to be used ONLY if the tablet is unavailable

List of required materials – In home visit

Equipment Needed	Supplies Needed	
Microlife blood pressure unit with medium and large cuff	 EMSI provided work order 	
SECA circumferential tape measure	Pre-printed Post-It notes	
Metal tape measure	Biohazard bag	
Carpenter's square	Vacutainer holder	
Health-o-Meter weight scale	21 gauge straight needle	Included
Spare batteries for Health-o-Meter scale (2 X CR2032)	21 gauge butterfly needle	in Add
Cooler/ice packs for cooling samples until centrifugation	Nitrile gloves	> Health
Sharps container	2° X 2° gauze pad	Blood
	Band-Aid	Draw Box
	Tourniquet	
	5 Vacutainer tubes ***	
	Alcohol prep pad	
	Cardiovascular Health Face	t Sheet
	Fact Sheet	
*** The 6 th Vacutainer tube (a 6 ml sodium fluoride tube) is information indicates it is to be collected.	required only if respondent's app	ointment
PRINT ALL RESPONSES IN	CAPS (NO CURSIVE)	

CIRCLE MULTIPLE CHOICE ANSWERS

Version 6.0

1|Page





Where Are We Today with Bio-Visits?

- 7,605 respondents consented
- 3,755 (49% of) home visits completed





ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS NUMBER, DURATION & TIME OF VISITS

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99
Exam Visits per Day	7.8	7.1	90.4	1.0	1.0	1.0	2.0	6.0	12.0	18.0	23.0	32.0
Exam Start Time (hour 0–23)	10.9	3.1	28.0	6.6	7.5	8.0	8.8	10.0	12.3	16.3	17.6	18.8
Exam Duration (min)	38.3	15.5	40.3	15.3	20.0	23.0	28.9	35.3	45.0	57.0	65.0	90.0







X axes = Exam date (3/24/2016-7/18/2018) = 95% Confidence Limits --- 95% Prediction Limits --- Regression 3,888 exams of 3,755 individuals on 496 exam days (3/24/2016-7/18/2018).



ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS INTERVALS

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99	
Interval (day): consent-exam	175.6	162.6	92.6	11.0	20.0	25.0	46.0	128.0	263.0	342.0	531.0	719.0	
Fasting Hours	9.4	5.9	62.1	0.0	0.5	1.1	3.4	11.2	13.5	15.4	16.8	24.0	
Interval (min): BP1–BP2	2.3	1.4	62.3	0.5	0.9	1.1	1.5	2.1	2.7	3.7	4.7	7.2	
Interval (min): BP2–BP3	2.0	3.4	170.3	0.5	0.8	1.0	1.4	1.8	2.3	2.9	3.5	5.3	
Interval (min): exam start-collect	25.5	10.8	42.4	9.0	12.7	15.0	19.0	24.0	30.0	38.0	43.5	62.0	
Interval (hr): collect-centrifuge	1.2	0.8	65.3	0.3	0.4	0.6	0.8	1.1	1.6	2.0	2.3	4.4	
Interval (hr): centrifuge-send	8.9	9.0	101.4	0.3	1.0	1.8	3.5	5.8	8.7	24.2	28.2	32.7	
Interval (hr): send-receive	17.5	7.1	40.4	12.5	13.3	13.7	14.8	16.1	17.7	20.4	23.1	44.4	





X axes = Exam date (3/24/2016–7/18/2018) = 95% Confidence Limits --- 95% Prediction Limits --- Regression 3,888 exams of 3,755 individuals on 496 exam days (3/24/2016–7/18/2018). Add Health The National Longitudinal Study of Adolescent to Adult Health

ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS CARDIOVASCULAR MEASURES

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99	
SBP23 (mm Hg)	122	15	12	94	101	105	112	121	131	140	147	165	
DBP23 (mm Hg)	79	11	13	59	64	66	72	79	86	93	97	107	
PR23 (bpm)	75	12	16	50	57	61	67	74	82	90	95	106	





X axes = Exam date (3/24/2016–7/18/2018) = 95% Confidence Limits --- 95% Prediction Limits --- Regression 3,888 exams of 3,755 individuals on 496 exam days (3/24/2016–7/18/2018).





ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS ANTHROPOMETRIC MEASURES

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99	
Arm (cm)	30.8	5.3	17.2	21.0	24.0	24.5	27.0	30.5	34.0	37.5	39.5	45.0	
Height (cm)	169.6	11.0	6.5	149.0	154.5	157.0	162.0	169.5	177.0	183.0	187.0	193.0	
Weight (kg)	89.1	27.7	31.1	47.0	55.7	60.0	70.5	85.4	102.0	123.0	137.0	173.5	
Waist (cm)	97.1	19.0	19.6	63.0	70.0	75.0	84.0	95.0	108.0	123.0	132.0	152.0	
BMI (kg/m²)	31.2	12.6	40.6	18.4	20.5	22.0	24.8	29.2	34.9	41.7	47.3	59.8	





X axes = Exam date (3/24/2016-7/18/2018) = 95% Confidence Limits --- 95% Prediction Limits --- Regression 3,888 exams of 3,755 individuals on 496 exam days (3/24/2016-7/18/2018).



ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS SHIPPED BLOOD VOLUMES

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99	
Sample volume (mL): 5 TIGER1	3.8	0.7	18.0	1.8	2.6	3.0	3.5	4.0	4.0	4.5	5.0	5.0	
Sample volume (mL): 5 TIGER2	3.8	0.7	18.3	1.5	2.5	3.0	3.5	4.0	4.0	4.5	4.9	5.0	
Sample volume (mL): 5 LAV KEDTA	4.2	0.9	21.5	1.0	2.7	3.0	4.0	4.1	5.0	5.0	5.2	6.0	
Sample volume (mL): 3 LAV KEDTA	2.9	0.6	22.6	1.0	2.0	2.0	2.5	2.8	3.5	3.5	3.5	4.0	
Sample volume (mL): 4 PACKED CELLS	4.2	0.9	22.3	1.5	2.8	3.0	3.9	4.0	5.0	5.0	5.5	6.0	
Sample volume (mL): 10 RED PAXGENE	8.6	0.5	6.0	7.0	8.0	8.0	8.3	8.9	9.0	9.0	9.1	9.3	





X axes = Exam date (3/24/2016-7/18/2018) = 95% Confidence Limits --- 95% Prediction Limits --- Regression 3,617 blood sample kits from 435 FedEx delivery days (3/29/2016-7/17/2018).



ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS METABOLIC MEASURES

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99	
GLUCOSE (SERUM) (mg/dL)	93.9	36.5	38.9	55.0	69.0	74.0	81.0	88.0	96.0	108.0	129.0	279.0	
HBA1C (%)	5.4	0.9	16.6	4.6	4.8	4.9	5.0	5.2	5.5	5.7	6.2	10.6	
TG (mg/dL)	127.4	92.2	72.3	35.0	45.0	52.0	70.0	101.0	154.0	233.0	291.0	507.0	
TC (mg/dL)	180.5	34.6	19.2	110.0	130.0	140.0	156.0	177.0	202.0	226.0	242.0	274.0	
HDL-C (mg/dL)	49.5	15.0	30.2	24.0	29.0	33.0	39.0	47.0	58.0	70.0	77.0	94.0	
LDL-C (mg/dL)	106.2	30.6	28.8	44.0	60.0	69.0	85.0	104.0	125.0	145.0	159.0	189.0	



CAROLINA POPULATION

CENTER

Add Health The National Longitudinal Study of Adolescent to Adult Health

ADD HEALTH WAVE V (2016–2018) 3. SUMMARY STATISTICS INFLAMMATORY/RENAL MEASURES

	MEAN	SD	CV	P1	P5	P10	P25	P50	P75	P90	P95	P99	
HSCRP (mg/dL)	3.9	8.9	229.9	0.2	0.2	0.4	0.7	1.7	4.5	9.6	15.9	29.0	
CREATININE (mg/dL)	0.8	0.4	42.4	0.5	0.6	0.6	0.7	0.8	0.9	1.1	1.1	1.3	
CYSTATIN-C (mg/L)	0.7	0.2	33.9	0.4	0.5	0.5	0.6	0.7	0.8	0.9	0.9	1.1	
GFR (mL/min/1.73 m²)	103.8	15.4	14.8	65.4	77.4	83.7	94.2	106.2	113.7	120.8	127.6	136.3	
GFR _{cp}	118.6	15.7	13.2	68.5	90.1	100.6	111.5	120.2	128.1	135.1	140.1	149.3	
GFR	114.5	15.7	13.7	74.7	89.7	95.7	105.5	115.4	124.3	132.6	137.8	149.1	





X axes = Exam date (3/24/2016–7/18/2018) = 95% Confidence Limits --- 95% Prediction Limits --- Regression Monthly assays through 6/22/2018 from 3,311 kits (HSCRP & CYSTATIN-C). Weekly assays through 7/6/2018 from 3,479 kits (CREATININE).



Quality Control Threats to Data Quality

- Poorly trained or monitored staff
- Departures from standardized protocol
- Use of heterogeneous, untested equipment
- Reliance on manual processes
- Missing data
- Measurement error
 - trend / cyclicity
 - digit preference
 - inaccuracy
 - unreliability





Quality Control Control of Data Quality

- Uniformly train & monitor staff
- Follow standardized protocol
- Use standard, tested equipment
- Automate processes / checks
- Track / reduce missing data
- Track / reduce measurement error
 - trend / cyclicity
 - digit preference
 - inaccuracy
 - unreliability





Quality Control Digit Preference

LIEAL THURSDAY DURING DOMO

	A	ANTHR	OPOM	ETRIC	MEASU	-2016) JRES		
Terminal	Al (C	RM m)	HEI (C	IGHT :m)	WEI (k	IGHT (g)	W/ (C	AIST m)
Ligit	N	%	N	%	N	%	Ν	%
0	3189	84%	2879	76%	1079	29%	3250	86%
1					302	8%		
2					242	7%		
3					261	7%		
4					275	7%		
5	624	16%	892	24%	467	13%	535	14%
6					263	7%		
7					279	8%		
8					275	7%		
9					260	7%		
Total:	3813	100%	3771	100%	3703	100%	3785	100%

MEASURE	k	n	ChiSq	p	DPS	FLAG
WAIST (cm)	2	3785	1947.5	0.000	71.7	1
ARM (cm)	2	3813	1725.5	0.000	67.3	1
HEIGHT (cm)	2	3771	1047.0	0.000	52.7	1
WEIGHT (kg)	10	3703	1606.4	0.000	22.0	1



Sorted from high to low DPS. DPS = Hense (1991) digit preference score = 100(Chisq/(n*(k-1)))**0.5. Range = 0–100. Chisq = goodness of fit test stat, where n[i] = observed cell freq & sum(n[i]/k) = expected cell freq in cell [i]. k = number of possible digits, i.e. 0 or 5 for terminal digits of arm, height, and waist; 0–9 for all others. p = p value. Bon Ferroni-corrected alpha = 0.05/13 = 0.00385.



Quality Control Digit Preference

ADD HEALTH WAVE V (2016–2018) CARDIOVASCULAR MEASURES

Terminal	SE (mm	3P1 1 Hg)	SE (mm	3P2 i Hg)	SE (mm	3P3 1Hg)	DE (mn	3P1 i Hg)	DE (mm	3P2 1 Hg)	DE (mn	3P3 1 Hg)	P (beat	R1 /min)	P (beat	R2 t/min)	Pl (beat	R3 //min)
Digit	N	%	Ν	%	N	%	N	%	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
0	418	11%	376	10%	436	12%	469	13%	428	12%	444	12%	427	11%	412	11%	422	11%
1	351	9%	335	9%	331	9%	332	9%	329	9%	323	9%	338	9%	366	10%	354	10%
2	400	11%	404	11%	383	10%	410	11%	423	11%	409	11%	412	11%	380	10%	403	11%
3	363	10%	333	9%	357	10%	409	11%	350	9%	386	10%	360	10%	347	9%	337	9%
4	361	10%	398	11%	389	10%	356	10%	404	11%	360	10%	391	11%	345	9%	426	11%
5	350	9%	366	10%	385	10%	348	9%	334	9%	342	9%	341	9%	392	11%	326	9%
6	372	10%	355	10%	349	9%	333	9%	395	11%	377	10%	387	10%	368	10%	360	10%
7	350	9%	370	10%	340	9%	339	9%	360	10%	333	9%	323	9%	347	9%	369	10%
8	395	11%	425	11%	407	11%	378	10%	358	10%	409	11%	382	10%	389	10%	372	10%
9	360	10%	357	10%	336	9%	346	9%	338	9%	330	9%	359	10%	373	10%	344	9%
Total:	3720	100%	3719	100%	3713	100%	3720	100%	3719	100%	3713	100%	3720	100%	3719	100%	3713	100%

MEASURE	k	n	ChiSq	p	DPS	FLAG
SBP3 (mm Hg)	10	3713	28.7	0.001	2.9	
SBP2 (mm Hg)	10	3719	21.4	0.011	2.5	
SBP1 (mm Hg)	10	3720	13.9	0.125	2.0	
DBP1 (mm Hg)	10	3720	48.3	0.000	3.8	
DBP3 (mm Hg)	10	3713	40.0	0.000	3.5	
DBP2 (mm Hg)	10	3719	33.8	0.000	3.2	
PR3 (beat/min)	10	3713	29.6	0.001	3.0	
PR1 (beat/min)	10	3720	27.3	0.001	2.9	
PR2 (beat/min)	10	3719	11.8	0.225	1.9	



Sorted from high to low DPS. DPS = Hense (1991) digit preference score = 100(Chisq/(n*(k-1)))**0.5. Range = 0–100. Chisq = goodness of fit test stat, where n[i] = observed cell freq & sum(n[i]/k) = expected cell freq in cell [i]. k = number of possible digits, i.e. 0 or 5 for terminal digits of arm, height, and waist; 0–9 for all others. p = p value. Bon Ferroni-corrected alpha = 0.05/13 = 0.00385.



Quality Control Inaccuracy

Race /		Glucose	Cystatin C
Ethnicity	Sex	Sub-Study [*]	Sub-Study ⁺
White	Male	12	12
	Female	12	12
Black	Male	12	12
	Female	12	12
Hispanic	Male	12	12
	Female	12	12
Other	Male	12	12
	Female	12	12
To	otal	96	96

*Involves collecting an extra (NaFI/KOx) tube of blood @ the same exam for a different glucose assay. Includes race/ethnicity-sex strata of 12 participants = 4 normal glucose + 4 pre-diabetes + 4 diabetes. †Involves measuring cystatin c using a new calibration assay. Includes race/ethnicity-sex strata of 12 participants = 4 + 4 + 4 with cystatin c < 0.6, 0.6-0.7, and > 0.7 mg/L.





Quality Control Inaccuracy

ADD HEALTH WAVE V (2016–2018) GLUCOSE SUB-STUDY

PARTICIPANT CHARACTERISTICS

Characteristic	Ν	%
Female	43	62%
Race/Ethnicity: Non-Hispanic White	25	36%
Non-Hispanic Black	14	20%
Hispanic	9	13%
Other	21	30%
Wave IV HBA1C: Normal (<5.7%)	29	42%
Pre-Diabetic (5.7–6.4%)	23	33%
Diabetic (>=6.5%)	17	25%
Pilot Study Participant	21	30%
With both a 5 Gray NAFL/KOX & an 8.5 Tiger	69	100%

_					BIAS				
	N	GLUCOSE (SERUM)	GLUCOSE (NAFL)	BIAS	BIAS	(95% Cl)	RB	%BIAS~=0	P
6	69	109.5	108.3	3.5	1.1	(-0.3,2.5)	1.0	100%	0.113







Quality Control Unreliability

		Intra-Individua
Race /		Variation
Ethnicity	Sex	Sub-Study [*]
White	Male	12
	Female	12
Black	Male	12
	Female	12
Hispanic	Male	12
	Female	12
Other	Male	12
	Female	12
To	tal	96

*Involves examining a participants 2x, 1-3 weeks apart, on ~ same day of week @ same time of day.





Quality Control Unreliability

ADD HEALTH WAVE V (2016–2018) INTRA-INDIVIDUAL VARIATION STUDY

PARTICIPANT CHARACTERISTICS							
Characteristic	N	%					
FEMALE	54	50%					
RACE/ETHNICITY: NON-HISPANIC WHITE	37	35%					
NON-HISPANIC BLACK	25	23%					
HISPANIC	23	21%					
OTHER	22	21%					
PILOT STUDY PARTICIPANT	5	5%					
WITH BOTH A v1 & v2	107	100%					
SAME DAY OF WEEK @ v1 & v2	58	54%					
SAME FIELD EXAMINER @ v1 & v2	106	99%					
FASTING >= 8 hr @ v1 & v2	83	78%					
FASTING >= 9 hr @ v1 & v2	80	75%					
ALL ADD HEALTH EQUIPMENT @ v1 & v2	103	96%					
ALL PREFERRED UNITS @ v1 & v2	101	94%					

BETWEEN-VISIT DIFFERENCES									
MEASURE	N	V1	V2	D	D	(95% CI)	PE	%D~=0	Р
Visit Day (1–366)	107	124.6	137.9	14.0	14.0	(12.96,15.13)	10.7	100%	0.000
Exam Start Time (hour 0-23)	107	9.8	9.6	1.3	-0.1	(-0.52,0.33)	13.1	95%	0.657
Fasting Hours	102	13.2	11.2	3.7	-2.0	(-3.19,-0.88)	30.6	96%	0.001

RELI					ITY			
	MEASURE	N	ICC	(95% CI)	MDC	MDD	UNIT	
	SBP23	107	0.72	(0.63,0.81)	21	2	mm Hg	
	DBP23	107	0.71	(0.62,0.80)	16	2	mm Hg	
	PR23	107	0.74	(0.65,0.82)	16	2	bpm	
	Arm	107	0.86	(0.82,0.91)	4.92	0.78	cm	
	Height	105	0.94	(0.92,0.96)	7.15	1.75	cm	
	Weight	105	1	(1.00,1.00)	2.84	4.43	kg	
	Waist	104	0.96	(0.94,0.97)	10.82	3.07	cm	
	BMI	105	0.98	(0.98,0.99)	2.9	1.3	kg/m²	
	GLUCOSE	98	0.94	(0.91,0.96)	31	7	mg/dL	
	HBA1C	96	0.99	(0.99,1.00)	0.3	0.2	%	
	TG	98	0.63	(0.51,0.75)	172	16	mg/dL	
	тс	98	0.88	(0.83,0.92)	34	6	mg/dL	
	HDL-C	98	0.95	(0.93,0.97)	10	3	mg/dL	
	LDL-C	98	0.86	(0.81,0.91)	30	5	mg/dL	
	HSCRP	85	0.83	(0.76,0.89)	5.2	0.7	mg/dL	
	CREATININE	98	0.94	(0.92.0.96)	0.1	0	ma/dL	





Quality Control Summary

- High to date!
- Still some room for improvement
- To that end, we are
 - targeting the problems I highlighted
 - intervening to attenuate them
 - monitoring intervention effects





BIRTH RECORDS





Birth Records Significance

- Perinatal Data as...
- Outcomes
- Predictors





Birth Records Goals

- Adult Records
- 8 states
- 1974-1983
- 6,000+ records

- Child Records
- •7 states
- 1988 present
- 5,000+ records





	NORTH G				DHUMAN SEF	RVICES				
	Registration	02111110								
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GHILD										
	5. FACILITY NAME (If not institution, give street and nu	nber)		CITY,	TOWN, OR LO	CATION OF BIR	тн	-	7. COUNTY OF	BIRTH
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MOTHER	So. MOTHER'S CURRENT LEGAL NAME (First, Middle,	Last, Suffix)				•	DATE OF I	iste 🖉	anth Says. Nav g	
	IC. MOTHER'S NAME PRICE TO FIRST WARRINGE (F	Rest, Middley, Last,	suffi)			M. BITHPLAC	pai la	ng a k	rápčanty	
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	104. STREET AND NUMBER					'	a.ZP CO	£	16	LINEDS CITY LINES?
	11. MOTHER'S MAILING ADDRESS: D Same as reade	nce, or State:		City, To	wn, or Location			_		Li tes Li No
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	American Indian or Alaska Native	C Filpino		(Specify)			(Spe	aity)		
	(Name of the enrolled or principal tribe)	D Japanese	8	Native H	evalue las or Chamotre		C Othe	r 1990		
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	D White	D Asian Indian		Vietname			C San	cen.		
	El Black or African American El American Indian or Alasia Nativa	C Chinese		Other As	ulan		1 Other	r Pacifi citul	s Islander	
	(Name of the enrolled or principal tribe)	D Japanese		Native H	awaian		0.004	e		
		Korean		Guanan	ian or Chamort		(Spe	city)		
	22. MOTHER MARRIED? pl/bits, conception, or any 5	ine between) 🖂	e befween) 🗆 Yes 🗆 No			23. SOCIAL SECURITY NUMBER REQUESTED FOR CHILD?				FOR CHILD?
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	25. FATHER OF HISPANIC ORIGIN? (Check the	E (m grade	e or iess			E Home	Birth:			
	box that best describes whether the father is	E 90-120	h grade, no dij col craduata c	piona or GED or	-	Planned to deliver at Home? Yes No Clinic/Doctor's office				
	SpenistvHispenicLatino. Check the 'No' box if father is not SpenistvHispenicLatino!	D Some co	lege credit bu	t no degr	-	C Other	(Readily)			
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	Heis, Mexican, Mexican Antendan, Chicano Yes, Pueto Rican	D Master's	degree (e.g.,	MA, MS, I	WEng, MEd,	at Recipity	ID. (NP4)			
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	box that best describes whether the mother is	E 9th - 12th	n grade, no dij ool graduate o	piona or GED or	mpieted					
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	C Presses	or resulted from infe	tilly treatment-if yes	D None	of the above			Vaginal/Spontaneous		
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	C Fedi	ty-enhancing drugs,	Artificial insemination	50. CHARAO	CTERRISTICS OF LA	BOK AND DELI	VERT	-	v aginary acuum	
	or int	suterine insemination	an	D indus	tion of labor			-	Celebration was a	trial of labor attances??
	C Assis	and reproductive two	hnology (e.g., in vitro	D Auto	entation of labor				CI Yes	
	Ter Till	tation (NY-), gamete	stratelopen tender	D Non-	vertex presentation			52. MATERNAL MORBIDITY (check all that apply)		
	0.00-1	0		E Stero	ide (glucocorticoide)) for fetal lung m	aturation			
	El Mother I	ad a previous cesar	ean delivery	necel	ved by the mother p	rior to delivery				
	If yes, ho	w nany	-	C Areb	iotics received by th	e mother during	Antibiotics received by the mother during labor			lated with labor and delivery)
	it yes, now many		Clinical choricamnionitis diagnosed during labor							
	D Note of	None of the above			al choricemnionitie	diagnosed durit	g labor		Matemai transfusik	an
	D Note of	Te shove		or ma	al choroamnionitis stemal temperature	alignated durin 2 30°C (100.4%	ig labor)		Matemai tranafusik Third or fourth deg	on pree perineal laceration
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Summary of Available Information on State-Level Birth Records, 1974-1983

Birth outcomes

Birth weight

Gestation length

Apgar (5-minute)

Infant characteristics

Infant sex

Birth order (singleton; 1st twin; 2nd twin; etc.)

Pregnancy characteristics / hx

Plurality

Month prenatal care began

Total number of prenatal visits

Date of last live birth

Medical risk factors (e.g., gestational diabetes)¹

Complications related to pregnancy

Total live births now living/now dead

Delivery characteristics

Labor/delivery complications Hospital size (e.g., < 20 beds; 100+ beds; etc) Birth attendant (physician; midwife; etc)

Parents' characteristics

Mother's and father's age

Mother's and father's race

Marital status

Mother's and father's education (years) Mother's and father's state/country of birth

Personal identifiers for linking

Child's date of birth (mmddyy) Child's first, middle, last name Mother's maiden name (first, middle, last) Mother's complete residence address Father's first, middle, last name

Add Health Design

- Nationally representative
 - region
 - population density
 - school size / type
 - ethnicity
- School-based sample, students grades 7-12 (n=20,745)
 - 80 high schools
 - 52 feeder schools
- Longitudinal

Wave	Years	Mode	Response Rate	Age (yr)
I	'94-'95	in-school & in-home	79%	10.00
П	'96	in-home	88%	} 12-20
Ш	'01-'02	in-home	77%	18-26
IV	'07-'09	in-home	80%	24-32
V	'16-'18	mixed		32-42





Risk Factor Distributions @ Wave IV







Surveillance Infrastructure @ Wave V



Component Progress: Tracing, Screening & Matching



Case Status	Wave III	Wave IV	Wave V	Total
Deceased or Unlocatable	96	131	168	395
Well-Identified (sent to NDI)	96	131	150*	377
Matched (1:1)	84 (88%)	118 (90%)	140 (93%)	342 (91%)

*Eighteen recently identified cases are pending NDI submission.





Geographic Distribution of U.S. Deaths







Temporal Distribution of Deaths*



*Includes 325 NDI matches; 9 international or recent, but obituary / death certificateconfirmed deaths; and 10 deaths pending NDI submission.





Demographic Distribution of All Deaths

Characteristic	Mean (Range) or %
Age, years	26.9 (22-39)
Female	33%
Race/ethnicity EA	53%
AA	23%
HL	9%
A/PI	3%
AI/AN	2%
O/M	10%





Component Progress: Investigation & Abstraction



Execution of Add Health-State* Agreements to Provide Death Certificates









Component Progress: Investigation & Abstraction





*Not published for all deaths. †Not releasable for 2 (<1%) of 364 deaths. ‡Not releasable for 52 (28%) of 187 deaths. §Unavailable for 45 (29%) and 26 (17%) of 153 deaths either purged or without consent/authorization.



Surveillance of Chronic Disease Events Surveillance Data Quality Control

Median (Range) Item-Specific Agreement

Abstraction Form	Agreement	К*
Obituary	0.86 (0.84-0.89)	0.83 (0.80-0.86)
Coroner/Medical Examiner Report	0.90 (0.87-0.93)	0.86 (0.83-0.90)
Death Certificate	0.93 (0.92-0.95)	0.92 (0.90-0.94)

*Prevalence & bias-adjusted kappa coefficient





Manner & Underlying Cause of NDI-Matched Deaths

Manner*	%	Underlying Cause*	%
Accidental	42.9	Motor Vehicle Accident	24.3
Natural	27.2	Suicide	13.8
Suicide	14.6	Accidental Drug Intoxication	12.0
Homicide	12.7	Cardiovascular Disease	11.1
Unidentified	2.6	Homicide	9.8
*From death certificate		Cancer	6.5
		Infectious Disease	6.2
		Other Accident	4.9

*From ICD codes (NDI)





Component Progress: Review, Classification & Adjudication



In Progress!





Summary

- Death & CVD Outcome Surveillance ongoing in this
 - Nationally representative
 - School-based
 - Longitudinal
 - Study of adolescence to mid-adulthood
- 364 deaths identified
- Most successfully investigated
- Preliminarily, > 25% due to natural causes
- Review, classification & adjudication in progress
- Stay tuned re data access!





Wave V Biology Project Importance of Biological Data

- One of Add Health's main strengths is its data
 - rich, high-quality
 - nationally representative & longitudinal
 - individual, multi-contextual <u>and</u> biological
- Collectively, the data constitute a valuable resource
- The resource can be leveraged toward understanding population health



