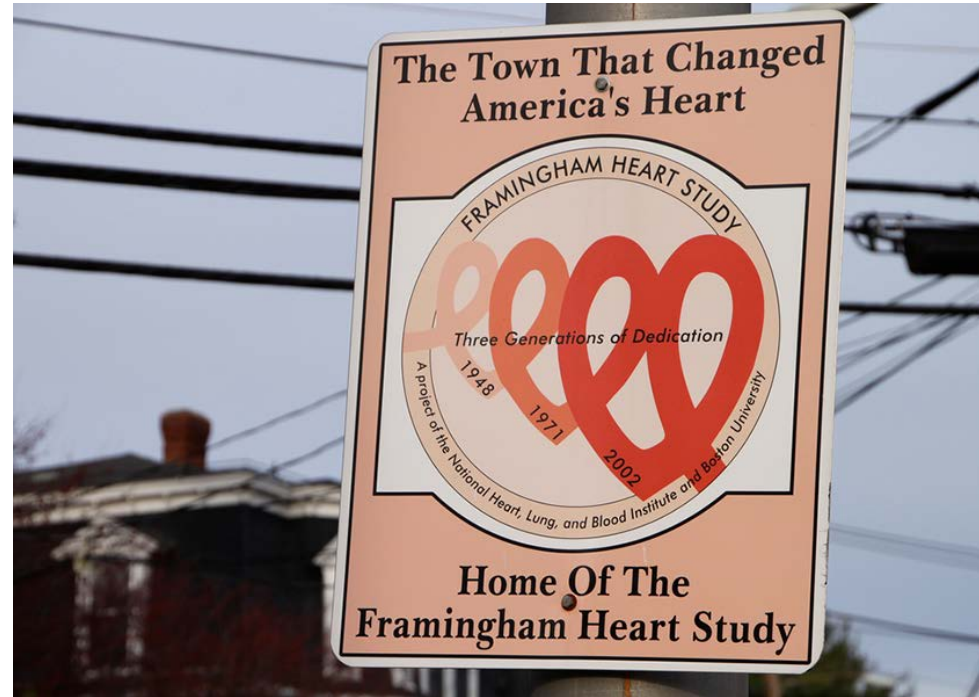


Understanding and Using Framingham Data

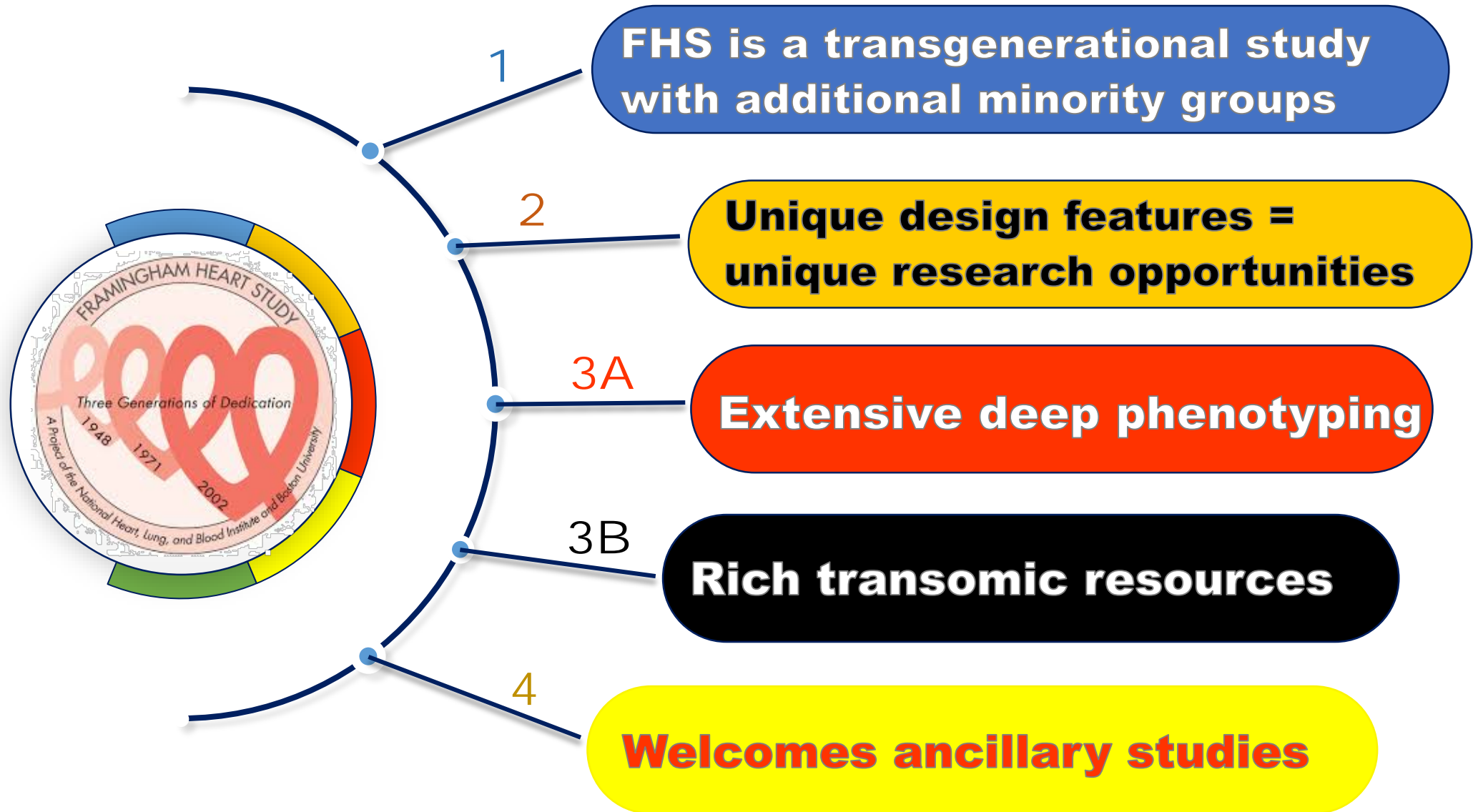
What Exists and How to Get It



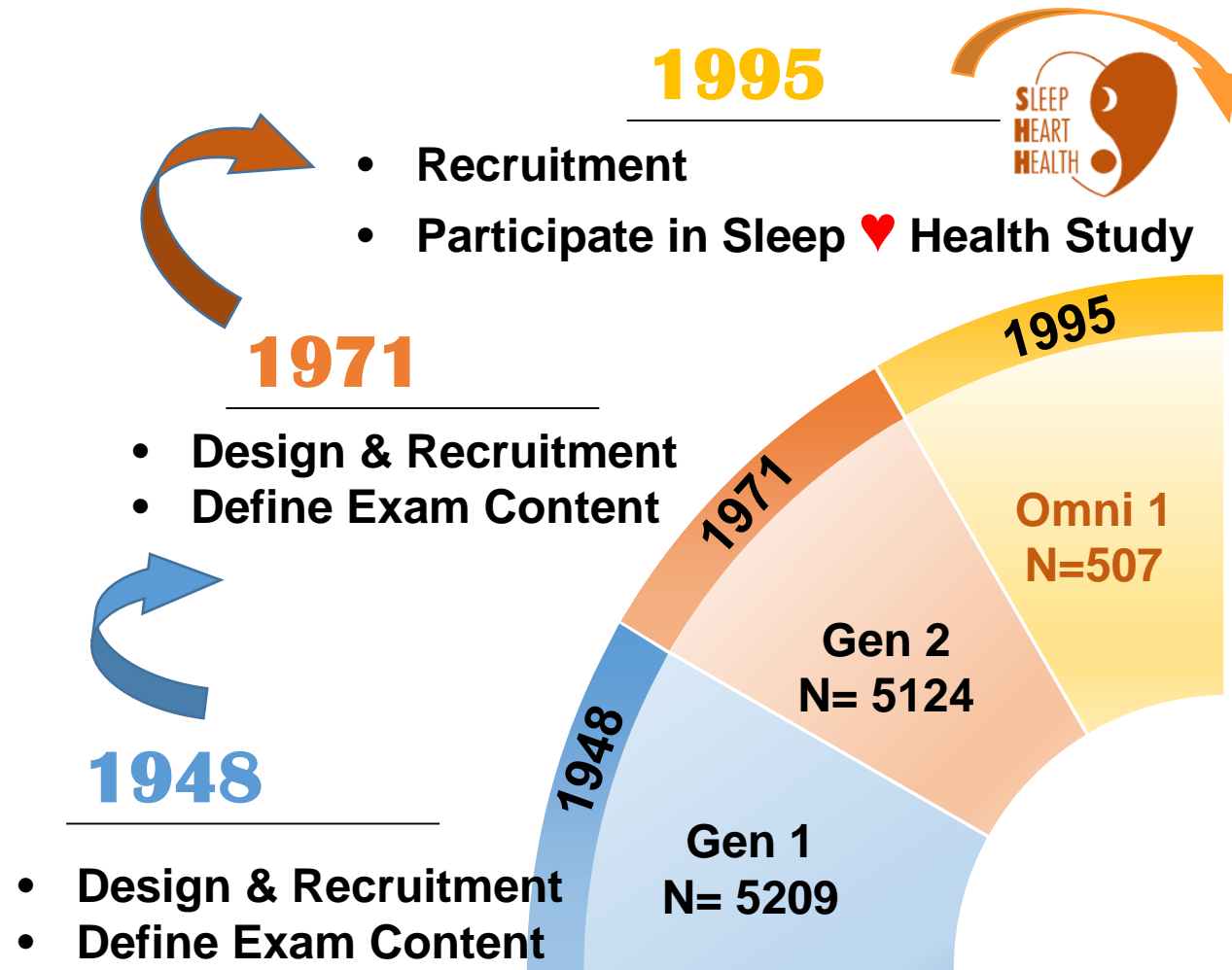
Vanessa Xanthakis, PhD FAHA
Investigator, Framingham Heart Study
Boston University Department of Medicine



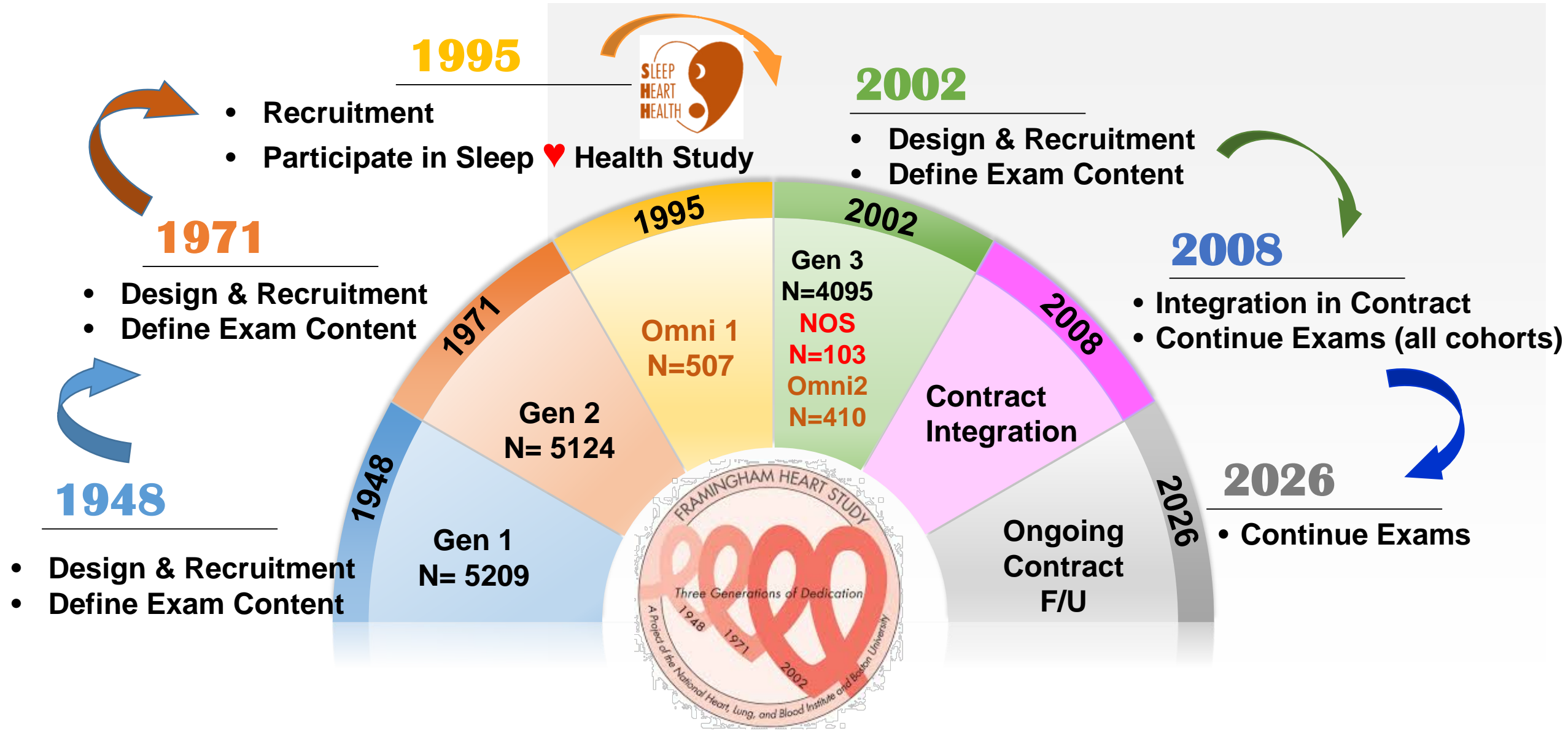
Framingham Heart Study



Overview of FHS Cohorts Recruitment Timeline: 1948-2026

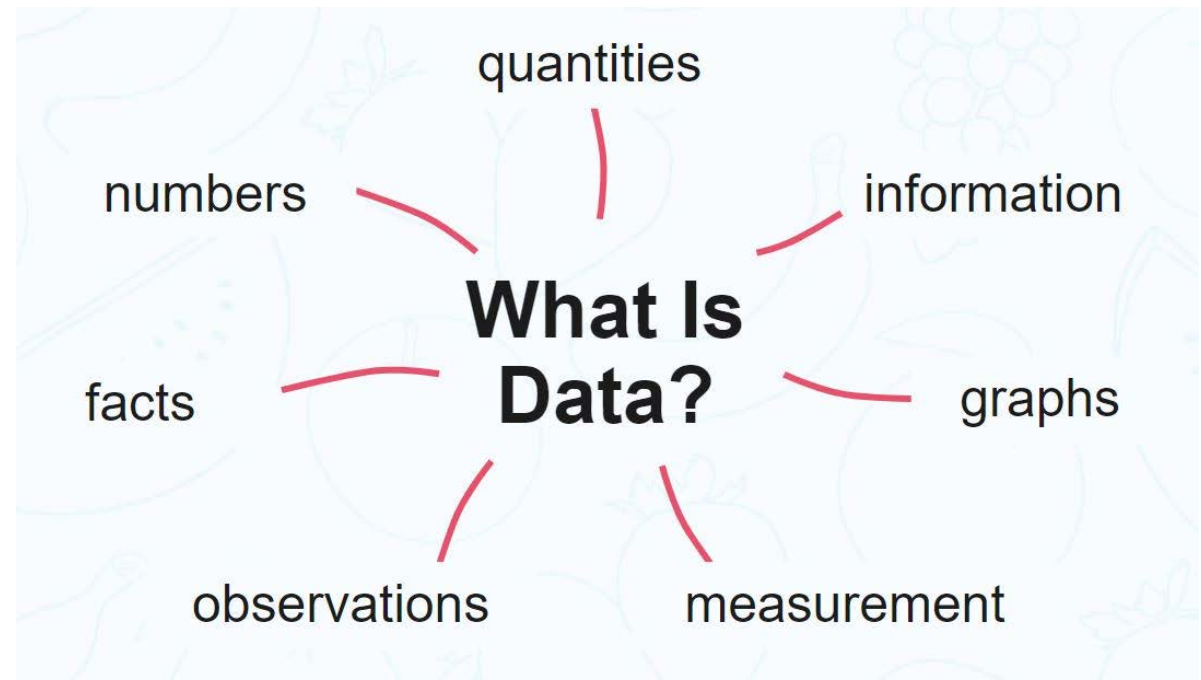


Overview of FHS Cohorts Recruitment Timeline: 1948-2026



Diversity and Inclusion in FHS

CODES OF FIRST SELF-REPORTED RACE FOR ALL COHORTS		
A	Asian	101
B	African American	271
H	Hispanic or Latino	371
M	Multiracial	124
N	American Indian or Alaskan Native	5
O	Other	133
P	Native Hawaiian or Pacific Islander	2
R	Prefer not to answer	7
W	White	14,424
Blank	Unknown	10
TOTAL		15,448



What types of data exist
at FHS?

www.framinghamheartstudy.org



Framingham Heart Study
Three Generations of Dedication

[About](#)

[Participants](#)

[For Researchers](#)

[Internal](#)

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Three Generations of Research on Heart Disease



For Researchers

Welcome, Researchers

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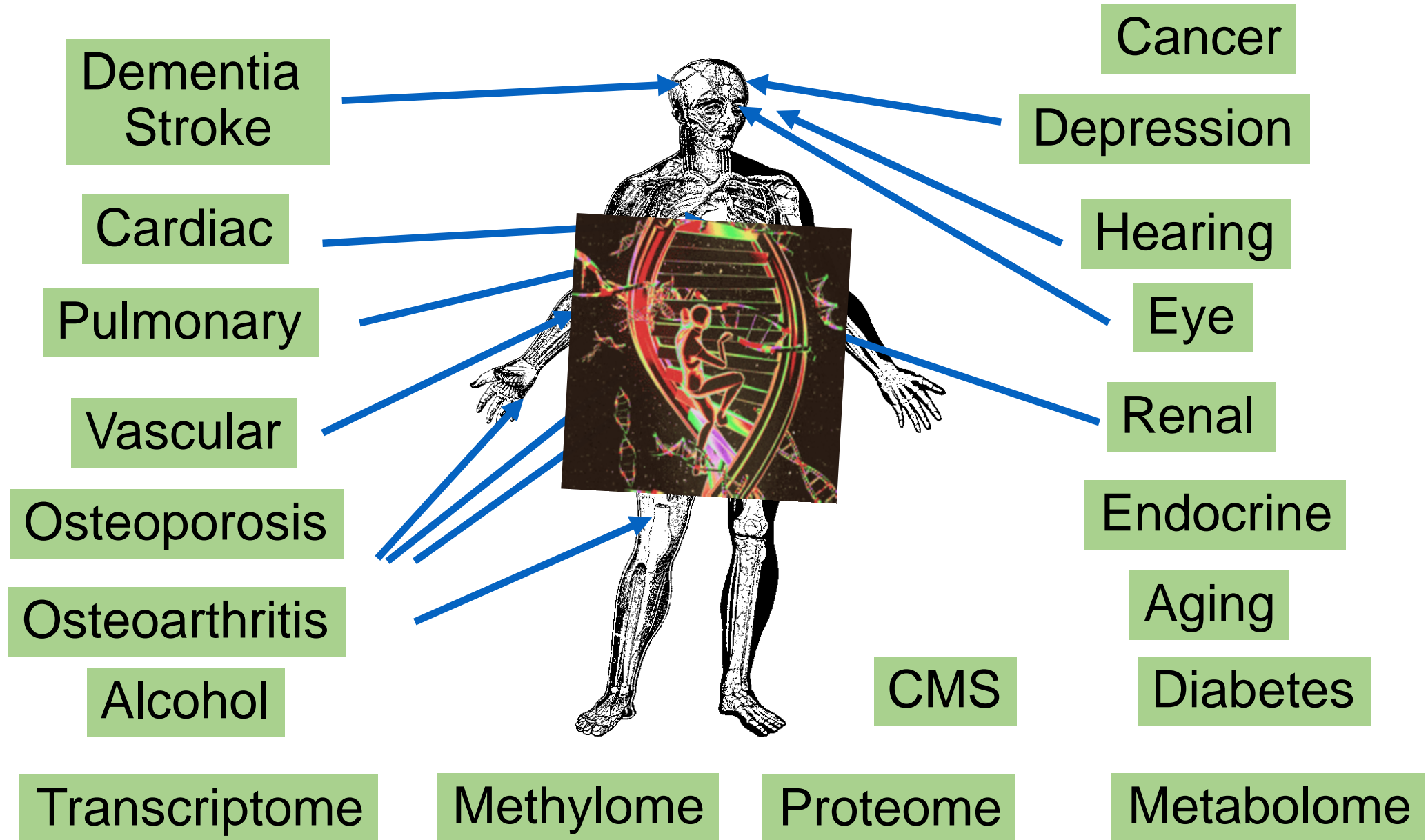
FHS Service Center

Selected Research Results



A	B		C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y
Nature of Data			Cohort							Non-invasive Tests / La															
										Non-invasive Test															
	Data Set	Name	Original Gen 1	Offspring Gen 2	New Offspring Spouse Gen 2	Generation 3 Gen 3	Omni 1	Omni 2	Time Interval	CT/PET	Physical Activity Monitor	Sleep Study	Body Composition	Carbon Monoxide	X-ray	Oscillograph/Vasculogram	Ankle-arm Blood Pressure	Bone Studies	Carotid Ultrasound	Echocardiogram	ECG	Hearing	Eye	Pulmonary Function Tests	
Abdominal Fat Study CT	abdomct1_7s		•						Exam 7	•															
Abdominal Fat Study CT	abdomct3_1s					•			Exam 1	•															
Physical Activity Index	act1_5s		•						Exam 5																
Physical Activity Index	act1_6s		•						Exam 6																
ADMA/SDMA/L-arginine Lab Data	adma1_6s		•						Exam 6																
Ankle-Arm Blood Pressure	ank0_23s		•						Exam 23								•								
Ankle-Arm Blood Pressure	ankle1_6s		•						Exam 6								•								
Ankle-Arm Blood Pressure	ankle1_7s		•						Exam 7								•								
Ankle Arm Doppler	ankle1_8s		•						Exam 8								•								

FHS: Deep Phenotypic Characterization



FHS: Deep phenotypic characterization

Available traits	EAs	AA, HA, AsA
<u>Traditional risk factors</u>		
Diabetes, glucose	MV	MV
Blood pressure	MV	MV
Fasting lipids	MV	MV
Biomarkers	MV	MV
Height, weight	MV	MV
Cognitive function	MV	MV
Depression or sx	MV	SV
Renal function	MV	MV
Medication use	MV	MV
<u>Omics risk factors</u>		
WGS	SV	SV
RNAseq	SV	SV
DNA methylation	MV	MV
Metabolomics	MV	MV
Proteomics	SV	SV

Available traits	EAs	AA, HA, AsA
<u>Outcomes</u>		
MI, stroke, TIA, PAD, HF	+	+
Atrial fibrillation	+	+
Dementia	+	+
Mortality	+	+
<u>Subclinical measures via</u>		
Electrocardiography	MV	MV
Echocardiography	MV	MV
Cardiac MRI	SV	SV
Carotid IMT	MV	ND
Cerebral MRI	MV	MV
Coronary calcium	MV	MV
CT fat depots	MV	MV
Ankle-brachial index	MV	SV
Pulmonary function	MV	SV
Eye exam	SV	SV

MV = multiple visits; SV= single visits; EA= whites; AA= blacks; HA= Hispanics; AsA= Asians

Data on 1000s of Longitudinal Phenotypes

<u>Routine Examination</u>	
Physical Exam	BP, ABI, Lungs, Heart, Neurological, Cognition
Lifestyle & Habits	Smoking, exercise, diet, Psychosocial Factors, alcohol
Medical History	Medications, Hospitalizations, Sxs, Diagnostic testing, Cancer
Labs	Lipids, diabetes, kidney, Novel biomarkers, DNA
Noninvasive	ECG, echo, Holter, carotid, vascular, PFT, brain, cardiac MRI, MDCT, bone
Endpoints	CVD, cancer, neuro, pulmonary, bone

Social Networks data in FHS

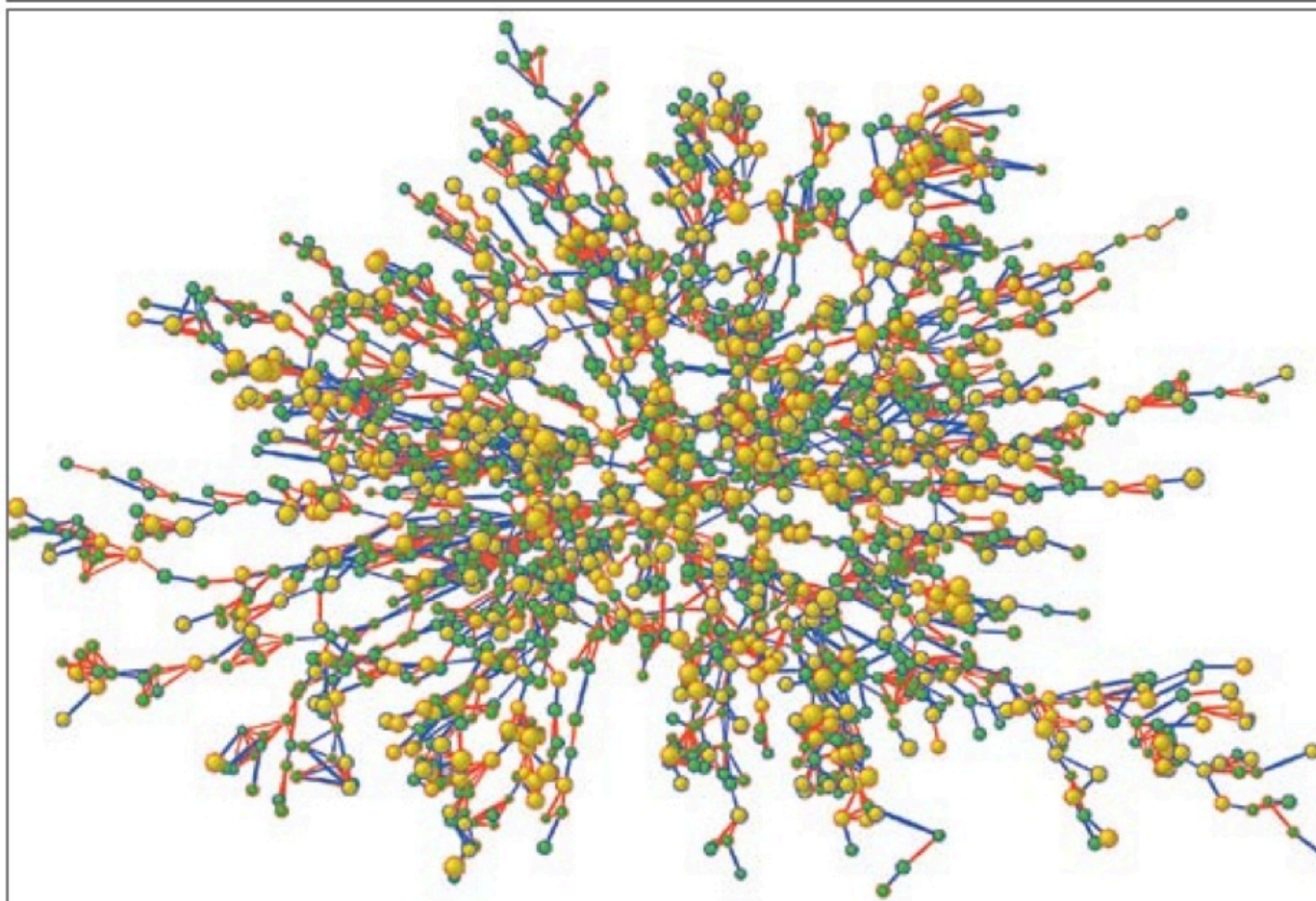


Figure 1. Largest Connected Subcomponent of the Social Network in the Framingham Heart Study in the Year 2000.

Each circle (node) represents one person in the data set. There are 2200 persons in this subcomponent of the social network. Circles with red borders denote women and circles with blue borders denote men. The interior color of the circles indicates the person's obesity status: yellow denotes an obese person (body-mass index, >30) and green denotes a nonobese person. The size of each circle is proportional to the person's body-mass index. The colors of the ties between the nodes indicate the relationship between them: purple denotes a friendship or marital tie and orange denotes a familial tie.

Minimal loss to F/U

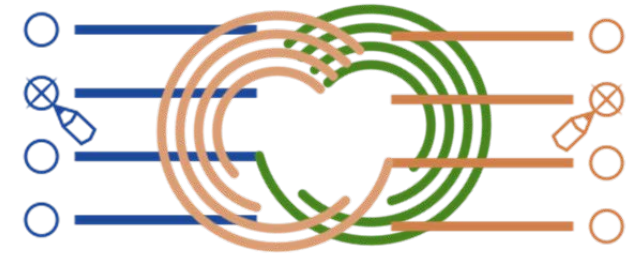
COHORT	ENROLLED	DECEASED N (%)	WITHDRAWN/LOST N (%)
Original	5209	5202 (99.9)	5(0.1)
Offspring	5124	2554 (49.8)	131 (2.6)
Gen 3	4095	127 (3.1)	54 (1.3)
NOS	103	30 (29.1)	2 (1.9)
Omni 1	507	84 (16.6)	58 (11.4)
Omni 2	410	17 (4.1)	10 (2.4)



Framingham Heart Study

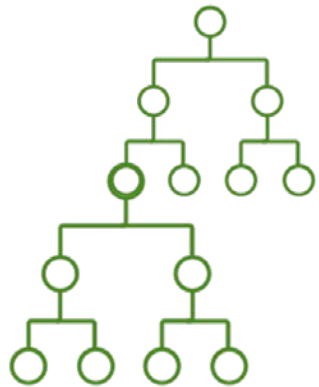
- **Deeply Phenotyped**

- FHS is ~ The Human Phenome Project



- **Longitudinal traits**

- Lifetime measures & Lifestyle measures
- Multiple cohorts, multiple time points



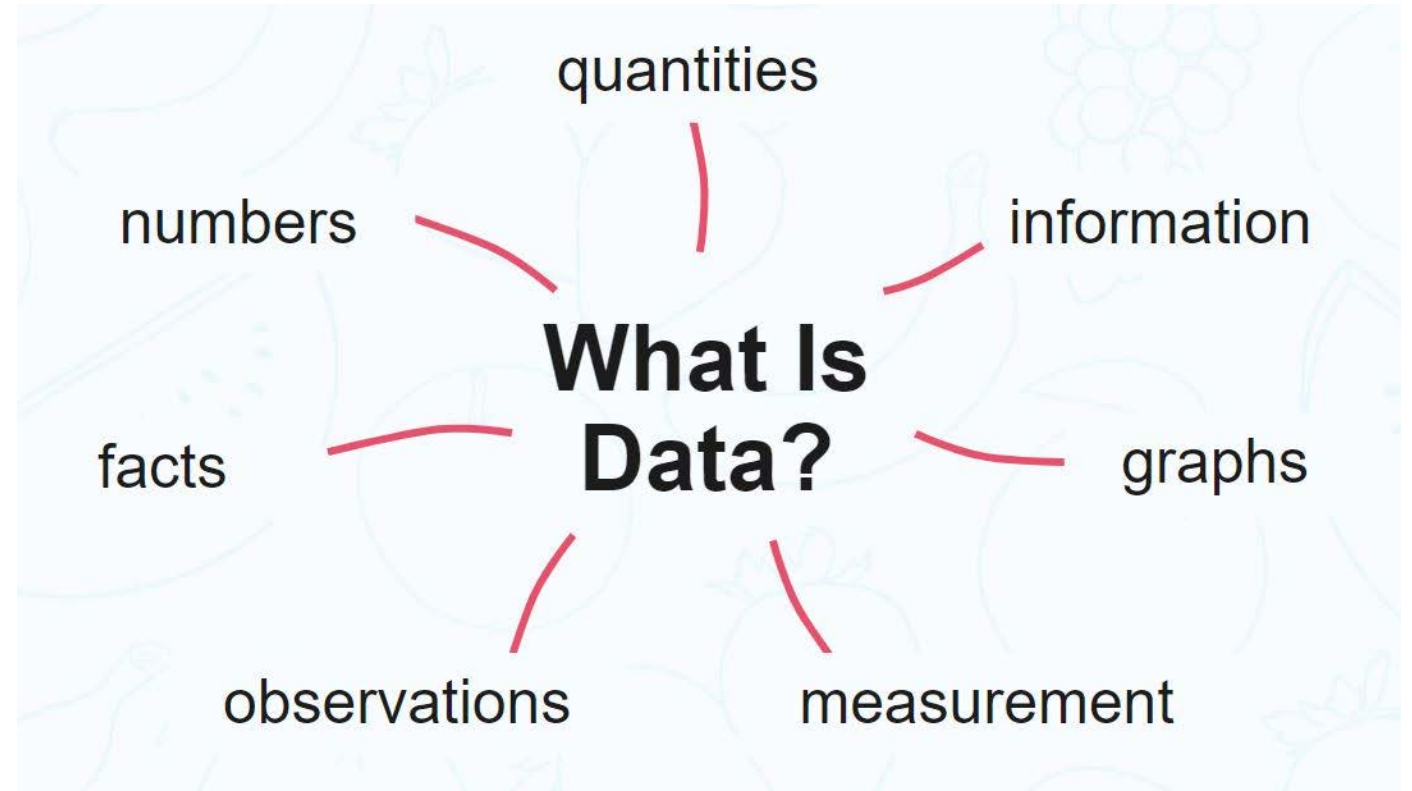
- **Family Study**

- Extended 3-generation pedigrees

- **Extensive Genetic/Genomic Resources**

- Unique Omics resources





Which FHS cohorts/exams should I use for my research question?



For Researchers

Welcome, Researchers

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Available FHS Data

Overview

The Framingham Heart Study (FHS) is an epidemiologic study begun in Framingham in 1948 with 5,209 men and women. Since that time the FHS has studied three generations of participants resulting in biological specimens and data from nearly 15,000 participants. This clinically and genetically well-characterized population is a valuable scientific source that is maintained under the joint stewardship of Boston University and the NHLBI. Since 1994, two groups from minority populations, including related individuals have been added to the FHS.

Please check the External Data Repositories before applying for data through FHS Repository. External repositories dbGaP and BIOLINCC do not require service fees to access their data, while the FHS Internal Repository may require service fees or subcontract for data access.

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[Phenotypic Data and Table of Exams](#)

[Genetic Data](#)

[Omics Data Workshop](#)

[Noninvasive and Biomarker Protocols](#)

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GWAS Pleiotropic Tool

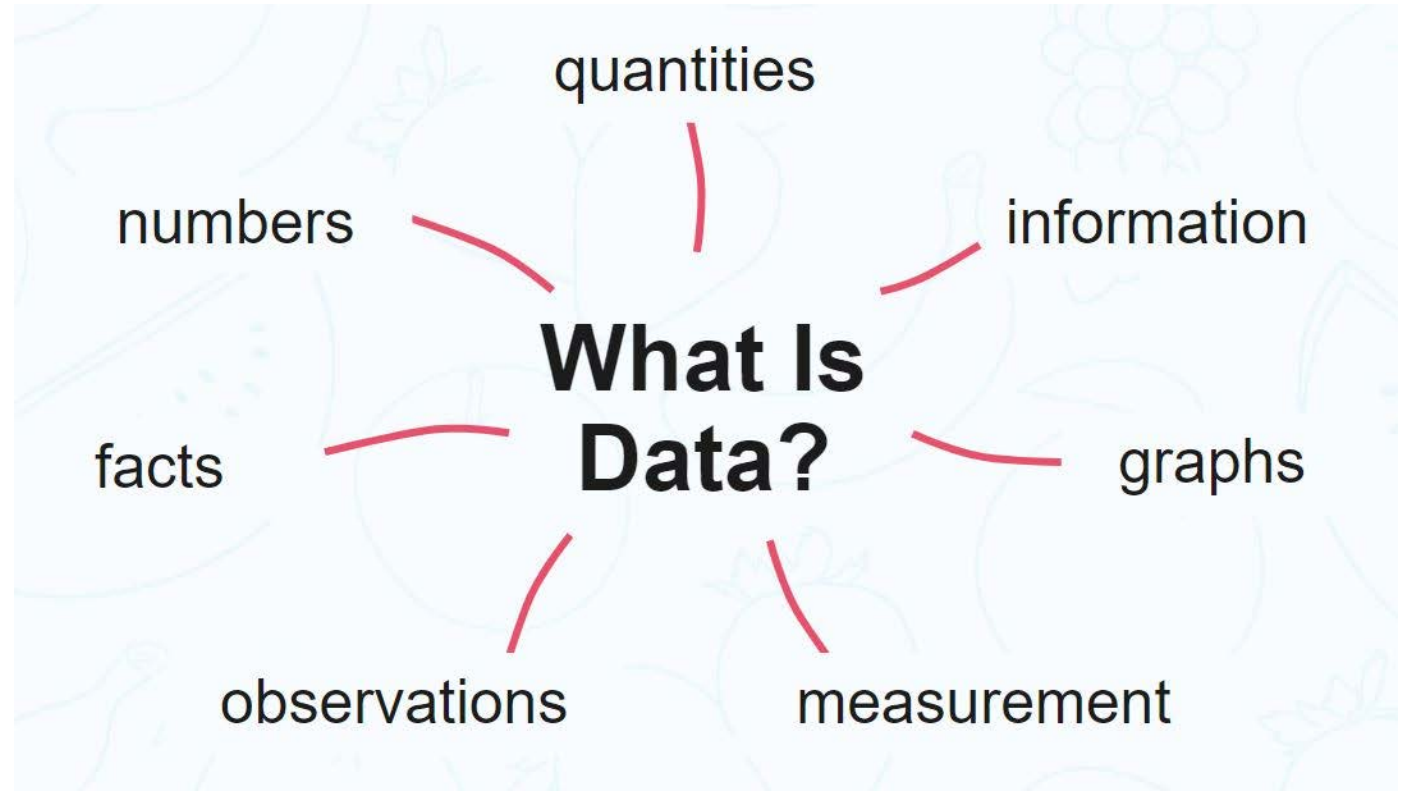
Exam Dates and Age Ranges as of 2019 - rev 9.11.2019

Original Cohort (idtype = 0)

Exam	Exam Date Range	Age Range	Mean Age	Attendees
Exam 1	1948 - 1953	28 - 74	44	5209
Exam 2	1950 - 1955	31 - 65	46	4792
Exam 3	1952 - 1956	32 - 67	48	4416
Exam 4	1954 - 1958	34 - 69	50	4541
Exam 5	1956 - 1960	37 - 70	52	4421
Exam 6	1958 - 1963	38 - 72	54	4259
Exam 7	1960 - 1964	40 - 74	55	4191
Exam 8	1962 - 1966	42 - 76	57	4030
Exam 9	1964 - 1968	44 - 78	59	3833
Exam 10	1966 - 1970	46 - 80	61	3595
Exam 11	1968 - 1971	49 - 81	62	2955
Exam 12	1971 - 1974	50 - 83	64	3261
Exam 13	1972 - 1976	53 - 85	66	3133
Exam 14	1975 - 1978	55 - 88	68	2871
Exam 15	1977 - 1979	57 - 89	69	2632
Exam 16	1979 - 1982	59 - 91	70	2351
Exam 17	1981 - 1984	61 - 93	72	2179
Exam 18	1983 - 1985	63 - 94	74	1825
Exam 19	1985 - 1988	65 - 96	75	1541
Exam 20	1986 - 1990	67 - 97	77	1401
Exam 21	1988 - 1992	69 - 99	79	1319
Exam 22	1990 - 1994	72 - 101	80	1166
Exam 23	1992 - 1996	73 - 101	81	1026
Exam 24	1995 - 1998	76 - 103	83	831
Exam 25	1997 - 1999	78 - 104	84	703
Exam 26	1999 - 2001	79 - 103	86	558
Exam 27	2002 - 2003	82 - 104	87	414
Exam 28	2004 - 2005	84 - 104	89	303
Exam 29	2006 - 2007	85 - 102	91	218
Exam 30	2008 - 2010	88 - 102	92	141
Exam 31	2010 - 2011	90 - 99	92	91
Exam 32	2012 - 2014	93 - 106	96	40

Offspring Cohort (idtype = 1)

Exam	Exam Date Range	Age Range	Mean Age	Attendees
Exam 1	1971 - 1975	5 - 70	36	5124
Exam 2	1979 - 1983	17 - 77	44	3863
Exam 3	1981 - 1987	18 - 77	48	3873



How do I get the FHS
data?



For Researchers

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The database of Genotypes and Phenotypes (dbGaP)

Framingham Heart Study molecular genetic data (e.g. SHARe (100K, 550K, and Omni5 SNPs), CARE (50K SNPs from ~2,100 candidate genes), Medical Resequencing (targeted re-sequencing), SABRe (proteomics, metabolomics/lipomics, immunoassays, gene expression and microRNA profiling), and ESP Heart-GO (exome sequencing)) in combination with the phenotypic data is now available through dbGaP at the Framingham Cohort link. New applications for all molecular genetic data linked to phenotypes should follow the process outlined at [dbGaP](#).

Biologic Specimen and Data Repository Information Coordinating Center (BioLINCC)

Much of Framingham's Original Cohort, Offspring, and Third Generation exam data is available through NHLBI's BioLINCC. New applications for clinical data should follow the process outlined at [BioLINCC](#).

<https://www.ncbi.nlm.nih.gov/gap/>

dbGaP

dbGaP

Search

Limits Advanced

Help



COVID-19 Information

[Public health information \(CDC\)](#) | [Research information \(NIH\)](#) | [SARS-CoV-2 data \(NCBI\)](#) | [Prevention and treatment information \(HHS\)](#) | [Español](#)



dbGaP

The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the data and results from studies that have investigated the interaction of genotype and phenotype in Humans.

Access dbGaP Data

[Advanced Search](#)

[Controlled Access Data](#)

[Public FTP Download](#)

[Collections](#)

[Summary Statistics](#)

Resources

[dbGaP Data Browser](#)

[Phenotype-Genotype Integrator](#)

[dbGaP RSS Feed](#)



[Software](#)

Important Links

[How to Submit](#)

[FAQ](#)

[Code of Conduct](#)

[Security Procedures](#)

[Contact Us](#)

Latest Studies

Study	Embargo Release	Details	Participants	Type Of Study	Links	Platform
<p>phs002172.v1.p1</p> <p>Gabriella Miller Kids First Pediatric Research Project in Microtia in Hispanic Populations</p>	Version 1: passed embargo	V D A S	403	Cohort, Parent-Offspring Trios	Links	
<p>phs002162.v1.p1</p> <p>Kids First: Genetics of Kidney and Urinary Tract Malformations</p>	Version 1: passed embargo	V D A S	147	Cohort, Parent-Offspring Trios	Links	

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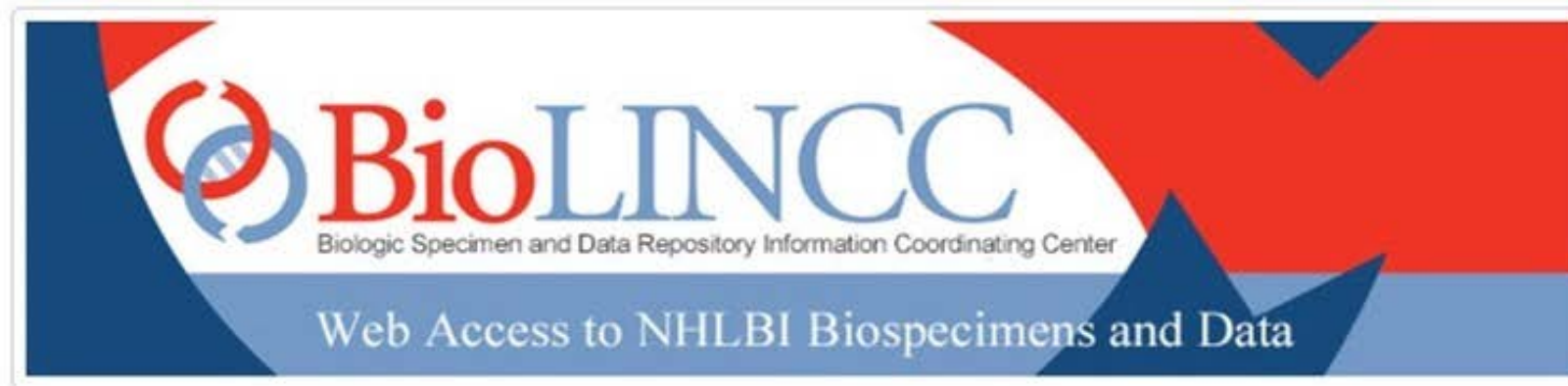
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<https://biolincc.nhlbi.nih.gov/home/>

Biologic Specimen and Data Repository Information Coordinating Center

[Home](#) [Biospecimen and Data Resources](#) [Procedures and Forms](#) [Build/Submit New Collection](#) [Contact Us](#)

[Home](#)



- ◉ Learn about the program: [The BioLINCC Handbook \(PDF - 2.4 MB\)](#)
- ◉ View the NHLBI Biorepository Guide to Building Biospecimen Collections
- ◉ Read about the establishment and development of BioLINCC

- ◉ [Register a BioLINCC Account](#), enabling you to request resources
- ◉ View the NHLBI Biorepository video: NHLBI Biospecimen and Data Repository Program: Advancing Medical Research
- ◉ Learn about the results of the first 6 years [of BioLINCC](#)

Featured News - 3 Items

Funding Opportunities Added

New information regarding secondary data and/or biospecimen analysis funding opportunities from NHLBI, NIDDK, and FDA has been added to the funding opportunities page. These NIH Exploratory (R21) grant funding opportunities may be applicable to research using BioLINCC resources. Additionally included is an NHLBI released Notice of Special Interest (NOSI) on

[Previous](#)

[Pause](#)

[Next](#)

Recent News

New Study: TMH-RING (data)

2021.10.07

BU-FHS service center fee structure

Rationale: to support non-core contract research

Service Type	Example		Fees
<u>Data requests</u>	<u>No. of exams</u>	<u>No. of variables</u>	<u>Amount</u>
Simple	1	≤ 100	\$3000
Moderate	Multiple	≤ 100	\$5000
Advanced	Multiple	>100	\$10,000
Lab requests			Varies
DNA/aliquot			Varies
Biospecimen/aliquot			Varies

**established July 1, 2014



How do I submit a
research proposal using
FHS data?





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Submitting a Research Proposal to FHS

Researchers are encouraged to review the linked guides (below) and detailed information on this page (further below) before submitting to a research proposal to the Framingham Heart Study.

- [A Guide for Investigators I – PIs interested in requesting FHS data](#)
- [A Guide for Investigators II – PIs interested in collaborating for FHS Gen 3/Omni2 Exam 4](#)

After your research proposal is approved, ancillary study investigators must also review and adhere to our [Policies and Procedures](#).

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[Gen 3/Omni 2 Exam 4
Collaboration](#)

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[Research Review Committees](#)

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For new and returning users: [FHS Research Application User Guide](#)

For additional help please email FHSapp@bu.edu

Once submitted, an administrator will guide the application to the appropriate review committee(s) based on requirements of the proposal as indicated in Part 3 of the application. FHS policies and procedures for research proposals are described under [Submitting a Research Proposal](#) and [Policies and Procedures](#).

IMPORTANT:

- Projects that are seeking sponsorship must be approved by the FHS Executive Committee before the study PI submits to a sponsor for funding.
- In order to recover costs to the Framingham contract associated with servicing ancillary studies, FHS will be assessing fees for data and material distributions as described in the FHS Service Center.

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FHS Research Application ('FHS ResApp')



Welcome to the web based Framingham Heart Study Research Application. The application is a single form for investigators to use to submit a research proposal for review by one or more FHS review committees.

Pre-submission:

1. **Review FHS policies and procedures** for research proposals are described on the FHS website under for [Submitting a Proposal](#) and [Ancillary Studies Policies and Procedures](#)
2. **Costs are the responsibility of the Ancillary Study.** The FHS Research Service Center at Boston University is established to provide ancillary studies with the services they require by structured fees or sub-contracts.
You are required to contact Nicholas DiPersio (dipersio@bu.edu) and complete the budget review process prior to your submission to a sponsor.
Please allow for adequate time to complete the process which may involve initial assessment and follow-up.
3. **Applications must obtain [FHS Executive Committee](#) approval prior to submitting to any sponsor.**
APPLICATIONS MUST BE SUBMITTED 6-8 WEEKS PRIOR TO YOUR SPONSOR'S DEADLINE FOR APPROPRIATE REVIEW BY FHS

Submission:

4. **Pay special attention to accurately answer questions in part 3** of the application 'Proposal Review Process'; once submitted, the application will be routed to the appropriate review committee(s) based on this information.

Post-Submission:

5. If you are seeking funding for your FHS EC-approved proposal, notify fhs@bu.edu when you receive your award.

Modifications

6. To make a revision of your approved application, revise the application online and attach a completed [Modification Form](#) as a cover letter that describes the proposed revisions.

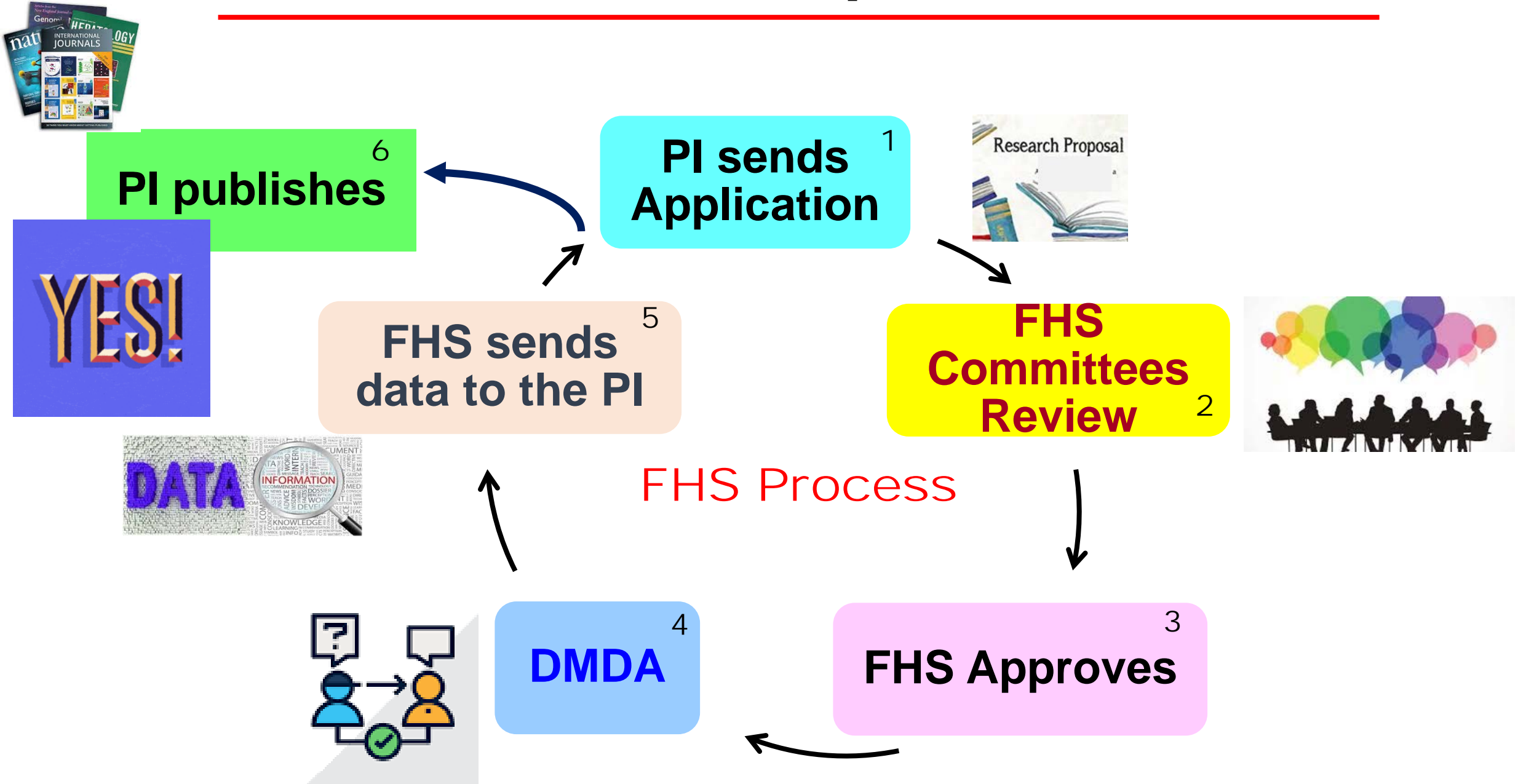
To get started please click 'Login' in the top right of this homepage.

Key Points for FHS review

- Respect participant **informed consent**
- Protect participant **confidentiality**
- **Feasibility** (samples and data are available?)
- **Overlap** with ongoing ancillary studies/funded research
- **Limit participant burden**
- **Scientific merit**



FHS Review process



Framingham Heart Study Biorepository

- Core mission: Preservation, tracking/distribution and appropriate utilization of biological specimens from FHS participants

- Compilation and curation of samples for
to central database by investigators
(dbGAP)

1.3 million biosamples (serum, plasma, buffy coat, red cells, urine) ...Waiting to be used!!

Thousands of variables available to be explored!!!



Summary

- **FHS:**

- looks forward to receiving applications for use of its pre-enrolled participant data & biosamples for research
- has simplified the application & review process
- is eager to help PIs
- Contact: fhs@bu.edu





Thank you!

