

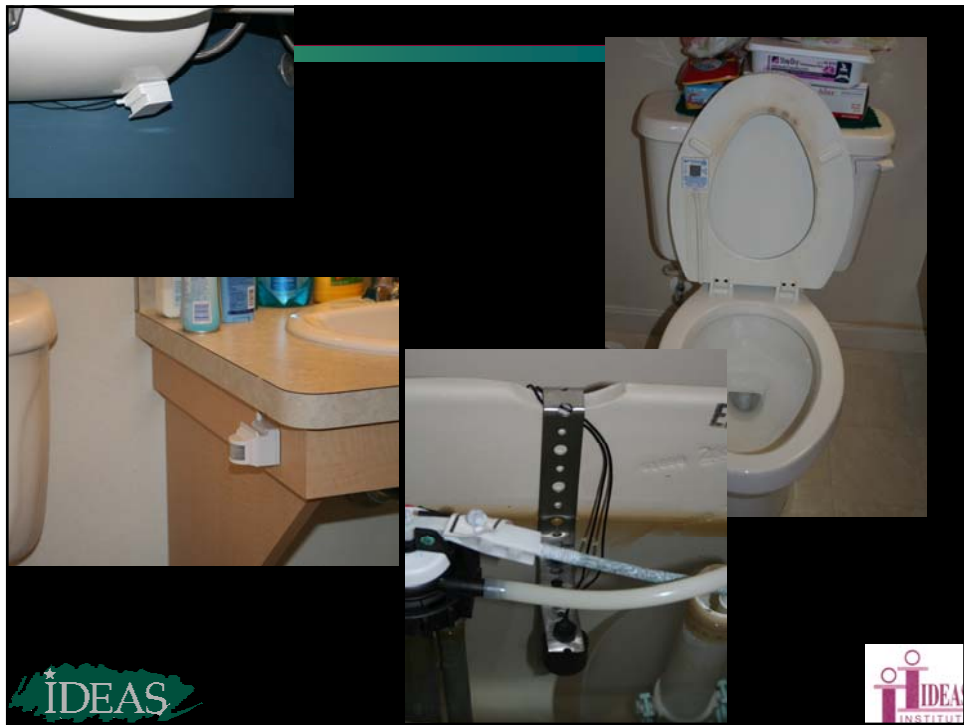
Ethics of Remote Monitoring in Research

Margaret Calkins, Ph.D.

President IDEAS Inc.

Mcalkins@IDEASConsultingInc.com





HealthSense™			
ADL Report			
Date/Time	Type	Generated By	Event
03/09/09 05:13:29	Motion Sensor	Motion SensorB	MOTION
03/09/09 05:17:24	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 05:17:26	Motion Sensor	Motion SensorB	MOTION
03/09/09 05:21:21	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 05:21:23	Motion Sensor	Motion SensorB	MOTION
03/09/09 05:25:18	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 05:25:19	Motion Sensor	Motion SensorB	MOTION
03/09/09 05:29:13	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 05:29:14	Motion Sensor	Motion SensorB	MOTION
03/09/09 05:33:09	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 05:33:59	Motion Sensor	Motion SensorB	MOTION
03/09/09 05:37:53	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 09:05:49	Key Fob	Home Key	PRESSED
03/09/09 09:11:23	Key Fob	Home Key	PRESSED
03/09/09 09:13:47	Motion Sensor	Motion SensorA	NO MOTION
03/09/09 09:13:50	Motion Sensor	Motion SensorB	NO MOTION
03/09/09 09:16:10	Motion Sensor	Motion SensorC	NO MOTION
03/09/09 09:19:34	Motion Sensor	Motion Sensor	MOTION
03/09/09 09:19:40	Motion Sensor	Motion SensorA	MOTION
03/09/09 09:23:27	Motion Sensor	Motion Sensor	NO MOTION
03/09/09 09:23:35	Motion Sensor	Motion SensorA	NO MOTION
03/09/09 09:23:38	Motion Sensor	Motion Sensor	MOTION
03/09/09 09:25:36	Motion Sensor	Motion SensorA	MOTION
03/09/09 09:27:32	Motion Sensor	Motion Sensor	NO MOTION
03/09/09 09:28:00	Motion Sensor	Motion Sensor	MOTION

Concerns Expressed

Staff discomfort with someone tracking
“their” resident’s behavior

Inability to differentiate who is in bathroom
(resident, staff, visitor)

But because data is anonymous, these
concerns were minor.



Value Added

Identify residents who are using bathroom multiple times (7-8+) each night.

Indicated UTI in 1 resident



Dressing Project

Goal is to increase independence in dressing in individuals.

Developed an “assistive wardrobe” that can be customized to meet the specific needs of the individual.



Data Collection Options

- 1) Researcher in room, videotaping during daily dressing
 - 1) More invasive
 - 2) More likely for non-typical behavior
- 2) Video camera to capture normal routine
 - 1) Less invasive
 - 2) Greater likelihood of capturing normal behavior







Consent Procedures

Resident AND family/guardian

Roommate AND his/her family/guardian

All residents & families on unit notified-
opportunity to object

Staff- sometimes all staff in building (opt out),
sometimes nursing, housekeeping, laundry
staff on specific unit (signed form)

Signs placed at NS and bedroom entrance for
others



Data Protection

- 1) Cameras only operate when closet door is open (contact switch) last 3 sites
- 2) Computer, proprietary program (not Windows® compatible), password protected, locked panel to access data port, in locked cabinet, in locked room.
- 3) Downloaded to removable hard drive, never left unattended until returned to office.
- 4) Computer in office used for analysis not connected to internet.



Challenges

Accused of being “peeping Toms”
Concerns about abuse and skin integrity
Roommate change situations
State Survey team not educated on research protocols
Concerns about privacy of visitors– need ability to completely erase data so it can’t be used in court proceedings

