

CASE STUDIES IN
SOCIAL SCIENCE HEALTH RESEARCH
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Nilalaman

- × Introduksyon: ilang dapat pansinin
- × Case studies
- × Kaugnay na isyung etikal
- × Solusyon sa mga isyu
- × Ilang prinsipyo at alituntunin

Mga dapat pansinin

- × Informed Consent
 - × Indibidwal-Pamilya-Komunidad
 - × Ang “buong” katotohanan
- × Mga insidental na pananagutan ng imbestigador
- × Di-inaasahang “findings”
- × Mga problema sa komunidad

Mga dapat pansinin

- × Respeto sa kultura
- × Konsultasyon
- × Karapatan laban sa panghihimasok
- × Integridad at pagkakakilanlan

Observing newborn care

- ✘ **Observational** study sa pagpalambo og paagi sa mas maayong newborn care
- ✘ Setting: komunidad nga naay taas nga infant mortality rate

Adapted from WHO. Casebook on Ethical Issues in International Health Research. **Editors:** Richard Cash, Daniel Wikler, Abha Saxena, Alexander Capron. 2009

Observing newborn care

- ✘ Mag-observer ang mga field workers sa kina-iyahan sa mga panimalay nga naay bata nga nag-idad ubos sa tulo ka bulan:
 - ✘ Kahimtang sa bata (kalimpyo, temperatura), pag-atiman (bisti, ligoan-an)
 - ✘ Relasyon sa bata ug sa mga tigbantay
- ✘ **Dili manghilabot!**

Observing newborn care

- ✘ Ang mga researchers nangayo ug informed consent sa inahan ug sa usa nga tigbantay o tig-amuma sa pamilya
- ✘ Sa tan-aw nimo kinahanglan pa nga magkuha ug informed consent gikan sa ubang miyembro sa pamilya?

Helsinki Declaration on Informed Consent

- × 24. ... each **potential subject** must be **adequately informed** of the:
 - × aims,
 - × methods,
 - × sources of funding,
 - × any possible conflicts of interest,
 - × institutional affiliations of the researcher,
 - × the anticipated benefits and potential risks of the study and the discomfort it may entail, and
 - × any other relevant aspects of the study. ...

Observing newborn care

- ✘ Dili manghilabot ang mga field researchers ug dili magpakita ug emosyon samtang nag obserbar
- ✘ Nabalaka ang usa ka researcher pagkakita niya nga ordinaryong tubig ra ang gamiton sa inahan sa pag andam ug gatas para sa bata
 - ✘ Ang tubig na gigamit wala gipabukalan
 - ✘ Ug sobra ka labnaw

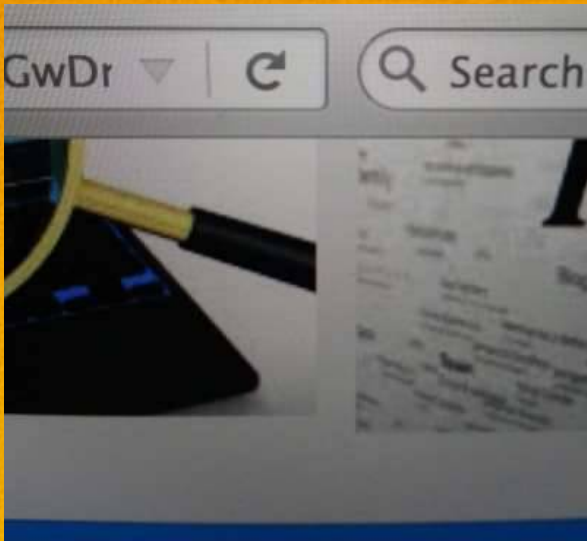
Observing newborn care

- ✘ Ethical ba nga ang researcher taman ra sa pag obserbar maskin kabalo siya nga ang gingbuhaton (sa inahan o tigbantay) makadaot sa bata?
- ✘ Unsa ang imo sugyot nga ilisan sa design sa study?

Helsinki Declaration

- ✘ 6. In medical research involving human subjects, the **well-being of the individual research subject must take precedence over all other interests.**

Online Research

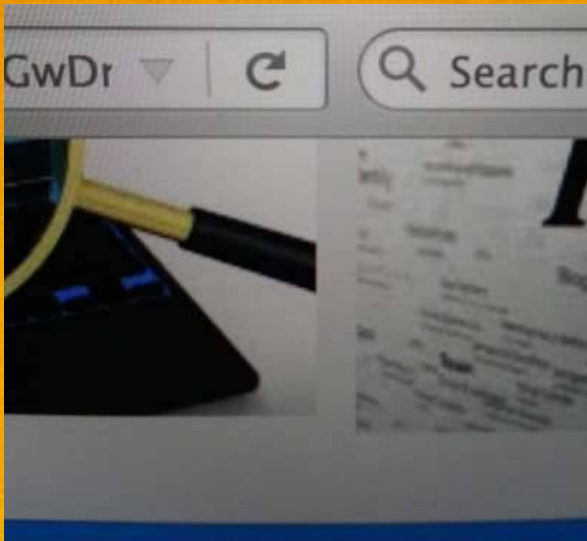


- Mga estudyanteng 18 yrs old pataas and kasama sa research na ito
- Para pag-aralan ang epekto ng online survey at feedback sa sobrang pag-inom ng alcohol
- Inemail ang mga estudyante para imbitahang sumagot sa ilang tanong tungkol sa kanilang pag-inom ng alcohol

Online Research

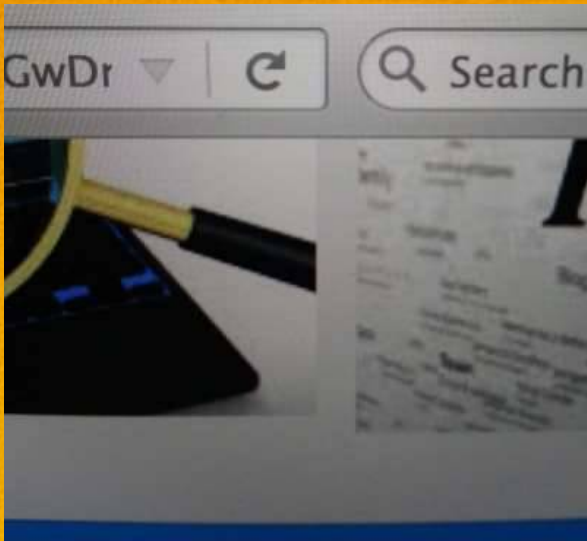
- × Ang mga malakas uminom ay nirandomize sa control o sa treatment group
- × Ang narandomize sa control ay pansamantalang dinedma na lang – walang sinabing dapat nilang gawin
- × Ang nasama sa treatment group ay tinanong ng mga detalye tungkol sa kanilang ugali sa pag-inom

Online Research



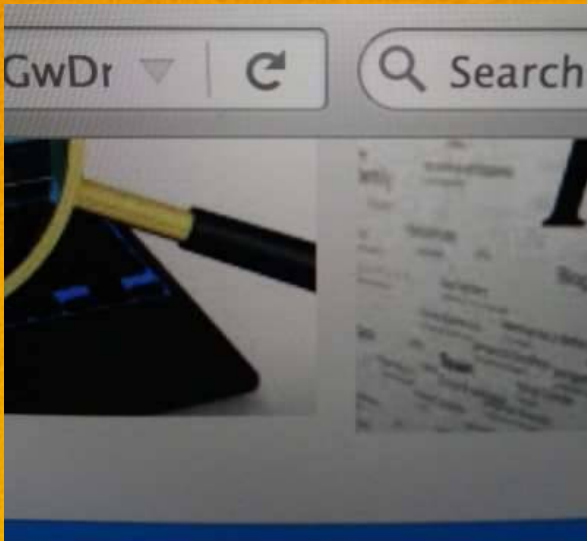
- × Batay sa mga sagot, pinadalhan sila ng feedback form na naglalaman ng:
- × Masamang epekto ng pag-inom ng alcohol sa kalusugan at panggastos,
- × Lakas ng kanilang pag-inom kumpara sa ibang tao

Online Research



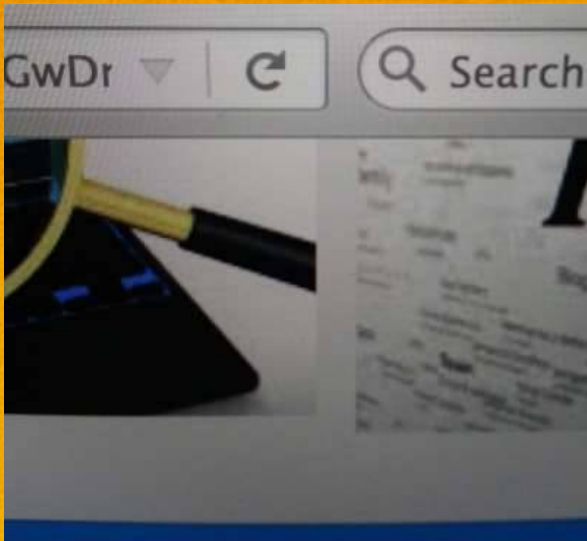
- × Batay sa mga sagot, pinadalhan sila ng feedback form na naglalaman ng:
 - × Pamamaraan para matigil ang pag-inom
 - × Online links tungo sa impormasyon sa reduksyon ng pag-inom

Online Research



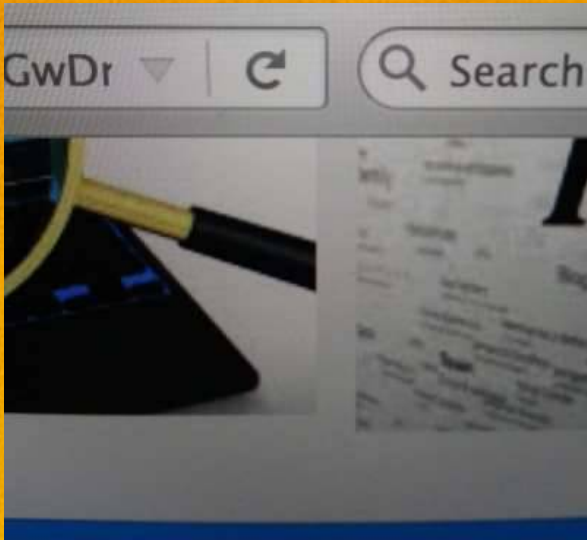
- × Paglipas ng limang (5) buwan inimitahan lahat ng kasali na sumagot sa follow-up survey tungkol sa:
 - × kanilang konsumo ng alcohol at
 - × epekto nito sa pag-aaral sa eskuwela

Online Research



- ✘ Sinabihan sila na sinusukat sa survey and karanasan ng mga estudyante sa alcohol pero
- ✘ Hindi sinabi na tinitignan ang epekto mismo ng survey sa kanilang konsumo ng alcohol

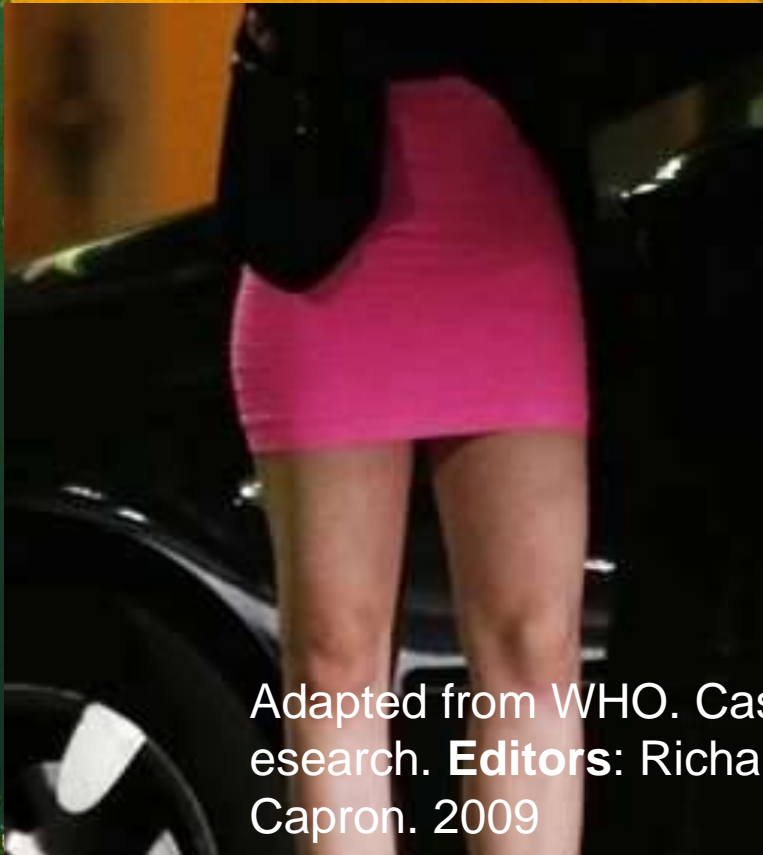
Online Research



- ✗ Nilalabag ba ang mga kundisyon ng informed consent dahil sa hindi pagsasabi ng buong katotohanan?
- ✗ Meron bang puwedeng magawa para maging mas katanggap-tanggap ang hindi pagsasabi ng katotohanan?
- ✗ OK lang ba kung walang informed consent para sa ganitong research?

Negotiating safe sex practices

- × Study to examine whether and how women in sex trade negotiate condom use by their male partners.
- × To help reduce incidence of HIV/AIDS



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Negotiating safe sex practices



- × Dr J, the medical anthropologist, was concerned that if women were to be asked directly they might not answer truthfully
- × Thus, study used participant-observation that depended on **deception**

Negotiating safe sex practices

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- × Researchers posed as male customers who casually met women to “negotiate for sex”
- × They asked the women how, why and with whom they engaged in casual sex
- × To avoid actual sex, an accomplice-researcher intervened to “rescue” the fake customer (investigator)



Negotiating safe sex practices

- ✘ Ethics Committee: Approved on condition that fake customers would compensate the women for “lost opportunities”
- ✘ Reviewer for a journal: the deception perpetrated by fake customers (researchers) violated informed consent requirements

Negotiating safe sex practices (Questions)

- × Was the team justified in using a research design founded on deception?
- × Using the same research design, do you think something could have been done to improve the ethical conduct of the study?
- × Can you think of an ethical research design that could have produced good findings that would have been as or better?

Negotiating safe sex practices

UNESCO Ethical Guidelines for Social Science Research

5. The researcher should be aware of any potential harmful effects; in such circumstances, the chosen method should be used only if no alternative methods can be found after consultation with colleagues and other experts
10. The research should avoid undue intrusion into the lives of the individuals or communities they study.

HIV/AIDS

QUICK FACTS

1984

First case of HIV infection in PH

Number of newly diagnosed HIV cases per day:



29,079

HIV cases reported from Jan 1984 - Oct 2015



26,689 were male



7,722 were youth aged 15-24

Median age: 28

May, June, July, September, December

Months with highest recorded cases in the past 5 years



1,359

deaths reported from Jan 1984-Oct 2015

STD Research and Minors

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- × Study: 27 % of newly diagnosed HIV cases in the country involved youth aged 15 to 24
- × 86 per cent of the sexually transmitted cases were among males who have sex with males
- × More than half (12,077 or 54%) of cases among MSM belong to the 25-34 year age group
- × 6,643 (29%) were youth 15-24 years old

STD

Research and Minors

× Pre-exposure prophylaxis (PrEP), when used together with safer sex practices, has been shown to be effective in high risk groups

× For PrEP to be approved for use in adolescents who fall into the high risk groups, studies must include adolescents



STD

Research and Minors

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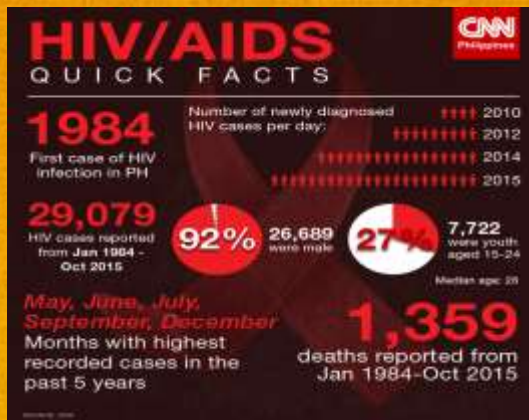


- ✗ Parental permission is a usual requirement for studies involving minors
- ✗ If parental permission is required, many adolescents may not participate for fear that their parents would learn of:
 - ✗ Their sexual orientation
 - ✗ Their being sexually active

STD Research and Minors

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- ✗ If many such minors refuse to participate:
- ✗ Scientific validity can be compromised
- ✗ Low enrolment
- ✗ Selection bias
- ✗ Eligible minors will lose the potential to benefit from PrEP
- ✗ Should the researchers proceed anyway without parental consent?



Waiving Parental Consent for STD Research:

- ✘ The waiver does not adversely affect the rights and welfare of the child,
- ✘ Risks associated with research are minimal, and
- ✘ Research is of high value and could not practicably be carried out without the waiver

Waiving

Parental Consent for STD Research

- ✘ Under the law, only a right bearer can waive a right – not an Ethics Review Committee.
- ✘ Only parents / legal guardians have the right to give consent in behalf of minors
- ✘ If the minor has no parents or the parents cannot be reached, the next of kin should be approached for consent.

BASIC ETHICAL PRINCIPLES

- × Respect for persons:
 - × Respect for autonomy--respect for their capacity for self-determination;
 - × Protection of persons with impaired or diminished autonomy (such as children or the mentally disabled)
 - × obligation to be sensitive to religious beliefs, cultural perspectives and traditions of human subjects

BASIC ETHICAL PRINCIPLES

- × Beneficence--maximize benefits and minimize harm
 - × Allowing harm to subjects cannot be justified by the prospect of benefits to others

BASIC ETHICAL PRINCIPLES

× Justice

- × Avoid particular groups of individuals who are likely to be subjects of over-researching;
- × ensure that the selection and recruitment of research subjects are fair; and
- × do not use race, age, gender, disability or religious beliefs for the selection and recruitment of actual or future participants, except where such exclusion or inclusion of particular groups is essential to the objective of the research (non-discrimination)

BASIC ETHICAL PRINCIPLES

× Justice

- × Researchers should exercise care that their research does not exacerbate existing inequities (e.g., gender-based inequities).
- × “Sponsors of research or investigators cannot, in general, be held accountable for unjust conditions where the research is conducted, but they must refrain from practices that are likely to worsen unjust conditions or contribute to new inequities” (CIOMS, 2002, p. 10).

Wakas

Magandang Araw