

T32 Data Mapping

Report by DACC

2010 Annual Meeting

Tempe, Arizona

Executive Summary

- NHGRI and advisors deem it important to assess the success and outcomes of the diversity action plan – Proper assessment relies on standardized data collection
 - T32s already vested in LARGE data collection efforts every 5 years
 - How can we leverage existing information (collected at great expense by the T32s) to get the required standardized data?
- This presentation discusses how to balance between what NHGRI needs and what is already available by ...
 - (1) identifying the players, (2) reviewing the basic questions, (3) reviewing the available data, (4) proposing a POA, (5) opening the discussion to all concerned and hammering out the details
- Our *goal* is to leave with a mutually-agreeable proposal that leads to a system of collecting the necessary data in a standardized format and that is efficient and sufficient for all concerned

Overview

I. Identify T32 programs

II. Basic Evaluation Questions

- A. Assess Success of T32 Programs
- B. Outcome Analysis

III. Summary of Already Collected T32 Information

- A. T32 Tables
- B. Trainee Appointment Form

IV. Consistency

- A. Among T32 grants?
- B. Across T32 vs MAP?

V. Are T32 Tables Sufficient?

VI. Additional Comments / Questions

VII. Where do we go from here?

OVERVIEW

- I. Identify T32 Programs

12 CURRENT PROGRAMS

Identify T32 Programs

Inception	Institution	Pre	Post	Program Director (s)	
1995	Stanford Univ.	✓	✓	Richard Meyers Arend Sidow	1995 – 2008 2008 – present
1995	U Michigan	✓	✓	Michael Boehnke	1995 – present
1995	U Washington	✓	✓	Barbara Trask Stanley Fields Willie Swanson	1995 – 2003 2003 – 2008 2008 – present
1995	Washington U	✓	✓	David States Sean Eddy Michael Brent	1997 – 2001 2001 – 2003 2003 – present
1999	U Pennsylvania	✓	✓	Chris Overton & Warren Ewens Lyle Ungar	1999 – 2006 2006 – present
2000	MIT	✓	∅	Isaac Kohane	2000 – present
2000	UC Berkeley	✓	✓	Daniel Rokhsar & Jasper Rine	2000 – present
2002	UC Los Angeles	✓	∅	Kenneth Lange & Janet Sinsheimer	2002 – present
2003	U Wisconsin-Madison	✓	✓	David Schwartz	2003 – present
2004	Princeton U	✓	∅	David Botstein	2004 – present
2004	Yale U	✓	✓	Mike Snyder Xing Wang Deng	2004 – 2009 2009 – present
2009	MIT/Broad	✓	∅	David Gifford	2009 – present

OVERVIEW

II. Basic Evaluation Questions

A. ASSESS SUCCESS OF T32 PROGRAMS

B. OUTCOME ANALYSIS

A. Assess Success of T32 Programs

1. Did student make successful transition from one career level to the next?
2. Did student remain in a STEM field or field requiring knowledge of STEM discipline?
3. Did student remain in research?
4. What tangible outcomes did training have?
5. Participation in other MAP or non-MAP training programs?
6. What was student's institution prior to MAP?
7. Where originally learn about MAP?

B. Outcome Analysis

1. Did we train leaders?
2. What elements of training impacted success?
3. What are predictors of success?
4. What/who influenced student's career?
5. How did duration of training impact success?

OVERVIEW

III. Summary of Already Collected T32 Information

A. T32 TABLES

B. TRAINEE APPOINTMENT FORM (TAF)

B. Trainee Appointment Form (Form PHS 2271)

- Information Available
 - Name, sex, Training Grant #
 - Prior NRSA support
 - SSN (do not want)!
 - Birthdate
 - **Citizenship**
 - Permanent mailing address
 - **Race, ethnicity**
 - **Disability status**
 - Disadvantaged background
- Information Available
 - Field of research training or career development
 - Education after high school (institution, degree, major, minor)
 - Specialty Boards
 - Degrees being sought
 - Dual degree (MD/PhD)
 - Expected completion date of degree
 - Type and amount of support

A. T32 Tables

1. Membership of participating departments
2. Participating Faculty Members
3. Institutional TG Support available to participating faculty members and departments
4. Grant and contract support of participating faculty members
5. Pre- and postdoctoral trainees of the participating faculty members (past 10 years)
6. Publications of Research completed by Trainees
7. Admissions and completion records for participating departments during past 5 years
8. Qualifications of recent applicants
9. Qualifications of current trainees clearly associated with TP
10. Admissions and completion records for URM (etc) clearly associated with TP
11. Appointments to TP grant for each year of past award
12. Trainees supported by this TP

A. T32 Tables

- Problems with tables
 - No single table has all information
 - Most have TOO MANY trainees listed
 - Some do not provide trainee names even though individual trainee information is provided

III. Summary of T32 Information

Tables

Information	5	6	8	9	10	12	TAF
Trainee Name	✓	✓				✓	✓
Sex / Race / Ethnicity / Disability & Disadvantaged status / DOB / Citizenship							✓
Faculty/Mentor Name	✓	✓		✓		✓	✓
Training Department				✓	✓		
Prior degree(s) (institution, degree, year)	✓		✓	✓			✓
Specialty Boards							✓
Career level during training (Pre- vs Post-doc)	✓	✓	✓	✓		✓	✓
Training period (Yr start , end)	✓			✓	✓	✓	✓
Research Topic	✓					✓	✓
Publication list (CV)		✓					
GRE scores (V, Q, W)			✓	✓			
Undergrad GPA			✓	✓			
Source of trainee's grant support					✓	✓	✓
Current status / position / employment	✓				✓	✓	
Prior NRSA support							✓
Permanent Mailing Address							✓
Problems: No names – Need PI/PD to help resolve missing information			✓	✓	✓		
Problems: Too many listed (must reduce to relevant trainees)	✓	✓	✓			✓	

OVERVIEW

IV. Consistency

A. AMONG T32 GRANTS

A. Among T32's: Table 5

Table 5: Pre and Post-Doctoral Trainees of Participating Faculty Members (Past 10 Years)

Boehnke, Michael

Faculty Name / Trainee Names	Pre- or Post-Doc	Training Period	Research Topic	Prior Degree(s)	Current Support or Current Position
Boehnke, Michael					
	Pre	1993 - 1999	The Application of Statistical Methods for Highly Stratified Data to Linkage and Association Analyses of Complex Genetic Traits	MS Nebraska 1986 MS Florida State 1988	Associate Professor Department of Biostatistics Wake Forest University Winston-Salem, North Carolina
	Pre	1992 - 2000	Bayesian Solutions to Problems of Uncertainty in Genetic Data	BA Walla Walla 1991	Research Area Specialist Lead Department of Biostatistics University of Michigan Ann Arbor, Michigan

Table 5. Pre- and Postdoctoral Trainees of Participating Faculty Members (Alphabetically by Faculty Member for the Past Ten Years)

Faculty Member Past and Current Students	Pre or Post	Training Period	Prior Academic Degree			Title of Research Project	Current Position (past trainees) Source of Support (current trainees)
			Degree (s)	Year (s)	Institution (s)		
	Post	96-00	Ph.D.	95	SUNY Buffalo	DNA Dielectrophoresis	Assist. Prof., Inst. Physics Acad. Sinica
	Post	04-07	PhD	03	Szaged	Nanotechnology in Biology	Post-doc, Harvard University
	Post	06-07	PhD	05	Princeton	Directed Evolution	Assist. Prof. Delft Technical University

A. Among T32's: Table 12

Table 12A. Predoctoral Trainees Supported by University of Michigan Genome Science Training Program (Past 10 Years)

Trainee	Faculty Mentor	Year Entered	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	Research Topic	Current Funding or Current Position
		1992	RG	RG									Quantitative Trait Locus Analysis in a Mouse Four-Way Cross	Research Specialist Lead, Department of Biostatistics University of Michigan
		1996	UF	UF	UF								Statistical Methods in Gene Mapping of Familial Traits	Assistant Professor Human Genetics Emory University
		1996	TG										A Glomerulonephritis Mouse Model	Bioinformatics Specialist Pfizer

Table 12A. Predoctoral Trainees Supported by this Training Grant (Renewal Applications and Non-Competing Continuation Progress Reports Only)

Predoctoral (and MSTP) Trainees (Listed sequentially by Entering Class):

Trainee, Year of Entry Prior Degree & Institution (Mentor Department/program)	Source(s) of Support Each Grant Year/Academic Year										Title of Research Project or Research Topic	Degree(s) Received (Year)	Current Position and Institution (grant support obtained)	
	01 04/05	02 05/06	03 06/07	04 07/08	05 08/09	06	07	08	09	10				
	TG/F	TG/TAF	RG	RG	RG								Protein interactions	In training
	TG/F	TG/F	TG/F	RG									Biological pathways/methods to profile chromosomal abnormalities	PhD (2007) Asst. Professor, Computer Science, University of Minnesota
	TG/F	ML	TG/F	RG	RG								Design of proteins <i>de novo</i>	In training

A. Among T32's: Table 6

Table 6. Publications of Trainees

Boehnke, Michael

Pre-Doctoral Trainees

Past Trainees:

(Burke)

, 2002, Mouse loci associated with life span exhibit sex-specific
Series A-Biological Sciences & Medical Sciences, 57:B9-15.

Burke DT, 2002, Coordinated genetic control of neoplastic and
gerontology Series A-Biological Sciences & Medical Sciences,

**Table 6. Publications of Research Completed by Trainees (or Potential Trainees)
(List Pre/Postdoctoral and Past/Current Trainees Separately and Alphabetically in Each Group)**

Past Trainees:

Name of Trainee (Years in Program)	Mentor(s)	Publication (Authors, Year, Title, Journal)
		B., Singh M. Organization of Physical Network Schemas. PLOS Computational
		R., Singh M. NetGrep: Fast network analysis. Genome Biology.
		I, E, Botstein, D, Genetic and hormonal response to

No Names

A. Among T32's: Table 9

Table 9A. Qualifications of the Current Predoctoral Trainees GSTP Trainees (2009-2010)

Trainee Department	Previous Institution(s)	Degree(s) & Year(s)	GRE Scores (Percentiles) V, Q, W	Undergraduate GPA	Current Research Mentor	Years in Program	Years Appointed to GSTP
1* Ecology and Evolutionary Biology	Wayne State University University of Michigan	BS 2002 MS 2004	780 (99%) 800 (92%) 6.0 (96%)	3.94	Zhang, J.	2003-present	2007-present
2* Human Genetics	Iowa State University	BS 2002	630 (88%) 730 (75%) 5.0 (71%)	2.95	Moran, J.	2003-present	2008-present
3* Biostatistics	Grand Valley State	BS 2007	570 (78%) 760 (85%)	3.96	Boehnke, M.	2007-present	2007-present

Table 9A. Qualifications of the Current Predoctoral Trainees Clearly Associated with the Training Program

Trainee (List by Number) Department or Program	Previous Institution(s)	Degree(s) & Year(s)	GRE Scores/(Percentiles) V, Q, Adv and/or MCAT Scores	Undergraduate GPA	Current Research Mentor	Years in Program	Calendar Years Appointed to this Grant
CS-7*	MIT / Univ Washington	BS '04/ MS '07	740, 800, NA	3.80	Singh, M.	07-present	None
CS-9*	Univ of Washington	BS'04/BS '07	530, 800, NA	3.89	Troyanskaya, O.	07-present	7/1/09-present
MB-1*	University of California, Los Angeles	BS '06	670, 730, NA	3.65	Kruglyak, L.	07-present	None (T32 GM007388)
PHY-7*	Harvey Mudd College	BS '06	730, 800, 910	3.78	Bialek, W.	07-present	7/1/08-present
CS-4	Tsinghua Univ	BEng '07	650, 790, NA	3.91	Singh, M.	07-present	None
MB-21	Tehran University	BS '06	520, 680, NA	3.93	Kruglyak, L.	07-present	None

OVERVIEW

IV. Consistency

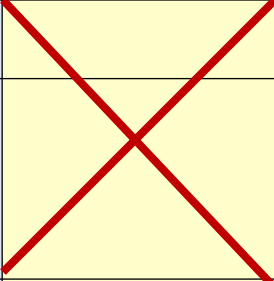
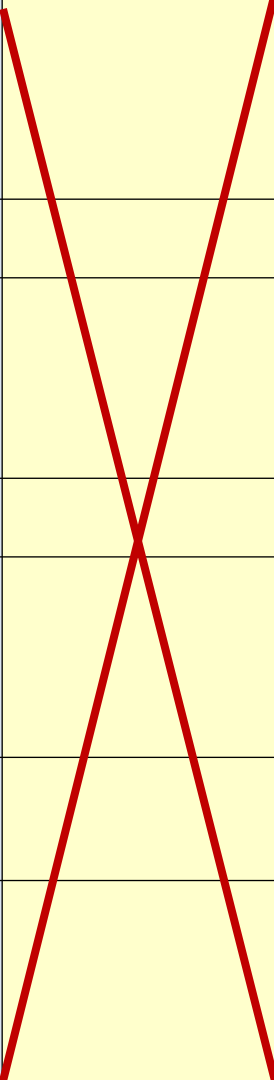
B. ACROSS T32 VS MAPS

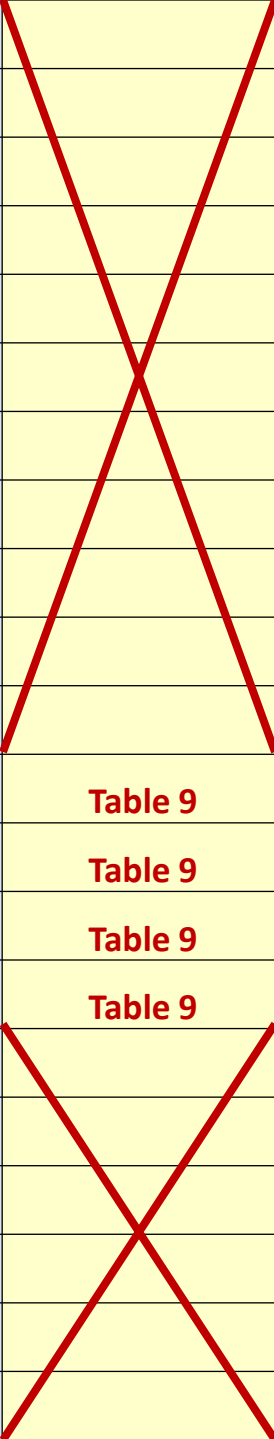
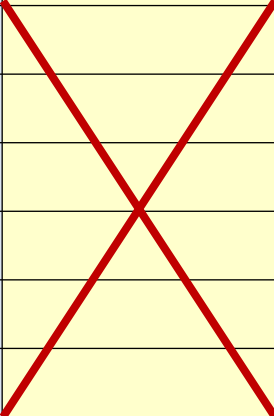
Item#	Variable / Field Name	Field Label	Description	T32 Tables
1	trainee_id	Trainee ID Number	Enter unique 5-digit code -- Assigned by program, see value range reserved for your program on Instructions page	Assigned
2	non_map_funded	Non-MAP-funded URM?	0 = No, 1 = Yes	Tables 10, 12, TAF
3	baseline_date	Date trainee entered program	Enter as YYYY-MM-DD	Tables 5, 9, 10, 12
4	pgm_grant_type	Grant Type	1 = CEGS 2 = Database 3 = Sequence 4 = T32 5 = Other	Given
5	pgm_type	Type of Program	1 = K-12 2 = K-12 and Undergraduate 3 = Undergraduate 4 = Post-Bacc 5 = Graduate 6 = Post-Doc 7 = Medical Fellow 8 = Faculty	Table 9, 12
6	map_point	Education level at time of MAP program enrollment/training: Choose one	1 = High school 2 = Trade school 3 = Two-year college 4 = Four-year college 5 = Post-Baccalaureate 6 = Master's 7 = Doctorate 8 = Medicine 9 = Post-doctorate 10 = Faculty enrichment or sabbatical 99 = Unknown	Tables 5, 8, 9, TAF

7	gender	Gender	1 = Male 2 = Female 99 = Unknown	TAF
8	ethnicity	Ethnicity	0 = Not Hispanic, Latino, or Spanish 1 = Hispanic, Latino, or Spanish 99 = Unknown	TAF
9	ethnic_latino____ 1	IF Hispanic, Latino, or Spanish Origin: Is trainee Mexican, Mexican American, or Chicano?	1 = Yes, else leave blank	TAF
10	ethnic_latino____ 2	IF Hispanic, Latino, or Spanish Origin: Is trainee Puerto Rican?	1 = Yes, else leave blank	TAF
11	ethnic_latino____ 3	IF Hispanic, Latino, or Spanish Origin: Is trainee Cuban?	1 = Yes, else leave blank	TAF
12	ethnic_latino____ 4	IF Hispanic, Latino, or Spanish Origin: Is trainee Other Hispanic, Latino, or Spanish origin (describe below)?	1 = Yes, else leave blank	TAF
13	ethnic_other	Other Hispanic, Latino, or Spanish Origin	Enter description	TAF

14	race___1	Race: White	1 = Yes, else leave blank	TAF
15	race___2	Race: Black, African American, or Negro	1 = Yes, else leave blank	TAF
16	race___3	Race: American Indian or Alaska Native (enter tribal information below)	1 = Yes, else leave blank	TAF
17	race_tribe	If American Indian or Alaska Native marked above, enter name of enrolled or principal tribe	Enter description	TAF
18	race___4	Race: Asian Indian	1 = Yes, else leave blank	TAF
19	race___5	Race: Chinese	1 = Yes, else leave blank	TAF
20	race___6	Race: Filipino	1 = Yes, else leave blank	TAF
21	race___7	Race: Japanese	1 = Yes, else leave blank	TAF
22	race___8	Race: Korean	1 = Yes, else leave blank	TAF
23	race___9	Race: Vietnamese	1 = Yes, else leave blank	TAF
24	race___10	Race: Other Asian (describe below)	1 = Yes, else leave blank	TAF
25	race_asian	If Other Asian Race marked above, enter description	Enter description	TAF
26	race___11	Race: Native Hawaiian	1 = Yes, else leave blank	TAF
27	race___12	Race: Guamanian or Chamorro	1 = Yes, else leave blank	TAF
28	race___13	Race: Samoan	1 = Yes, else leave blank	TAF
29	race___14	Race: Other Pacific Islander (describe below)	1 = Yes, else leave blank	TAF

33	learn_map___1	Where did trainee find out about MAP program: SACNAS?	1 = Yes, else leave blank	Table 9, TAF
34	learn_map___2	Where did trainee find out about MAP program: ABRCMS?	1 = Yes, else leave blank	
35	learn_map___3	Where did trainee find out about MAP program: Principal Investigator?	1 = Yes, else leave blank	
36	learn_map___4	Where did trainee find out about MAP program: Mentors?	1 = Yes, else leave blank	
37	learn_map___5	Where did trainee find out about MAP program: Social Networking?	1 = Yes, else leave blank	
38	learn_map___6	Where did trainee find out about MAP program: Contacts with former MAP students from home institution?	1 = Yes, else leave blank	
39	learn_map___7	Where did trainee find out about MAP program: Contacts with students from another MAP program?	1 = Yes, else leave blank	
40	learn_map___8	Where did trainee find out about MAP program: Some other source?	1 = Yes, else leave blank	
41	learn_map_other	If other, describe	Enter description	
42	come_from	What institution did trainee come from before participating in the current program?	Enter name of institution	

43	gpa_hs	High School GPA	Enter number	
44	gpa_hs_s	High School Grading Scale	1 = 4.0 Scale 2 = 5.0 Scale 3 = Other	
45	gpa_ug	Undergraduate GPA	Enter number	Table 9 
46	gpa_ug_s	Undergraduate Grading Scale	1 = 4.0 Scale 2 = 5.0 Scale 3 = Other	
47	gpa_ms	Master's Level GPA	Enter number	
48	gpa_ms_s	Master's Level Grading Scale	1 = 4.0 Scale 2 = 5.0 Scale 3 = Other	
49	gpa_phd	Doctoral GPA	Enter number	
50	gpa_phd_s	Doctoral Grading Scale	1 = 4.0 Scale 2 = 5.0 Scale 3 = Other	
51	gpa_g	Other Graduate School GPA	Enter number	
52	gpa_g_s	Other Graduate Grading Scale	1 = 4.0 Scale 2 = 5.0 Scale 3 = Other	

53	sat	Did trainee take the SAT?	0 = No, 1 = Yes		
54	sat_math	Math score	Enter score (range 200-800)		
55	sat_verbal	Critical Reading score	Enter score (range 200-800)		
56	sat_writing	Writing score	Enter score (range 200-800)		
57	sat_total	Total score	Enter score (range 600-2400)		
58	act	Did trainee take the ACT?	0 = No, 1 = Yes		
59	act_english	English score	Enter score (range 1-36)		
60	act_math	Math score	Enter score (range 1-36)		
61	act_reading	Reading score	Enter score (range 1-36)		
62	act_science	Science score	Enter score (range 1-36)		
63	act_composite	Composite score	Enter score (range 1-36)		
64	gre	Did trainee take the GRE?	0 = No, 1 = Yes		Table 9
65	gre_verbal	Verbal score	Enter score (range 200-800)		Table 9
66	gre_quant	Quantitative score	Enter score (range 200-800)	Table 9	
67	gre_writing	Analytical writing score	Enter score (range 0-6)	Table 9	
68	mcats	Did trainee take the MCAT?	0 = No, 1 = Yes		
69	mcats_verbal	Verbal score	Enter score (range 1-15)		
70	mcats_phys	Physical score	Enter score (range 1-15)		
71	mcats_bio	Biological score	Enter score (range 1-15)		
72	mcats_composite	Composite score	Enter score (range 3-45)		
73	mcats_writing	Writing score	Enter score (range J-T)		

74	oth_map	Has trainee participated in other MAP training programs?	0 = No 1 = Yes 99 = Unknown		
75	non_map	Has trainee participated in non-MAP training programs?	0 = No 1 = Yes 99 = Unknown		
76	sc_total	Number of trainee's scholarships / fellowships	Enter number		
77	cdaward_total	Number of trainee's career development / K awards	Enter number		
78	gaward_total	Number of trainee's peer-reviewed grants or research awards	Enter number		
79	pres_total	Number of trainee's presentations at baseline	Enter number		Table 6
80	pub_total	Number of trainee's publications at baseline	Enter number		Table 6
81	pat_total	Number of trainee's patents and copyrights at baseline	Enter number		
82	trn_comments	Comments on trainee at baseline	Enter any comments on the trainee at baseline that are not included elsewhere		

Item#	Variable / Field Name	Field Label	Description	T32 Tables
1	trainee_id	Trainee ID Number	Enter unique 5-digit code -- Assigned by program, see value range reserved for your program on Instructions page	Assigned
2	fu_date	Date of LAST known follow-up assessment	Enter as YYYY-MM-DD, Leave blank if no follow-up and provide detail in comments at end of this section (Trainee Challenges text)	Report Date
3	fu_current_status	What is trainee's current primary status?	1 = Student 2 = Employed 3 = Seeking employment 4 = Neither employed nor student by choice 5 = Other 99 = Unknown	Tables 5, 10, 12
4	fu_other_status	If other status above, describe	Enter description	Tables 5, 10, 12
5	fu_educ_stem	Is trainee currently a STUDENT involved in a STEM field?	0 = No 1 = Yes 99 = Unknown	Tables 5, 10, 12
6	fu_educ_research	Is trainee currently a STUDENT involved in RESEARCH?	0 = No 1 = Yes 99 = Unknown	Tables 5, 10, 12
7	fu_emp_stem	Is trainee currently EMPLOYED in a STEM field?	0 = No 1 = Yes 99 = Unknown	Tables 5, 10, 12
8	fu_educ_research	Is trainee currently EMPLOYED in RESEARCH?	0 = No 1 = Yes 2 = Teaching related to research 99 = Unknown	Tables 5, 10, 12

9	fu_current_degree	Education level at follow-up	1 = High school 2 = Trade school 3 = Associate's 4 = Bachelor's 6 = Master's 7 = Doctorate 8 = Medicine 9 = Post-doctorate 10 = Faculty 99 = Unknown	Tables 10, 12
10	fu_oth_map	Has trainee participated in other MAP training programs since enrollment?	0 = No 1 = Yes 99 = Unknown	
11	fu_non_map	Has trainee participated in any non-MAP training programs since enrollment?	0 = No 1 = Yes 99 = Unknown	
12	fu_sc_total	Number of trainee's scholarships / fellowships at follow-up	Enter number	
13	fu_cdaward_total	Number of trainee's career development / K awards at follow-up	Enter number	
14	fu_graward_total	Number of trainee's peer-reviewed grants or research awards	Enter number	
15	fu_pres_total	Number of trainee's presentations at follow-up	Enter number	Table 6
16	fu_pub_total	Number of trainee's publications at follow-up	Enter number	
17	fu_pat_total	Number of trainee's patents and copyrights at follow-up	Enter number	
18	fu_trn_success	Trainee Successes	Enter any other successes this trainee has had and what contributed to those successes (if known)	
19	fu_trn_challenge	Trainee Challenges	Enter any challenges this trainee has had and how these were addressed or overcome (if known)	

OVERVIEW

V. Sufficiency?

**IS CURRENT T32 INFORMATION
SUFFICIENT?**

Is current T32 information sufficient?

- Most BASELINE information can be derived from
 - TAF: Defines master list of trainees for that T32
 - Who has copies of all TAFs for given program (PI/PD)
 - Tables 6, 9 and 12 provide some additional information
- Nominally consistent AND sufficient compared to MAP information
- Follow-up will fill in the holes

OVERVIEW

VI. Additional Comments / Questions

NEW QUESTIONS?

NON-URM

IRB?

Additional Comments / Questions

- **Questions to add to database based on T32?**
 - Research Topic (name of research topic) ?
- **Non-URM**
 - Most T32s have few individuals from qualified groups
 - WILL T32S COLLECT DATA ON ALL TRAINEES OR ONLY ON QUALIFIED (BASED ON RACE, ETHNICITY AND DISABILITY)
- **IRB issues**
 - Do T32s need IRB?
 - YES ... OR ... SIGNED Informed Consent before DACC can accept data
 - Suggest: T32's ask for expedited review requesting exempt status?
 - DACC will provide example forms / write-up / informed consents as we did for MAPs

OVERVIEW

VII. Where do we go from here?

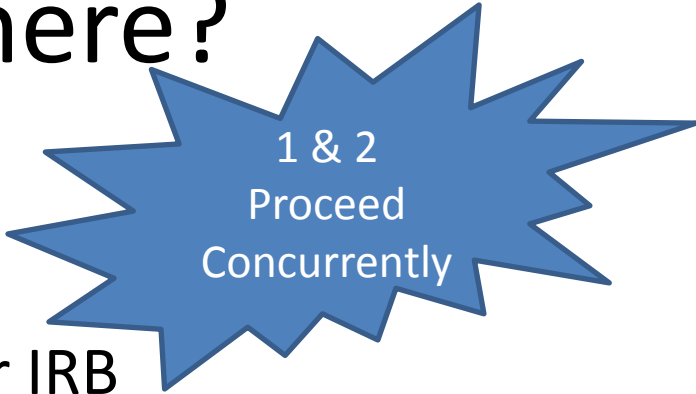
IRB

DATA COLLECTION PROTOCOL

Where do we go from here?

1. Begin IRB process

- a) DACC provides draft documents
- b) Each T32 begins dialog with their IRB



1 & 2
Proceed
Concurrently

2. “Enroll” all trainees on T32 grants

- a) Use Trainee Application Form (TAF)
 - Enter TAF info for all T32 trainees
 - Who were supported on your T32
 - Regardless of ethnicity/race
- b) Supplement TAF information with (see next slides)
 - Table 6: Publication list
 - Table 9: GRE scores (will need to add names)
 - Table 12: Current position / location / funding source

Where do we go from here?

- **IRB Process**

- Why consider IRB?

- TRADITIONALLY DO NOT NEED

- Usually, each training program

- Is educational

- Is NOT considered research

- And consequently does NOT need IRB review

- Until this last year, this has been the case ...

Where do we go from here?

- **IRB Process**

- DO NEED IF considered “RESEARCH”

- EVERY IRB DEFINES “research” DIFFERENTLY !!!!!

- At Washington University

- Defined as “research” if , among others ...

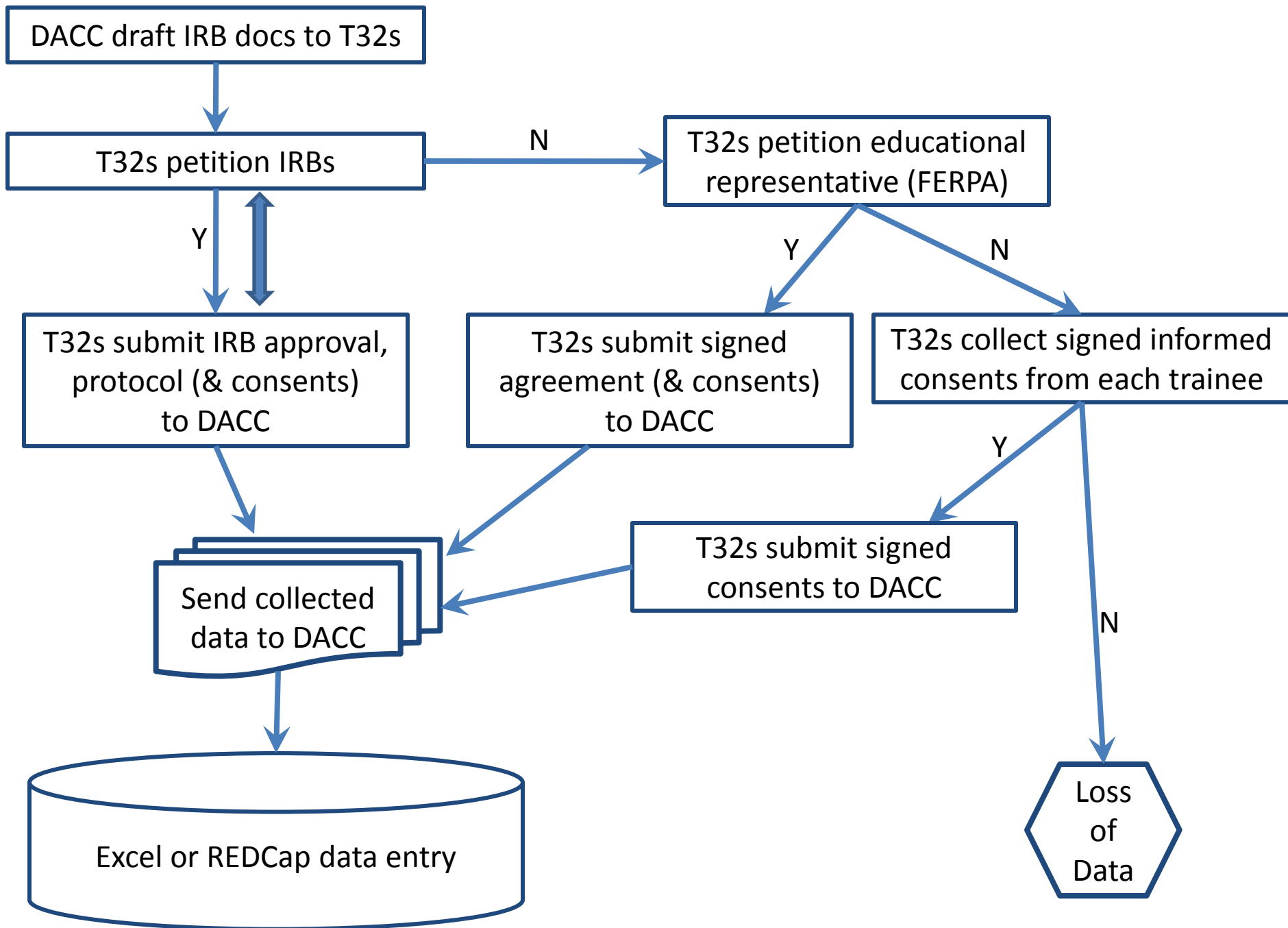
- i. SHARING data with a 3rd party who was not “actively engaged” in your study

- ii. Have plans to PUBLISH the data



Where do we go from here?

- DACC will *require*
 - Approval from your end before you can send your data to us
 - May take form of ...
 - YOUR IRB approval
 - YOUR Institutional education representative (FERPA) approval
 - » Has not worked very well in 2 cases
 - SIGNED CONSENT FORM FROM EACH TRAINEE
 - » WU has set of WU IRB approved Informed Consent forms



Where do we go from here?

- **IRB Process**

- DACC cannot receive your data until one or more of the **approval conditions*** are fully satisfied
- Two data capture systems set up
 - EXCEL:
 - For those without approval AND for “Enrollment”
 - » Data entered, but retained by MAP each program (NOT sent to DACC) until full approval is obtained
 - REDCap:
 - For those with full approval AND for “Follow-up”
 - » Data sent directly to DACC through web-based entry system

*IRB or institutional representative approval or signed informed consents

Where do we go from here?

2. “Enroll” all trainees on T32 grants

a) Use Trainee Application Form (TAF)

- Enter TAF info for all T32 trainees
 - Who were supported on your T32
 - All, regardless of ethnicity/race ???

b) Supplement **TAF** with additional information

- Table 6: Publication list
- Table 9: GRE scores (will need to add names)
- Table 12: Current position / location / funding source

17. NAME OF SPECIALTY BOARDS (if applicable)

18. DEGREE(S) SOUGHT YES NO | If yes, indicate type of degree

Are you in a dual degree program (e.g., M.D./Ph.D.)? YES NO

19. EXPECTED COMPLETION DATE OF DEGREE REQUIREMENTS (if applicable)

20. SUPPORT FOR PERIOD OF APPOINTMENT

TYPE	Total for this Grant (Credit cents)
Stipend / Salary / Other Compensation	\$
Tuition/fees (estimated)	\$
Travel (estimated)	\$
TOTAL	

21. STATEMENT OF NONDELINQUENCY ON U.S. FEDERAL DEBT: Is the appointee delinquent on the repayment of any U.S. Federal debt(s)?

NO YES (If "Yes," please explain below.)

22. CERTIFICATION AND ACCEPTANCE: I certify that the statements herein are true and complete to the best of my knowledge and that I will comply with all applicable Public Health Service terms and conditions governing my appointment. I am aware that any false, fictitious or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties.	(a) SIGNATURE OF APPOINTEE	(b) DATE
23. This individual is qualified for this program and is eligible to receive financial support for the period specified above. A copy of this appointment form will be given to the individual.	(a) SIGNATURE OF PROGRAM DIRECTOR	(b) DATE

(c) TYPED NAME OF PROGRAM DIRECTOR

(d) INSTITUTION'S NAME, ADDRESS, AND PHONE NO.
(Street, city, state, zip code)

Department of Health and Human Services
Public Health Services
Statement of Appointment
(Please Type)

Follow attached instructions carefully. Submit this form at the time the individual is appointed, is reappointed, or the reported appointment is amended. Return this form to the PHS awarding component. For new postdoctoral trainees under NRSA, signed and dated payback agreement **must** accompany this form.

<p>1. PHS GRANT NUMBER</p> <table border="1" style="width:100%; border-collapse: collapse;"> <tr> <td style="width:25%;">Type</td> <td style="width:25%;">Activity</td> <td style="width:50%;">ID Serial No.</td> </tr> </table>			Type	Activity	ID Serial No.	<p>2. APPOINTEE'S NAME (Last, first, initial)</p>		<p>3. SEX</p> <p><input type="checkbox"/> M <input type="checkbox"/> F</p>																		
Type	Activity	ID Serial No.																								
<p>4. TYPE OF ACTION (Check only one type)</p> <p><input type="checkbox"/> NEW appointment (NOT previously supported by this grant)</p> <p><input type="checkbox"/> REAPPOINTMENT (Previously supported by this grant)</p> <p><input type="checkbox"/> AMENDMENT of items checked: <input type="checkbox"/> 2 <input type="checkbox"/> 9 <input type="checkbox"/> 15 <input type="checkbox"/> 20</p>			<p>5. PRIOR NRSA SUPPORT (Individual or institutional)</p> <p><input type="checkbox"/> NO <input type="checkbox"/> YES (If "Yes," see instructions)</p>																							
<p>6. SOCIAL SECURITY NO. XXX-XX-</p>			<p>7. BIRTHDATE (Month, day, year)</p>																							
<p>8. CITIZENSHIP (See instructions)</p> <p><input type="checkbox"/> U.S. Citizen or Noncitizen National</p> <p>Non-U.S. Citizen</p> <p><input type="checkbox"/> With a Permanent U.S. Resident Visa ("Green Card")</p> <p><input type="checkbox"/> With a Temporary U.S. Visa</p> <p>If not a U.S. citizen, of which country are you a citizen?</p>			<p>9. PERMANENT MAILING ADDRESS</p> <p>E-mail _____</p>																							
<p>10. Are you Hispanic (or Latino)? <input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Do Not Wish to Provide</p>																										
<p>11. What is your racial background? Check one or more</p> <p><input type="checkbox"/> American Indian or Alaska Native</p> <p><input type="checkbox"/> Native Hawaiian or other Pacific Islander</p> <p><input type="checkbox"/> Asian</p> <p><input type="checkbox"/> Black or African American</p> <p><input type="checkbox"/> White</p> <p><input type="checkbox"/> Do Not Wish to Provide</p>			<p>12. Do you have a disability?</p> <p><input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Do Not Wish to Provide</p> <p>If yes, which of the following categories describe your disability(ies):</p> <p><input type="checkbox"/> Hearing <input type="checkbox"/> Mobility/Orthopedic Impairment</p> <p><input type="checkbox"/> Visual <input type="checkbox"/> Other</p>																							
<p>14. FIELD OF RESEARCH TRAINING OR CAREER DEVELOPMENT (for this appointment)</p> <p>Enter a 4 digit code from instructions: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p>			<p>13. Are you from a disadvantaged background?</p> <p><input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Do Not Wish to Provide</p>																							
<p>15. PERIOD OF APPOINTMENT (Month, day, year)</p> <p>From: _____ To: _____</p>																										
<p>16. EDUCATION – AFTER HIGH SCHOOL (Indicate all academic and professional education. For foreign degrees, give U.S. equivalent.)</p> <table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th rowspan="2">(a) Name of Institution and Location (List most recent first)</th> <th colspan="2">(b) Degree(s) Received</th> <th rowspan="2">(c) Major Field</th> <th rowspan="2">(d) Minor Field</th> </tr> <tr> <th>Degree</th> <th>Mo./Yr.</th> </tr> </thead> <tbody> <tr> <td> </td> <td> </td> <td> </td> <td> </td> <td> </td> </tr> <tr> <td> </td> <td> </td> <td> </td> <td> </td> <td> </td> </tr> <tr> <td> </td> <td> </td> <td> </td> <td> </td> <td> </td> </tr> </tbody> </table>					(a) Name of Institution and Location (List most recent first)	(b) Degree(s) Received		(c) Major Field	(d) Minor Field	Degree	Mo./Yr.															
(a) Name of Institution and Location (List most recent first)	(b) Degree(s) Received		(c) Major Field	(d) Minor Field																						
	Degree	Mo./Yr.																								

Where do we go from here?

2. “Enroll” all trainees on T32 grants

a) Use Trainee Application Form (TAF)

- Enter TAF info for all T32 trainees
 - Who were supported on your T32
 - Regardless of ethnicity/race
- Use TAF to form “Master List” of trainees

b) Supplement TAF with additional information

- Table 6: Publication list
- Table 9: GRE scores (will need to add names)
- Table 12: Current position / location / funding source

T32 Tables

- ~~Table 5~~
- ~~Trainees, past 10 years~~
 - ~~Available Information~~
 - ~~Faculty & Trainee names~~
 - ~~Pre vs Post~~
 - ~~Years start and end~~
 - ~~Research Topic~~
 - ~~Prior Degrees~~
 - ~~Degree, institute, year~~
 - ~~Current support or position~~
 - ~~Problems~~
 - ~~Too many (all trainees from any support source listed)~~
 - ~~Resolution: Use TAF as “master list” to select only relevant trainees~~

- Table 6
- Trainee publications
 - Available Information
 - Faculty & Trainee names
 - **Complete citation of publications (CV style)**
 - Problem
 - Too many (all trainees from any support source listed)
 - Resolution: Use TAF as “master list” to select only relevant trainees

T32 Tables

- ~~Table 8~~
- ~~Qualification of recent applicants~~
 - Available information
 - Previous institute
 - Degree & year
 - GRE scores (VQW)
 - Undergrad GPA
 - Support from this grant?
 - Problems
 - No trainee names
 - Too many (all trainees from any support source listed)
 - Resolution: PI/PD add trainee names

- Table 9
- Qualification of current trainees
 - Available information
 - Department
 - Previous institute
 - Degree & year
 - **GRE scores (V,Q,W)**
 - **Undergrad GPA**
 - Mentor name
 - Yrs in program
 - Years appointed to TP
 - Problems
 - No trainee names
 - Resolution: PI/PD add trainee names

T32 Tables

- Table 10
- Admissions records for URM, etc
 - Available information
 - Year entered
 - Department
 - Grant support source
 - Includes “other” sources
 - Current status
 - In training, completed, employment
 - Problems
 - No names
 - Resolutions: PI/PD add trainee names

- Table 12
- Trainees supported by TP in past 10 years
 - Available information
 - Trainee & Faculty names
 - Year entered
 - Delineates type of support for each year
 - **Research topic**
 - **Current funding or position**
 - Problems
 - Too many trainees
 - Resolutions: Use TAF as “master list” to select only relevant trainees

Notes / Proposed Action Items

Action Items	Timeline
<p>DACC: Will send 'draft' IRB documents – protocol, informed consents, questionnaires</p> <ul style="list-style-type: none"> (1) collecting and sharing current and past evaluation info with DACC (2) publication of aggregate results (across multiple programs) in the future (3) allow DACC to contact trainees personally in future, but ONLY if necessary 	
<p>ALL: Determine what information should be collected</p>	TODAY
<p>DACC: Develop excel file format based on agreed-upon questions and send to T32s</p>	
<p>T32s: Collect TAF forms for each trainee ever trained on T32 – Form master list</p>	
<p>T32s: Start abstracting relevant info from Tables 6, 9, 12 on relevant trainees</p>	
<p>DACC: ?? Need volunteer “Beta” test sites for testing the excel formats</p>	
<p>Will use REDCap web-based data entry for annual follow-up</p>	
<p>RELIES ON HAVING IRB approvals (same as with MAPs)</p>	

Notes / Proposed Action Items

Action Items	Timeline

Extra Slides

- Privacy Statement in TAF

Privacy Act Statement

The PHS maintains application and grant records as part of a system of records as defined by the Privacy Act: 09-25-0112, Grants and Cooperative Agreements: Research, Research Training, Fellowship, and Construction Applications and Related Awards. The Privacy Act of 1974 (5 USC 522a) allows disclosures for "routine uses" and permissible disclosures.

Some routine uses may be:

1. To the cognizant audit agency for auditing.
2. To a Congressional office from a record of an individual in response to an inquiry from the Congressional office made at the request of that individual.
3. To qualified experts, not within the definition of DHHS employees as prescribed in DHHS regulations (45 CFR 5b.2) for opinions as part of the application review process.
4. To a Federal agency, in response to its request, in connection with the letting of a contract or the issuance of a license, grant, or other benefit by the requesting agency, to the extent that the record is relevant and necessary to the requesting agency's decision on the matter.
5. To organizations in the private sector with whom PHS has contracted for the purpose of collating, analyzing, aggregating, or otherwise refining records in a system. Relevant records will be disclosed to such a contractor, who will be required to maintain Privacy Act safeguards with respect to such records.
6. To the sponsoring organization in connection with the review of an application or performance or administration under the terms and conditions of the award, or in connection with problems that might arise in performance or administration if an award is made.
7. To the Department of Justice, to a court or other tribunal, or to another party before such tribunal, when one of the following is a party to litigation or has any interest in such litigation, and the DHHS determines that the use of such records by the Department of Justice, the tribunal, or the other party is relevant and necessary to the litigation and would help in the effective representation of the governmental party.
 - a. the DHHS, or any component thereof;
 - b. any DHHS employee in his or her official capacity;
 - c. any DHHS employee in his or her individual capacity where the Department of Justice (or the DHHS, where it is authorized to do so) has agreed to represent the employee; or
 - d. the United States or any agency thereof; where the DHHS determines that the litigation is likely to affect the DHHS or any of its components.

8. A record may also be disclosed for a research purpose, when the DHHS:
 - a. has determined that the use or disclosure does not violate legal or policy limitations under which the record was provided, collected, or obtained;
 - b. has determined that the research purpose (1) cannot be reasonably accomplished unless the record is provided in individually identifiable form, and (2) warrants the risk to the privacy of the individual that additional exposure of the record might bring;
 - c. has secured a written statement attesting to the recipient's understanding of, and willingness to abide by, these provisions; and
 - d. has required the recipient to:
 - (1) establish reasonable administrative, technical, and physical safeguards to prevent unauthorized use or disclosure of the record;
 - (2) destroy the information that identifies the individual at the earliest time at which removal or destruction can be accomplished consistent with the purpose of the research project, unless the recipient has presented adequate justification of a research or health nature for retaining such information; and
 - (3) make no further use or disclosure of the record, except (a) in emergency circumstances affecting the health or safety of any individual, (b) for use in another research project, under these same conditions, and with written authorization of the DHHS, (c) for disclosure to a properly identified person for the purpose of an audit related to the research project, if information that would enable research subjects to be identified is removed or destroyed at the earliest opportunity consistent with the purpose of the audit, or (d) when required by law.

The Privacy Act also authorizes discretionary disclosures where determined appropriate by the PHS, including to law enforcement agencies, to the Congress acting within its legislative authority, to the Bureau of the Census, to the National Archives, to the General Accounting Office, pursuant to a court order, or as required to be disclosed by the Freedom of Information Act of 1974(5 USC 552) and the associated DHHS regulations (45 CFR Part 5).