## Working With People

#### Outline

- Additional Details on Projects
- Working with human subjects

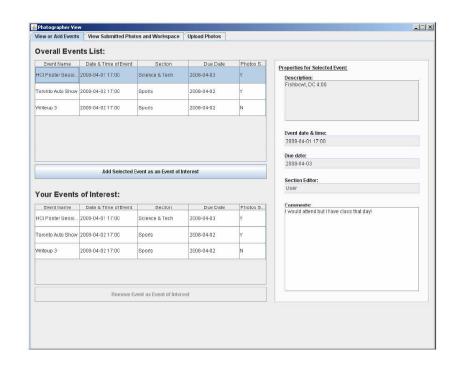
#### CS 449 Projects

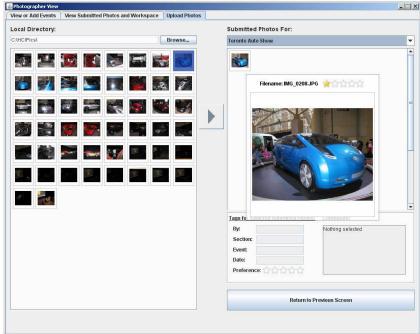
- Must design to user needs, not to your whims
- Must demonstrate how your proposed system will improve users' lives
- Proof-of-concept prototyping means designs can take many forms...
- Must be possible using current technology

#### Basketball Scorekeepers

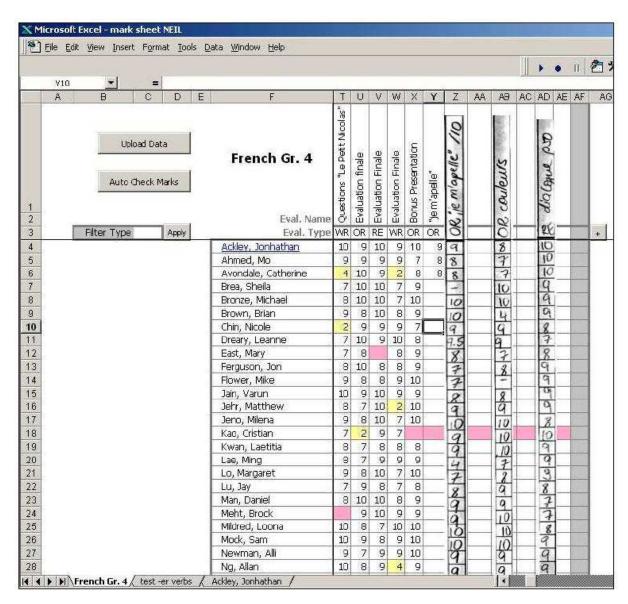


#### **Newspaper Section Editors**

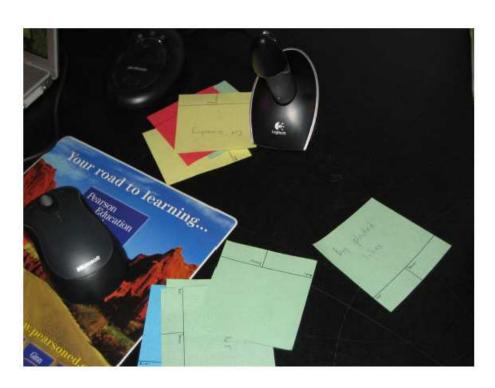


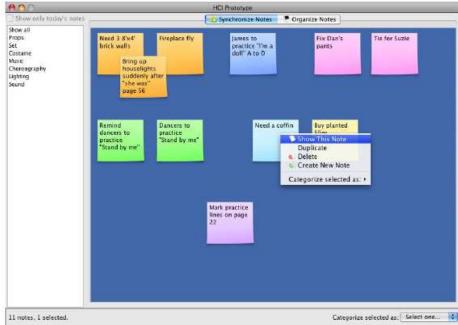


#### **Teachers**



## Stage Managers





#### Other Project Issues

- IP in this course is your own
- You cannot sign:
  - NDAs
  - IP ownership rights
- But, there is some shared aspect to IP
  - Collaboration on publications
  - Start-ups require some discussion

#### **Human Participants**

- Why this lecture
- Your recruitment process
- Ethics review and what we had to do
- Consent forms that you must have signed
- Informed consent
- Privacy

## Why human participants?

- In general?
- In this course?
- In general:
  - New knowledge and new understanding
  - Benefit to subjects
  - Benefit to society

#### In this course

- Subjects are your link to data
  - Without subjects, you have no project
  - You will be interviewing them and watching them as they work
  - You will be interrupting and disrupting what they do
- Always respect
  - Subject's time
  - Subject's attitude and environment
  - Subject's desire for privacy

#### Why lecture on research ethics

- In this course?
  - Process and protections ensure study is done correctly with proper forethought
    - School teachers
    - Nurses
  - ... and you may want to publish
  - ... or you may want to commercialize

# University of Waterloo Ethics Requirements

- University has a formal process for ethics
  - Not something you need to deal with
  - I created letters, modified protocol, etc.
- Why would the university have ethics requirements for a course?

#### Principles

- Respect for human dignity
- Respect for free and informed consent
- Respect for vulnerable persons
- Respect for privacy and confidentiality
- Respect for justice and inclusiveness
- Balancing harms and benefits
- Minimizing harm
- Maximizing benefits

#### **Ethics Review**

- All research that involves living human subjects requires review and approval before research is started
- When do projects require review?
  - Whether funded or not
  - Whether subjects are from university or not
  - Whether subjects are paid or not
  - Whether research is conducted inside university or not
  - Whether conducted by faculty or students
  - Whether information is collected from subjects or not
  - Whether published or not
  - Whether focused on the subject or not
  - Whether observation, experimental, or descriptive
  - Whether basic or applied
  - Whether for teaching or training or research
- Even naturalistic observation requires review
  - Especially when staged

#### Ethics Review (2)

- Research Ethics Board (REB) at Waterloo can:
  - Approve, reject, propose changes, or terminate any work with human subjects by members of the university
  - This includes you.
- REB consists of five members
  - Both men and women
  - One member knowledgeable in ethics
  - Two members have expertise in fields covered by REB
  - One member knowledgeable in biomedical law
  - One member from outside university
  - Goal is breadth want a balanced perspective on projects being examined

#### Ethics Review (3)

- Course project is one of Minimal risk
  - Probability and magnitude of harm should be no greater than in everyday life
  - This can also be how you test new treatments on people (e.g. experimental surgeries or cancer treatments)
- Greater than minimal risk requires greater corresponding benefits
  - Benefit outweighs risk
  - May need peer review

#### Ethics Review (4)

- Canadian and UW guidelines
- They consider
  - Recruitment
  - Voluntary participation
  - Confidentiality and anonymity
  - Risks/benefits
  - Fully informed consent

#### Recruitment

Use subject consent form

- Gatekeepers permission: use manager's consent form to obtain permission to use subjects
  - I prefer you contact subjects first
  - No on one = no on both

#### **Consent forms**

## Informed Consent (1)

- Disclosure
- Comprehension
- Voluntariness
- Competence
- Agreement

### Informed Consent (2)

- Should normally involve full and frank disclosure
  - Information that it is a research project, on the purpose of the project, on the procedures, and any perceived harms and benefits
  - Assurance subjects are free not to participate
  - Any possibility for commercialization and/or conflict of interest
  - May need to practice some deception, but if so must document that:
    - Minimal risk
    - Change won't affect rights/welfare
    - · Research requires the deception
    - Subject informed after
- Must be voluntary
  - Subjects must be free to say yes or no, and can stop at any time
  - Military (for example), my own students
- Subjects must be competent
  - This is why no children
  - This is a risk for healthcare settings
- Typically by a signed statement
  - Can also be implied
    - Filling out a survey

## Informed Consent (3)

 Subjects can refuse to answer and can stop participating at any time

If they say they don't want to participate, their involvement is done

 Never, ever push subjects for information they cannot or do not want to disclose

### Informed Consent (4)

- They can consent to all or part of process
  - Consider consent forms
  - Make them aware of selective exclusion
- As a minimum
  - Audio + photos + anonymous quotations are useful, but can say no.

#### **Questions or Problems**

- For questions, give subjects my email and office phone number
  - Also supervisors/managers

- If any problems occur, contact me immediately
  - Must be reported

#### **Privacy and Confidentiality**

- Any information disclosed must be held confidential
  - Legal and moral requirement
- Best protection is anonymity
  - All data will be anonymized for your studies
  - Use code names (e.g. P1) to refer to people
- Personal Information = need for REB approval
  - Name, age, occupation, etc.
- Secondary data, or re-contact with people who provided data by new researchers also requires approval

#### Privacy and Confidentiality (2)

#### You will

- Anonymize everything
- Always refer to subjects by code, even in your notes, labels for tapes, files, etc.
- Anonymize pictures you plan to use
- Extends to organizations
  - Do not say 'the campus theatre group'
  - Say 'a local theatre company'
- Regardless, participant always has option to review data and relevant text of report

#### Take Aways

- You will be working with people in this course
- Must be mindful of their right to privacy and safeguard this
- Must study people in a way that ensures that they understand and agree to everything done

- Next day
  - Collecting data: interviewing participants