Privacy and IRB Issues: Breaking News from the SHRP 2 Naturalistic Driving Study

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Major Hurdles

- Defining types of participants
- Defining and distinguishing types of information and data
- Defining data flow
- Defining data access
 - Some IRBs want detailed info up front
- IRB Coordination
 - Virginia Tech, 6 site IRBs, National Academies
 - Certificate of Confidentiality

Three Types of Participants

Type I. Primary Drivers: main focus of the study

- Asked to provide other drivers with basic information
- Special consideration of minor participants

Type 2. Fully Participating Secondary Drivers

Type 3. Other Secondary Drivers

- Regularly drive instrumented vehicle of a primary driver but decided not to participate fully; or
- Only drive instrumented vehicle of a primary driver occasionally or incidentally; or
- Are not allowed to participate as secondary drivers because they are minors.

Type 3 Participants: Issues

- Can we collect the data?
 - Waiver of consent to collect the data was requested and obtained from VT IRB
- Can we use the de-identified data?
 - NAS IRB required that the data from Type 3 be expunged
- Are they covered by the Certificate of Confidentiality?
 - Application for C of C requested that these data be covered until driver ID is performed and data is de-identified or deleted
 - No response yet

Types of Information and Data

- I. Contact information (name, phone, etc.)
- 2. Auxiliary study information (license plate, bank, SSN)
- 3. Driver data (questionnaires, assessments)
- 4. Vehicle data (make, model, condition, equipment)
- Driving data (continuous recording of video and sensor/parametric data)
- 6. Additional crash data (detailed crash investigations for selected crashes)
- Separate effort: roadway/roadside characteristics and features from mobile data collection vans and external sources

Camera Views



Blurred snapshot of vehicle interior will be used to count passengers

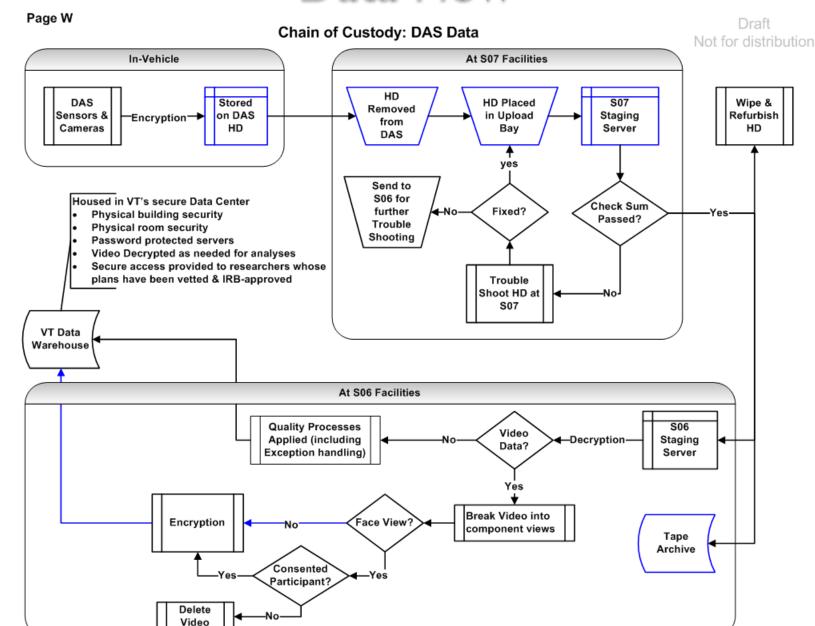
Identifying Data

- Identifying: participant can be identified from the data
 - Face video
 - GPS coordinates of home and work
 - Combinations of items (rare combinations of vehicle type, age, medical conditions, etc.)
- Non-identifying: participant cannot be identified from the data
 - Identifying data that has been de-identified
 - Data can be non-identifying in its nature (traces of vehicle speed; questionnaire answers with only a participant number attached)

Examples of Data Requiring Particular Care

- Participant information file
- Driver face video
- GPS coordinates of home, work, or school
- Vehicle Identification Number
- Crash investigation data in combination with other information (small town, few crashes, news stories)
- Possibly other combinations of data that by themselves would not reveal identity
- Other video in case of severe/fatal crash (may be sensitive even if not actually revealing identity)
- Forward/rear video (other drivers/license plates)?

Data Flow



IRB Coordination: Status of Approvals

	Field Protocol	Amend 1	Amend 2	Amend3	Call Center
VT	✓	✓	✓	In process	√
CUBRC- NY	✓	✓	Some points		
Indiana	Submitted, issues discussed; approved pending C of C				
Battelle	Preliminary discussion of issues; pending submission				
PennState	Submitted, initial round of questions answered, final submission this week				
CUBRC-FL	Initial round of questions answered				
Westat	Signed letter of reliance naming VT as IRB of Record				
NAS	Conditional approval granted yesterday				In review